

**Persistent Abdominal Pain:  
Challenges  
and  
Models of Care**

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A thesis presented in fulfilment of the requirements for the degree of  
Doctor of Philosophy

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## Statement of Originality

*The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository\*\*, subject to the provisions of the Copyright Act 1968.*

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Date: .....

Gena Lantry

## Dedication

It is with gratitude I submit this work, achieving its realisation is the result of:

My parents, Peter and Daphne's unconditional love, support and encouragement, without which I would never have endured the journey.

My Nan, who continues to support and inspire me.

My brothers, Brett, Darren and Chad for their unwavering encouragement and support.

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My sincere gratitude.

## Key to Transcript

The following abbreviations and conventions have been used throughout the presentation of this thesis.

<i>"Italics"</i>	Quoted material from focus group participants (patient, family member/carers and health care professional)
<i>Calligraphy</i>	The researcher's reflective statements and interpretations
'emphasis'	Emphasis within comments
...//...	Material edited from transcribed or quoted statements
Block quotation	Material quoted from transcripts of focus group interviews
"Block quotation"	Material quoted from literary sources

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## GLOSSARY OF TERMS

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Acronym	Definition
APS	Acute Pain Service
AUD	Australian Dollar
CBT	Cognitive Behavioural Therapy
CNC	Clinical Nurse Consultant
CNS	Clinical Nurse Specialist
CPS	Chronic Pain Service
CT	Computerised Tomography
CVC	Central Venous Catheter
DRG	Diagnostic Related Group
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED	Emergency Department
GP	General Practitioner
IASP	International Association for the Study of Pain
IBS	Irritable Bowel Syndrome
ICD	International Classification of Disease
IPS	International Pain Summit
ITD	Intrathecal Devices
IVP	Intravenous Pyelogram
LHD	Local Health District
LOS	Length of Stay
MUS	Medically Unexplained Symptoms
NHS	National Health Service (UK)
NMDA	N-methyl-d-aspartate
NPS	National Pain Strategy
NSAID	Non-Steroidal Anti-inflammatory Drug
NSW	New South Wales
NUM	Nurse Unit Manager
PCA	Patient-Controlled Analgesia
PCEA	Patient-Controlled Epidural Analgesia

<b>Acronym</b>	<b>Definition</b>
PEG	Percutaneous Gastrostomy
QLD	Queensland
RN	Registered Nurse
SCS	Spinal Cord Stimulator
TPN	Total Parental Nutrition
VMO	Visiting Medical Officer
WA	Western Australia
WHO	World Health Organization

## ABSTRACT

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**Purpose:** The purpose of this study was twofold: First to assess the impact of persistent (chronic) abdominal pain on patients, carers, health professionals and the health care service within a large tertiary referral hospital in New South Wales (NSW), Australia. Second to examine ways in which the current model of care could be improved.

**Research Design:** The study employed a four-phase sequential, explanatory, mixed methods design. Interpretive description provided a framework for analysis of narrative accounts.

**Participants:** The study involved all major stakeholders: patients, carers and health care professionals. There were a total of 112 participants involved in the study: seven patients, six carers, and 95 clinicians, representing 15 clinical specialities, including 10 general practitioners (GPs) and four health service administrators.

**Outcomes:** Findings from this study highlight the challenges and frustrations experienced by all stakeholders. Preliminary recommendations are made in relation to the broad principles and essential elements that participants considered necessary for a revised model of care to achieve optimal therapeutic outcomes for the patient cohort.

**Conclusions:** The clinical encounter in relation to persistent abdominal pain is fraught with complexities, frustrations and challenges for all stakeholders involved. The acute care system offers little in the way of workable alternatives for patients or clinicians seeking effective and efficient therapeutic outcomes. Subscribing to an acute reactive biomedical model for the management of complex bio-psychosocial phenomena has been well documented to be ineffective and as this study illustrates, in some cases detrimental to good patient outcomes for patients with significant and complex bio-psychosocial issues. Designing a model of care that is concerned with managing the study phenomenon from a life course approach rather than an acute episodic event approach was the preferred model that participant clinicians developed collaboratively. The proposed model could be utilised for delivering care to patients with persistent abdominal pain, both in the acute care setting and the community.

## Chapter 1 Introduction

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### 1.1 Introduction

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The understanding of pain as a personal and subjective experience is now well accepted. However, the dualistic nature of pain as both a physiologically mediated phenomenon and a subjectively constructed human response, continues to create tensions for patients and health care providers as they attempt to negotiate the complex intersection of multiple factors that impact on chronic pain patients and their management within health care facilities. The thesis of this research is that without critical examination of these tensions and their consequences, patients will continue to be at risk of suboptimal care and health professionals will continue to experience dissonance resulting from the inability to provide truly person-centred care. In order for change to occur, the full impact of current practices and models of care needs to be exposed, together with the marshalling of collective will and expertise directed towards a robust plan for revision of unsatisfactory and often damaging practices.

Currently, 3.2 million Australians suffer from chronic pain and this figure is predicted to escalate to 5 million by the year 2050 (Access Economics, 2007). The socioeconomic impact and burden of these conditions are significant, not only for the individual and families whose lives are interrupted and disrupted by chronic pain, but also for health care budgets and society more generally. The estimated cost of chronic pain to the Australian economy has been reported by Access Economics, (2007) to be AUD 34.3 billion per annum or AUD 10,847 per person suffering with chronic pain. The Australian Health Care System reportedly contributes AUD7 billion per annum toward providing care for patients suffering with chronic pain complaints (Access Economics, 2007).

## 1.2 Background of the study: Managing persistent pain in the context of contemporary health care

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The past three decades have provided exponential growth in our understanding of the biological, biochemical and psychosocial bases of pain processing. These developments have allowed significant improvements to be made in the management of pain, thus reducing the suffering of patients. In addition, multiple sophisticated, pharmacological, therapeutic and procedural advances have been made in clinical practice. However, these developments have not necessarily translated to improved patient outcomes. Despite the extraordinary advances, many people continue to suffer from unrelieved pain, and for some, the situation has been worsened by an over reliance on curative expectations on the part of health practitioners.

Persistent abdominal pain, arguably the most compelling and illustrative case, highlights this assertion. Confining a multidimensional, multimodal phenomenon such as the experience of pain, to a mechanistic appreciation of cause and effect, with a similar expectation of intervention and subsequent cure, is likely to result in patient disappointment, and, in turn, to clinician frustration. However, as a society, we have come to expect nothing less than a diagnosis for which a cure is readily available.

Patients who suffer from persistent abdominal pain illustrate the consequential and deleterious outcomes that follow when an acute care paradigm is applied to the management of patients with chronic and complex care needs. Typically, these patients have long associations with acute care facilities due to multiple hospital admissions and prolonged hospital stays. They have long and difficult medical histories, they access multiple health care providers and they utilise disproportionate amounts of health care resources as a consequence of numerous, repeated, extensive and invasive investigations and treatments, including surgeries. Despite considerable health care inputs, these patients' overall health and experience of pain tends to deteriorate rather than improve (Charles & Miller, 2008; Drossman, 2008; International Association for the Study of Pain [IASP], 2012).



The evidence suggests that best practice for the management of patients who suffer from chronic pain includes a multidimensional approach delivered within a comprehensive multidisciplinary specialist pain service (Kames et al., 1990; McGarrity et al., 2000; Gatchel et al., 2007; Kerns et al., 2011). However, despite the introduction of multidisciplinary chronic pain management teams and centres, many chronic pain sufferers do not have access to appropriate forms of treatment (Cousins, 2012; Hogg et al., 2012; Semple & Hogg, 2012). As a result, patients continue to be cared for within the acute care hospital system. This has proven to be problematic, as these patients are repeatedly exposed and conditioned to the acute care system, the biomedical model that underpins it, and the reactive and curative paradigms that direct much of the care delivery. In addition, utilising an acute care model for the management of patients with chronic and complex conditions has been shown to compound the problem of ongoing pain and disability for this patient group (Gourlay et al., 2005; Thompson & Wolfe, 2005).

In order for a contemporary, evidenced-based model of care to be developed for these patients, better insights must first be gained into the effectiveness or otherwise of the current model of care utilised for their management. In addition, appreciating how patients, carers and clinicians have come to understand and respond to their respective situations within the phenomenon will expose the evolution and maintenance of particularly unhelpful behaviours that can conspire against the goals of optimal health for patients and reduction in hospitalisations.

This study evolved as a pragmatic response to requests from work colleagues for the author to conduct a study to provide some understanding of the phenomenon of persistent abdominal pain as it exists within the acute care setting of an Australian tertiary referral hospital. Empirical evidence is required to substantiate anecdotal reports suggesting that this patient cohort has a significant and deleterious impact on the utilisation of clinical services and system operations within the health care facility. The premise of anecdotal reports was that hospital system efficiency and outcomes are impacted through bed and access block, which results in increased lengths of hospital stays for many patients, increased elective surgery waiting list times, as well as an

increased number of unplanned separations and hospital admissions. Clinically, persistent pain sufferers are among the most difficult and complex patients admitted to the facility. They are difficult to identify early in their trajectory and respond poorly to conventional medically based treatments. Additionally, they are often at the centre of clinical encounters characterised by tension, conflict and hostility. These difficult clinical encounters typically emerge from conflicting treatment paradigms used by various treating clinicians, and disparate patient, carer and health professional treatment objectives.

Hence, this study began as a naturalistic enquiry to explore the multiple, holistic and constructed realities that existed for stakeholders at the centre of the study phenomenon. Subscribing to a philosophical tenet that was concerned with identifying a single truth or antecedent that could be generalisable outside 'time and context' was incongruent with appreciating stakeholders', particularly patients', lived experiences of persistent abdominal pain. Acknowledging the philosophical view that people construct their own understandings of reality and that realities are assembled intersubjectively via the meanings and understandings developed socially and experientially was commensurate with the researcher's belief that study stakeholders (including the researcher) would function as co-constructors in producing the knowledge, understandings and interpretations required to inform efforts to improve clinical practice (praxis) surrounding the management of persistent abdominal pain (Guba, 1985; Guba & Lincoln, 1994; Lincoln et al., 2012).

Further, the paucity of published work describing the phenomenon of persistent abdominal pain from multiple stakeholder perspectives and the related impact the phenomenon has on patients, carers, health care professionals and the health care system underpinned the need for a naturalistic enquiry. Accessing contextually based understandings about how events, processes and practices influence stakeholders' experiences, is necessary if improved care is to be achieved for patients who remain entrenched in the acute biomedical model despite suffering deleterious outcomes, and being on a trajectory toward deteriorating health.

### **1.2.1 Study purpose and aims**

The primary aim of the study was to critically review the experiences, expectations and perceptions of stakeholders (patients, carers and health professionals) central to the construction of the phenomenon of chronic abdominal pain. In addition, the study aimed to identify those clinical practices and organisational procedures, embedded within the current model of care that could be identified as constraining good patient outcomes. Finally, the study was concerned with gaining stakeholder consensus regarding an alternative treatment approach for current and possibly emergent patient cohorts with persistent abdominal pain.

### **1.2.2 Research aims**

Specifically, the study aimed to:

- Identify patients who regularly present to the hospital study site with persistent abdominal pain and to identify those clinical speciality groups and individuals most often utilised for the management of these patients
- Quantify health care utilisation for the selected cohort within a defined timeframe
- Identify system and process issues that either impede or facilitate optimal management for patients presenting with persistent abdominal pain to the study site hospital
- Qualify major stakeholders' experiences and perceptions of the suffering of, the support provided for and the care delivered to patients with persistent abdominal pain, both within the acute care environment and the community
- Identify and gain broad agreement (from all stakeholders) around the principles and essential elements of a revised model of care to better manage patients when they present with acute symptoms to the study site hospital
- Facilitate clinician engagement, ownership, commitment and mobilisation in identifying and implementing a revised model of care for the identified patient cohort.

### 1.2.3 Research questions

- i. What are the experiences, expectations and perceptions of stakeholders (patients, carers and health professionals) central to the construction of the phenomenon of persistent abdominal pain?
- ii. What are the nature, extent and impact of repeated hospital presentations on stakeholders in response to unresolved persistent abdominal pain?
- iii. What would need to change in order to provide a more efficient and effective model of care for current and emerging patient cohorts with persistent abdominal pain?

### 1.2.4 Study site and participants

The study was conducted in an Australian tertiary referral hospital located within a large Local Health District (LHD) in regional NSW. The LHD services approximately 840,000 people covering a geographical area of 130,000 kilometres. Participants were patients suffering from persistent abdominal pain, their carers and the clinical staff involved in the care of these patients. The patients, and often their carers and families, were well known to the clinicians and to the hospital management. Clinicians included professionals across a range of disciplines who were employed by the hospital in the Emergency, Gastroenterology, Surgical, Psychiatry, Allied Health and Pain Management Departments, as well as General Practitioners (GPs) involved in the patients' care.

### 1.2.5 The Australian context

The introduction of specialist pain management services into the Australian health care arena began to emerge in the mid to late 1980s (Macintyre et al., 1990; Breivik, 1995). The advent of these services brought significant improvements to the clinical outcomes for patients, particularly for those suffering with acute postoperative and post-trauma pain. Historically, patients with significant acute pain following extensive surgery and traumatic events were cared for within intensive care units or similar specialist services. Typically, these patients would be intubated and ventilated to provide them

with significant analgesic doses, and as a consequence of the technical complexities required to humanely manage their acute pain without serious side effects.

Following advances in scientific understandings about pain processing within the central and peripheral nervous systems, pharmaceutical companies began formulating new and improved medications (opioids, non-steroidal anti-inflammatories [NSAIDs] local anaesthetics, membrane stabilisers and antidepressants) to enhance clinicians' ability to provide superior analgesia, with fewer side effects (Schug et al., 1995; Schug, 2006; Schug & Manopas, 2007). As a result of the dose-sparing capacity associated with these improved preparations, in addition to improved understandings of pain pathways, clinicians began to employ multimodal approaches in the pharmacological management of pain. For example, the used opioids, NSAIDs, local anaesthetics, membrane stabilisers and antidepressants concurrently for the management of acute, subacute and some chronic pain conditions.

Following these developments in clinical approaches, medical product companies refashioned old and designed new and more advanced delivery systems (patient-controlled analgesia [PCA] pumps, peripheral nerve catheters, patient-controlled epidural analgesia [PCEA], spinal cord stimulators [SCSs], and intrathecal delivery devices [ITDs]) to better manage pain. Consequently, advanced technologies and pharmacological preparations flooded the clinical arena, particularly the acute care environment. As a consequence, patients in hospitals were being provided with superior analgesia via increasingly sophisticated technology.

At the same time, skilled and specialist teams formed under the banner of an Acute Pain Service (APS) program began providing clinical support and expertise and focusing attention on improving pain management as mainstream hospital care. Collectively, these events led to the development of a highly specialised and technically oriented approach toward the management of acute, subacute and post-trauma pain.

Undoubtedly, these clinical advances generated many improved patient and system outcomes. Patients no longer requiring extensive medical treatment (through intensive

care admissions) were now managed within the general ward areas of the hospital. Consequently, generalist ward clinicians were required to provide clinical care for patients with increasingly more sophisticated forms of analgesia and these clinicians gained improved knowledge about pain and evolving pain treatment approaches (Breivik, 1995; Barton et al., 2004). Clinicians previously confronted with difficult-to-resolve pain management situations now witnessed the successful treatment of patients reporting clinically uncharacteristic symptomologies of pain patients who had previously been relegated to the psychological scrap heap in the belief that such pains were 'all in their head'. For example, phantom limb and neuropathic pain were now responding to new and improved pain management approaches. The emergence of these events, while providing significant improvements in clinical and humanitarian outcomes for patients and economic benefits for hospital administration, worked to reinforce adherence to orthodox medical expectations regarding diagnosis and cure, particularly as it related to the management of pain.

Whilst managing pain is fundamental to all health care professionals' clinical responsibilities, the exponential growth in knowledge and the production of new and innovative ways of applying this knowledge stimulated the evolution of pain as a clinical speciality. Pain specialist services, whilst originally dedicated to the safe and efficient application of improved management approaches in the acute postoperative hospital setting were subsequently joined by chronic pain outpatient services. These services, responding to the continuum of pain (acute, subacute and chronic cancer and non-cancer pain), began to emerge both nationally and internationally in response to not only new found biological, pharmacological, procedural, and therapeutic knowledge and applications but also to emerging approaches for managing the psychosocial and behavioural aspects of, in particular, chronic pain. These events were being reflected in the proceedings occurring at the study site facility. As managing pain gathered increased prominence within the hospital, and the clinical benefits of these revised approaches accrued, demand for pain management-related services increased.

Increasingly, the APS was being called upon to:

- be more proactive toward the pre-emptive management of patients at risk of progressing to chronic pain states
- assist in the management of patients with persistent pain problems during times of hospitalisation resulting from acute exacerbations, and
- manage patients with cancer and non-cancer pain complaints who required more specialised and invasive pharmacological, procedural and interventional approaches to pain management

In the case of the APS at the study hospital site, this expansion included consultative services beyond the inpatient group, resulting in outpatient clinics being established to accommodate the increased demand. These medically focused services were provided by the APS located adjacent to the recovery ward and were highly technical, procedural and pharmacological in nature. Thus, the evolution of a comprehensive, multidisciplinary, multimodal and biopsychosocial approach to the management of pain within the study site was firmly embedded in the biomedical model of acute curative care.

This historical context is significant since it provides the backdrop to how patients with persistent abdominal pain became known to the APS and later the Chronic Pain Service (CPS). Clinicians challenged by patients' frequent and repeated admission to the hospital for symptoms largely associated with refractory pain, and complicated by disproportional responses to conventional medical approaches, often referred such patients to the pain service for consultative input. Initially, these patients were referred to the APS in a bid to optimise pain management approaches during inpatient admissions. Later, with the introduction of the CPS, such patients were also referred to the CPS to help improve their pain management in the community. Patients with persistent abdominal pain represent such cases. It was within this context that the study was envisaged and undertaken.

### 1.3 Locating myself within the study

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I began my nursing career in the early 1980s in a small Australian country hospital. It was here that I was first introduced to the presiding, dominant and somewhat revered biomedical model and the notion of nursing work as facilitative to the enacting of the medical model. This is not to say that the nurse educators, mentors and role models who influenced me during these years subscribed to that dominance in a way that denigrated nursing or those who chose to dedicate their working lives to the profession. On the contrary, it was here that I learnt to be technically competent, and to navigate the biomedical model with confidence and competence, whilst simultaneously quietly and attentively engaging in the covert work of nursing. It was an interesting time, and only after reflecting on the past 30 years of being a nurse can I appreciate the influences that these earlier experiences have had on both my professional and personal development.

In describing my nursing career to date as predominantly technical in orientation, my intent is not to overlook the skills and competencies I gained during this time but rather to highlight the evolving domains of practice inherent within my socialisation as a health care professional. The term technical is used to refer to that work that enabled me to be clinically and technically competent in providing care for patients. The work I describe as nursing, is that which I enacted from a more holistic platform, the ability to integrate my technical skills and humanistic capacities to provide care for patients, an approach that I became more comfortable with and cognisant of in the later years of my nursing career. In discussing the evolutions of these work orientations, I am not inferring the differing domains are mutually exclusive or that one was more important than the other. However, in the context of a culture that highly regards the biomedical, and in doing so values the technical over the holistic, integrating both domains of practice produces significant challenges, particularly for novice nurses. Being able to concentrate my efforts within pain management offered an opportunity to explore my desire to be recognised as technically competent while being attentive in recognising that people's needs extend beyond those that can be addressed solely by technical medical interventions.



My involvement with pain services has been extensive. From the original development and implementation of acute pain services, my role as a nurse consultant in pain management has been fundamental. I have witnessed first-hand the transforming landscape of managing pain (acute, chronic and cancer pain) within contemporary health care.

During my 15 years working in pain management, I helped facilitate the development of an APS and a Regional Multidisciplinary CPS in NSW, Australia. During this time, I maintained both a strong clinical role as a Clinical Nurse Consultant (CNC) and a managerial role as Service Director. In these roles, I was responsible for overseeing the development and implementation of multidisciplinary pain services responsible for the management of acute and chronic cancer and non-cancer pain. Within my clinical capacity, I was responsible for the provision of specialist based nursing knowledge to ensure the safe and effective introduction of new and expanding clinical approaches being introduced at the hospital and regional level. The early days of developing and implementing acute pain services resonated comfortably with my technical and biomedical skills, competencies and affiliations. However, as the pain services clinical directives expanded to account for chronic, malignant and non-malignant pain, I was faced with having to evolve beyond these comfortable boundaries and gain further confidence and competence in my nursing work. This was necessary, as I frequently encountered and later became responsible for those patients who become labelled 'difficult', who represent the limitations of biomedicine, and for whom such approaches seem to produce poor outcomes. My commitment to this evolving multidisciplinary speciality, and the greater insights and appreciations I gained from working within a multidisciplinary team (which was also considering the multidimensional experiences of patients in pain as a means to providing therapeutic interventions) was where I wanted to practise as a nurse. Hence, a desire grew to redirect my nursing efforts towards the broader perspectives reported on in this study.

I have enjoyed the benefits of collegiality with medical colleagues, which has been the impetus for many of my professional achievements. Undoubtedly, acquiring a level of technical expertise (the social capital needed to thrive in health care, particularly in the

acute care arena) has provided a foundation for building mutual respect and collegiality. However, I see this expertise as the common ground from which I have been able to engage my colleagues in an attempt to enact my nursing work, in much the same way that any other craft group operating within the health care divisions of labour operationalise their respective professional mandates. Additionally, I have formed enduring relationships with medical colleagues in the pursuit of improving patient care in the acute care clinical arena and in the community. They have supported me in my early endeavours of implementing an APS and subsequently a CPS within the LHD. In addition, these colleagues have supported many research and clinical improvement activities and service initiatives that I have championed; they have also been supportive of my professional development, including my desire to complete doctoral studies.

The purpose of this section was to illuminate the powerful forces of my professional preparation and in turn illustrate the constructed and contextual nature of my position in relation to issues involving health, illness and health care provision. In examining this background, through critical reflection, my intention was to present the foundations from which my assumptions and preconceptions may have come to influence the conceptual, theoretical, and interpretive tenets of the research reported within this thesis.

## **1.4 Significance of the study**

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Although previous research emphasises the challenges associated with diagnosing and treating persistent pain, there have been no studies that focus specifically on chronic abdominal pain, particularly from a whole of phenomenon perspective. Further, the omissions within the literature in relation to the impact that chronic abdominal pain has on patients, families and health professionals needs to be addressed if progress is to be made in improving outcomes for this overlooked patient population. The lack of empirical data both nationally and internationally makes this patient population particularly vulnerable to receiving suboptimal care, and hence underpins the need for the study.

A better understanding of patient characteristics, including patterns of current health care utilisation, evaluations of current models of care and consideration of patient, health care provider and family expectations, experiences and perceptions of current treatment regimens will help identify treatment inadequacies. This understanding can be directed toward advocating for more contemporary, evidence-based approaches to therapies.

The proposed study is significant in that it will help move current understandings beyond anecdotal evidence, to identify current capacity and barriers to a more effective and appropriate model of care for this specific group of patients. It will benefit health professionals dealing with difficult clinical decisions regarding the clinical management of patients with persistent abdominal pain, inform more cost-effective regimens and most importantly help to provide a more patient-centred service with improved outcomes for patients and their families.

## **1.5 Structure of the thesis**

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Having provided the background to the study in Chapter 1, the relevant literature is reviewed in Chapter 2. This is followed by a discussion on methodology and the conceptual framework guiding data collection and analysis in Chapters 3 and 4. In Chapter 5, quantitative data are presented. These data were collected to identify the patient cohort, gain an appreciation of the impact that pain has on their lives, and the impact it has on health systems and services. These data provide a composite profile of patient participants that identifies the nature, extent and impact that persistent abdominal pain has on them and other stakeholders at the centre of the study phenomenon. Chapter 6 describes the experiences of patients, family members/carers and health care professionals at the centre of the phenomenon, so as to identify factors contributing to the maintenance of unhelpful health-related behaviours and to provide insights into potential improvements in clinical management that might translate to better health outcomes for the current and emerging patient cohorts with persistent abdominal pain. Finally, in Chapter 7, a summary, discussion and synthesis of the study findings are presented. Recommendations are made for a revised model of care

that might be more appropriate for managing present and future patients who suffer from chronic abdominal pain. Limitations of the study and suggestions for further research are also provided.

## **1.6 Conclusion**

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This study resulted from a desire to illustrate and unravel the complexity associated with existing practices and to improve care delivered to patients with persistent abdominal pain. The utilisation of both qualitative and quantitative methods was deemed necessary to understand the complex nature of the phenomenon being investigated. The research was designed to answer questions addressing the impact that chronic abdominal pain has on patients and their carers, whilst at the same time considering their impact on health care utilisation.

It was anticipated that the study findings, together with recommendations from the literature, would inform the development of a more contemporary, evidenced-based model of care for patients suffering persistent abdominal pain.

## Chapter 2 Engaging with the literature

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### 2.1 Introduction

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Chapter 1 introduced the phenomenon at the centre of this research project and highlighted the impetus for undertaking the study. Chapter 2 presents a synthesis and critical review of the literature, identifying what is already known of the phenomenon and positioning this study within the existing body of knowledge and theory.

The body of literature related to pain is vast. Researchers from almost every domain of medical, health and related service practices have contributed. The emergence of pain discipline-specific journals, in addition to the increased frequency with which the topic features across diverse disciplinary journals is testimony to the prominence the phenomenon has within clinical practice internationally. The diversity of disciplinary and theoretical perspectives and empirical approaches (qualitative and quantitative) employed by authors and researchers requires a review method that subscribes to what Smythe and Spence (2012, p.12) propose as one, “deriving from a Gandamerian perspective”. That is, conducting a literature review for which the purpose is beyond:

...simply laying down pre-articulated knowledge, merely to show a gap in the literature, or as a means to argue the catalyst for ongoing research ...//... (Instead) the key purpose of the endeavour is to provide context and to provoke thinking ...//...the process and outcome is a reflexively critical understanding of the pertinent literature (2012, p.14).

Approaching the review from this perspective allows the researcher to engage with the literature, the “treasure house of knowledge” (Gandamer, 2007) that is not only in keeping with the methodological approach, but also ensures that “fore-understandings” are kept open and engaged, for the purpose of promoting emergent thinking on the phenomenon of interest (Smythe & Spence, 2012).

In this study, this approach was important because there was a need to set aside my preconceived ideas as outlined in Chapter 1 and allow the stakeholder narratives to emerge and evolve into one overarching and composite narrative involving

descriptions that would enable deeper interpretation and critical appraisal of what had actually happened over a number of decades. It involved: i) those individuals who had taken a journey with chronic abdominal pain as a feature of their daily lives and ii) the carers and the clinicians whose stories were inextricably linked to the patients' narratives. It also considered these events within the broader medico-sociocultural and political landscape upon which they were occurring. Employing an interpretive descriptive framework required the researcher to engage initially with the literature to help design and direct the study, and then to re-engage with additional literature in a dialogic partnership between the study findings and the relevant literature (Smythe & Spence, 2012). These are processes that gave the researcher access to emergent thinking about the study phenomenon, and they provided an approach described by Thorne (2008, p.35) as being one that:

...creates the context in which engagement with the data extends the interpretive mind beyond the self-evident – including both the assumed knowledge and what has already been established to see what else might be there. (Hence offering) ...//... the potential to deconstruct the angle of vision upon which prior knowledge has been erected and to generate new insights that shape new enquiries as well as applications of evidence to practice.

Thorne defends the utility of such an approach by claiming:

We desperately need new knowledge pertaining to the subjective experiential, tacit and patterned aspects of human health experience – not so that we can advance theorizing, but so that we have sufficient contextual understanding to guide future decisions that will apply to the lives of real people (Thorne, 2008, p.36).

Therefore, rather than providing a systematic review of the infinite number of concepts inherent within the phenomenon of pain, it seemed more appropriate to consider the literature from a broader, more conceptual and contextual orientation. Hence, the researcher elected to consider or problematise the situation within context and respond to the literature hermeneutically. This approach was primarily motivated by the need to access a heuristic approach and hence a reconceptualisation of the phenomenon that could effectively be translated into meaningful clinical practice improvements (Thorne, 2008; Smythe & Spence, 2012).

## 2.2 Processes guiding engagement with the literature

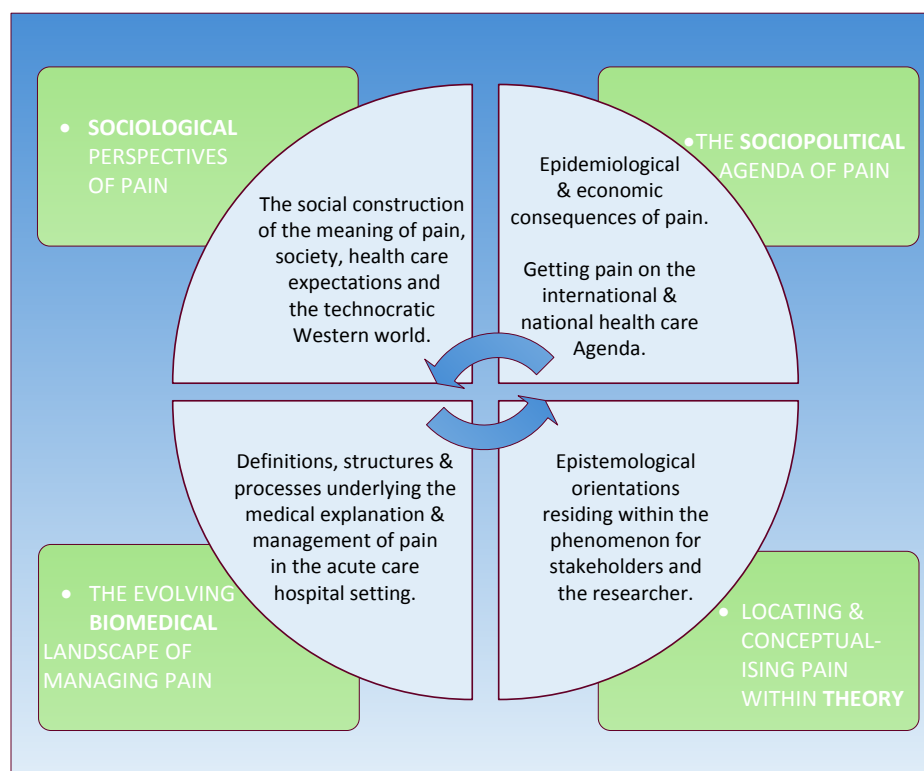
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Four overarching concepts were utilised to guide engagement with the literature reported on in this chapter (Figure 2.1). Using the organisational constructs of the sociological perspectives of pain, the sociopolitical agenda of pain, the evolving biomedical landscape of managing pain, and, locating and conceptualising pain within theory, supported an engagement with the literature that Smythe and Spence describe as an “essential dialogical partnership” fundamental to producing “scholarly thinking and new insights” (2012, p.12).

An ongoing and cyclical engagement with the literature was conducted initially from an historical and sociopolitical perspective and then the focus turned to the more pertinent and contemporary clinical issues related to the study phenomenon. This process is described by Smythe and Spence as a:

...restless back and forth process between tradition and the experiencing, interpretive person...//...  
(that enables the) successful completion of the act of understanding...//...(which) requires not only  
a consciousness of one’s historical horizon but an appreciation or an examination of its effect (2012,  
p.13).

Both seminal as well as more contemporary literature (2000–2012) was used as part of the review. The databases accessed were: Medline, Embase, PsycINFO, the Cochrane library and CINAHL. In addition, grey literature consisting of government websites, conference papers and theses and official government and health service publications and statistics along with seminal texts and books (non-fiction) were reviewed. This type of literature review is conceptual and critical and necessarily moves across disciplinary knowledge in search of disparate and alternative explanations that engender deeper philosophical understandings, rather than providing a recount of pre-articulated knowledge (Smythe & Spence, 2012).



**Figure 2.1 Organisational Constructs Guiding Engagement with the Literature**

## 2.3 Perspectives on pain

### 2.3.1 Historical medical and sociopolitical perspectives

The delivery of health care is not enacted in a social vacuum; rather it reveals the social and cultural conditions of society at large, reflecting the political, economic and religious agendas of the time. To this end, the enactment of health care service provision represents constructed social conditions and priorities that have acquired, through public demand and expectation, a sanctioned salience. The conceptualisation and hence treatment of pain provides a particularly illustrative account of this. This assertion has been discussed by countless authors and is eloquently described by Morris in his book *The Culture of Pain*, where he claims:

Our culture, our Western, industrial technocratic world has succeeded in persuading us that pain is simply entirely a medical problem...//... Doctors who serve as shorthand for the entire system of modern health care, play a large role in the cultural construction of pain because the scientific worldview of medicine so thoroughly dominates our society (1993, p.2).

Golub (1997, p.10) concurs with Morris stating, “most of us have been reared with the heroic version of scientific and medical history and that we have come to expect



medical science to find the equivalent of the ‘magic bullet’ to cure chronic diseases”. Golub’s early contentions have been echoed by many authors such as Illich (1975/2010) who suggests life has been “medicalised”, and in many contemporary authors’ works (Broom, 2007; Bortz, 2011; Lupton, 2012) as they agitate for a new paradigm in medicine. The latter is, described by Bortz (2011, p.9) as a “rebalancing of disease ‘Panacea’ medicine, and health ‘Hygeia’ medicine” that shifts precedence of health care from the dominant focus of repair of health, back to medicine’s original mission of the preservation of health. Bortz (2011) suggests that this conceptual shift from a disease-centric to a health-centric model needs to be the foundation from which, as he refers to it, *Next Medicine* must proceed.

Thomas Kuhn (1997) an historian of science, and noted author on scientific revolutions coined the term ‘paradigm shift’ to describe the emergence of an alternative approach to conceiving and managing problems. He asserts that such paradigm shifts are preceded by a pronounced professional insecurity generated by the persistent failure of the puzzles of normal science, or of politics, to come out as they should. Thus failure of existing rules he suggests, is the prelude to a search for new ones. Medicine and health care have transited a number of paradigm shifts over the millennia. Considering briefly those that have occurred within the arena of pain management is fundamental in helping provide insight into how we could envisage the future. Morris (1993) supports such an approach, stating:

It is the past that helps us understand how we got where we are now. It is where the future begins...//...it is only knowledge of past pain that will allow us to understand the future *as* future, not just the present in disguise...//... [pain, he suggests], is always historical – always reshaped by a particular time, place, culture and individual psyche (1993, p.6).

It is to these paradigm shifts that the following discussion now turns – those shifts in thinking that have characterised the conceptualisation and management of pain within contemporary health care. These have provided the medico-sociopolitical landscape upon which patients have received and health care professionals have delivered, care for chronic and in particular, persistent abdominal pain.

## 2.4 Understanding the nature of pain: From dualistic to holistic perspectives

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The field of pain has traditionally been dominated by biomedicine and the pursuit of elucidating neurophysiological pathways so as to improve the medical management of its sensory dimension. This becomes readily apparent when reviewing the literature on the phenomenon. Early medical and health-related literature concerned with pain are replete with numerous studies detailing the significant advances in understandings about the biological, biochemical, neurophysiological and neuro-immuno-physiological pathways involved in the sensory dimension of pain. As basic scientists discovered more detail regarding pain processing pathways, within ascending and descending spinothalamic tracts of the spinal cord, opportunities to modulate these pathways and hence reduce people's suffering became apparent. The potential of translating these increased biological understandings into clinical practice was quickly realised. Pharmacological companies re-engineered the old and developed new analgesic preparations, particularly opioids. Concurrently, medical supply companies developed specialised devices and delivery systems to better isolate and treat discrete pain pathways, for example, spinal cord stimulators (SCSs) and intrathecal devices (ITDs). Consequently, the momentum and exponential growth in activities directed toward elucidating and managing the neurophysiological aspects of pain, were focused in such a way that they resulted in the phenomenon being largely "medicalised" (Wolf & Thompson, 1991; Morris, 1993; Bendelow & Williams, 1995; Stanton-Hicks & Hassenbusch, 1995, 1996; Walker & Cousins, 1997; Willis & Westlund, 1997; Melzack et al., 1999; Wolf & Mannion, 1999; Bridges et al., 2001; Siddall & Cousins, 2004; Loeser, 2012; Lupton, 2012).

Whilst philosophers, sociologists and social commentators have always commented on and sought to extend dualistic appraisals to accommodate more sociological and phenomenological conceptualisations, such works feature infrequently in emerging pain literature, particularly as they relate to the clinical management of pain. Behaviourists', psychologists' and psychiatrists' work relating to the experiential nature of pain and the impact of behaviour, culture, personality and psychology slowly

became more prominent in the literature and this pattern accelerated from the mid to the late 1990s (Fordyce, 1976; Sternbach, 1986; Craig, 1994; Gamsa, 1994; Asghari & Nicholas, 1999; Turk, 1999; Nicholas et al., 2000; Keefe et al., 2005; Gatchel et al., 2007; Hinrichs-Rocker et al., 2009; Kerns et al., 2011).

Table 2.1 chronicles the concurrent trajectories of pain conceptualisation and the consequential key clinical management approaches that have influenced the treatment of pain over time. The historical developments of understanding the nature of pain and attempts to move from dualistic to more holistic conceptualisations represent the dominant paradigmatic shift that has characterised postmodern approaches to appraising and managing the phenomenon. The major sources, their key elements and the accompanying translation into clinical application are diagrammatically represented in order to provide a comprehensive distillation of the contextual medico-sociopolitical contexts within which these events have occurred.

**Table: 2.1 Concurrent Trajectories Affecting the Conceptualisation and Management of Pain**

CLINICAL / MEDICAL TREATMENT TRAJECTORY	SOCIOPOLITICAL CONTEXT	YEAR	BASIC SCIENCE / RESEARCH TRAJECTORY	PSYCHOSOCIAL / BEHAVIOURAL TRAJECTORIES
	<b>Foucault</b> – The Birth of the Clinic/Hospital	1664	<b>Descartes</b> – Stimulus Response Model	
		1803	<b>Surturner</b> – Cocanisation	
		1811	<b>1811 Bell</b> – Specificity Theory	
<b>1861 Bier</b> – Intrathecal analgesia		1861		
<b>1885 Corning</b> – Epidural analgesia		1885		
<b>1890 Quinche</b> – Lumbar dural puncture		1890		
		1894	<b>1894 Von Frey</b> – Cutaneous categorisation senses in periphery	
Salicylates – Aspirin (pre-prostaglandin period 1897–1970)		1897–1901		
<b>1900 Pitesti</b> – IT Opioids				
<b>1901 Katawata</b> – IT Morphine				
		1920	<b>Head</b> – Thalamus is Pain Centre in Brain	
<b>1933 Doglioti</b> – Epidural		1933		
<b>1943 Lofgren</b> – Lignocaine	<b>1943</b> Emergence of Biomedicine attributed to: <u>Rationalisation</u> : rise of modern scientific knowledge <u>Sensitisation</u> : modern medical knowledge replacing religious belief about sickness <u>Differentiation</u> : separation of religion from medicine and emergence of specialised medical profession		<b>1953 Bonica</b> – Pain Fibres	<b>1956 Beecher</b> – Pain Environment Describing cognitive impact, expectations, emotional state on pain perception therefore debunking stimulus–response model
		1943–1960s		<b>1957 Keele</b> – Spinothalamic Tracts
<b>1960 IM Analgesia</b> – Hypodermic needles	<b>1960s–1980s</b> The rise of the modern “institutional” hospital and the politicising of health care	1960		
<b>1963 IV Opioids</b>				
		1965	<b>1965 Melzack &amp; Wall</b> – Gate Control Theory	
	<b>1966 Christopherson</b> – “culture” Cultural impact on pain perception	1966	<b>Signalled end mind–body split</b>	
		1967		<b>1967 Merskey &amp; Speer</b> – Depression & anxiety
TENS; Spinal Cord Stimulation			<b>Melzack &amp; Wall</b> Revised Gate Control Theory Appreciation of synergy between ascending and descending pathways	
<b>1969 Reynolds</b> – Mechanism of opioid analgesia		1968		

**Thesis: Persistent Abdominal Pain: Challenges  
And Models of Care**

CLINICAL / MEDICAL TREATMENT TRAJECTORY	SOCIOPOLITICAL CONTEXT	YEAR	BASIC SCIENCE / RESEARCH TRAJECTORY	PSYCHOSOCIAL / BEHAVIOURAL TRAJECTORIES
NSAIDs; Post Prostaglandin Period multimodal analgesia	<b>Bromage</b> – “modernised epidural analgesia” – surgery, obstetrics, pain management	1970s–1980s	<b>Nociception &amp; neuropathy</b> Nociception, neuromodulation & neurotransmitters	<b>1972 Beecher</b> – “Emotional Impact” Pain perception, Cognitive, Personality, Anxiety & Cultural Impact on Pain Behaviour
	<b>1973 Bonica</b> – 1 <sup>st</sup> symposium on Pain IASP Association formed and introduced	1973		
		1974		<b>Lozer</b> – Behavioural management <b>Sternbach</b> – Pain is primarily psychological experience
	<b>1975</b> 1 <sup>st</sup> World Congress on Pain 1 <sup>st</sup> quarterly Journal Pain			<b>1975 McGill</b> – Questionnaire measure emotional & affective behavioural component of pain – “still tendency to psychopathologise emotional reaction to pain – perpetuating mind–body divide”
		1975		<b>1976 Fordyce</b> – operant behavioural model & role of social contingencies on pain behaviour
			<b>1977 George Engel</b> proposed the biopsychosocial model whereby illness exists within a matrix of biological, psychological and social issues	
		1977		
PCA Devices	1 <sup>st</sup> list pain definitions Australian Pain Society formed as a chapter of IASP	1979		
NMDA receptor	“Pain is a basic human right” IASP		<b>Neuropathic/central pain mechanisms &amp; processes elucidated</b> Neuropathic pain, dorsal horn & windup	
Pre-post op epidural analgesia		1980–1990s		
IT opioids				
Spinal cord stimulators				
– Implanted devices				
			<b>1983 Elton</b> – “all organic pain has a psychological component” <b>Turk et al.</b> – Cognitive behavioural perspective	
	<b>Searle</b> – 1 <sup>st</sup> Acute Pain Service AHCPR clinical practice guidelines for management pain including cancer			
	<b>McQuay &amp; Moore</b> Oxford Pain Research Group 1 <sup>st</sup> publication IASP Taxonomy of Pain	1986		
	<b>1987</b> IASP affiliation with WHO			
	<b>1989</b> Formation of IASP Special interest groups (paeds, central pain, etc.)			
PCEA		1990–2000	<b>Neuroplasticity</b>	

**Thesis: Persistent Abdominal Pain: Challenges  
And Models of Care**

CLINICAL / MEDICAL TREATMENT TRAJECTORY	SOCIOPOLITICAL CONTEXT	YEAR	BASIC SCIENCE / RESEARCH TRAJECTORY	PSYCHOSOCIAL / BEHAVIOURAL TRAJECTORIES
COX1, COX2 – coxibs	Management of Acute Pain IASP Pub.	1992	neuroplasticity – pain genetics “physiological and pathophysiological (clinical) PAIN	Flore et al. – meta-analysis, cost effectiveness of interdisciplinary pain management
	1994 2 <sup>nd</sup> publication IASP Taxonomy of Pain	1994		
	1997 NHMRC Scientific Evidence for management of Acute Pain and subsequent proliferation of pain management services worldwide	1996	1996 Turk & Monarch – Biopsychosocial Model	
	1998 US launched National Pain Management Strategy US congress designates 2001–2010 the Decade of Pain Control & Research	1997		
Refinement of all technologies for local, systemic, epidural, intrathecal and spinal cord stimulation hardware		1998		
		2000–2012	Pain as a disease “Siddall & Cousins” – pain is not a nonspecific symptom of a disease IT IS A disease with pathology, signs & symptoms	
Clinical practice guidelines for the management of pain, particularly acute pain in hospital settings	JACO-accredited standards Pain Assessment & Treatment	2001	Pain catastrophising (2001) Fear avoidance (2000) Low self-efficacy (1988)	Lack of perceived control (1988) Passive pain coping (2003)
	2003 American Productivity Report lost-cost CP \$61 billion	2003		
	2004 Global Day Against Pain & Global Year Against Pain	2004		
	2010 (Aust) National Pain Summit – National Pain Strategy Commitment QLD, WA, NSW	2010		
	2011 Declaration Montréal of World Medical Association “People have a right to appropriate pain management”			
	2011 European Chapter ‘Road-map development of Pain Services’	2011		
	2012 British Pain Summit “Putting Pain on the Agenda”			
	2012–2013 “Global Year Against Visceral Pain”			

Sources: (Fordyce, 1976; Engel, 1977; Sternbach, 1986; Woolf, 1991, 1992, 1999; Dahl & Kehlet, 1993; Gamsa, 1994; Flor et al., 1995, 1998; Schug et al., 1995; Siddall et al., 1995; Stanton-Hicks & Hassenbusch, 1995; Willis, 1997; Turk, 1999; Nicholas et al., 2000; Bridges et al., 2001; Siddall & Cousins, 2004; McMahon & Koltzenburg, 2006; Flor, 2010; Kerns et al., 2011).

### 2.4.1 Conceptualising pain as biomedical

The medicalised or mechanistic appraisal of illness is described as the Cartesian or the mind-body dualistic divide. Inherent in this dualism is the suggestion that the body as a machine, its systems and processes, is easier to understand, explain, objectify and manipulate. In contrast, the mind is more mysterious, more difficult to understand and is characterised by infinite subjective possibilities and explanations. Consequently, the eminence of first the biological over the psychological, and second the expertise of the “beneficent god-like physician” (Lupton, 2012, p.1) over the autonomy of the individual, has endured in the health care arena for millennia. This approach has offered seductive, albeit simplistic explanations of illnesses, including pain and has consequently encouraged a deferral of responsibility of individuals for their own health and wellbeing, to that of the keepers of such knowledge, that is, health care professionals (Illich, 1975/2010).

Early explanations of pain derived from Descartes’ (1644) beliefs that mathematics and science provided explanations for everything in the universe. His proposition that a hard-wired circuitry within the body was responsible for the transmission of the sensation of pain, from the skin to a pain centre in the brain, became the Specificity Theory of pain that endured as an explanation for centuries. Following these early explanations, Von Frey (1894), described the categories of preferentially sensitive (touch, cold, warmth and pain) pain receptors (nociceptors) at the periphery. In 1920, Head identified the thalamus as the pain centre of the brain and proposed the potential for the brain (cortex) to have an inhibitory role in the processing of painful stimuli. In 1957, Keele traced the ascending spinothalamic tract as containing the sensory pathways via which pain travelled from nociceptors to the brain, thereby extending Descartes’ earlier Specificity Theory. It was not until the 1960s that the Specificity Theory of pain was challenged. Prominent pain researchers and clinicians Melzack and Wall (1968) pursued explanations of pain that were not adequately explained by the Specificity Theory and the hard-wired stimulus response model it proposed. They sought explanations regarding the following questions:

- i. How can pain be felt in locations remote from the area of damage?

- ii. How can pain persist in the absence of injury?
- iii. How do the location and nature of pain change over time?
- iv. How can certain types of pain can be unresponsive to treatment, e.g. back pain, headache?

Answers to these fundamental questions would provide insight into the clinical problems clinicians were describing at the time, for example, phantom limb pain and causalgia. In 1968, Melzack and Wall proposed the seminal Gate Control Theory. The theory hypothesised that the dorsal horn of the spinal cord functioned much like a gate, having the ability to increase or decrease the degree to which pain impulses were transmitted from peripheral nerves into the central nervous system. In addition, it theorised that psychological and social variables (heavily influenced by sociocultural learning and experiences) impacted on the physiological processes in human pain perception and response. The premise of the Gate Control Theory provided the impetus for researchers and clinicians to then consider the interrelationship between the body and the mind in the processing of painful stimuli in the central nervous system. Subsequently, this hypothesis was explored by Beecher (1956/1972) and helped provide the foundation for explanations he offered in his landmark works that described the role of cognition, personality, psychology and culture in the experiential dimension of pain (Gatchel, 2005; Gatchel et al., 2007).

Although highlighting the potential for psychosocial variables to impact a patient's experience of pain, much of Melzack and Wall's subsequent research was directed toward developing Bonica's (1953) findings. Bonica identified preferential sensitivity and threshold-dependent characteristics of two different nerve fibres thought responsible for the sensory transmission and characteristics of pain. In doing so, Melzack and Wall described the A $\delta$  fibres responsible for transmitting fast acute or sharp pains into the spinal cord and the C fibres responsible for the transmission of the slower, chronic, dull aching, throbbing pains into the spinal cord (Gatchel, 2005; Gatchel et al., 2007).

Research directed toward extending these afore mentioned scientific explanations of pain, particularly those related to the transmission of the sensory stimuli, accelerated. An explosion of basic science research regarding the neurophysiological, biochemical pain pathways in addition to emerging conceptualisations of neural plasticity within the spinal cord and its



implication on refractory pain conditions dominated the 1970s. These research endeavours saw the identification of N-methyl-d-aspartate (NMDA) receptors, the identification and classification of additional opioid receptor sites, and an increased understanding of the role of inflammation in transmitting pain and maintaining some pain conditions. These developments had significant clinical implications, providing increased explanations of previously 'difficult to explain' pain conditions such as complex regional pain syndromes and hyperalgesic states, for example, neuropathic pain. In turn, these major scientific advances underpinned important clinical applications with the development of more sophisticated analgesic medications, for example newer generation opioids, NSAIDs and NMDA antagonists (Siddall & Cousins, 2004; Gatchel, 2005; Gatchel et al., 2007).

Much of the work in the 1970s and 1980s centred on making distinctions between nociception (tissue damage) and neuropathy (nerve damage) and the role of the central nervous system in processing, maintaining and amplifying some chronic pain conditions. Specifically, efforts to understand the processing of pain within the dorsal horn of the spinal cord had significant potential to influence clinical practice, and thus research in the basic science arena continued and remained heavily focused on better elucidating these pain pathways. During the late 1990s and into 2000s, modelling of inflammatory pain, neuropathic pain and cancer pain continued, augmenting established knowledge and leading to a more refined understanding, and increasingly more sophisticated treatment approaches, for example, neuromodulatory and neuro-ablative techniques. More contemporary work has begun to move toward discovering molecular and genetic explanations, the role of stress and lifestyle, and the impact on neuro-immunological pathways and their roles in the processing of pain (Siddall & Cousins, 2004; Gatchel, 2005; Gatchel et al., 2007).

In response to the exponential growth in the field of pain management, and as the momentum for implementing basic scientific research into clinical practice gathered, a new clinical speciality in pain management evolved. During the 1980s, the worldwide spread of accredited pain specialist services, and dedicated pain health care professionals began to emerge. With the advent of these new services, clinicians were implementing new and improved pharmacological preparations, refining old techniques, and utilising a vast and expanding repertoire of new and more sophisticated technologies to better manage pain.

Clinical reports recounting these experiences and numbers of clinical trials reported compelling data on the human and economic benefits associated with utilising these more efficient and effective modalities of pain treatment (Macintyre et al., 1990, 2010; Breivik, 1995, 2002, 2009, 2010; Schug et al., 1995; Kehlet, 1999).

Pain management had become a clinical speciality in its own right, and the politicising of pain gathered momentum when the World Health Organization (WHO) in collaboration with the International Association for the Study of Pain declared the management of pain “a basic human right”. This was the prevailing sociopolitical landscape upon which most, particularly in Australia, pain management services were introduced (Cousins, 2004). Hence, pain and its management had become, through the Kuhnian (1977) process of “puzzle solving”, been termed a “normal science”, a speciality in its own right, with a body of knowledge unique to its discipline requiring specialised skills to address the complex and multifactorial problems associated with its consequences (Abercrombie & Turner, 2006).

As compelling clinical outcome data amassed, there was a worldwide proliferation of clinical practice guidelines and hospital accreditation criteria for the appropriate management of pain, in particular acute postoperative pain. Around the same time the International Association for the Study of Pain (IASP), supported the introduction of National Pain Chapters throughout the Western world. Hence, pain and the management of pain were becoming visible as clinical, social, economic, political and humanitarian issues with significant ethical and moral imperatives.

Appreciating the emergence of the overarching ‘paradigm shift’ occurring in pain medicine is essential to understanding the evolution of the conceptualisation, and in turn, treatment of pain, particularly from the perspective of clinicians. The paradigm shift occurring in the context of understanding and managing pain was characterised by health professionals’ responses to advances in basic science research, particularly in relation to pain processing and neural plasticity. Clinicians’ quests to seek alternative approaches for the management of pain had the potential to lack consideration of the impact on consumers and patients and to overlook the complexity of meeting the needs of the consumers within health services. It was

necessary to consider these movements as part of the early stages of the literature review to fully appreciate these evolutionary processes and consider the potential impact on patients.

The following discussion is directed toward issues depicted within the paradigm shift (Table 2.1) in pain management within society the movement away from appraising pain from a reductionist biomedical approach toward a more holistic biopsychosocial appreciation. Acknowledging the evolution of these increased understandings and their impact on the medical response to the treatment of pain is consistent with the culture and context within which the participants in this study were treated for their persistent abdominal pain complaints. Hence, the literature related to defining chronic pain and the difficulties associated with defining chronic abdominal pain in particular, and the subsequent impact this has on clinical practice, need to be considered. One of the major issues surrounding the experiences of patients with persistent abdominal pain is the extensive resource utilisation and associated costs that occur in the context of providing health care for unresolved pain (Blyth et al., 2004). These issues also need to be discussed and considered within international, national, and for the present study, the NSW contexts. It is also necessary to examine the literature surrounding the more contemporary models of care utilised for managing patients with chronic and complex conditions such as persistent abdominal pain. Finally, consideration regarding the difficulties associated with the management of opioid therapies within the context of chronic non-malignant pain need also to be discussed.

Table 2.1 demonstrates an evolution of perspectives on pain, its derivation and ways of controlling it. Concomitant paradigm shifts in scientific appraisals of causes and effects of pain are aligned with those shifts in responses by health professionals as they attempted to accommodate the new ideas available to them in the diagnosis and treatment of patients suffering with pain.

#### **2.4.2 Diagnoses and pain: Diagnosis as labelling**

The classification of illness is fundamental to medicine. In contemporary medicine, the classification of ill health is represented by diagnostic labels. Diagnoses incorporate a constellation of signs and symptoms, the prerequisites for specific conditions that fulfil medically sanctioned categories. Hence, diagnosis is:

...integral to the system of medicine and the way it creates social order...//...organising illness, identifying treatment options, predicting outcomes and providing an explanatory framework (Jutel, 2009, p.278).

Diagnostic labels become social capital for clinicians, providing “structure to a narrative of dysfunction, or a picture of disarray, and impose official order sorting out the real from the imagined, the valid from the feigned, and the significant from the insignificant” (Jutel, 2009, p.279). For patients, diagnoses represent the currency required to legitimise their suffering and hence secure the passport required to navigate the medical landscape of health care as a “legitimate and rightful” citizen (Kleinman, 1995; Jutel, 2009; Lupton, 2012).

However, the ‘work’ of making meaning of medical diagnostic nomenclature and its explanatory rubric extends beyond the provision of sharing meanings regarding ill health. In addition to providing an organising framework of illness, diagnosis is inherently a powerful social tool. Jutel describes, diagnosis as “both a process and a label” (2009, p.278). It is in the processing of diagnosis that the social work is done. Being diagnosed gives permission to be sick; the provision of a diagnosis offers legitimacy, and legitimacy within sickness affords numerous social acceptances, namely:

- acceptance of a deviation from wellness
- permission to be exempt from the responsibilities and expectations of social participation and engagement through work, school, household duties; what Parsons (1951) refers to as a “claim of exemption” and
- permission to access services and payments (sickness and disability pensions and compensations) as a consequence of ill health (Van Krieken et al., 2006).

Brown (2008) contends that better understanding the work of diagnosis is fundamental to gaining insight into the forces that shape understandings of illness, and consequently treatments directed toward them. One only has to consider the various diagnostic inventories that underpin medical practice – The International Classification of Disease (ICD), The Diagnostic and Statistical Manual of Mental Disorders (DSM), IASPs, Taxonomy for the Classification of Pain – to appreciate how illness and disease are socially constructed. These social constructions occur principally in response to and “stemming from political action, cultural context and technological advancement” (Jutel, 2009, p.281). Evidence of this is

represented in the evolving editions, now the 10<sup>th</sup> edition of the ICD, the removal of homosexuality as a mental disorder in the DSM (as a consequence of social and political activism), and more recently, the classification of pain as a disease in and of itself on the basis of improved basic research being able to objectify and demonstrate the damage that occurs in the central nervous system as a consequence of unrelieved pain (Siddall & Cousins, 2004). Hence, this demonstrates that “sociology of diagnosis has a salient role to play in understanding health, illness and disease” (Jutel, 2009, p.294).

Jutel contends, “diagnosis takes place at a salient juncture between illness and disease, patient and doctor, complaint and explanation” (2009, p.278). In situations characterised by no discernible diagnosis, this juncture provides an opportunity for the social work, or the ‘sociology of diagnoses’ to occur (Kleinman, 1995; Brown, 2008; Jutel, 2009). When these junctures signify implausible pathways characterised by a ‘misfit’ between patient’s symptoms and biomedical explanatory models, or a discord between patient and clinician understandings, values and beliefs surrounding illness, then disruption to the social order of medicine follows. Such are the experiences encountered by stakeholders at the centre of this study.

Without adequate explanations (diagnosis) of patients’ symptoms, clinicians are confronted by illusive and inadequate aetiologies for which care is being sought. Patients then become concerned about questions of authenticity in regard to their complaint and the system is challenged, lacking suitable alternatives to assist those who do not fulfil the prescribed schemes for being granted legitimate “citizenship within the kingdom of the sick” (Sontag, 1978, p.3). “Diagnosis structures the reality of individuals, as it clarifies and sometimes explains what they experience” (Jutel, 2009, p.293). Accessing a diagnosis for pain, particularly persistent pain in the absence of proportional, discernible, objective pathology is difficult. It challenges the biopsychosocial, cultural and political ideologies upon which, illness and health care have been historically erected.

### **2.4.3 Defining chronic pain**

A taxonomy of pain terms and the classification of pain syndromes were first published in 1994. This taxonomy has been critical to the evolving speciality of pain’s developing

nomenclature and has consequently aided improved communications, understandings and the treatment of many pain conditions (Siddall & Cousins, 2004; Harden et al., 2007). The classification system accounts for the multi-axial classification of pain, and hence reflects the phenomenon's multidimensional aetiologies. As new knowledge about the clinical and scientific understandings of pain has evolved, pain terminology has been revised. The taxonomy, last updated in 2011, reflects the consensus agreements about definitions and diagnostic criteria (based on available scientific knowledge), upon which the speciality has encouraged the standardisations and applications of diagnoses and recommendations for treatments (Siddall & Cousins, 2004; Harden et al., 2007).

Pain is defined by the IASP as an "unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (Merskey & Bogduk, 1994). Chronic pain is defined as "pain of an intermittent or constant nature, lasting for three months or more" (Merskey & Bogduk, 1994). The IASP advises that the essential criterion of chronic pain is related to the cognitive-behavioural aspects. Although it serves no biological function, chronic pain can result in several physical, emotional and socioeconomic stressors on the patient, family and society.

The Cartesian approach to understanding the neurophysiological mechanisms of pain's sensory transmission (referred to earlier) has paved the way to elucidating the constellation of biological, biochemical, neurochemical, immunological, psychosocial and behavioural responses to pain. The suggestion that chronic pain has its own signs, symptoms and pathology (based on the evidence that the structure of the central nervous system alters as a result of neuroplasticity and consequently distorts and amplifies pain sensations) is the fundamental hypothesis of the more contemporary assertion that persistent pain is a disease. In their seminal paper, *Persistent Pain as a Disease Entity: Implications for Clinical Management*, Siddall and Cousins (2004) have sought to advance this reconceptualisation of persistent pain as a disease entity. The authors suggest that persistent pain meets all the criteria of being a disease in that "physiological changes occur which manifest as constellations of signs and symptoms that indicate pathology" (Siddall & Cousins, 2004, p.517). While acknowledging that pain is primarily caused by pathology, Siddall and Cousins (2004) argue that pain, either

in the absence of pathology or amplified over time, is of itself a disease; they refer to this as secondary pathology.

#### **2.4.3.1 Defining and diagnosing persistent abdominal pain**

As discussed earlier, the historical approach to medicine and diagnosis within medicine is largely based on a disease model. Constellations of signs and symptoms are classified, diagnosed and interventions directed toward the diseased or malfunctioning physiology. Hence, diagnosis tends to be formulated in terms of structural and functional failures and represents basic science and clinical understandings of the time (Van Krieken et al., 2006; Jutel, 2009).

Whilst the definition and classification of pain have improved understandings and treatments directed toward pain management, these considerations have largely been founded on the principal assumption that pain is a non-specific symptom of a disease, thus prompting attention toward underlying disease(s) causing pain. Henceforth, the disease-oriented approach to the diagnosis and treatment of, for example, acute pain adheres well to the underlying construct (Siddall & Cousins, 2004). However, in situations where significant and debilitating pain ensues in the absence of diagnosable 'organic' disease, such simplistic mechanistic appraisals provide inadequate explanations (Williams & Johnson, 2011). These events lead to confusion in the clinical arena as clinicians' roles and purposes are challenged by divergences from the normalised and socialised patterning of biomedical diagnosis and treatment. Without categorical, objective and proportional symptoms, diagnosis and explanations become illusive, treatments cannot be identified and care cannot be organised. Consequently, the social order of the biomedical environment is disrupted (McFarlane et al., 2008; Lupton, 2012).

The phenomenon of persistent abdominal pain represents a condition not readily amenable to the disease model of diagnosis and treatment. A disease in this biomedical context is defined as a "disorder with a specific cause and recognisable signs and symptoms" (Oxford Medical Dictionary, 1990). When patients present with a disorder for which a specific cause cannot be found, the fundamental tenet of diagnosis and treatment and therefore, medicine, is challenged (Williams & Johnson, 2011). These situations are difficult for clinicians and equally

difficult for patients seeking reasons for and legitimisation of their suffering. Without objective explanations or medically sanctioned and consistent diagnostic labels capable of encapsulating patients' signs and symptoms, patients in these situations are assigned numerous, vague and often interchangeable diagnoses. The variable diagnoses often attributed to chronic abdominal pain reflect the dynamic assumptions of clinicians' biomedical appreciations regarding the genesis of these patients' complaints; that is as:

- a symptom of a disease, for example, Irritable Bowel Syndrome (IBS)
- representing a constellation of inexplicable signs and symptoms, for example, Medically Unexplained Symptoms (MUS)
- a consequence of iatrogenesis, for example, Narcotic Bowel Syndrome
- a consequence of aberrant psychology, for example, Psychogenic Abdominal Pain, and now as more contemporary diagnoses filter into the literature and hence clinical practice
- reflective of the 'disease' of pain itself, for example, Visceral Hyperalgesia

Thus, accessing a definition of chronic abdominal pain is not straightforward. Difficulties associated with defining and thus diagnosing persistent abdominal pain are a consequence of the nonspecific nature and overlapping clinical features (irrespective of the underlying cause) characteristic of the phenomenon. A number of descriptive and diagnostic terms are used in the literature and therefore filter into clinical practice; these broadly refer to pain within the abdomen that has been present either intermittently or constantly for at least 3 months (IASP, 2011). Accessing a definition that provides greater specificity and hence clarity regarding the origin (organ/tissue) and mediator (chemical, mechanical or functional) of chronic pain in the abdomen is difficult and leads to confusion, particularly within the clinical arena. Table 2.2 lists the various and interchangeable diagnostic and descriptive terms most frequently used to describe chronic pain of the abdomen.



**Table 2.2: Diagnostic Labels, Symptoms & Descriptors Associated with Chronic Abdominal Pain**

A symptom of disease	Inexplicable signs and symptoms and possible psychosocial aetiologies	Pain as a disease
Organic abdominal pain Irritable bowel syndrome Gastric dysmotility Neoplasms (benign or malignant) Pancreatitis Crohn's disease Ulcerative colitis Chronic diverticulitis Cholelithiasis Cholangitis Cholecystitis	Psychogenic abdominal pain Non-organic abdominal pain Abdominal migraine Hypochondriasis Somatisation Functional abdominal pain syndrome (FAPS) Functional gallbladder & sphincter of Oddi disorder Functional gastrointestinal disorders (FGID) Functional dyspepsia Pain-predominant functional bowel disorders Functional bowel disorder	Chronic abdominal pain Persistent abdominal pain Recurrent abdominal pain Chronic non-malignant visceral pain Visceral pain Visceral hyperalgesia
Source : Wall and Melzack, 2006; IASP fact sheets on visceral pain at; <a href="http://www.iasp-pain.org/GlobalYear/VisceralPain">www.iasp-pain.org/GlobalYear/VisceralPain</a>		

In attempts to maintain congruence with the disease model, patients presenting with somatic symptoms that defy medical explanation, 'medically unexplained symptoms' (MUS), particularly those reporting significant and debilitating chronic abdominal pain, have historically been considered as having pain originating from 'organic', or 'non-organic' aetiologies (Williams & Johnson, 2011). In the absence of objective organic pathology, patients have often been assigned a psychiatric diagnosis of hypochondriasis, abdominal migraine, somatoform or conversion disorders (Morris, 1993; Kleinman, 1995; Broom, 1997, 2007; Lupton, 2012). These conceptualisations and diagnostic labels have helped perpetrate the notion that pain resides in either the body or the head and underpins sufferers being considered as discreditable or stigmatised as factitious (Cousins, 2012).

More recently, with the advent of the Rome III criteria for diagnosing abdominal, mostly gastrointestinal conditions (Drossman, 2004, 2008; Sperber & Drossman, 2011), improved clarity and specificity regarding diagnosis in this area has begun to emerge. Diagnostic labels that are prefaced by a descriptive label 'functional' are being slowly adopted in clinical practice and attempt to account for the nonspecific nature and overlapping clinical features (biological and psychological) of the phenomenon. In addition, these diagnostic labels make provisions for evolving scientific understandings regarding pain being a disease capable of generating significant symptoms in the absence of structural, organic or metabolic disease, for

example, visceral hyperalgesia (Nimnuan et al., 2001; Siddall & Cousins, 2004; Brown, 2006; Salmon, 2007; McFarlane et al., 2008; IASP, 2011).

Thus, as patients' trajectories of illness, particularly those at the centre of this study have traversed evolving medical understandings regarding persistent abdominal pain, so too have the types of diagnostic labels, and hence treatment agendas they have received during this time.

## **2.5 The prevalence and impact of chronic pain**

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Chronic pain has become a major health problem, characterised by increasing prevalence and considerable social, economic and personal burden (Blyth et al., 2001, 2004; Harstall, 2003; Gatchel et al., 2004a, 2004b, 2007; Von Korff et al., 2005; Langley, 2011). In a systematic review conducted by Harstall (2003), world-wide (North West Europe, North America and Australia) chronic pain prevalence rates are reported to be between 10.1% and 55.2%, with rates higher amongst females. Recently, Langley (2011) reported a population prevalence of 8.85% across five countries (United Kingdom, France, Spain, Germany and Italy). An epidemiological study conducted in Australia revealed that approximately 18% of a randomly sampled population within NSW reported having persistent pain defined as "pain every day for 3 of the 6 months prior to interview". Further, Australian prevalence of chronic pain is projected to increase from 3.2 million Australians in 2007 to 5 million by 2050 (Blyth et al., 2004). Currently, epidemiological studies in Europe, North America, Canada and Australia reveal that one in five people suffer severe to moderate daily chronic pain (Blyth et al., 2001, 2004; Harstall, 2003; Langley, 2011).

International population-based studies have documented a correlation between chronic pain and high health care utilisation (Von Korff et al., 1991; Blyth, 2001; Anderson & Newman, 2005; Dominick et al., 2012; Gore et al., 2012). In a landmark study conducted by WHO across 15 countries to identify the extent of persistent pain in primary care, 22% of primary care patients reported suffering from chronic unrelieved pain (Gureje et al., 1998). In the USA, pain accounts for over half of all outpatient visits: 25 million visits for back pain and 12.3 million for abdominal pain (Bair, 2008); whilst in Australia, approximately 20% of all general practitioner consultations are related to chronic pain (BEACH, 2010).

Chronic disabling pain is commonly reported to result in frequent and repeated primary care visits and hospital ED presentations. In Australia, Blyth et al. (2004) reported on the predictive value of high pain-related disability and increased health care utilisation. After adjusting for known predictors of high health care utilisation (age, gender and co-morbidities), the authors reported that patients with high levels of pain-related disability (6.8% of the NSW study cohort) recorded a twofold increase in hospitalisations and a fivefold increase in GP and ED presentations, concluding that:

...increasing levels of pain related disability have emerged as key predictors of health care use...//...and (hence) deserve greater recognition for their impact on services as well as on individuals ( Blyth et al., 2004, p.51).

International and national studies conducted to identify the patterns and characteristics of frequent hospital ED presentations consistently reveal that issues related to chronic pain are instrumental in motivating patients presenting to EDs (Fry et al., 1999; Blyth et al., 2004; Todd et al., 2010; Woodhouse et al., 2010; Pines et al., 2011; McLeod & Nelson, 2013). A North American multicentre study revealed that chronic pain conditions are reported by 40% of all patients presenting to EDs, with half of these patients reporting an exacerbation of their pain as the principal cause for ED presentation (Cordell et al., 2002). In addition, a number of studies have identified the disproportionate amount of health services that patients with chronic pain consume (Rask et al., 1998; Hansagi et al., 2001; Jorgensen, 2007; Raven, 2011). In a pilot study conducted by Jorgensen (2007), the author reported that 3% of patients who habitually presented to an ED for chronic pain accounted for 12.4% of the total cost, at \$1,799/per visit. A number of authors have cited the following as foundational issues contributing to high levels of ED service utilisation: ineffective and repeated use of monotherapies (Access Economics, 2007); limited access to primary care clinicians (Pines et al., 2011); suboptimal environments for meeting these patient needs (Woodhouse et al., 2010); low care priorities for chronic pain (Wilsey et al., 2008); poor ED clinician time and specialist knowledge (Fosnocht et al., 2005); and poor patient coping strategies (Woodhouse et al., 2010).

Increased understandings of the correlation between pain-related disability and its impact on health care utilisation have important implications for health service policy and planning.

Understanding the issues, characteristics and determinants of high health care utilisation, identifying those at risk and directing efforts toward improving access, coordination, management and social circumstances outside the acute care environment offer potential pathways for, not only better directing limited acute care resources, but also improving patient outcomes. This is particularly relevant for patients regularly accessing urgent care environments for the management of chronic pain. Such environments have been documented to be ineffective in providing care for these patients, and as such, underpin poor patient outcomes and satisfaction (McLeod & Nelson, 2013).

## **2.6 The prevalence and impact of chronic abdominal pain**

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Prevalence figures for persistent abdominal pain are difficult to access. These difficulties are associated with the challenges reported earlier regarding the complexities of differentially diagnosing the phenomenon, and poorly defined subcategories within chronic abdominal pain. This leads to the variance in prevalence rates reported in the literature. Depending on the method and population sampled, prevalence rates are reported for chronic abdominal pain, of between 3% and 17% (Townsend et al., 2005) and for functional abdominal pain (pain without detectable organic aetiology) of between 0.5 and 1.7% (Sperber & Drossman, 2011). However, what is consistently reported in both the national and international literature is that chronic pain is a pervasive and difficult clinical issue requiring urgent attention (Drossman, 1982, 1996; Townsend et al., 2005; Camilleri, 2006; IASP, 2011). Annual treatment costs for patients with chronic abdominal pain have been reported to be \$16.6 billion dollars in the USA and €28.4 billion across Europe (IASP, 2011).

In Australia, abdominal pain represents a major clinical issue for which significant numbers of patients seek considerable health care services (BEACH, 2004). Presentations of abdominal pain to Australian GPs between 1998 and 2004 were reported by the BEACH program as 2.1 per 100 encounters, amounting to approximately 2 million Australian occasions per year. Of the 12,194 abdominal pain presentations during this study period, 24% remained undiagnosed at the end of their encounter and were described by the GP as being “the most problematic” subgroup of abdominal pain patients. For this patient group, pathology tests were ordered at twice the usual rate, whilst orders for imaging were documented at six times

the average rate, with ultrasound being the most common diagnostic investigation. In addition, there was a documented 10% referral rate to specialists, with just under half (4.6%) being referred to gastroenterologists (BEACH, 2004).

Patients with chronic abdominal pain present significant diagnostic and therapeutic challenges for health care providers. These patients are consistently reported to consume significantly higher quantities of health care resources than patient cohorts without chronic pain (Beach, 2004; Access Economics, 2007). Significant features of these patients' health care utilisation patterns are the frequent engagement of many health care providers (Townsend et al., 2005), being subject to numerous and repeated diagnostic procedures (Beach, 2004; Meyer, 2008; Sperber & Drossman, 2011), and remaining engaged with the health care service, particularly acute care services for extended periods of time (Camilleri, 2005; Drossman, 2008; Dorn, 2011).

Patients with persistent abdominal pain represent a subgroup of those with chronic pain conditions who consume considerable health care resources as a consequence of their atypical clinical presentations and their characteristic non-response to usual treatment pathways (Townsend et al., 2005; Drossman, 2008). As a group, these patients have been documented to represent one of the most challenging patient cohorts that clinicians manage in their professional capacities (McGarrity et al., 2000; Dick, 2004; Holland-Hall & Brown, 2004; Drossman, 2008; Sperber & Drossman, 2011). The implications of managing patients with persistent abdominal pain for both health service providers and professionals are beginning to be documented in the contemporary literature. Studies conducted both nationally and internationally (McGarrity et al., 2000; Rothley, 2004; Bicanovsky, 2006; Camilleri, 2006; Drossman, 2008; Dorn et al., 2011) highlight the universal appraisal of the group representing a relatively small patient cohort who consume disproportionate quantities of health care resources in the midst of presenting significant clinical, therapeutic, organisational and ethical challenges during encounters with health care providers.

## 2.7 The political work of pain: Getting pain on the health care agenda

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Numerous national and international efforts have been directed toward documenting the societal impact of chronic pain. The availability of contemporary national and international epidemiological studies, particularly here in Australia, has begun to highlight its significant social, economic and personal burden. Thus, chronic pain has been removed from the shadows of other chronic disease conditions such as heart disease and diabetes to be considered a “clinical entity in its own right, requiring specialised, multifaceted care that brings real improvements to patient well-being” (Cousins, 2012, p.373). Consequently, chronic pain, and efforts directed toward better understanding and managing it, has become a major health care priority for governments and health care providers world-wide. This has been reflected in a number of key political events (Conway & Higgins, 2011; Hogg et al., 2012).

In Australia, a draft National Pain Strategy (NPS), the result of extensive consultation with clinicians, consumers and service providers was released at a National Pain Summit in 2010. The strategy included an explicit plan to address inadequacies in pain management within NSW Australia and was the impetus for a number of significant events. As a result of the NPS (2010), the Queensland Government allocated \$39 million to a Persistent Pain Health Service Strategy, Western Australia developed a Spinal Pain Model of Care and in NSW the government responded by directing funding toward implementing the NPS recommendations for improving access and speciality care for patients with persistent pain conditions (Cousins, 2012; Hogg et al., 2012; Semple & Hogg, 2012). The recommendation made within the NPS (2010) was for a multidisciplinary pain management network that would emphasise primary and community care and a stratified approach to providing specialist pain management services throughout the state (NPS, 2010). The NPS (2010) recommendations included efforts directed toward addressing:

- destigmatisation of people with pain
- education for all health care professionals on treating chronic pain as a chronic disease
- adequate management of acute pain to minimise the risk of it progressing to chronic pain
- introduction of a monitoring system for opioid prescriptions to reduce the risk of inappropriate use (Cousins, 2012, p.374).

Internationally, similar efforts have been documented. In 2011, The International Pain Summit (IPS) produced a broad framework for the management of pain suitable for use by any country, and saw the 2011 council of the World Medical Association produce a declaration resolving that, “people facing pain have a right to appropriate pain management” (Cousins, 2012, p.373). Around this same time, a number of countries (United States, United Kingdom, Canada and some European nations) developed and implemented proposals for the management of pain within their respective nations (Semple & Hogg, 2012). This international movement has not only helped mobilise respective governments to acknowledge the need to redress the current shortfalls in managing pain, but has also facilitated dialogue regarding evidenced-based approaches to management strategies and to consider how best to facilitate equitable access for all patients in need of appropriate and timely pain treatment.

Underpinning these efforts resides the paradigm shifts that have occurred within the speciality of pain medicine and to some extent within medicine itself. The reconceptualisation of pain away from a dualistic, Cartesian approach to include its multifaceted dimensions has been instrumental here. Further, the more recent moves to have persistent pain acknowledged as a “disease entity” has further boosted these political and improved patient health care agendas (Siddall & Cousins, 2004). The concept of pain being a disease has been supported by scientific advances and increasing levels of evidence suggesting the structural and functional changes that can occur within the nervous system of people with chronic pain, and of pain-related psychological and environmental changes (Siddall & Cousins, 2004; Tracey & Bushell, 2009).

While these understandings and reconceptualisations have helped facilitate significant momentum in attempting to improve the management of patients with persistent pain, the movement (to have pain classified as a disease) has been met with variable responses and critical debate. Clinicians, pain specialists, scientists, sociologists and academics have taken up the debate in earnest. Some register concern that a paradoxical outcome will result in the propagation of the notion that “pain is something that exists in the body as an entity of itself” (Hancock et al., 2011; Buchanan et al., 2012; Loeser, 2012; Moseley, 2013), and potentially

undermines gains made over the past two decades to move conceptualisations of pain from reductionist disease models, to more holistic appraisals (Buchanan et al., 2012).

While accepting, what appears to be a developing paradigm shift occurring in the conceptualising of persistent (chronic) pain, and in particular, chronic pain conditions in the absence of primary disease, pathology or inflammation, considerations beyond aetiologies and diagnosis to consider current and emergent treatment approaches are reviewed.

## **2.8 Chronic pain and treatment approaches**

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Over the past two decades, considerable progress in the medical management of pain has been made. Improved neurophysiological understandings, the exponential growth in analgesic and other pain medication and the explosion of technical devices illustrates our contemporary Westernised, industrial, technocratic approach to managing this basic human experience in the 21st century. Arguably, few medical specialities have witnessed such an exponential growth in basic science knowledge, translational research and ultimately revised clinical practices. Despite these vast scientific advances, unresolved pain, particularly chronic pain, remains a significant individual, societal and economic burden the world over (Henry, 2008; Conway & Higgins, 2012; Loeser, 2012).

In addition to basic science advances, behavioural researchers have investigated the psychosocial dimensions of the experience (Gatchel et al., 2007). To a lesser degree, work has also been directed toward the phenomenological, cultural and social constructions thought to shape the beliefs and meanings that people attribute to the experience of pain (Morris, 1993; Kleinman, 1995; Broom, 1997, 2007). However, despite these better understandings that have resulted in a paradigmatic shift away from biological appreciations to more holistic views of the pain phenomenon, pain remains one of the most challenging and disabling conditions of modern humanity (Henry, 2008; Cousins, 2012; Loeser, 2012).

One reason for this may be the relative prominence the scientific agenda occupies within contemporary society and the reverence it receives. The elevation of the biological over the psychological is embedded deep into our social history and this shapes the way we conceptualise the pain experience. We have grown up with the pervasive appeal of a mastery over the mechanical aspects of our human machinery and the concomitant expectation that



this mastery will afford the curing of all human ills (Sontag, 1989; Golub, 1997; Bortz, 2011; Lupton, 2012). Notions of self-reliance and autonomy over one's health status have been relegated to the shadows of the "medical monopoly", whereby society has "transferred to physicians the exclusive right to determine what constitutes sickness, who is or might become sick, and what shall be done to such people" (Illich, 1975/2010).

Despite our cultural and social preference to defer to the seductive allure of biomedicine, and the embedded belief that health care professionals possess the 'magic bullet' to manage all illnesses, including pain, it has become widely accepted that, the biopsychosocial model for managing pain is the most heuristic approach to treatment (Nicholas et al., 2000; Gatchel et al., 2007).

Within the recent decade, as depicted in table 2.1, the movement of approaches to health care away from reductionist biomedical appraisals for the management of pain, toward a more biopsychosocial model has occurred. This move highlights the notion that pain, particularly chronic pain, is one of the most challenging and disabling conditions that has been plagued by variable and suboptimal success in its (biomedical) management. The move toward more comprehensive conceptualisations and treatments therefore represents the inadequacies and failures of the puzzles of normal science of the time to adequately help patients suffering with some pain conditions. Consequently, these failures of historically embedded biomedical approaches have provided the impetus for reconceptualisations, based on which alternative approaches have been recommended (Gatchel et al., 2007).

### **2.8.1 Defining new models of care: Beyond the biomedical approach**

It is widely accepted that pain, and particularly chronic pain, is best considered as a biopsychosocial construct (Engel et al., 1977, 2005; Siddall & Cousins, 2004; Gatchel et al., 2007; Loeser, 2012). Patients suffering from complex chronic pain conditions do not fit into the traditional biomedical or disease-centred model of illness. Hence, patients suffering from chronic abdominal pain would be best understood from a biopsychosocial perspective, whereby interactions between psychosocial factors and altered physiology via the brain-gut axis result in chronic abdominal pain conditions and symptomology (Drossman, 1996; Banez, 2008).

In the past two decades, increased understandings of neurophysiological processing, central nervous system modulation, and the impact of afferent processing on pain perception and pain behaviour have helped clinicians better understand the mind–body connection in the presence of, in particular, chronic non-cancer pain (Siddall & Cousins, 2004; Bicanovsky et al., 2006; Drossman, 2008; Meyer et al., 2008; Farmer & Aziz, 2009; Sperber & Drossman, 2011). Despite these greater understandings, few references are made in the literature to studies of clinical care where the broader treatment approaches in the management of chronic abdominal pain have been adopted and the scientific understanding integrated.

A study that is worth considering was conducted by Gerson and Gerson (2003). They compared a collaborative treatment model (gastroenterologist and psychologist working together, compared with medical treatment or psychological treatment alone) that involved 41 patients with IBS randomly assigned to three different treatment groups. The study demonstrated that “short-term treatment with gastroenterologists and psychologists working together was more effective than medical treatment ( $p < 0.05$ ) in relieving symptoms in patients with chronic IBS” (Gerson & Gerson, 2003, p.446). The importance of this study is the recognition of the potential use of an integrated interdisciplinary collaborative model, whereby clinicians see patients together, and work with the assumption that there are “no psychological problems without biological features and no biomedical problems without psychosocial features” (Gerson & Gerson, 2003, p.451). Although the evidence strongly supports the multidisciplinary, multimodal management of patients with chronic pain conditions, these services have been traditionally delivered in a sequential fashion, possibly overlooking the powerful nature of integrated care delivery for chronic pain populations.

Although the literature reflects attempts to better understand chronic abdominal pain, and hence direct efforts toward identifying better therapeutic strategies, more recent studies centre mostly on child and adolescent populations. Much of the empirical data are directed toward the better identification and differential diagnosis of “functional abdominal pain” in children, and have culminated in the development of The Rome III Criteria for Functional Bowel Disorders – a symptom-based classification of functional disorders associated with abdominal pain in children (American Academy of Paediatrics Subcommittee on chronic abdominal pain, 2005). However, there have been no reports of the clinical application, and

hence the Rome III Criteria in differentially diagnosing adult patients with functional abdominal pain from organic abdominal pain aetiologies have not been tested for their validity or sensitivity.

Little evidence exists in the current literature in relation to best practice for the management of either child, adolescent or adult populations with chronic abdominal pain. The literature describes therapies that include conventional approaches of reassurance, symptom-based pharmacological (opioids, NSAIDs, tricyclic antidepressants, membrane stabilisers) and procedural (trigger point injections, intercostal nerve blocks) therapies, and psychological and behavioural treatments (cognitive behavioural therapies) (Jackson et al., 2000; Drossman et al., 2003). Much of the work in this area has been descriptive, focusing on specific syndromes associated with chronic abdominal pain, such as IBS or disease-specific case studies. The empirical support for treatment strategies is lacking.

It appears from the literature review that adults with chronic abdominal pain are mostly cared for within acute care systems by individual medical specialists (Sperber & Drossman, 2011). Few studies document the involvement of multidisciplinary pain services, or even the concurrent use of psychotherapeutic interventions. This continued engagement in the biomedical, curative paradigm may explain some of the commonly documented features of patients presenting with chronic abdominal pain. That is, chronic abdominal pain patients typically have frequent hospital presentations and admissions, usually via hospital EDs, have large numbers of diagnostic investigations and surgeries, and overall consume disproportionate amounts of health care services (Drossman, 2008; Austin & Henderson, 2011), with a tendency toward deterioration rather than improvement over time.

Using an acute care framework to manage patients with chronic complex illnesses, including those with persistent abdominal pain is problematic (Access Economics, 2007; Conway & Higgins, 2011; NPS, 2011; Hogg et al., 2012). Some of the problems include poorly coordinated interventions delivered within unidimensional models of care, professionally based siloed approaches, lack of coordinated and consistent care planning, the use of conflicting approaches and treatment paradigms, and inadequate discharge planning and community-based care. On the basis of this argument, it could be claimed that the current approach to

managing patients with chronic abdominal pain is not only inefficient, but also ineffective. These treatment approaches are confusing for the patient and lead to conflict and hostility within and between treatment teams as well as between patients, their families and the hospital staff; escalation in patients' reports of pain; and inevitably, repeated hospital admissions.

Although considerable work has been done in developing, implementing and validating the management of chronic pain using the biopsychosocial model (Gatchel et al., 2007), chronic pain continues to be a significant social, political and individual problem (Blyth, 2004; Cousins, 2012; Hogg et al., 2012). It is not clear why this is so, given the significant advances in pain management (Access Economics, 2007; Conway & Higgins, 2011; NPS, 2011; Hogg et al., 2012).

A recent literature review conducted by Conway and Higgins (2011) scoped the types and efficacy of a range of care delivery models utilized for the management of pain, mostly chronic pain, within NSW, Australia. The authors summarised the major problems underpinning the shortfalls of current approaches as residing in the following:

- an overreliance on the biomedical view of pain and a concomitant lack of services within the biopsychosocial approach to responding to chronic pain
- limited timely access to existing services for a range of reasons
- a need to develop capacity to respond to increasing demand for pain management, particularly chronic pain, as people survive conditions that are associated with or lead to persistent pain, and
- a need to better target services to clients experiencing pain who have differing needs (Conway & Higgins, 2011, p.13).

Whilst Conway, Higgins and others (Blyth et al., 2001; Access Economics, 2007; NPS, 2011; Cousins, 2012; Hogg et al., 2012; Semple & Hogg, 2012) illuminate short falls in access to, and coordination of more appropriate biopsychosocial pain management speciality services both in primary and tertiary health care settings, other authors offer additional insights into potential short-comings' of current approaches (Broom, 2007).

Broom (1997, 2002, 2007) argues that despite twentieth century thinking extending beyond the dualism of the mind–body divide with the advent and uptake of both the biopsychosocial and the more recent psycho-neuro-endocrino-immunology models of illness, he suggests these conceptualisations continue to reside within the strait-jacket of the ‘physicomaterialism and rationalism’ of the biomedical model. He goes on to submit that any suggestion that these models are “more accommodating than the biomedical model is an illusion” (2002, p.25). He qualifies this by suggesting that, the biopsychosocial model, although an advance on the biomedical model, collapses at two critical points; first, because of its “underlying assumption of mind–body separateness”, and second, because of its inability to “suggest how after a meaning is converted into a brain activity, the nervous, immune and endocrine can project such meaning out into the periphery” (2002, p. 21). Thus, he concludes that the “biopsychosocial model cannot accommodate specificity of meaning” (Broom, 2002, p.22).

Broom proposes we need a new model of “personhood and disease”, within which we can situate “subjective meaning and physicality in the same space” (2002, p.21). From this paradigmatic position, Broom submits the notion of “meaning-*fullness* of disease”, whereby “the categories of mind, body, meaning, experience and language are interpenetrating, entangled, reciprocal, and mutually sustaining” (2007, p.33). It is a notion he describes as foundational to the clinical phenomenon of “somatic metaphor”, whereby “language representations and bodily representations are remarkably congruent” (2007, p.53).

Broom is a medical immunologist and a psychotherapist. In clinical practice he admits to being able to leave neither training orientation “at the door of his consulting room” and hence draws on two decades of experiences of “bridging body, mind and spirit perspectives with people who suffer chronic illness”(2007, p.9). He offers his reconceptualisations of pain, described in terms of meaning-*fullness* of disease and somatic metaphor, not as an alternative to biomedicine, but rather as an adjunct. Within his conceptualisation of mind–body medicine, he proposes that:

...much of today’s illness is the expression of “stories” – events in a person’s life that took on particular meanings that somehow couldn’t be expressed, except as a symptom of disease. Patients who do not respond to medical treatments get better when their stories are finally heard and people are seen as wholes. The very existence of meaning-*full* disease is something we [health care professionals] do to the

patients/client; it is something we impose on reality resulting in a foolishness, a waste of time and other resources that we can get into when we separate the minds and bodies of our patients (Broom, 2007, p.8).

## **2.8.2 Managing acute exacerbations of chronic abdominal pain**

The continued pursuit of attempting to identify organic aetiologies results in expensive diagnostic testing and invasive procedures and surgeries that ultimately burden the clinician, the health care system and significantly impact on the physical and social wellbeing of the patient (Drossman, 2008; Sperber & Drossman, 2011). Consequently, the frustration encountered by clinicians, patients, and family members inevitably threatens therapeutic relationships. Frustrated clinicians appraising chronic abdominal pain from a disease-based, biomedical model perspective, and faced with diagnostic complexities and therapeutic challenges in the absence of objective diagnostic criteria, often resort to concluding that chronic abdominal pain is psychosomatic. Further, when applying the reductionist framework of the biomedical model to a biopsychosocial phenomenon, the possible role of iatrogenesis in the maintenance of chronic abdominal pain conditions cannot be overlooked.

Approaching illness and particularly chronic pain from a Cartesian duality whereby illness is perceived as a problem of the body **or** the mind, was challenged by George Engel (1977) when he proposed the “bio-psychosocial model of illness”. The model proposed that rather than perceiving illness within a framework of “biology versus psychology”, it should be conceptualised as a “complex matrix of biological, psychological and social issues” (Barbuto et al., 2008, p.80). Since the late 1970s, the literature related to biopsychosocial management of illness has exploded. In pain management clinics throughout the world, the biopsychosocial model became the *modus operandi* from which pain services derived. Utilising a multidimensional framework of illness appraisal, pain management clinics assessed, managed and employed treatment approaches. However, despite attempts to broaden approaches and conceptualisations regarding the integrated nature of pain and psychology, much has continued to conspire against this approach, making it harder to implement and achieve successful outcomes from such approaches.

Barbuto et al. (2008) recognise that the chronic pain syndrome is dynamic in that, “the relative contribution of the biological, psychological and social factors shift balance” (2008, p.82). This appreciation implicates clinicians managing it, to regularly assess and readjust treatment

approaches in response to these dynamic changes. This is often the situation that arises for patients with persistent abdominal pain during acute exacerbation and escalation of perceived pain intensity who require hospitalisation. In these situations, those authors recommend that clinicians consider pain in these contexts as being a result of one or a combination of:

- altered biological processes, for example, bowel obstruction
- anguish (emotional suffering)
- addiction (substance abuse)

The authors contend that to do no harm in the management of chronic pain, then optimal management resides in three tools, “i) the bio-psychosocial model of assessment, ii) treatment centred on pathophysiology, rather than pain verbiage, and iii) an ongoing evaluation of total social function as a solid measure of treatment effectiveness” (Barbuto et al., 2008, p.82).

Similarly, Paterson (2001) offers some insights into the dynamic contexts within which patients with chronic diseases perceive and hence react to their illnesses. She explains that a “perspective of chronic illness” has elements of both illness and wellness, where a perspective represents “beliefs, perceptions, expectations, attitudes and experience about what it means to be a person with a chronic illness within a specific context”, and hence “determines how people respond to the disease, themselves, caregivers, and situations that are affected by the illness” (2001, p.23). In this way, the author describes how chronically ill people shift the precedence they assign to perspectives, holding “illness in the foreground and wellness in the background” or vice versa.

Characteristic of “illness in the foreground” is an orientation toward focusing on “sickness, suffering, loss and burden”; the illness is viewed as destructive to oneself and others, and is ‘all-consuming’ for the patient, precluding other responsibilities, even the attentions and needs of significant others. This orientation, Paterson suggests, has a “protective, maintenance, or utilitarian function”, and hence can “provide a means for people to maintain the identity they desire, and to provide evidence to others that the illness is real” (2001, p.23). In contrast, a “wellness in the foreground perspective” represents an orientation within which patients have come to reconcile a self-identity independent and distinct from “the diseased

body". This enables the body to be "objectified" such that its needs, those demanded by illness, can be tended whilst concurrently allowing the chronically ill person to "focus on the emotional, spiritual and social aspects of life, rather than primarily on the diseased body" (Paterson, 2001, p.24).

Complex pathophysiological, psychological, social and behavioural interactions make managing chronic pain difficult in any setting. Managing chronic pain, particularly in the midst of an acute exacerbation within the acute hospital setting, is particularly difficult. However, providing clinicians with some appreciation of the motivations and possible orientations of patients' behaviours may help in directing more appropriate and timely care and thus reduce tendencies toward ill-conceived treatment approaches. However, it is well recognised that the acute care environment conspires against such treatment approaches. Care delivered in these contexts is inhibited by time, efficiency mandates, competing clinical urgencies, the lack of specialist resources and an overall prevailing ideology of cure (Wilsey et al., 2008; Todd et al., 2010; Woodhouse et al., 2010; Althaus et al., 2011; McLeod & Nelson, 2013).

Thus, whilst acknowledging there are complex interactions among physical, psychological and social mediators within the phenomenon of persistent pain states, and that patients in these situations remain engaged with acute care service providers over extended periods of time, the role of iatrogenesis within these contexts cannot be overlooked.

Acute care treatments directed toward the amelioration of chronic non-cancer pain have been widely reported to contribute to patients' ongoing pain, disability and suffering (Mitka, 2003; Portenoy, 2004; Sullivan & Ferrell, 2005; Camilleri, 2006; Barbuto et al., 2008; Dorn et al., 2011; Loeser, 2012) and are largely a consequence of the long-term administration of opioid therapy. Whilst the long-term administration of opioids for the management of chronic non-malignant pain has been reported by some authors to offer therapeutic utility (Fields, 2011), the clinical management of this approach requires significant clinician input to effectively manage the 'risk-benefit' ratio of the treatment approach. Difficulties associated with drug tolerance and increased pain, driven via NMDA receptor activation, in addition to issues related to dependence and addiction, regularly confront clinicians caring for patients on long-



term opioids (Fields, 2011). Such scenarios have been documented by clinicians, particularly those working in acute care environments, for example, ED physicians and surgeons, as being indicative of their most difficult clinical encounters (Denisco et al., 2008; Fishbain, 2008; Hawkins et al., 2008; Fields, 2011).

### **2.8.3 The challenges of opioids in the management of chronic non-malignant abdominal pain**

Opioids and the relief of pain have always been intrinsically linked. From the discovery of the opium poppy with its powerful sedative and analgesic properties to the discovery of opioid receptor sites, the cloning of opioid receptor subtypes, followed by the manufacturing of synthetic opioids and of a vast array of equipment to augment endogenous analgesic pathways, the enduring message remains: opioids are our most powerful analgesic (Kalso et al., 2004; Fields, 2011).

Since the 1970s, there has been a crusade directed toward the aggressive management of pain and particularly cancer-related pain. The response to this has been significant. International and national efforts have been directed toward increasing the availability of opioids and educating clinicians, in an attempt to overcome “opioid-phobia”, and the under-treatment of pain (Portenoy, 2004, 2011). In addition to these efforts, basic scientific research studies, in attempts to elucidate pain mechanisms, have consistently reported the physiological and psychological consequences of suboptimal management of acute postoperative and post-trauma pain (Breivik, 1995; Macintyre et al., 2010). Managing acute and cancer-related pain is generally guided by clear therapeutic goals, that is, in cancer treatment, mercy and comfort, and in acute pain, maximising analgesia whilst minimising side effects in order to expedite recovery and prevent progression to chronic pain states. However, difficulties arise when applying the same principles in the clinical context of chronic non-malignant pain (Pergolizzi et al., 2008, 2012). This becomes increasingly problematic when symptomologies are objectively unsubstantiated and consequently treatment goals are seemingly vague and unclear (Sullivan & Ferrell, 2005), a scenario characteristic of persistent abdominal pain states.

Managing chronic non-malignant pain, and in particular, chronic abdominal pain with long-term opioids has been a contentious issue debated in the literature over a number of decades (Mitka, 2003; Portenoy, 2004; Dorn et al., 2011). Proponents from disparate positions, those

advocating the liberalising of opioids and their utility in improving quality of life for patients with persistent pain states (Zenz et al., 1992; Portenoy, 2004, 2011) and those who condemn their use and criticise their increased prevalence as foundational to the growing incidence of prescription drug abuse, death and addiction (Chou et al., 2003, 2009; Mitka, 2003; Barbuto et al., 2008; Dorn et al., 2011; Pergolizzi et al., 2012), continue to debate the relative merits of the therapeutic benefits.

These dilemmas become particularly poignant in clinical practice. Clinicians confronted with patients with persistent pain conditions are faced with the dilemma of how best to:

- identify those patients who might benefit from long-term opioid management as an adjunct to their therapy so as to maximise function and minimise disability-related pain and the associated psychosocial issues of anxiety and depression in addition to costs, both economic and personal
- identify those at risk of developing issues related to iatrogenesis and the side effects of prescription drug misuse, (iatrogenic) addiction, and drug-related deaths
- manage issues related to aberrant behaviour associated with opioid analgesics as well as manage issues related to opioid tolerance and escalating dose requirements (Chou et al., 2003, 2008, 2009; Sullivan & Ferrell, 2005).

These clinical dilemmas are particularly significant for patients with persistent abdominal pain. The risks associated with administering opioids to this patient group include: i) exacerbation of underlying conditions of pain as a result of constipation and reduced gut motility, ii) escalating doses due to variable gut absorption rates, and/or malabsorption syndromes, iii) increased pain via anti-nociceptive pathways or as a result of activating NMDA receptor sites and sensitising the central processing of pain, and the iv) development of iatrogenic conditions, for example, narcotic bowel syndrome and/or addiction. These are all issues that can outweigh perceived potential benefits from implementing such a therapy (Wiedemer et al., 2007; Loeser, 2012).

The difficulties clinicians face in this arena are reflected in a number of relatively recent events: the emergence of medical malpractice allegations of iatrogenic addiction (Fishbain et al., 2010) and medical abandonment (Fishbain et al., 2009b) during chronic opioid analgesic

therapy. In addition, increasing numbers of publications report on the variable efficacy of opioids in the management of chronic pain, including chronic abdominal pain (Dorn et al., 2011). Moreover, a systematic review on chronic opioid therapy for chronic non-cancer pain concludes that “evidence is limited in many areas related to use of opioids for chronic non cancer pain” (Chou et al., 2003, p.114). Nevertheless, opioids remain a therapeutic option for chronic non-cancer pain conditions frequently implemented by attending clinicians, a trend reflected in the doubling of opioid prescribing (5.9% to 12.2 %) related to chronic abdominal pain between 1997 and 2008 (Dorn et al., 2011). In response to these worldwide trends, policy makers have been mobilised to consider providing more explicit ethical frameworks that provide goals of therapy and consider issues related to the appropriate selection and maintenance of treatment regimens for patients on chronic opioid therapy (Chou et al., 2009).

An expert panel commissioned by the American Pain Society and the American Academy of Pain to review the evidence of chronic opioid use in the management of chronic non-malignant pain and to develop clinical guidelines concurred that, because of the “lack of high quality evidence” available to conduct a systematic review, only four of their 25 recommendations were based on “moderate quality evidence”. The panel came to the consensus that:

Optimally balancing benefits and risks of chronic opioid therapy for chronic non-malignant pain is dependent upon careful patient evaluation and structuring of opioid therapy to accommodate identified risk, appropriate initiation and titration of chronic opioid therapy, regular and comprehensive monitoring while on chronic opioid therapy, and anticipation of opioid-related adverse effects. Other areas of strong consensus include recommendations to use therapies targeting psychosocial factors and to identify a medical home for all chronic pain patients (Chou et al., 2009, p.124).

Whilst these guidelines provide some assistance and support for clinicians as they navigate the ethical challenges of prescribing opioids in the context of chronic non-malignant pain, the reality remains that there are many situations that conspire to make implementing these guidelines difficult (Mitka, 2003; Sullivan & Ferrell, 2005; Sullivan & Main, 2007). Such situations, although often referred to as ‘outlying scenarios’, are those that typify the most challenging and complex clinical encounters and are characterised by i) patient non-compliance with agreed treatment pathways, including functional restorative treatments, ii) clinicians’ non-responsiveness to treatment guidelines and electing to prescribe rather than

rehabilitate, iii) no or limited access to appropriate multidisciplinary pain specialist services that can support the multidimensional, multimodal management of patients' opioid, psychosocial and functional therapeutic interventions, iv) clinicians employing and patients accepting opioids as unidimensional treatments, v) clinicians without the necessary skills to undertake assessments, that is, opioid pain-responsiveness appraisals, substance abuse histories and psychosocial assessments or those who operate as solo practitioners who initiate and maintain long-term opioids in isolation from broader professional groups and treatment approaches, and vi) patients who access multiple (prescribing) health care providers for the medical management of their chronic pain complaints (Chou et al., 2003, 2008, 2009).

Although APS guidelines and those that have proliferated world-wide offer some advancement, particularly for the management of prospective patient cohorts suitable for opioid therapy, the legacies of past ill-informed mismanagements of chronic opioid treatment remain problematic in current clinical practice (Mitka, 2003; Loeser, 2012). The therapeutic challenges associated with managing these patients are variably discussed in the literature. However, what is apparent is that these reports generally relate to individual case reports rather than discussing the difficulties of managing patients currently 'entrenched' in these situations and informing clinicians about alternative approaches in the midst of ongoing and often escalating pain.

Barbuto et al. (2008) recognise that fundamental to the problems associated with prescribing opioids to patients with chronic non-malignant pain, is the "vague and subjective nature of pain symptoms". In their paper, *Chronic Pain: Second, do no harm*, they draw on the Hippocratic Oath "*Primum non nocere – first do no harm*" and its inherent recognition for medicine:

"...to produce adverse outcomes, exacerbation or iatrogenic disease", to locate the assertion, that "the mismanagement of chronic pain (for which they refer to as drug addiction, prescription drug-related deaths and drug diversion) is a consequence of misguided response to verbal pain complaints" and the belief "that all pain, no matter what level should be chemically treated, or that all pain words have equal veracity" (2008, p.78).

Whilst Barbuto et al. (2008) provide some helpful insights and recommendations toward overcoming situations of “misguided responses” to the management of chronic non-malignant pain, the remnants of a Cartesian duality remain evident within their conceptualisations and recommendations. The clinical assessment of these clinical scenarios is not straightforward, and hence, the propensity to defer to embedded orientations of appraising illness (mind–body divide) inevitably surface. In attempting to provide guidance regarding the appropriate selection criteria for commencing patients on long-term opioid therapy, Barbuto et al. refer to clinicians needing to, “discern if patients have pain that correlates with sufficient explanatory objective pathology” (2008, p.82). Such appraisals revisit and continue to propagate implications of organic versus non-organic pain, real versus imagined pain, and physiological versus psychological/psychogenic pain. Once again, this serves to potentiate the stigma long associated with patients having persistent pain states (Sullivan & Ferrell, 2005; Cousins, 2012) often referred to as malingering, drug seeking, exaggerating and manipulating (Fishbain et al., 2009a), resulting in what Sullivan and Ferrell (2005, p.5) say is a “prelude to sending the patient elsewhere for treatment”.

Sullivan and Ferrell (2005) challenge such a notion of pain appraisal and treatment by reframing the situation and suggesting that the essential question is not whether chronic non-malignant pain is real or proportional to disease severity, but how its management contributes to a patient’s overall quality of life. The difficulties associated with the long-term administration of opioids in the context of non-malignant pain are the source of considerable tension for all stakeholders within the clinical setting. This is particularly the case in situations of persistent abdominal pain, where the treatment is fraught with considerable challenges related to compounding symptomologies of the patients’ underlying abdominal condition. These issues are discussed in Chapter 7 as they relate to the implications regarding revising a more appropriate model of care for the management of persistent abdominal pain.

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## 2.9 Conclusion

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The body of literature that examines pain is vast and diverse. The extensive basic science and therapeutic literature reflects an exponential growth in evolving knowledge regarding the phenomenon. Physiological pathways, biological impacts and the social and psychological consequences of the pain experience for patients, care givers and the health care system have

been increasingly documented. Appreciating these developments within the larger sociopolitical context within which they have occurred illuminates the overarching paradigm shift (Kuhn, 1977) that has occurred in the field of pain management, particularly over the past three to four decades. The shifts in interventions for the symptoms of pain and associated disease relate to the responses of health professionals to advances in the basic sciences. The quests by clinicians for alternative approaches to the management of pain had the potential to lack consideration of the impact on consumers and patients and to fail to recognise the complexity of meeting the needs of the consumers within changing contexts of practice and in changes in the health services and the way they were organised. It was also illuminating to recognise that changes in the patients' experiences themselves altered as they were subjected to different approaches that had currency at the time or were becoming out of vogue.

Numerous studies could be directed toward providing explanations for various treatment approaches, the nature and extent of resolution of presenting issues and symptoms for the ill-defined patient cohort of people experiencing persistent abdominal pain. The rationale for any number of approaches to studies could be legitimised by claims of fulfilling the numerous gaps that currently exist in the contemporary literature regarding the nature of treatment, experiences and outcomes of this patient group. Rather than adding to the basic scientific literature regarding a single dimension (biological, psychological, sociological) of chronic abdominal pain that could contribute to the evolution of medical knowledge regarding this currently ill-defined population, the study was directed toward considering the phenomenon as it exists and hence is experienced by the major stakeholders within the context within which it occurs. Thus, an interpretive descriptive approach was chosen in order to identify:

...knowledge pertaining to the subjective, experiential, tacit, and patterned aspects of human health experience...//...so that we have sufficient contextual understanding to guide future decisions that will apply evidence to the lives of real people (Thorne, 2008, p.36).

In this chapter, I have critically reviewed historical and contemporary literature that highlights the biases toward the medicalised and biological understanding and management of pain. In addition, by highlighting the paradigmatic shifts that have occurred within the pain management arena, and to which the study stakeholders, including patients, have been

exposed, I have illuminated the contexts within which the patients have traversed their illness trajectories as they have sought treatment for persistent abdominal pain. In the following chapter, I will describe the methodological and theoretical underpinnings of the study.

## Chapter 3 Methodology

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### 3.1 Introduction

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The present study was not commenced with one particular philosophical or theoretical orientation. Rather, the study evolved as a pragmatic response to requests from colleagues to provide increased understanding of the phenomenon of persistent abdominal pain within the acute care setting of an Australian tertiary referral hospital. The study began as a naturalistic enquiry that was concerned with conceptualising the many and varied contexts of patients suffering from persistent abdominal pain characterised by frequent presentations and admissions to hospital, in relation to carer support and the treatment and services provided by health care professionals.

In addition, the absence of published works within the contemporary literature related to this study prompted a naturalistic approach directed toward exploratory and explanatory research agendas. Since the study was conceptualised by treating clinicians, including myself, in response to perceived deficits in current clinical understandings and management of persistent abdominal pain, an inductive approach guided the study from its inception.

Hence, rather than identifying antecedent conditions, the research project was principally concerned with improving knowledge about the nature, extent and impact of persistent abdominal pain from all stakeholder perspectives. Further, it was envisioned that this improved disciplinary knowledge would present the impetus and direction for subsequent phases and approaches of the research project that were principally directed toward identifying how the clinical management of current and emerging patients with persistent abdominal pain could be improved, particularly within the acute care arena. In keeping with this purpose, the study moved beyond the original instrumental quantitative first phase to embark on a more comprehensive engagement marked by a 'pluralistic philosophical orientation' to accommodate 'unpacking' what clinicians, patients and family members/carers



believed to be deleterious to, or facilitative of good patient outcomes associated with the medical management of persistent abdominal pain. Some philosophical questions posed by the researcher at the outset were:

- How did these people experiencing chronic debilitating pain arrive at this point in their lives?
- Why do these patients continue to rely on the acute health care system?
- To what extent do these people think health care providers are responsive to their health care needs?
- What is it like to suffer with, support or provide health care services to people with persistent abdominal pain?
- What happens for all stakeholders in the midst of an acute exacerbation of pain that requires a presentation or admission to an acute care facility?
- When things go wrong, what happens? When things go well, what happens? How do these situations affect family/carers and health care professionals?
- To what extent do patients with persistent abdominal pain impact on the health care service?
- How are the system's (hospital's) efficiencies and efficacies impacted as a consequence of managing this patient group? Where and how can improvements be made?
- What are the resource implications of caring for this patient group?
- What would need to change in order to provide a more efficient and effective model of care for current and emerging patient cohorts with persistent abdominal pain?

Creswell and Plano Clark (2011) elaborate on the value of interrogating multiple perspectives such as those outlined above by stating that when multiple paradigms need to be accommodated, mixed methods is worthy of consideration and represents:

...the selection of multiple worldviews that relate to the type of mixed methods design used rather than a worldview based on how the researcher attempts to 'know' the social world (2011, p.45).

Mixed methods is a "procedure for collecting, analysing and mixing or integrating both quantitative and qualitative data at some stage in the research process within a single study for the purpose of gaining a better understanding of the research problem" (Ivankova et al.,

2006, p.3). The rationale for using the approach is grounded in the fact that neither methodological approach is sufficient in and of itself to “capture the trends and details of a situation” but rather, in combination, they complement each other, taking advantage of the relative strengths and minimising each of their inherent weaknesses (Creswell, 2009; Teddlie & Tashakkori, 2009; Creswell & Plano Clark, 2011).

Given the diverse and multiple perspectives from which the researcher seeks to gain increased understandings, a mixed methods research approach offers the methodological umbrella under which a pluralistic approach to research methods can be employed in order to best answer the research question(s). Therefore, the study presented in this thesis was conducted using a mixed methods approach. Issues inherent in choosing the methodological approach, the underlying philosophical orientation, and hence the theoretical assumptions, followed by the practicalities of employing such an approach, are considered within the discussions that follow.

### **3.2 Reconciling multiple perspectives**

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In determining a methodological approach, the researcher’s challenge is to “fit the research methods to the evaluation problem without parochialism” (Reichardt & Cook, 1979, p. 27).

The bottom line is that research approaches should be mixed in ways that offer the best opportunities for answering important research questions (Johnson & Onwuegbuzie, 2004, p.16).

A belief that a one-to-one relationship exists between a research paradigm, its underlying philosophical position and subsequent methods of enquiry have propagated polarised positions of the traditional research methodologies. Paradigm ‘purists’ from both research cultures, particularly those in the qualitative domain during the 1970s and 1980s, contended that “accommodation between paradigms is impossible...//...we are led to vastly diverse, disparate and totally antithetical ends” (Guba, 1990, p.81). The view that research enquiry in its ‘purist’, and hence most valid, form should reside in either of the traditional qualitative or quantitative approaches has extended to include the position that their respective philosophical underpinnings and hence methodological approaches are “incompatible” (Howe, 1988, 2004; Creswell & Plano Clark, 2011). In contrast, Feilzer asserts that:

...paradigms could be interpreted as prescriptive and as requiring particular research methods and excluding others...//...and in that sense, a paradigm can constrain intellectual curiosity and creativity, blind researchers to aspects of social phenomenon, or even new phenomenon and theories and limit the sociological imagination (Feilzer, 2010, p.7).

Until recently, research communities within the social and behavioural sciences have primarily been ensconced in either a qualitative or quantitative domain of research practice (Creswell, 2009; Teddlie & Tashakkori, 2009; Creswell & Plano Clark, 2011). Both these approaches with their subsequent guiding philosophical underpinnings have origins in, a positivist/postpositive (quantitative) or constructivist/interpretive (qualitative) paradigm or worldview. Commentators on research methodologies have challenged the usefulness of mutually exclusive paradigmatic approaches and posit the idea that research methodological approaches are located along a 'continuum' of enquiry. Thus, traditional research methods are now being viewed as predominantly embodying either a qualitative OR a quantitative approach (Creswell, 2009). The notion that there is one absolute truth that can be identified by an 'objective and value-free enquiry' (quantitative research) or that subjective enquiry (qualitative research) is the only means by which a researcher can understand a phenomenon has been challenged by the emergence of a methodological approach known as *mixed methods* research. This approach works toward integrating research strategies in an attempt to minimise the weaknesses and capitalise on the strengths of the respective qualitative and quantitative methodologies. Hence, disparate views that have underpinned notions of research methodologies as being polar or dichotomous are now being contested (Andrew & Halcomb, 2009; Creswell, 2009; Teddlie & Tashakkori, 2009; Feilzer, 2010; Creswell & Plano Clark, 2011).

### **3.3 Making way for appreciating multiple perspectives: Mixed methods research**

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In considering the paradigmatic discourse that has fuelled methodological 'turf wars', it would be erroneous to overlook the contribution that Howe's (1988) Incompatibility Thesis has had on the ongoing debate. Howe, in his paper *Against the Quantitative–Qualitative Incompatibility Thesis or Dogmas Die Hard*, argues that "the possibility of modifying a paradigm in response to the demands of research seems to go unnoticed", and that "eschewing this

kind of tyranny of method of the epistemological over the practical, of the conceptual over the empirical is the hallmark of pragmatic philosophy". Hence, the writer offers an alternative, a pragmatic philosophical perspective and purports that, "no incompatibility between quantitative and qualitative methods exists at either the level of practice or that of epistemology and that there are thus no good reasons for educational researchers to fear forging ahead with "what works" (Howe, 1988, p.13).

Dualism, whether applied to research methodologies such as those evidenced in research paradigm debates or that described by the mind-body dualistic approach, which currently characterises much of the biomedical management of patients with persistent abdominal pain, serves little in the way of providing better understandings and better management of the "real-world phenomenon (including psychological, social and educational phenomena)" (Johnson & Onwuegbuzie, 2004, p.17), within the context within which it occurs. Thus, one cannot ignore the metaphorical parallels that exist between research when dualistic methodological approaches and medical management approaches are implemented in the face of multidimensional complex problems. Turf wars about research methodology, involving positivists versus constructivists for primacy, and to do with patients seeking treatment for persistent abdominal pain, involving biomedical versus biopsychosocial approaches, are all eliminated within this study.

The emergence over the past two decades of a third research paradigm and its accompanying pragmatic approach to enquiry has helped galvanise the notion of a 'continuum' of research methodologies. In so doing, it has also offered an alternative to the traditions that require the researcher to capitalise on the relative strengths while they minimise the inherent weaknesses of each of the qualitative and quantitative research domains. Further, the historical view that methods of enquiry are intrinsically linked to specific research domains and epistemological and ontological orientations has been challenged. "Linkage between research paradigm and research methods is neither sacrosanct nor necessary" (Johnson & Onwuegbuzie, 2004, p.15). Therefore, the research endeavours made within this study are well suited to mixed methods/methodological approaches. These include the current research, which is concerned with understanding phenomenon from a pluralistic perspective, as a consequence of their multiple meanings and constructions; phenomenon that occur within complex and dynamic

environments; phenomenon that have specific and competing sociopolitical agendas; and phenomenon that are largely concerned with generating outcomes that affect multiple stakeholders. Such research questions require a type of methodology that “transcends the micro and macro levels of understandings” (Andrew & Halcomb, 2009, p.6). Further, the context within which contemporary healthcare is delivered, and the need to provide evidenced-based, cost-effective, efficient and effective treatments, require:

...multifaceted approaches to develop understandings and insights, mixed methods offers a means by which to achieve this aim whilst still providing a rigorous methodological framework (Andrew & Halcomb, 2009, p.6).

Johnson and Onwuegbuzie (2004) qualify this further by contending that research is being conducted in increasingly more “interdisciplinary, complex and dynamic” environments that therefore require and justify multiple research approaches and superior methodological and philosophical understandings to better facilitate “communications and collaborations between disciplines”. Further, those authors claim that “epistemological and paradigmatic ecumenicalism is within reach in the research paradigm of mixed methods research” (2004, p.15). This resonates with Mason’s assertion that a mixed methods approach is:

...less concerned with theoretical wrangles about how we should conceptualise these domains and dualisms than with the point that lived experience transcends or traverses them and, therefore so should our methods (Mason, 2006, p.12).

### **3.4 Defining mixed methods research**

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The definition of mixed methods research has evolved over the past two decades. Earlier definitions primarily focused on key elements of research methods, their processes and designs, and sought to clarify the numbers and types of methodological approaches utilised in a study, i.e. qualitative or quantitative (Greene, Caracelli & Graham, 1989), and therefore were largely ‘methods’ orientated. Later definitions extended to include ‘mixing methods’ as well as ‘methodological orientations’ (Tashakkori & Teddlie, 1998). Consequently, these definitions gave consideration to not only the types of methods utilised in an enquiry but extended to include how, when and to what extent and purpose data collected during mixed methods research endeavours would be ‘mixed’. This extension to include mixing underlying

philosophical assumptions as well as processes of enquiry pre-empted the ideology that “mixed methods research has evolved to the point it is a separate methodological orientation with its own worldview, vocabulary, and techniques” (Creswell & Plano Clark, 2011, p.3).

The editors of the first edition of the Journal of Mixed Methods Research encouraged debate and dialogue from mixed methods researchers in an attempt to gain consensus regarding a “composite understanding” related to an “expanded” definition and the prescribed elements of mixed methods research. The definition used to pre-empt the debate was that of Tashakkori and Creswell, who stated:

...mixed methods research is defined as research in which the investigator collects and analyses data, integrates the findings, and draws inferences using the qualitative and quantitative approaches or methods in a single study or program of enquiry (2007, p.4).

Although the definition offered a methodological approach, as well as the processes inherent within a mixed methods enquiry, Greene (2007, p.20), in her definition (and at the behest of the journal’s editors), sought to broaden the context within which mixed methods enquiry should be located, i.e. within a “social world”. In so doing, she proposed that a mixed methods enquiry be considered from a broader social context, thereby leading to an acknowledgement of the complex and pluralistic nature of society. This would inevitably require mixed methods researchers to consider multiple perspectives and hence multiple paradigms in order to better understand the phenomenon under study in a manner:

...that actively invites us to participate in dialogue about multiple ways of seeing and hearing, multiple ways of making sense of the world, and multiple standpoints on what is important and to be valued and cherished (Greene, 2007, p.20).

The definition most often referred to in the contemporary literature describing mixed methods in research, and that which underpins this study, is that of Creswell and Plano Clark (2011, p.5). This definition reflects the evolutionary efforts of many commentators, hence describing a methodological orientation for mixed methods research while adhering to the ‘spirit’ of Greene’s ‘diverse viewpoints’. Therefore, the definition provides “characteristics of a mixed methods enquiry, combines methods, a philosophy, and a research design orientation” (Creswell & Plano Clark, 2011, p.5). Mixed methods research is a research design with philosophical assumptions as well as methods of enquiry:

As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis and the mixture of qualitative and quantitative approaches in many phases of the research process. As a method it focuses on collecting and analysing, and mixing both qualitative and quantitative data in a single study or a series of studies. Its central premise is that the use of quantitative and qualitative approaches, in combination, provides a better understanding of research problems than either approach alone (Creswell & Plano Clark, 2007, p. 5).

Greene and Caracelli (2003) refer to the “dialectical thesis”, whereby an appreciation of the intrinsic value of all paradigms having value in “contributing to the greater understanding of a phenomenon under study” (Teddle & Tashakkori, 2009, p.99) is assumed. Greene (2007) and others (Howe, 1988; Mason, 2006; Morgan, 2007; Feilzer, 2010) suggest subscribing to “a mixed methods way of thinking”, defined as the:

...planned and intentional incorporation of multiple mental models ... into the same enquiry space to better understand the phenomenon under study... further enables a dialectic mixed methods enquiry by considering opposing viewpoints and interacting with the tensions caused by their juxtapositions (Teddle & Tashakkori, 2009, p.100)

Greene and Caracelli suggest that it “is in the tension (of different paradigms) that the boundaries of what is known are most generatively challenged and stretched” (1997, p.12). This commitment to the multiple and diverse perspectives of social enquiry is primarily concerned with the phenomenon under study rather than the philosophical orientations of study.

Thus, mixed methods research offers the methodological framework within which this study could be located. It accommodates the use of multiple data sources (qualitative and quantitative), reflecting an enquiry concerned with appreciating multiple perspectives (methodologies) for the purpose of gaining increased understandings (breadth and depth of understanding and corroboration) related to the study phenomenon, by employing a ‘methodological pluralism’ that facilitated the researchers’ epistemological orientation of appreciating the ‘multiple ways of knowing’ (Johnson et al., 2007).

However, despite increased uptake in mixed methods research, particularly in the applied health arena, criticism of the methodology abounds within the contemporary literature. Discourses surrounding these criticisms are primarily directed toward concerns that:

- epistemological and ontological orientations are not compatible (Yanchar & Williams, 2006) and therefore that mixed methods studies are nothing more than the sum of their respective parts (Bazeley, 2002)
- the qualitative dimension within mixed methods studies has been shown to simply elevate and further perpetrate primacy of the positivist domain of quantitative research agendas (Howe, 2004; Denzin & Lincoln, 2005)
- the application of methodological pluralism is considered to provide evidence of sloppy, atheoretical research (Yanchar & Williams, 2006)
- the justification of approaches to research based on the credo of “what works” absolves mixed methods researchers from the obligation of providing rigorous research outputs (Yanchar & Williams, 2006).

### **3.5 Criticisms of mixed methods research**

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Fundamental criticisms of mixed methods research are primarily derived from claims of paradigmatic incompatibility and the prioritising of practical over theoretical considerations and rigor. These criticisms will be explored in the following section.

Theoretical and methodological orientations largely influence the way researchers set about acquiring knowledge. Theoretical orientations inform our methodological approaches and hence research questions largely become methods-driven as a consequence of the researcher’s methodological orientation. Researchers largely adopt the beliefs and values of a particular methodological orientation because of their training, and hence operate within a defined scope of enquiry that can potentially lead to research questions being largely ‘methods driven’. This is not unreasonable because a researcher’s education and experience will have focused largely on one of the two historically embedded research approaches of qualitative or quantitative enquiry (Mason, 2006; Creswell, 2009).

The criticisms surrounding the incompatible nature of methodological orientations and their underlying methods were the foundation of the ‘incompatibility thesis’ discussed earlier in this chapter. The mixed methods community countered this position by challenging the one-to-one relationship of methodology to methods by offering the ‘compatibility thesis’ and



positing its paradigmatic foundation within an epistemological orientation of pragmatism (Teddlie & Tashakkori, 2009):

...the pragmatism of employing multiple research methods to study the same general problem by posing different specific questions has some pragmatic implications for social theory. Rather than being wedded to a particular theoretical style ... and it's most compatible methods that would encourage or even require integration of different theoretical perspectives to interpret the data (Brewer & Hunter, 2006, p.55).

Howe (1988), considers that pragmatism, which underpins his 'compatibility thesis', supports "combining quantitative and qualitative methods...//...and denies that such wedding is epistemologically incoherent". This contrasts with a postpositivist orientation concerned with identifying antecedent conditions. Hence, within the context of mixed methods research, this 'third paradigm' offers researchers the potential to explore phenomenon that arise out of "actions, situations and consequences" (Creswell, 2009, p.10) by applying pluralistic approaches to accessing those understandings. This gives primacy to the research problem (Tashakkori & Teddlie, 2009; Creswell & Plano-Clark, 2011) rather than to the research method, and thereby seeks to employ 'what works' to derive knowledge about a study phenomenon (Creswell, 2009).

Acknowledging Dewey's seminal contributions to the worldview of pragmatism, Creswell (2009, p.10) offers this epistemological orientation as the philosophical basis from which he philosophically orientates the conduct of mixed methods research. He states:

- pragmatism is not committed to any one system of philosophy and reality (hence in mixed methods research)...//...enquirers draw liberally from both qualitative and quantitative assumptions
- researchers are free to choose the methods techniques and procedures of research that best meet their needs and purposes
- pragmatists do not see the world as an absolute unity. It is not based in a duality between reality independent of the mind or within the mind, hence in mixed methods research ... researchers look to many approaches for collecting and analysing data rather than subscribing to only one way

- truth is what works at the time...//...investigators (therefore) use both qualitative and quantitative data because they work to provide the best understanding of a research problem
- the pragmatist researcher looks to the what and how to research, based on intended consequences (hence, it is concerned with solutions-based research) ...//... needing to establish a purpose of mixing; it is why the respective data needs to be mixed in the first place
- pragmatists agree that research always occurs in social, historical, and political and other contexts.

Thus, for mixed methods researchers, pragmatism opens the door to multiple methods, different worldviews and different assumptions, as well as different forms of data collection and analysis (Creswell, 2009, p.10).

Hence, it is not surprising that a clinician/researcher primarily concerned with wanting to improve the health care outcomes of patients with persistent abdominal pain, while attempting to engage and mobilise the numerous health care professionals at the centre of this improvement agenda and being cognisant of the complex sociopolitical landscape upon which finite health care resources are allocated and services delivered, would find the methodological orientation of mixed methods research and its accompanying pragmatic approach facilitative of such an expansive agenda. Contemporary approaches to improving the health care management of patients, particularly within acute care hospitals, are rarely considered from a unidimensional perspective or solely as an academic endeavour. Contemporary health care is delivered by increasingly more diverse clinical speciality services; hence, interdisciplinary, multidimensional research agendas are more representative of contemporary health care service provision from which research questions generally evolve. Further, clinicians/researchers, in a bid to improve the health care outcomes of their patients, are increasingly required to consider their activities and proposed recommendations within the sociopolitical agendas from which decisions regarding the delivery of health care largely emanate. Thus, the pragmatics of employing multiple methods assists researchers/clinicians in fulfilling numerous mandates within a single research endeavour and thereby provides a compelling case for the utility of the methodology in guiding

contemporary health care developments. Being able to view the research questions examined in this study, from multiple perspectives, enabled the researcher to engage pivotal stakeholders from 'their perspectives' (epistemological orientations). This allowed an appreciation of the issues at the centre of the clinical phenomenon of persistent abdominal pain to be shared, and thereby helped mobilise and integrate these diverse appreciations and understandings into a 'united and collaborative' approach to reorganising subsequent clinical management strategies. In short, the utility of a mixed methods approach in this instance was that it facilitated the researcher's efforts to get all relevant stakeholders 'on the same page' by appealing to their preferred way of understanding the study being undertaken, for the purposes of challenging current management strategies and identifying a 'collective' way forward, with findings that also bear relevance for the hospitals' organisational, governance and financial responsibilities.

In acknowledging that research, particularly social research, does not operate in a vacuum devoid of sociopolitical influences, and that lived experiences are multidimensional, Mason, makes the following point:

Social experience and lived realities are multi-dimensional and that our understandings are impoverished and may be inadequate if we view these phenomena only along a single dimension...//...we need a methodology and methods that open our perspective to the multi-dimensionality of the lived experience (2006, p.10).

She argues that the dualistic approaches inherent in the theoretical underpinnings of the qualitative–quantitative divide have no basis in social enquiry because “the lived experience transcends or traverses them (theories) and, therefore so should our methods” (Mason, 2006, p.13). Further, she states that “social science research methods need to match up to this complexity of multi-dimensional experience”. In proposing that mixed methods offer potential utility that accommodates this framework, the author provides a rationale in three parts:

- mixing methods encourages us to think outside the box – research strategies are driven by research questions, and mixing methods provides opportunities to explore new dimensions of experience in social life and intersections between these

- mixing methods can enhance our capacity for theorizing beyond the micro and macro representations of research data sets
- mixing methods can enhance and extend the logic of qualitative explanation.

Mason (2006) qualifies her belief that, as part of the ability of mixed methods research to enhance and extend the logic of qualitative explanation, there are two dimensions. These dimensions are the qualitative logic of comparison and the ability to provide cross-contextual and contextual explanations in which the “strength of qualitative research lies in its intimate and habitual concern with context, within the particular, and with understanding the situatedness of social experience, process and change. Understanding how social processes and phenomenon are contingent upon or embedded within specific contexts is a vital part of meaningful social explanation” (Mason, 2006, p.17).

Hence, criticisms generated from paradigmatic ‘turf wars’ appear to be slowly dissipating within the literature and giving way to sentiments similar to those expressed by Reichardt and Cook (1979, p. 27,) that challenge researchers to:

...stop building walls between the methods and start building bridges...//...the real challenge is to fit the research methods to the evaluation problem without parochialism ... and this may well call for a combination of qualitative and quantitative methods.

Responding to the more contemporary criticism surrounding the use of mixed methods research and the variable degree to which methodologists suggest published works to date demonstrate a capacity to “truly integrate” data sets considered to be representative of mutual reciprocity (Bazeley, 2002), commentators have diverse perspectives. While these debates have necessarily helped advance the methodology, given its relative infancy, such discussions have not resulted in a consensus statement or a standard criteria that can guide researchers when undertaking mixed methods studies or against which studies using the methodology can be evaluated.

Bryman (2006) suggests that there are few published works from which researchers can draw in an attempt to identify how data derived from such studies are “truly integrated” in a way that demonstrates a mutual reciprocity. Similarly, Bazeley (2002, p.3) contends that few mixed methods studies go beyond “reporting either parallel or sequential component designs”.

While Mason (2006) argues that, rather than considering whether data from mixed methods studies are integrated, we should consider “linking” or “meshing” data in a way that respects the “creative tension” inherent in the mixed methods approach.

Issues in relation to “genuine integration”, by way of demonstrating that data sets are “mutually illuminating”, form the basis of a paper titled *Barriers to Integrating Quantitative and Qualitative Research* (Bryman, 2007). The paper, in its attempt to understand the criticisms levelled at mixed methods researchers, presents the findings from 20 interviews with mixed methods social researchers from the United Kingdom with varying degrees of experience in mixed methods research. The results of the study suggest that there are nine possible reasons for the apparent lack of integration of data sources in current published studies using mixed methods designs.

The author presents these reasons in three broad categories:

- there are barriers that exist to integrating data sets due to the “intrinsic nature” of the respective methodologies of qualitative and quantitative research
- issues in relation to how a mixed methods project is conceived and implemented make integration difficult
- the belief that whichever of the methodologies is employed first will, along with the momentum of conducting the study, influence the relative importance given to each of the respective methodologies.

Hence, the author argues that the study’s orientation, if not integrated at conception, may make it difficult to integrate data sets in a mutually illuminating way when it comes time to writing up results.

Issues in relation to the wider institutional context of mixed methods research whereby a perceived bias that favours one methodology over the other, in terms of publications, readership and the practical issues imposed by editors such as word limits, were identified by Bryman’s (2007) study participants as impeding mixed methods research in a way that demonstrated data being “mutually illuminative”.

Bazeley, in recognising the documented shortcomings of mixed methods studies contends:

The use of component designs in which the different elements are kept separate, thus allowing each element to be true to its own paradigmatic and design requirements raises the issue of whether, in such cases, these really do constitute a mixed methods study or rather, are two separate studies which happen to be about the same topic (2002, p.3).

She suggests this is possibly a result of the necessary “technology for managing integrated analysis” not currently being available to researchers wanting to embark on mixed methods research.

To mitigate these difficulties, Bryman suggests that mixed methods researchers conceive and design their projects with these issues in mind, such that the equitable staging and implementation of each of the qualitative and quantitative methodologies might overcome relative emphasis being placed on one particular methodology. He also encourages the researcher “not to lose sight of the rationale for conducting mixed methods research in the first place ... and to return to their grounds for conducting such research in the first place” (2007, p. 18), so that an analysis that is truly integrative will be able to answer the question:

Has my understanding of my qualitative/quantitative findings been substantially enhanced by the virtue of the fact that I also have qualitative/quantitative findings, and I have demonstrated that enrichment? (Bryman, 2007, p.20).

Criticisms about the methodology include assertions that mixed methods research, inclusive of its qualitative domain of enquiry, does little more than provide an “auxiliary role” to support quantitative data, hence privileging quantitative data and thereby elevating quantitative methodology to the “top of the methodological hierarchy” (Howe, 2004, p.52). Criticism that the methodology fails to engage critical interpretive approaches (Denzin & Lincoln, 2005) has also been hotly contested within the contemporary mixed methods literature (Creswell et al., 2006; Mason, 2006).

Mixed methods methodologists (Greene, 2007; Creswell, 2009; Teddlie & Tashakkori, 2009; Creswell & Plano Clark, 2011) have provided typologies that suggest that mixed methods research can be “qualitatively driven” within the mixed methods research agenda. Similarly, prominent commentators such as Mason (2006), Sandelowski and Barroso (2003) and Creswell and Plano Clark (2006) claim there is complementary rather than submissive utility of qualitative methodologies within mixed methods enquiries, suggesting that:

...mixed methods can (since the social life is not defined by either qualitative or quantitative, or by simply the macro- or the micro approaches) extend the logic of qualitative explanations about the social world ... (whereby) ... Qualitative research makes context explicit in explanations, rather than attempting to control them or edit them out (all the while seeking) dialogic explanations – multiple relevancies held together in creative tension...//...goals similar to the qualitative constructivist epistemology” (Mason, 2006, p.17).

Prominent writers and applied researchers (Mertens, 2003, 2006; Thorne et al., 2004a) have published mixed methods studies demonstrating critical interpretive accounts of their research within the contemporary literature, thus helping to rectify the deficits of such reports. These authors provide readers with invaluable examples of such studies being conducted within an interpretive framework. Bazeley (2013), in a more recent text, provides valuable and pragmatic guidance on how to achieve qualitatively driven interpretive mixed methods research outputs that are more than “topographical surveys”.

This study has employed a qualitatively driven mixed methods approach to the sequential exploration of the study of persistent abdominal pain. This framework provides the foundation for the researcher’s predisposition toward an interpretivist/constructivist epistemology that places importance on inductively derived knowledge. It has thus facilitated the researcher’s intent to accommodate the multiple and constructed realities (within context) considered inherent within and characteristic of the phenomenon of persistent abdominal pain. These viewpoints are evident in the orientation of the research questions, the methods employed, the inferences drawn and the interpretations/findings reported. In addition, the researcher’s position within this research project is also reflected in the title of the thesis and in the emphasis and subsequent weighting given to the qualitative interpretations/chapters. Hence, they demonstrate the researcher’s primary concern and orientation toward the qualitative agenda and the use of an interpretive framework within this agenda, supporting what Creswell et al. contend is indicative of a qualitatively driven mixed method approach and for which they espouse that “interpretive qualitative research can extend mixed methods research” (2006, p.1).

Further discussions related to the location of the researcher within this research project are presented in Chapter 4. The preceding discussions relate to the methodological approach of

interpretive description, since this was the primary method used to study the qualitative dimension of this mixed methods project.

### **3.6 Interpretive description within mixed methods**

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The primary intent of this study was to understand the clinical phenomenon of persistent abdominal pain, particularly as it occurs within the acute care hospital environment. A better understanding would allow clinicians to make ethically, morally and clinically responsible recommendations regarding proposed clinical improvement activities for patients suffering with persistent abdominal pain. Studying the phenomenon from a multidimensional, contextually embedded perspective required an approach that was capable of providing findings that extended beyond description alone to afford an understanding that evolved from “exploring meanings and explanations”, including “illuminating characteristics, patterns and structures” (Thorne et al., 2004b, p.3), which are representative of and inherent within the study phenomenon. These accounts would subsequently inform activities directed toward improving the health care outcomes for current and emerging patient cohorts with persistent abdominal pain. Utilising an interpretive descriptive approach to the management of the qualitative dimension of this mixed methods study facilitated this initiative:

Interpretive description is an inductive analytic approach designed to create ways of understanding clinical phenomenon that yield application implications (Thorne et al., 2004b, p.1).

Mixed methods leading to interpretive description, with its roots in the traditional conventions of qualitative research, offered a methodological approach that provided “an integrity of purpose deriving from two sources:

- an actual practice goal as articulated in the research questions; and
- an understanding of what we do and don’t know on the basis of the available empirical evidence from all sources” (Thorne, 2008, p.35).

However, this interpretive descriptive approach to the qualitative data demands an approach to data analysis that:

Generates questions from that grounding, pushes one into the “field” in a logical, systematic and defensible manner, and creates the context in which engagement with the data extends the interpretive mind beyond



the self-evident – including both the assumed knowledge and what has already been established – to see what else might be there. As such it offers the potential to deconstruct the angle of vision upon which prior knowledge has been erected and to generate new insights that shape new enquiries as well as application of “evidence” to practice. We desperately need new knowledge pertaining to the subjective, experiential, tacit and patterned aspects of human health experience – not so that we can advance theorizing, but so that we have sufficient contextual understanding to guide future decisions that will apply evidence to the lives of real people (Thorne, 2008, p.35).

These motivations have a foundation in interpretivism, a philosophy that Angen (2000) describes as not:

...concerning itself with considerations of realism beyond how we experience it in our everyday lives. Interpretivism grounds itself in the phenomenological understanding that we carry out our lives in an intersubjective realm that we experience sensually and know linguistically from moment to moment and day to day...//...living in the world as it exists apart from us, but we only know it and understand it through our attempts to meaningfully interpret it, and those attempts at interpretation are in turn influenced by our temporal and cultural location...//...understanding therefore cannot be separated from context. Interpretive research is predicated on the desire for a deeper understanding of how humans experience the life world through language, local and historical situations, and the intersubjective actions of the people involved (Angen, 2000, p.385).

Hence, a philosophy that subscribes to the pluralistic nature of social enquiry and the concomitant requirement to engage ‘methodological pluralism’ as a means of accessing the multidimensional facets characteristic of social phenomena utilises research methods that “transcend or even subvert the so-called quantitative–qualitative divide” (Mason, 2006, p.9) in order to accommodate the complexities and multiplicities inherent in our contemporary world. Therefore, to achieve the purpose of the study from this epistemological orientation, it was inevitable that the researcher would navigate within and between diverse epistemological and ontological orientations. However, while appreciating the differing epistemological foundations and their utility of informing the research agenda, it was within the philosophical interpretivist domain that the researcher and thus the project principally resided.

Despite the well-founded philosophical orientations of interpretive mixed methods studies, interpretive naturalistic criticism about eclectic methods selection remains. While criticisms about the selection of methods within mixed methods studies were addressed earlier in this

chapter, 'cautionary tales' from qualitative methodologists about employing multiple qualitative approaches as a basis for interpretive descriptions will be briefly considered here.

Heeding Morse (1989), who decried the resultant "methodological slurring" and the consequential erosion of the "credibility of the qualitative genre", in addition to criticisms concerning the potential lack of "epistemological and methodological grounding" (Caelli et al., 2003, p. 6), Thorne argues that interpretive description provides a convention that:

...names and references the kind of well-founded logic that clinical researchers have been coming up with in applying qualitative research within the health domain...//...and provides a more appropriate and viable option than watering down or modifying phenomenology, ethnography or grounded theory and hoping that no one notices the methodological violations (Thorne, 2008, p.35).

Further, she states that interpretive description has a "philosophical alignment with interpretive naturalistic orientations" that "acknowledges the constructed and contextual nature of human experience that at the same time allows for shared realities" (Thorne, 2004b, p.5).

Subscribing to the philosophical foundations of naturalistic enquiry, Thorne et al. (2004b) draw on the key axioms of naturalistic enquiry delineated by Lincoln and Guba (1985), as the philosophical underpinnings for research design. These include the notions that:

- there are multiple constructed realities that can be studied only holistically; thus, reality is complex, contextual, constructed, and ultimately subjective
- the inquirer and the "object" of enquiry interact to influence one another; indeed, the knower and known are inseparable
- no a priori theory could possibly encompass the multiple realities that are likely to be encountered; rather, theory must emerge or be grounded in the data (Thorne et al., 2004b, p.5).

Hence, Thorne et al. (2004b) argue, "While the techniques for data collection and even analysis may vary within interpretive descriptive studies, this coherent epistemological foundation distinguishes it from the inconsistencies of underlying assumptions characteristic of method slurring" (Thorne et al., 2004b, p.5).

Appreciating and respecting that there exist multiple and shared 'socially constructed' realities for all stakeholders at the centre of the phenomenon, and understanding the imperative of the 'contextually derived' nature within which these realities characterise the phenomenon, as experienced by patients, carers and health care professionals, was a main focus of this study. In presenting and examining the qualitative data in light of the research questions, some of the conventions characteristic of thematic narrative analysis were selected and utilised. With its foundation in interpretive phenomenological analysis (Riessman, 2008, p.74), representing the stakeholders' dialogues in this way has made it possible to present the stakeholders', particularly the patients', stories in a way that honours their construction. Thus, to some degree this provides insight into the interpretive beliefs that stakeholders, particularly patients, understand as the basis of their suffering, carers supporting, and health care professionals delivering health care in response to the experience of persistent abdominal pain. Thus, in working with the qualitative data and subsequently presenting some examples within the thesis, efforts have been made to:

...keep the story intact for interpretive purposes.....preserving sequence rather than thematically coding...//...striving to preserve sequence and the wealth of detail contained in long sequences...//...and ... theorizing from the case rather than from component themes (categories) across case (Riessman, 2008, p.53).

Consequently, the presentation of the qualitative data in the findings chapters (Chapter 6 and Chapter 7) represents some individual as well as composite narrative accounts. The findings have been divided into two chapters to manage the vast and diverse data sets, not only to honour their constructions as mentioned previously but also to reveal to the reader the "particular" within the "general" as it relates to some of the poignant themes highlighted within the study phenomenon as recounted from multiple study participant perspectives. In addition, preserving the contextual backdrop upon which these accounts were delivered prevents such accounts being taken out of context and also assists in making some of the researcher's interpretations, inferences and conceptualisations more discernible.

In adopting thematic narrative analysis to manage the centrality of the patients' stories as being the major component of the qualitative data from this study, the accounts of participants are presented without interrupting their stories – an outcome considered important, right from the outset of the study. In this way, the unique individual accounts of

the phenomenon under study have been preserved for “the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding” (Thorne et al., 2004b, p.5). The consequences of their experiences, however, are central to the experiences of the stakeholders. Hence, (other) stakeholders’ responses to the patients’ experiences are presented in response to and after the patient stories.

In addition to gathering increased insights into stakeholders’ experiences of the study, particularly the patients at the centre of the study, the author was also curious to explore what such a well-versed stakeholder group would recommend in relation to the essential elements of an improved model of care. In particular, it was of interest to note whether patient expectations of the ancillary health care services provided and their corresponding treatment goals were congruent with those held by attending clinicians, particularly those responsible for the management of the patient group when hospitalised as a consequence of an acute exacerbation of their underlying pain complaint.

The study was also concerned with identifying the efficiencies and efficacies of the current model of care, as perceived by multiple stakeholders as a result of their experience of receiving, delivering or supporting care directed toward the clinical management of patients suffering from persistent abdominal pain.

As a result of these endeavours, it was anticipated that these findings, along with the relevant contemporary literature would inform the basis for the development of an alternative model of care for the management of patients presenting to acute care facilities with persistent abdominal pain.

Subscribing to the pluralistic nature of social enquiry, and hence the concomitant requirement of a multidimensional appreciation of social phenomenon, research methods that “transcend or even subvert the so-called quantitative–qualitative divide” (Mason, 2006, p.9) were required to truly understand the complexity and pluralism of our contemporary world. In attempting to fulfil this research agenda, it was inevitable that diverse epistemological and ontological orientations were utilised.

The phenomenon at the centre of this study was the experience of stakeholders (patients, carers and health care professionals) in relation to patient suffering and in relation to supporting or delivering care for patients with persistent abdominal pain. Central to this study is the patients' experiences. Their experiences are central to the development of their persistent abdominal pain, and of being chronically unwell and in pain and having to regularly seek health care services in crisis situations related to that underlying persistent abdominal pain.

Patients with persistent abdominal pain do not become patients with chronic pain overnight. Their 'journey of becoming' and their 'experience of being' a patient with persistent abdominal pain within the context of life in and outside of the acute hospital environment and how this 'reality' for patients had been constructed was of great interest. There was a need to consider the "particularities" and context of this cohort, derived from the descriptive quantitative data and other qualitative data about their journeys. The primary aim was to improve patient care through better understandings of these 'socially constructed realities', which, together with the implicit mandate of aiming to provide translational research, dictated a methodological approach that extended beyond the qualitative traditions of ethnography, grounded theory and phenomenology.

Supporting the pluralistic pragmatic philosophical assumption is the ontological position of valuing single and multiple realities. Subscribing to this orientation, the present study employed multiple methods (retrospective hospital chart audits, hospital activity and cost analysis reports, health professional demographic and activity questionnaires/surveys, health professional focus group interviews, individual patient interviews, carers' questionnaires, and nominal group workshops) in order to understand, and, in part, to explain the multidimensional nature of the lived realities of all stakeholders involved in the phenomenon of persistent abdominal pain and its management. Similarly, from an epistemological perspective, collecting data to answer the research question(s), and thereby valuing both subjective and objective knowledge, are inherent in the conduct of this study; these approaches support pragmatism as the worldview or overarching philosophical orientation of the study.

Methodologically, a mixed methods approach to research accommodates the use of multiple and diverse data sources in attempts directed toward providing better understandings of phenomenon, especially social phenomenon, from multiple perspectives. Creswell et al., state, “mixed methods research is both a methodology and a method, and it involves collecting, analysing, and mixing qualitative and quantitative approaches in a single study or a series of studies” (2006, p.1). With primacy given to the research questions and what is required to answer them, a particular philosophical affiliation was required to focus attention toward collecting, analysing, interpreting and reporting data sets that best informed the research. Hence, the research needed to be carried out within the context of the phenomenon under study. Since phenomenon are rarely unidimensional, especially social phenomenon, multidimensional approaches are required to inform and provide understandings of all the variables inherent within the phenomenon of a patient experiencing, a carer supporting, a health care professional or a health service providing health care to patients experiencing persistent abdominal pain. Thus, in an attempt to understand the occurrence of persistent abdominal pain within the acute care setting, both subjective and objective accounts are necessary to capture all stakeholders’ experiences, perceptions and recommendations within the context of receiving, supporting and delivering health care. A mixed methods research design provides the necessary framework to conduct such an enquiry.

### **3.6.1 Study purpose**

The primary aim of the study was to critically review the experiences, expectations and perceptions of stakeholders (patients, carers and health professionals) central to the construction of the phenomenon of chronic abdominal pain. In addition, the study aimed to identify clinical practices and organisational procedures, embedded within the current model of care that could be identified as constraining good patient outcomes. Finally, the study was concerned with gaining stakeholder consensus regarding an alternative treatment approach for current and possibly emergent patient cohorts with persistent abdominal pain.

### **3.6.2 Research aims**

The study aimed to:

- Identify patients who regularly present to the hospital study site with persistent abdominal pain and to identify those clinical speciality groups and individuals most often utilised for the management of these patients
- Quantify health care utilisation for the selected cohort within a defined timeframe
- Identify system and process issues that either impede or facilitate optimal management for patients presenting with persistent abdominal pain to the study site hospital
- Qualify major stakeholders' experiences and perceptions of the suffering of, the support provided for and the care delivered to patients with persistent abdominal pain, both within the acute care environment and the community
- Identify and gain broad agreement (from all stakeholders) around the principles and essential elements of a revised model of care to better manage patients when they present with acute symptoms to the study site hospital
- Facilitate clinician engagement, ownership, commitment and mobilisation in identifying and implementing a revised model of care for the identified patient cohort.

### **3.6.3 Research questions**

The research questions to be answered in this study were as follows:

- i. What are the experiences, expectations and perceptions of stakeholders (patients, carers and health professionals) central to the construction of the phenomenon of persistent abdominal pain?
- ii. What are the nature, extent and impact of repeated hospital presentations on stakeholders in response to unresolved persistent abdominal pain?
- iii. What would need to change in order to provide a more efficient and effective model of care for current and emerging patient cohorts with persistent abdominal pain?

In summary, the study aimed to build a composite cohort profile of people with similar experiences of pain, and to identify, qualify and quantify the impact associated with their

experience of disease from a patient, as well as from an economic/system (health care utilisation) perspective. In addition, the study sought to identify clinical and organisational processes and procedures that stakeholders (clients, carers and clinicians) considered limited or that constrained good patient outcomes. Finally, it was anticipated that these deeper and more diverse understandings of these patient situations and experiences, together with recommendations from the literature, would inform the provision of a more contemporary, evidenced-based model of care for patients suffering with persistent abdominal pain who regularly access acute care facilities.

### **3.7 Validation of data collection approaches**

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Considering Bazeley's (2013) contentions that few mixed methods research reports are explicit about the relative merits of the methods employed, this study used the various data sets to facilitate a greater appreciation of the phenomenon of suffering with, caring for and delivering health care in relation to persistent abdominal pain. This study has incorporated an interpretive framework by employing an approach that "empowered participants, recognised their silenced voices, honoured their individual differences and positioned both the researcher and the individual participants' views in a historical/personal/political context" (Creswell et al., 2006, p.5).

The rationale for undertaking mixed methods research is:

...grounded in the fact that neither qualitative nor quantitative methods are sufficient by themselves to capture the trends and details of a situation. When used in combination, quantitative and qualitative methods complement each other and allow for a more robust analysis, taking advantage of the strengths of each (Ivankova et al., 2006, p.3).

A number of rationales have been proposed for the implementation of mixed methods research. Greene et al. (1989) and Bryman (2006), having each on separate occasions reviewed the theoretical and empirical literature on the subject, have contributed significantly to this commentary. A compilation of their works identifying the main rationales/benefits for conducting mixed methods research is presented in Doyle et al. (2009, p.178):



*Triangulation:* this allows for greater validity in a study by seeking corroboration between quantitative and qualitative data.

*Completeness:* using a combination of research approaches provides a more complete and comprehensive picture of the study phenomenon.

*Offsetting weaknesses and providing stronger inferences:* many authors argue that utilising a mixed methods approach can allow for the limitations of each approach to be neutralised while the strengths are built upon thereby providing stronger and more accurate inferences.

*Answering different research questions:* mixed methods research helps answer the research questions that cannot be answered by quantitative or qualitative research questions alone and provides a greater repertoire of tools to meet the aims and objectives of a study. The combination of research approaches is useful in areas such as nursing because of the complex nature of the phenomenon and the range of perspectives that are required.

*Explanation and findings:* mixed methods studies can use one research approach to explain the data generated from a different research approach.

*Illustration of data:* using qualitative research approaches to illustrate quantitative findings, helping to paint a better picture of the phenomenon under study.

*Hypotheses development and testing:* a qualitative phase of a study may be undertaken to develop hypotheses to be tested in a follow-up quantitative phase.

*Instrument development and testing:* a qualitative study may generate items for inclusion in a questionnaire to be used in a quantitative phase of a study.

Employing a mixed methods approach in this study highlighted the utility of the methodology in furnishing a significant number of these documented rationales. Primarily, this rationale resided in the methodology's capacity to offer corroboration between and within the data sets. This was particularly useful for validating issues central to the phenomenon; for example, patients' complaints relating to delays in receiving care, clinicians'

complaints in relation to delays in expediting specialist clinician input, both areas highlighted by study participants as leading to prolonged lengths of hospital stays (validated by the activity data) for the study patient cohort. In addition, a broader and more comprehensive appreciation of the phenomenon from multiple dimensions and perspectives enabled not only validation in relation to key issues but also aided a more complete understanding of the phenomenon under study.

### **3.8 Data analysis and interpretation**

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First, in an attempt to understand the phenomenon around a patient experiencing the symptoms related to chronic abdominal disease, particularly in the context of being an inpatient in an acute care hospital, semistructured interviews were held with each of seven study patient participants. The patients' individual stories, the meanings they had attributed to their situations, and the interpretations that they had made of various elements within their clinical scenarios were of particular interest. An assumption was made that these issues were foundational to their belief system(s), those that they had constructed either consciously or subconsciously, about the nature of their illness, which in turn seemed to subsequently foster illness behaviours that at times appeared to be unhelpful and even harmful to them.

The second item of interest was whether the patients' experiences, perceptions and expectations of their health care encounters were congruent with those of their carers' and those of the health care professionals responsible for delivering much of the health care they received, both as outpatients and when admitted to an acute care facility. As a clinician, implicit in many of the clinical encounters, there were significant tensions surrounding divergent treatment agendas, those of the health care professionals and those of the patients. An initial research assumption was that the conflicting ideological platforms from which stakeholders operated were instrumental in producing 'therapeutic impasses'. It seemed important to acknowledge that these ideological platforms, the consequence of powerful political, social, cultural and educational forces influencing the subjective experience of the individual at the centre of the phenomenon and situations, required due consideration beyond merely the descriptive. There was a greater need for the 'explanatory' to address the 'so what' questions and answer these in a way that facilitated not only utility in the health

care arena but also provided a sense of positive therapeutic outcomes for these patients (Riessman, 2008; Thorne, 2008; Bazeley, 2013).

Finally, discovering what patients, who are well versed in the organisation and implementation of health care within an acute care hospital, thought facilitated a positive outcome – one which they saw as overcoming barriers to good clinical outcomes for themselves and other emerging patient cohorts suffering persistent abdominal pain – was of great relevance. Also of interest was finding out what they perceived as the essential elements of a revised model of care that could be implemented at the study site as a consequence of the study.

By using a mixed methods approach incorporating an interpretive description of the qualitative data sets, the researcher therefore needed:

- to collect and analyse persuasively and rigorously both qualitative and quantitative data (based on research questions)
- to mix (or integrate or link) the two forms of data concurrently by combining them (or merging them) sequentially, either by having one build on the other or by embedding one within the other
- to give priority to one or to both forms of data (in terms of what the research results and findings emphasised)
- to use these procedures in a single study and in multiple phases of the program of study
- to frame these procedures within philosophical worldviews and theoretical lenses; and
- to combine the procedures into specific research designs that directed the plan for conducting the study (Creswell & Plano Clark, 2011, p.5).

The processes utilised to apply these conventions are discussed in detail (Chapter 4) as they relate to each of the four phases within the sequential explanatory mixed methods approach.

The researcher's constructive/interpretive orientations are:

- exposed through the emphases that reside within the research questions
- evidenced by the decisions made in conducting the research through accessing naturalistic environments and considering multiple perspectives

- cognisant of the recognition and subscription to the belief that perspectives are constructed realities created within the milieu of the sociopolitical contexts within which they occur, in contrast to being value-free, neutral or absolute truths.

The research approach reflects a commitment to a research logic that is predominately inductive while still remaining cognisant of the relative synergistic utility of the deductive and abductive logics in informing research agendas, particularly concerning changes to clinical practice.

The goal of attempting to improve patient outcomes through a research program has its basis in the researcher being a clinician with a history of implementing new clinical services. Such services required competing for limited health care resources, and possessing a realist/pragmatic orientation. This orientation to the research involved:

- having experienced how clinicians respond to proposed changes to their clinical management of their patients
- having witnessed how management and administrative bodies consider options and what they value as potential prospects for enhancement funding within clinical practice, and
- being cognisant of and ethically responsible to the broader health care strategies of the state and national governments and of how the research agenda could help facilitate this broader agenda were all experiences that informed the decisions and hence the approach taken in conducting this study.

Having made explicit the philosophical orientation and intrinsic motivations underpinning the conception and conduct of the study, prominence has been given to the qualitative dimension of the study. The qualitative phase of the project was pivotal to providing understanding about the past clinical management of the study patient group and identifying a more contemporary approach to future management strategies. The qualitative data were concerned with attempting to appreciate how the study patients had arrived at a point in their lives that required such extensive and intrinsic links with the acute care health system; why the study patients continue over many years to require such intensive interaction with the acute care health system; and how it is possible to implement change that might potentially result in a better quality of life for the patients and their families. Hence, the

explanatory phase involved understanding the past in order to inform the future. Given the significance of the work associated with and dependent upon distilling the qualitative data, discussions related to data analysis and rigor will focus on the management of these qualitative data sets, reflecting the mainly qualitatively driven approach to this mixed methods study.

### **3.9 Summary**

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The study presented in this thesis is a four-phase sequential explanatory interpretive mixed methods study. In undertaking the study, multiple methods (retrospective hospital chart audits, hospital activity and cost analysis reports, health professional demographic and activity questionnaires/surveys, health professional focus group interviews, individual patient interviews, carers' questionnaires/surveys and nominal group workshops) have been employed to provide comprehensive understandings of persistent abdominal pain. Although subscribing to a pragmatic approach in conducting the study, an interpretivist/constructivist epistemological orientation has taken theoretical precedence in the conception, undertaking and representation of study findings presented in this thesis. In keeping with this theoretical orientation, an inductive logic was utilised to provide explanations relating to the study phenomenon. These activities were undertaken with an expressed intent to develop a revised model of care to which all stakeholders at the centre of the study had contributed during its evolution. Hence, the study represents a patient-focused, collaborative and interdisciplinary research agenda that had a practice-orientated research outcome as its primary impetus, and for the most part reflects the types of agendas characteristic of contemporary health care research.

### **3.10 Conclusion**

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Chapter 3 has explored the utility of mixed methods research in exploring phenomenon from multiple perspectives. Transcending methodological paradigmatic tensions that arise from positivist versus constructivist approaches for primacy, the 'third paradigm' of mixed methods accommodates research projects concerned with the sociopolitical, complex and dynamic environments within which phenomenon occur.

Subscribing to Greene's 'multiple perspectives' mixed methods has provided a methodological framework within which this study could be conceived, implemented and findings extrapolated. The ability to accommodate multiple data sets and multiple perspectives to provide better insights into persistent abdominal pain has enabled multiple ways of seeing circumstances characteristic to the phenomenon. Gaining access to these multiple orientations not only reflects the pluralistic nature of the context within which the study phenomenon occurs, but also reflects contemporary research approaches within health care. Attempting to improve health care outcomes for patients requires an approach that accommodates the multiple perspectives and hence agendas that are inherent within contemporary health care service provision. Mixed methods and in particularly qualitatively driven approaches facilitates the agency of patients within this broader agenda.

In the subsequent chapter, Chapter 4 attention will turn to describing the processes and procedures utilised throughout the study to examine the study phenomenon from all stakeholder perspectives. It was envisioned that, though these explorative and explanative research approaches better insights would illuminate how future clinical managements could be improved for the study patient stakeholder group and their families.

## Chapter 4 Study design and methods

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### 4.1 Introduction

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As discussed in Chapter 3, mixed methods research provides an alternative to the historically embedded dichotomous approaches to conducting research. This ‘third paradigm’ enables a more comprehensive appreciation of multiple and diverse perspectives and constructions of the phenomenon under study through both qualitative and quantitative approaches to data collection, analysis, interpretation and presentation.

Having previously located the study within the context of a ‘qualitatively driven’ agenda and a constructivist/interpretivist epistemological and ontological orientation (Chapter 3), this Chapter is directed toward presenting the process and procedures utilised during the conduct of the study. The research aims and question(s) that guided this study were instrumental in identifying “what (methods) works” (Creswell & Plano Clark, 2011, p.43); and these methods allowed the research questions to be answered.

In applying the mixed methods credo of ‘what works’, this study does not give credence to a methodological eclecticism that disassociates theory from method. Rather, the theoretically informed decisions made in both conceiving and conducting the study and that inevitably underpin the subsequent interpretations derived from this study will be clarified.

#### 4.1.1 Study purpose

The primary aim of the study was to critically review the experiences, expectations and perceptions of stakeholders (patients, carers and health professionals) central to the construction of the phenomenon of chronic abdominal pain. In addition, the study aimed to identify clinical practices and organisational procedures, embedded within the current model of care that could be identified as constraining good patient outcomes. Finally, the study was concerned with gaining stakeholder consensus regarding an alternative treatment approach for current and possibly emergent patient cohorts with persistent abdominal pain.

### **4.1.2 Research aims**

The aims of the project were to:

- Identify patients who regularly present to the hospital study site with persistent abdominal pain and to identify those clinical speciality groups and individuals most often utilised for the management of these patients
- Quantify health care utilisation for the selected cohort within a defined timeframe
- Identify system and process issues that either impede or facilitate optimal management for patients presenting with persistent abdominal pain to the study site hospital
- Qualify major stakeholders' experiences and perceptions of the suffering of, the support provided for and the care delivered to patients with persistent abdominal pain, both within the acute care environment and the community
- Identify and gain broad agreement (from all stakeholders) around the principles and essential elements of a revised model of care to better manage patients when they present with acute symptoms to the study site hospital
- Facilitate clinician engagement, ownership, commitment and mobilisation in identifying and implementing a revised model of care for the identified patient cohort.

### **4.1.3 Research question**

The research questions addressed in the project are as follows:

- i. What are the experiences, expectations and perceptions of stakeholders (patients, carers and health professionals) central to the construction of the phenomenon of persistent abdominal pain?
- ii. What are the nature, extent and impact of repeated hospital presentations on stakeholders in response to unresolved persistent abdominal pain?
- iii. What would need to change in order to provide a more efficient and effective model of care for current and emerging patient cohorts with persistent abdominal pain?

In summary, the study aimed to build a composite cohort profile of people with similar experiences of pain, and to identify, qualify and quantify the impact associated with their experience of disease from a patient, as well as from an economic/system (health care



utilisation) perspective. In addition, the study sought to identify clinical and organisational processes and procedures that stakeholders (clients, carers and clinicians) considered limited or that constrained good patient outcomes. Finally, it was anticipated that these deeper and more diverse understandings of these patient situations and experiences, together with recommendations from the literature, would inform the provision of a more contemporary, evidenced-based model of care for patients suffering with persistent abdominal pain who regularly access acute care facilities.

Phenomena that are characteristically complex and multidimensional require an approach that takes these complexities and diversities into account. Such phenomena are inherent in contemporary health care service provision, and research into these phenomena requires contemporary methodological approaches. Inevitably, this requires researchers to move beyond methodologically purist orientations, the hallmark of discipline-specific education and research affiliations. Mixed methods approaches allow more diverse and comprehensive studies to be done to improve patient care. While such approaches do not preclude either of the methodological traditions from making their respective and invaluable contributions, a synthesis of combined approaches may allow greater insights to be gained into a phenomenon under study, rather than being constrained by philosophical tenets inherent in either of the two mainstream methods that are generally applied. Working toward these shared and synthesised understandings opens up opportunities for interdisciplinary research about contemporary health care delivery and reflects the types of multifaceted and complex clinical concerns that clinicians/researchers are choosing to investigate, such as those studied within this thesis.

Johnson and Onwuegbuzie (2004) contend that research is being conducted within increasingly more interdisciplinary, complex and dynamic environments that therefore require and justify multiple research approaches and superior methodological and philosophical understandings to facilitate better communications and collaborations between disciplines. Further, the authors assert that “epistemological and paradigmatic ecumenicalism is within reach in the research paradigm of mixed methods research” (p.15).

In determining a methodological approach, the researcher's challenge is to "... fit the research methods to the evaluation problem without parochialism" (Teddlie & Tashakkori, 2009, p.17). Johnson and Onwuegbuzie state "...the bottom line is that research approaches should be mixed in ways that offer the best opportunities for answering important research questions" (2004, p.16).

#### **4.1.4 Study design**

The mixed methods literature is replete with "typology-based approaches" to mixed methods study designs (Mertens, 2003; Tashakkori & Teddlie, 2003, 2009; Creswell & Plano Clark, 2007, 2011; Tashakkori & Creswell, 2007). In keeping with the pragmatic philosophical assumptions underpinning mixed methods research, the classifications and design strategies offered are supported by a particular studies purpose and its accompanying research question(s).

The typologies available to classify and identify types of mixed methods strategies are influenced by a number of key procedural issues. These issues are related to the timing, weighting and mixing of the respective qualitative and quantitative data sets within a single study or program of research study. When data (qualitative and quantitative) are collected sequentially, initial data are used to inform subsequent data sets, whereas data collected concurrently are gathered simultaneously during the data collection phase. The relative priority or 'weighting' adopted highlights the pre-eminence given to one or the other of the respective qualitative or quantitative data sets, for example (QUALITATIVE + Quantitative or QUANTITATIVE + Qualitative), or in the case of equal priority (QUALITATIVE + QUANTITATIVE). The issue of 'mixing' relates to when and how data, philosophies and interpretations are combined in such a way that they are mutually illuminating. Such procedural approaches are described as being: 'connected' when one data set will inform the other during discrete phases of a study; 'integrated' when data sets are merged, or 'embedded' when one data set provides a supplementary role to another. Finally, consideration of how data are derived (knowledge is generated), either inductively or deductively, orientates the researchers' philosophical foundation from which the study has been conceived, conducted and findings interpreted (Creswell & Plano Clark, 2007, 2011; Andrew & Halcomb, 2009; Creswell, 2009; Teddlie & Tashakkori, 2009).

The procedural elements given within the typologies have been extensively described in the literature by authors such as Mertens (2003), Morse (2003), Creswell and Plano Clark (2007, 2011), Creswell (2009), Teddlie and Tashakkori (2009). However, few accounts offer practical guidance or illustrative examples that can assist mixed methods researchers' to overcome the methodological wrangles inherent in sequencing, weighting and integrating the methodological approaches and their underlying philosophical assumptions. Despite this and despite considerable criticism from research methodologists claiming methodological incompatibility (Chapter 3), mixed methods research continues to gain momentum and credibility in the contemporary health care literature.

There are a number of potential research designs within the mixed methods arena from which researchers can choose when undertaking a mixed methods approach to research enquiry. However, despite having these prescriptive schematic approaches that function to convey rigor about the methodology, and to guide researchers in relation to the implementation and conduct of a mixed methods study, the fact remains that the research question is the fundamental driver in identifying which is the most appropriate of the typologies to employ for any given mixed methods project (Bryman, 2006; Creswell & Plano Clark, 2007, 2011; Leech et al., 2011).

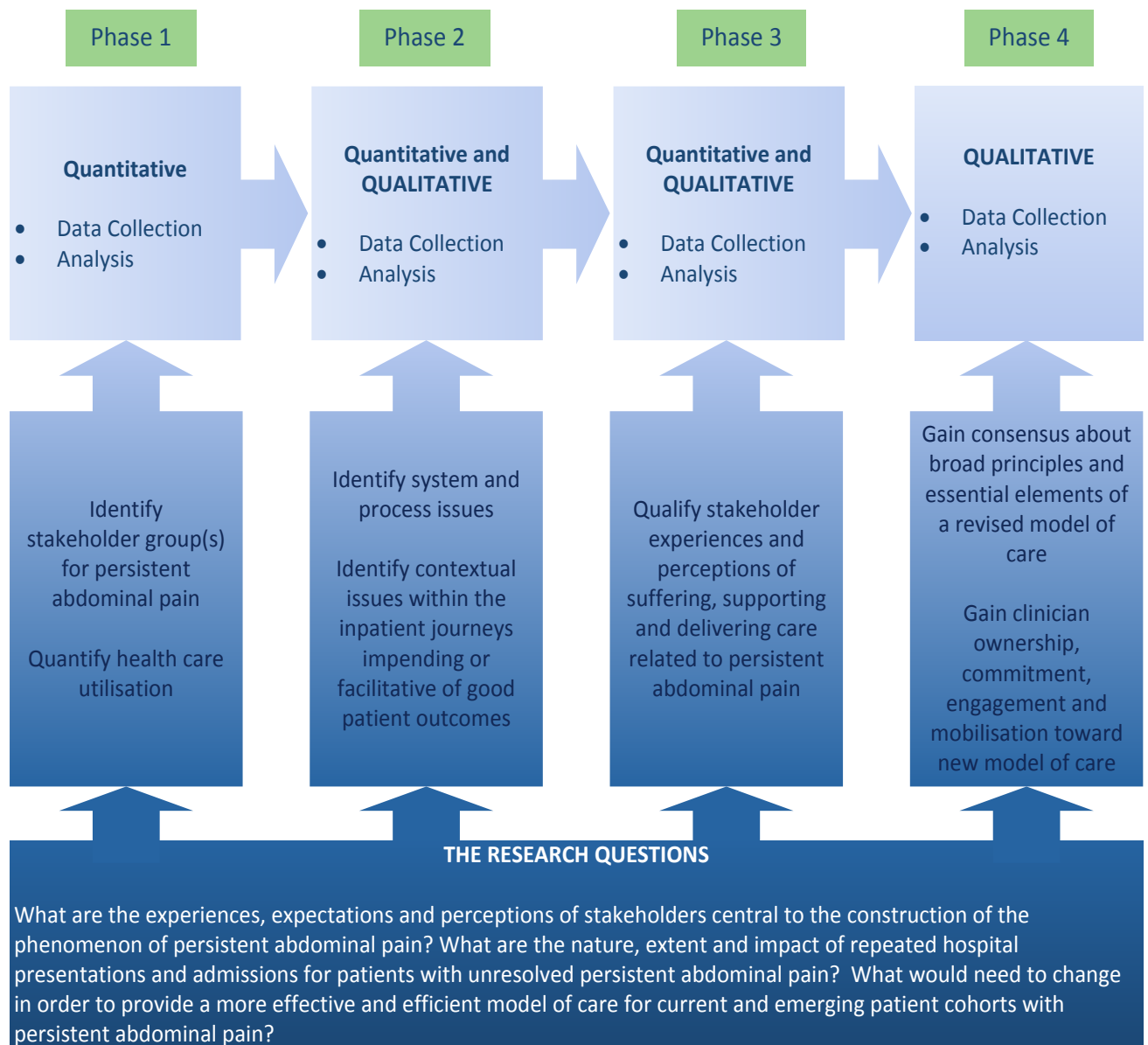
Guided by Creswell and Plano Clarks' (2011), revision of mixed methods typologies, the study presented in this thesis employed a four-phase explanatory sequential design (Figure 4.1). The design chosen allowed the following aims to be investigated: i) to identify all stakeholder study cohorts (patients and clinicians) plus the relative characteristics of the health care utilisation patterns of the patient cohort; ii) to scope the extent of the problem (quantitatively and qualitatively); iii) to move toward the explanatory phase through qualitative enquiry in an attempt to better appreciate the 'how' and 'why' questions generated by the quantitative findings; and finally iv) to gain stakeholder consensus about the essential elements of an alternative model of care for the study group and for emerging patient cohorts with persistent abdominal pain. Hence, this study subscribes to Creswell and Plano Clarks' (2011) stated purpose for undertaking explanatory design mixed methods studies, that is:

The purpose of this design is to use a qualitative strand to explain initial quantitative results...//....when the researcher wants to form groups based on quantitative results and follow up with the groups through subsequent qualitative research or to use quantitative results about participant characteristics to guide purposeful sampling for a qualitative phase...//...and is most useful when the researcher wants to assess trends and relationships with quantitative data but also be able to explain the mechanism or reason behind the resultant trends (Creswell & Plano Clark, 2011, p.82).

The rationale for utilising the design has been previously discussed (Chapter 3), but principally resides in:

...the fact that neither quantitative nor qualitative methods are sufficient by themselves to capture the trends and details of a situation...but...when used in combination, qualitative and quantitative methods complement each other and allow for a more robust analysis taking strengths of each (Ivankova, Creswell & Stick, 2006, p.3).

The utility of such an approach, that which offers broader and deeper appreciations of a complex and multidimensional phenomenon within its naturalistic context, is depicted when considering the questions this study sought to address, and of how a mixed methodological approach helps to facilitate such an expansive research agenda.



**Figure 4.1 Four-Phase Sequential Explanatory Design**

Source: Adapted from Creswell and Plano Clark (2011, p. 69).

The remainder of this chapter will further describe the study design, including phases of the study, data instruments, collection processes and analytical procedures, as well as study participant selection, ethical considerations and constraints and limitations inherent in the study. To contextualise the research endeavour, an overview of the study setting is first presented.

#### **4.1.5 The study setting**

The study was conducted in an Australian tertiary referral hospital located within a large Local health district (LHD) in NSW that services approximately 840,000 people and covers a geographical area of 130,000 kilometres.

The LHD employs 15,500 staff members who provide specialist and supportive care to 12% of the state's population, and expends AUD1.7 billion per annum in attending to this mandate. The study site's ED delivers over 60,000 occasions of service per year (since 2009). Presentations to the ED related to pain in the abdomen or nausea and vomiting represent 26% of all presenting problems to the department, ranking it at number one of the top ten presenting complaints (Hospital Performance and Activity database, Accessed 2012).

An integral part of the study site hospital's tertiary referral status is the provision of area-wide consultative and specialist medical and allied health services. Included in these specialist and consultative services are dedicated inpatient and outpatient pain management services. These pain management services provide consultative services for the management of acute postoperative, post-trauma, chronic cancer and non-cancer pain for both inpatients and outpatient residing within the study site's LHD.

In 1993, an acute pain service (APS) was implemented at the study site hospital for the inpatient management of acute postoperative and post-trauma pain. The APS was created and implemented based on the recommendations of comparable services developed in Seattle by Ready (1994), and in South Australia by Macintyre et al. (1990) and Schug and Torrie (1993). The APS is primarily responsible for the safe and effective delivery and monitoring of pain management at the study site's hospital. The service takes a consultative approach and is made available 7 days a week. Attached to it is a consultant anaesthetist pain management specialist, a consultant pain management nurse, rotating anaesthetic registrars, a part-time

pain management nurse specialist and registered nurses. The service has a long tradition of clinical pain management innovation. It has been at the forefront of inpatient APS provision within the Australian context, particularly in relation to identifying and managing patients at risk of progressing to persistent pain states.

In 1997, additional pain management services were introduced into the study site hospital. A multidisciplinary pain management service was implemented with the intent to provide pain management services that extended beyond inpatient acute pain management activities, to accommodate people with persistent, non-cancer and cancer pain in the community and during hospitalisation related to an acute exacerbation of a chronic pain complaint. The multidisciplinary team provides specialist services in relation to the assessment, diagnosis, procedural, medication and non-pharmacological approaches (Cognitive Behavioural Therapy [CBT]) to the management of persistent and cancer-related pain. In addition, it has a commitment to health promotion and collaboration with general practitioners in the region in an attempt to enhance population approaches to the management of pain and improve the health care outcomes for patients in the LHD with pain-related issues.

## **4.2 Conducting the study**

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### **4.2.1 Phase One: Scoping the extent of the problem**

The initial phase of the study was implemented in response to anecdotal reports of high health care utilisation and associated clinical difficulties for patients regularly presenting and being admitted to hospital for persistent abdominal pain.

Although there was general clinician consensus surrounding the ‘difficulties’ associated with this patient cohort, no previous attempts had been made to collect, collate and integrate data, so that no meaningful accounts, or even a basic descriptive account, of health care utilisation patterns had been gathered to substantiate such anecdotes. Hence, in an attempt to identify the extent and scope of the problem, Phase One of this study drew on existing multiple databases to identify the nature, extent and scope of the health care utilisation for patients identified as suffering with persistent abdominal pain (Figure 4.2).

Following ethics clearance from the institution's Human Research Ethics Committee, the Hospital's Activity and Performance Database was accessed to identify patients who had been admitted to the study site two or more times per year during the prescribed study period (2003, 2004, and 2005) suffering from abdominal pain. In addition, the study site's ED Patient Activity Database was accessed to identify patients who regularly presented to the department during the study period with abdominal pain. Finally, the Acute and Chronic Pain Services' Patient Activity Databases' were utilised to capture those patients who had required consultative services from the multidisciplinary chronic pain service, and who had subsequently been diagnosed with persistent abdominal pain.

Cross-referencing the four databases was required to identify potential study patients based on activity (health care utilisation  $\geq 2$  hospital admissions per/year, every year for the study period 2003–2005) and diagnosis (persistent abdominal pain, IASP's definition of chronic pain, that is, "pain > 3 months' duration" (Merskey & Bogduk, 1994). This was necessary for two reasons. First, the current classification system utilised to code patients' primary and secondary diagnosis is not sensitive or specific enough to discern between abdominal pain related to a persistent or chronic underlying condition(s), and those related to an acute episode(s). Second, the researcher was aware (given her clinical experience), of one patient who despite not fulfilling the activity inclusion criteria, did fulfil the diagnosis criteria of persistent abdominal pain. This patient had relocated to the study region in 2005, had a long history in a different LHD, with problems associated with persistent abdominal pain, and since arrival, had had a number of lengthy and difficult inpatient encounters at the study site hospital related to her long-standing chronic abdominal pain issues. Her inclusion into the study was therefore based on diagnosis rather than activity.

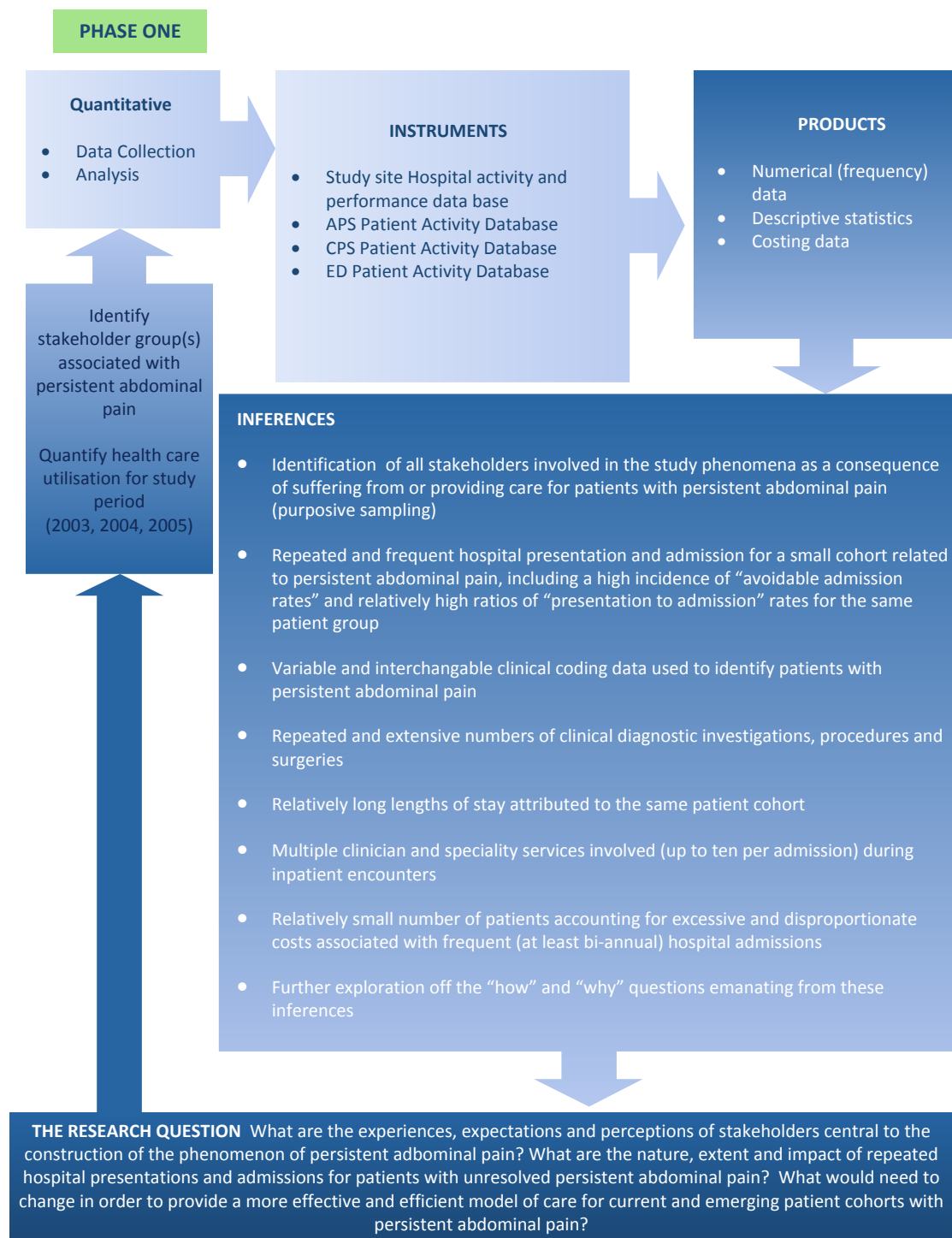
In addition to identifying the study patient cohort, other relevant information collected during this phase helped to inform the study by identifying:

- which Diagnostic Related Groups (DRGs) are most frequently utilised in coding the patient cohort when they present to the study site with symptoms related to persistent abdominal pain



- the presentation and admission profiles of the selected patient cohort, e.g., which hospitals within the LHD they access, how frequently they access these services, if admitted into the service, for how long do they stay (length of stay – LOS), and what is the time interval between discharge and readmission to the acute care facility (avoidable admissions)
- which clinical services (medical, nursing and allied health) are most frequently accessed to provide inpatient care, and to which ward areas within the hospital are they most frequently admitted; and
- what diagnostic, investigative, procedural and surgical events are characteristic of the patients' ED encounters and hospitalisations, and what are the costs associated with these procedures and surgeries (limited to the study period).

In summary, the initial phase of the study identified the patients and clinicians involved in the study phenomenon. It highlighted the various and interchangeable diagnostic criteria used to code patients presenting with symptoms related to persistent abdominal pain, and also the difficulties associated with locating such patient cohorts within existing hospital databases for a clinical condition that appears to have no appropriately assigned diagnostic related category. In addition, this first phase identified presentation and admission profiles and clinical activity data characteristic of the patient cohort when presenting and being admitted into an acute care facility within a LHD. The relevant diagnostic, procedural, interventional and surgical procedures and their associated costs were also collated for the study patient cohort within the prescribed study period. These data sets were retrieved and collated to produce a composite profile of patients who presented and were admitted (at least biannually for each of the study years 2003, 2004, 2005 or who had been diagnosed with chronic abdominal pain) to the study site hospital for the management and treatment of persistent abdominal pain.



**Figure 4.2 Phase One: The Sequential Explanatory Design Study**

## 4.2.2 Phase Two: The quantitative data within context

After substantiating anecdotal reports of high health care utilisation patterns characteristic of patients with persistent abdominal pain, the contextual underpinnings of these findings were investigated by considering the ‘how’ and ‘why’ questions inherent in the quantitative

findings. These comprised the subjects of the second and third explanatory phases of this mixed methods study depicted in Figures 4.3 and 4.4, respectively.

Having identified the patient group (purposive sampling – Phase One) who would be the focus of the study, retrospective hospital chart audits were carried out based on each patient's hospital admissions records within the study period. This was done to gain an understanding of those contextual issues that could help explain the quantitative findings of Phase One of the study. Because the study was designed to examine this patient cohort not only within context, but also over time, a 3-year study period (2003–2005) was employed. Using a longitudinal rather than a 'selective' episodic approach to the retrospective chart audits helped to:

- legitimise interpretations and inferences drawn that were more representative of the study phenomenon, thereby minimizing misrepresentations and generalisations that may have resulted if 'known difficult hospital admissions' were purposely selected for review, and
- overcome clinician concerns that such misrepresentations could potentiate unhelpful stereotyping of the patient cohort (relational ethical issues inherent in the study are discussed later in this chapter) and in turn negatively influence subsequent encounters with health care professionals at the study site hospital.

Hence, the study period selected was based on the ability to access the three most recent consecutive years for which completed data sets were accessible, particularly completed costing data.

Conducting the retrospective chart audits required in excess of 500 research hours. Given the labour-intensive nature of this phase of the study, a small research grant was provided by the hospital's Nursing and Midwifery Department to employ a registered nurse to assist the researcher in carrying out the chart audits. The assistant employed was a recently retired nurse, a consultant in stomal and enteral therapy who had been employed at the hospital for over 30 years, and who in the course of her own clinical work had been involved in the care of some of the study patients. Her extensive clinical experience helped to ensure the reliability and trustworthiness of the data being extracted. A Chart Audit Form was specifically

designed to aid data collection (Appendix 1). Data captured during this phase were concerned with identifying contextually relevant details, related to system efficiency and effectiveness (task times, wait times, hands off occasions, access and exit blocks).

Issues relating to hospital system efficacy and effectiveness were measured according to the correlates identified and defined by the United Kingdom National Health Service Modernisation Agency (2004) and the NSW Department (2005), considered to significantly influence hospital system efficiency and efficacy. The correlates utilised, their associated definitions, and their contextual applications for the purposes of conducting a study related to the hospital inpatient management of patients with persistent abdominal pain are presented in Table 4.1.

**Table 4.1: Measurements Used to Quantify System Efficiency and Effectiveness**

Measurements	Definitions
Access Block	The time interval taken to admit a patient from the hospital's ED to a hospital ward.
Exit Block	Time interval taken to discharge a patient from a hospital
Hands Off	When a patient is handed from one health care professional to another
Task Times	Time taken to perform a task. e.g. Insertion of Central Line
Wait Times	Time interval between ordering. e.g. an investigation and the same being performed
Unplanned Readmissions	Readmission to hospital within 28 days after discharge from hospital
Source: MHS Modernisation Agency (2004); NSW Health (2005) <a href="http://www.health.nsw.gov.au">http://www.health.nsw.gov.au</a>	

In addition to examining these efficiency issues, other contextual issues considered relevant (as a consequence of extensive clinical exposure of the researcher to the study patient cohort) were reviewed. Such reviews took into account how patients presented to the hospital, including whether they elected to present to the hospital by private transport or by using the State's ambulance service. Such information was deemed important in terms of shedding light on clinician assertions that accessing the ambulance service facilitated two important patient imperatives; these were perceived to be:

- expediting transit times through the ED; and
- procuring additional opioid analgesia whilst en route to the hospital.

Similarly, referral patterns (via GPs or other health care providers) were also considered in the chart audits. Knowing whether patients were referred to the hospital by a primary health care provider with or without supporting documentation and pre-emptive communications,

via phone message or fax was instrumental to 'unpacking' hospital clinicians' concerns and perceptions that:

- GPs were abdicating responsibilities in caring for these patients in the community
- such patient cohorts were not managed by a general practitioner in the community and therefore the patients relied on the hospital system to provide their primary care needs; and
- the study patient cohort is characterised by 'Doctor and Hospital Shopping'.

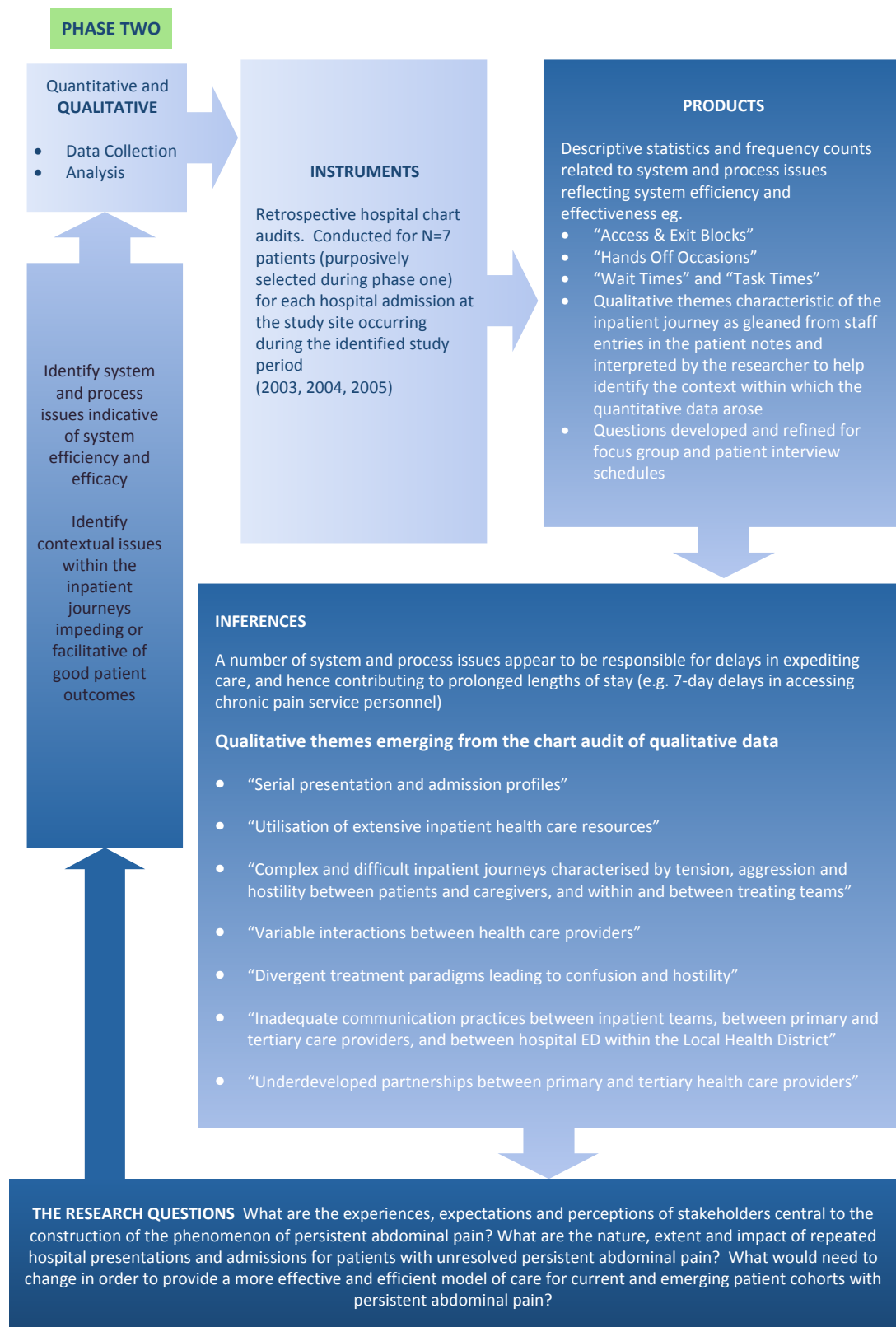
Further, the nature, frequency and scope of diagnostic, therapeutic, procedural, surgical and pharmacological events were also captured, again in a bid to provide a comprehensive overview of what happens to patients when presenting or being admitted into the acute care system with symptoms related to persistent abdominal pain. Originally, it was thought that by capturing such data, clinicians' concerns about the occurrence of unnecessary duplications and implementations of diagnostics and therapeutics could be examined and illuminated. However, further interpretation of these data was not appropriate, as it would have been contingent on the subjective value judgements, made out of context, by a researcher ill-equipped to make such assertions. Thus, the utility of the data remains consistent with providing descriptive base-line information about clinical interventions that subsequent studies might potentially use for comparative and further interpretive purposes.

Additionally, the diagnostic classifications used to describe the study patient cohort's presenting clinical features required further consideration (identified in Phase One). It had become apparent during the course of conducting the first phase of this study that, in the absence of a diagnostic code (DRG) that adequately reflects the symptomology and diagnostic criteria (ICD-10) for persistent abdominal pain, many varied and often interchangeable diagnostic criteria are used by attending clinicians. The current constellation of diagnostic criteria is the foundation on which the state health funding model for hospitals operates; and important implications arise in further highlighting this relational issue (Chapter 5).

Conducting the retrospective chart audits, and in turn identifying emergent themes characteristic of the study patients' inpatient journey, aided a more informed approach to developing interview schedules for the focus group and individual interview participants

(Phase Three). Based on initial meetings and after examining other comprehensive studies (both quantitative and qualitative) prior to meeting with and interviewing study participants, particularly health care professionals, more detailed and where appropriate, clinical speciality-specific issues, could subsequently be explored. This was an important feature of the study, in that capturing multiple perspectives was fundamental to appreciating the study phenomenon as a whole rather than viewing it just from its respective parts. In addition, it was necessary to appreciate the pragmatics of attempting to engage vast numbers of very senior and junior medical staff, typically sceptical of the utility of qualitative methodologies, and to construct, conduct and deliver research outputs that were commensurate with their commitment to involvement. Achieving success in this was considered fundamental by the researcher to allow subsequent mobilisation of clinician engagement, commitment and collaboration toward achieving the ultimate study outcome, of revising and implementing a new model of care for the study's patient participants and possibly for emerging patient cohorts with persistent abdominal pain.

Similarly, interview schedules designed for the study of patient and family member/carer cohorts were constructed around the emergent themes arising from the retrospective chart audits. This provided structure for interviews that might otherwise have been sabotaged by, for example, a particular participant's agenda or difficulties recounting the specifics of otherwise informative inpatient events.



**Figure 4.3: Phase Two: The Sequential Explanatory Design Study**

### 4.2.3 Phase Three: Stakeholders' experiences

The experiences, expectations and perceptions of stakeholders (patients, carers, family members' and health care professionals) in relation to suffering with, supporting and delivering health care to patients with persistent abdominal pain were central to this study. The intent of the third (qualitative) phase of the study was to gain a deeper appreciation, beyond descriptive statistics, to provide explanations for and interpretations of the phenomenon under study (Figure 4.4). To fulfil this research agenda, a series of focus group and individual patient interviews were conducted with consenting stakeholders purposively identified during the initial phases of the study (Table 4.2).

**Table 4.2: Study Participant Stakeholder Groups**

Stakeholder Groups	N=number of people interviewed
Individual Patients Interviews	7
FOCUS GROUP INTERVIEWS	
Nominated Family Members/Carers	6 3 (focus groups) + 3 (carers interviewed with patients)
Accident & Emergency Department Head of Department, Staff Specialists, Medical Consultants, Advanced Trainees, Registrars, and Residents	10
Accident & Emergency Department Nursing Staff (RN, CNS & CNC, NM)	10
Surgical Medical Consultants, Head Of Department, Staff Specialists, VMO, Advanced Trainees, Registrars and Residents	15
Gastroenterology Medical Consultants, Staff Specialists, Head Of Department, VMO, Advanced Trainees, Registrars and Residents	10
General Surgical Ward Nurses (RN , CNC & NUM)	10
Anaesthesia and Pain Management Head of Department, Pain Fellow, Staff Specialists, Consultants, VMO, Registrars and Residents	10
Specialist Pain Management Nursing Staff (RN, CNS & CNC)	10
Allied Health Professionals ( Psychiatry, Psychology, Social Work, Physiotherapy, Dietetics, Drug & Alcohol)	10
General Practitioners	10

As a clinician integral to the management of the study patient cohort for over a decade, the researcher was cognisant of the multiple and at times divergent interpretations held by stakeholder groups. Reflecting on these 'constructed realities' awakened a sensitivity to the behavioural responses evidenced in practice. Access to these 'constructed realities' within their 'naturalistic' context was thus considered paramount to providing the depth and breadth of interpretive understandings believed necessary to meaningfully inform the study. Therefore, in honouring these multiple and diverse constructions, the third QUALITATIVE phase was designed to capture the unique and diverse views and experiences that collectively



create the social and professional milieu in which persistent abdominal pain patients and professionals come together. Consequently, rather than using multidisciplinary focus groups comprised of health care professional stakeholders, individual speciality-specific, and professionally separated (medical, nursing, allied health) focus groups were conducted. Similarly, study patient participants were interviewed individually rather than collectively in a single focus group. Hence, this phase of the study was directed toward accounting for the complexities, multifactorial, diverse and individual experiences of a vast number of stakeholders at the centre of the study phenomenon. Central to the study phenomenon was the patients' experiences.

#### **4.2.3.1 Individual patient interviews**

Upon receiving patients' verbal consent (facilitated by clinicians) to participate in the study, patients were mailed an information pack that contained; a study information sheet (Appendix 2); and a patient consent form (Appendix 3). Patients were requested to forward the signed consent form to the researcher if they were interested in participating in the study. Upon receiving the consent form, patients were contacted and individual one-on-one interview(s) were scheduled. Interviews were conducted in a venue convenient to the patient. In keeping with the previously stated agenda of unpacking patients constructed realities, individual interviews were conducted and recorded for verbatim transcription using a semistructured interview schedule (Appendix 4). The interviews were directed toward gaining insights into:

- the patients' developmental histories
- events leading up to what they perceived as the precipitating incident(s) from which the subsequent persistent abdominal pain condition resulted
- the experiences surrounding the development of persistent abdominal pain
- the experiences related to being chronically unwell, in pain and having to regularly access health care, particularly related to acute pain exacerbations
- the experiences related to living with persistent unresolved chronic abdominal pain
- perceptions related to facilitative and impeding events, and situations considered by patients to be conducive or otherwise to good patient outcomes (as defined by the patient)
- the patients' recommendations for a revised model of care.

All patients nominated to be interviewed in their homes. Four of the patient participants were interviewed alone, whereas three nominated that a family member/carer also be present in lieu of their participation in the nominated family member/carer focus group. The duration of interviews was one and a half to two and a half hours, during which time the patients were repeatedly asked if they wanted to conclude or break from the interview. One patient interview needed to be rescheduled as a consequence of them being too sedated to participate in the interview.

#### **4.2.3.2 Family member/carer focus group interviews**

Following a patient's consent to take part in the study, patients were asked to nominate a family member or carer whom they thought would be prepared to participate in the family member/carer dimension of the study. These potential family member/carer participant nominations were based on the premise that these nominees:

- were  $\geq 18$  years
- were the principal carer/support person, partner or relative of one of the study patient participants and who,
- lived with the study patient participant.

Following these nominations, family members/carers were mailed an information pack regarding the scope and purpose of the study (Appendix 5). Within the pack was an invitation for the nominee to attend a family member/carer focus group interview. Upon receipt of a consent form (Appendix 6) from the participant, the focus group was organised and subsequently conducted in a meeting room within the hospital. The interviews were conducted in a low-key and conversational, although semistructured fashion, with questions directed toward accessing carers'/family members' experiences, interpretations and understandings of issues related to them supporting a loved one who had been diagnosed with persistent abdominal pain (Appendix 7) including:

- the impact the diagnosis had had on them and other members of the family
- the impact of having long associations with the health care service and appraisals of these contacts from all dimensions, over time

- observations about the most recent hospital encounters related to events in the emergency department and on the ward, throughout the hospital stay, including interactions with health care professionals, and what happened upon discharge
- comments related to perceptions regarding how well or otherwise current treatment approaches are facilitative and obstructive toward good health outcomes for their loved ones
- ideas for inclusion in a new model of care for them and new families embarking on a similar health care journey.

The family member/carer focus groups, as well as health care professional focus group interviews were conducted by the researcher as the assistant moderator and by a consultant employed to be the principal moderator. The moderator, a university staff member employed at the local university's Faculty of Health, School of Nursing and Midwifery has experience and expertise in conducting focus groups and as such her skills and expertise were considered critical, not only to the successful outcome of this phase of the study, but also in providing a degree of credibility and validity, inherent in her professional competency/position. This in turn helped facilitate the positive and productive engagement with a methodological approach that some, particularly medical stakeholders, may have deemed difficult.

Initially, the intent was to provide a single focus group interview for the family/carer stakeholder group. However, at the close of the first meeting, participants requested a subsequent interview, claiming that they would appreciate further opportunity to share additional insights and concerns. Hence, two family member/carer focus group interviews were conducted during the course of the study. Each was attended at the study site hospital for up to two and a half hours. Both focus group interviews contained the same three participants. In addition, three consenting family members/carers nominated to be interviewed during their (patient) relative/loved one's individual patient interview for a number of reasons. One relative experienced difficulties accessing child care. Another felt uncomfortable and confronted by participating in a group discussion. Another declined on the basis of having had previous negative encounters with pain management self-help groups and expressed a desire not to associate with a group that he perceived would be

*“unproductive”*. For the final study patient, their relatives/carers declined any invitation to participate in either the focus group interview or being included during their daughter’s individual interview. The relatives cited an ongoing dispute with the hospital over the inpatient management of their daughter’s pain related admissions foundational to their preference not to participate in this aspect of the study.

One of the potential shortcomings of conducting this phase of the study was omitting the attendance of study patient participants’ children to a focus group analogous to that provided for adult family members and carers. During the design phase of this aspect of the study, the inclusion of such a focus group was considered, but later rejected, given the considerable inherent ethical and moral contingencies. The potential for inciting emotional trauma for such a vulnerable group was considered disproportionate to any potential benefits of their inclusion. Issues relating to the generational impact as a consequence of parental figures suffering from chronic pain conditions have previously been documented. However, a worthy postdoctoral study would be to remain focused on this study’s patient cohort and consider the longitudinal impact of the study phenomenon for these patients’ offspring. This would offer significant insights beyond what has been recounted ‘second hand’ by the parents participating in this study.

#### **4.2.3.3 Health care professional stakeholder focus group interviews**

Attempting to better understand the study phenomenon within context implicated all health care professionals responsible for providing health care services to the study patient cohort for symptoms related to persistent abdominal pain. In attending to this initial, and the subsequent study mandate of gaining insights into a potential revised model of care for patients with persistent abdominal pain, considering multiple clinicians’ perspectives was critical.

As established during the initial quantitative phase of the study, patients with persistent abdominal pain are typically cared for by a considerable number of clinicians, allied health, nursing and medical speciality staff during inpatient hospital stays. For this patient cohort, initial quantitative data revealed (and were confirmed by retrospective chart audits) that a maximum of ten inpatient health care speciality services are frequently and repeatedly

mobilised to provide inpatient care during hospitalisations for this patient group. Having confirmed which clinical speciality groups were involved, a meeting was scheduled with the Head of Department of each of these respective clinical specialties and disciplines.

The purpose of these individual meetings was to inform Department Heads about a proposal for how the study was to be conducted and to provide information in relation to the data that had been collected and collated thus far and the purpose of the study. These meetings were useful in setting the agenda, engaging pivotal clinicians/administrators and seeking assistance in the 'arm's length' recruitment of potential clinician focus group interviewees (Appendix 8). To this end, a study information pack (Appendix 8) was left with Department Heads. A request was made of Department Heads to help advertise and support the running of the study at staff meetings, grand rounds and education meetings and by placing study information letters and consent forms (Appendices 9 & 10) in staff tea rooms. Medical staff who cared for the study patients in their clinical capacity as a specialist consultant and visiting medical officer (VMO), were contacted at their private rooms, informed of the study and invited to participate in the study by attending a focus group interview for their respective clinical discipline. These conversations preceded the provision of the study information pack, which included a formal and written invitation to participate.

Individual hospital inpatient clinical speciality focus group interview(s) were conducted: seven for speciality domain specific health care professionals, one for allied health staff and one for general practitioners. All focus group interviews were conducted on site at the hospital, with the exception of the GP focus group interview, which was conducted in a meeting room within a convention centre easily accessible for these clinicians coming to and going from work. Focus group interviews for all stakeholder groups had a minimum of 10 and a maximum of 15 consenting participants. The Department of Surgery utilised their scheduled focus group meeting as a compulsory education session for medical surgical trainees to attend and observe. This was an unexpected, although welcome, outcome highlighting the Department's commitment to engaging in the study. Each focus group interview was conducted for between 90–120 minutes, with many clinicians having arranged cover for their respective clinical commitments in order to ensure their availability and attendance for the entire interview session. Again, these actions were unprovoked by the

researcher and possibly facilitated by department heads; they were nevertheless indicative of clinicians' commitment to participating in and being concerned about the research agenda.

All health care professional focus groups were directed toward accessing participants' professional experiences in providing health care services to patients with persistent abdominal pain. In addition, views were canvassed, and guided by a semistructured interview schedule (Appendix 11) in relation to:

- concerns/issues related to the patient group under study
- the adequacy or otherwise of the current model of care (inclusive of the participants' particular area of clinical practice/speciality)
- the personal and professional impact associated with caring for the patient group
- opinions or recommendations on alternative approaches to the clinical management of the study patient group.

Given the purposive nature of the composition of the focus groups, which was a consequence of clinical specialism homogeneity, discussions were directed toward attempting to identify the craft group beliefs and mores that underpin current clinical practices. The safety that these discrete speciality-specific groups offer, enabled attendees to capitalise on the opportunity of being amongst like-minded clinicians to discuss issues – potentially contentious issues – from a speciality rather than an individual position, shifting the emphasis toward improvement rather than apportioning blame.

Krueger (1994, p.187) makes reference to the expanded and contemporary utility of the focus group method engendering collaborative efforts toward research agendas that are beyond providing descriptive reports as a consequence of:

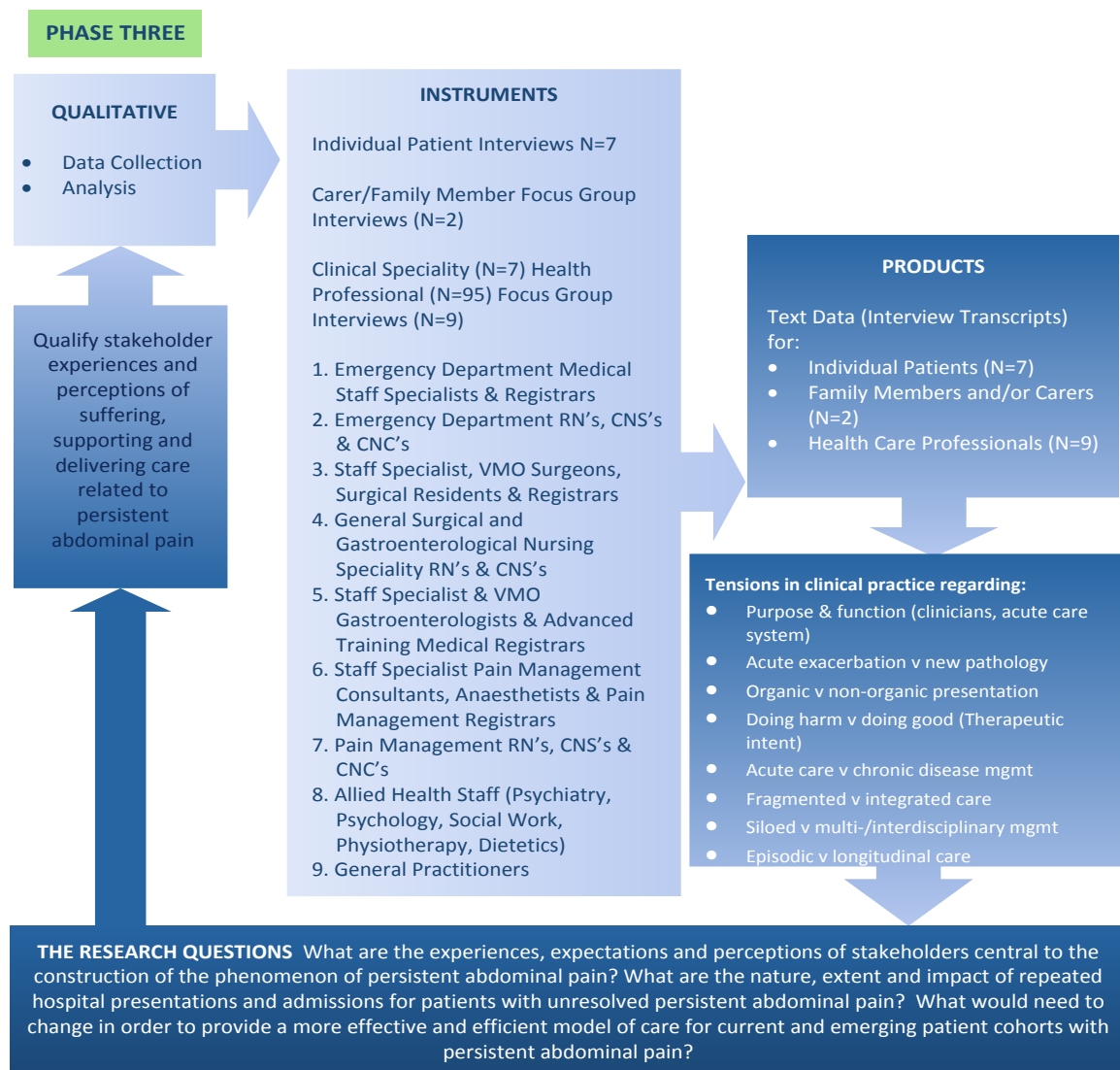
...placing volunteers, staff members, and non-researchers in the centre of the focus group project, these individuals are charged with conducting a study that will tap into various parts of the Organisation, institution or community. These individuals are carefully recruited and possess certain talents and resources that can contribute to overall success...//...introducing complexities and difficulties but also yielding additional benefits. With the collaborative approach, extra goals are included: developing skills among participants, creating awareness among influential individuals, generating support for viable solutions, producing a believable and trustworthy report, and ensuring that recommendations are practical

and useful. The process of data gathering and listening takes on more importance and may be equivalent in importance to the information that is collected.

The focus group interviews were particularly powerful in engaging all stakeholders and providing a non-threatening, conciliatory approach toward acknowledging the shortcomings of past clinical management and committing to the collaborative efforts required to identify a way forward for improving outcomes for the study group and for emerging patient cohorts with persistent abdominal pain. This strong resolve toward the research agenda was supported by requests from numerous stakeholders (patients, clinicians and relatives) to progress the study further (Phase Four), with the specific intent of refining and developing a model of care that could potentially be utilised for trial purposes within the study site hospital. These requests were made of the researcher both verbally and in writing.

At the conclusion of each of the focus group interviews, all participants were invited to complete a questionnaire designed to capture demographic data (Appendix 12). In addition to providing these details, participants took the opportunity to make further comments related to the study, including registering their commitment for future involvement and consultation in subsequent phases of the study.

At this point, the researcher delivered a presentation to the Hospital Administration and Clinical Innovations Units and at a NSW Hospital Clinical Innovations Meeting. The study findings (Phases One to Three) were presented, along with the expressed collective commitment from all key stakeholder groups to subsequently engage with and progress the study. A request for funding to support the subsequent phase of the study was granted by the hospital administration, and both financial and administrative support was provided in order for the fourth phase of the study (nominal group workshops) to be undertaken (Figure 4.5). This financial assistance was instrumental in enabling significant clinician inputs from diverse clinical specialities. In providing relief from or reimbursement for lost clinical time, key clinician stakeholders were able to come together in order to develop a revised model of care for patients presenting to the study site with persistent abdominal pain (Phase Four).



**Figure 4.4: Phase Three: The Sequential Explanatory Design Study**

#### **4.2.3.4 Phase Four: The nominal group workshops**

Harnessing clinicians' collective good will and commitment was essential to producing salient study outcomes. These outcomes, expressed by stakeholders attending the focus group interviews were:

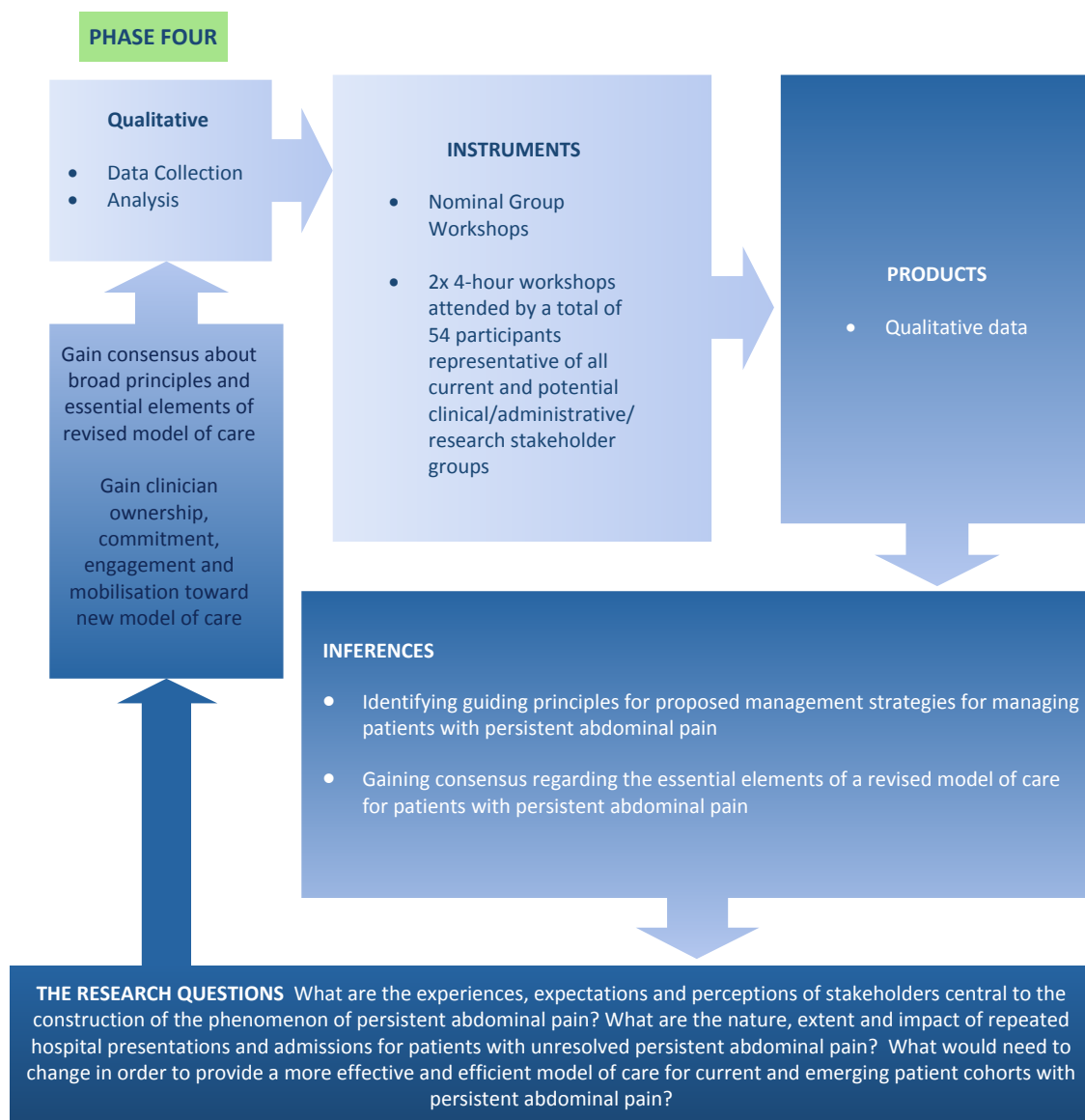
- to develop a collectively sanctioned consensus statement regarding the treatment approaches to be implemented for study patients in the event of their presentation and admission to the study site hospital



- to gain consensus regarding the essential elements of a revised model of care for the patient cohort
- to gain clarity in relation to issues concerning ownership and engagement during study patients' presentation and admission to the hospital
- to devise a model of care for the hospital inpatient management of the study patient group, and later for emerging patient cohorts with persistent abdominal pain.

Consensus methods are often utilised to address issues in health care service provision, particularly in situations characterised by insufficient, discordant and conflicting evidence related to clinical treatments (Fink et al., 1984; Jones & Hunter, 1995; Rubin et al., 2006). In situations that rely on empirical evidence, consensus provides a foundation from which theories can be developed, and treatment approaches, guidelines, and recommendations can originate. Making initial attempts to gather 'expert opinion' and build consensus statements/approaches by synthesising expert knowledge and experience with what information is available provides "an environment in which experts are given the best available information, and will allow their solutions to problems to be more justifiable, valid and credible than otherwise" (Fink et al., 1984, p.981). Phase Four of this study provided an opportunity to deliver this outcome for clinicians, an outcome that would ultimately benefit patients, in that issues identified as being fundamental to the inherent 'difficulties' characteristic of the study phenomenon could be overcome, for example, divergent and competing treatment paradigms/approaches.

The fourth phase of the study (Figure 4.5) was considered a juncture between events of the past and possibilities for the future. In attending to this transition, a series of nominal group workshops were conducted.



**Figure 4.5: Phase Four: The Sequential Explanatory Study Design**

Nominal Group Technique is a well-recognised consensus method directed toward achieving consensus by using a structured meeting attended by ‘experts’ (Fink et al., 1984). The meeting is guided by a set of predetermined structured questions (Harvey & Holmes, 2012) that attempt to generate views and prioritise problems and issues through group discussion (Jones & Hunter, 1995), and to overcome problems associated with traditional group discussions, such as domination by individuals or coalitions with a vested interest (Jones & Hunter, 1995; Rubin et al., 2006).

In identifying areas of consensus, the principal concerns about establishing and then prioritising issues for change can be elucidated. It is not surprising that this approach is well received by 'front line' clinicians, as it examines the 'best available evidence' in a way that has clinical utility and offers a degree of credibility that participant clinicians' treatments may not otherwise possess. Outcomes of such endeavours provide clinicians (particularly those in the midst of providing care for patients in sensitive or difficult areas, for which little research exists) with a platform of expert opinion that guides and substantiates their clinical practice. Since the approach is largely dependent on input from the clinicians at the centre of the issue, it potentially explains the inherent collaboration, ownership and ultimate increased uptake of recommendations documented to arise from the method (Fink et al., 1984; Vella et al., 2000; Rubin et al., 2006).

Fundamental to developing a revised model of care for study patients, was gaining consensus and a collective re-alignment to the guiding principles that expert clinicians believed should govern treatment approaches for patients presenting with persistent abdominal pain. Highlighting these guiding principles was vital to establishing the foundations from which recommendations regarding the essential elements of the proposed model would derive. These activities represented a pivotal point in the research agenda whereby clinicians, in making recommendations for subsequent treatment approaches, now had a 'collectively sanctioned' framework within which these recommendations could be situated.

Identifying whether the existing guiding principles were accepted would emerge largely from the qualitative findings of clinician stakeholder focus group interviews. By asking clinicians to reflect on their experiences in managing the patient cohort and identifying facilitative and obstructive approaches that they considered affected good patient outcomes, their individual and collective appraisals would become instrumental in revealing what they (expert clinicians) understood to be important for the optimal management of patients with persistent abdominal pain. A presentation of these findings along with data from all phases of the study, inclusive of a synthesis of the available literature on the subject, provided the platform from which nominal group workshops were subsequently conducted.

### ***The Nominal Group Workshops***

The Nominal Group Workshops were conducted over the course of 2 consecutive days in September 2007. The LHD supported the days by making funds available: to hold the workshops in a convention centre away from the hospital, to provide financial assistance for the release/replacement of all clinician attendees, and to employ the services of an expert facilitator for each of the workshops. Such investments from the LHD were positively interpreted by clinicians, undoubtedly leading to maximum attendance rates, particularly of key and senior clinicians. In addition, these supportive gestures appeared to infuse the workshops with a sense of united concern and purpose among hospital administrative and clinical staff in relation to a significant clinical issue.

A total of 54 clinicians (five of whom were also department heads) representing 15 clinical speciality groups, and four senior hospital and LHD administrators attended the nominal group workshops. Workshop participants were recruited in response to:

- their current involvement in the clinical management of the patient cohort at the study site hospital
- their clinical experience associated with managing this patient cohort and similar patient cohorts with difficult and complex clinical issues inclusive of substance abuse and psychological/psychiatric illnesses
- those clinicians considered to be potentially involved in developing the revised model of care for the patient cohort
- those LHD, hospital and department managers who held positions of influence over financial and clinical proceedings related to service provision/delivery for the patient cohort.

These recruitment procedures were consistent with those recommended by Fink et al.:

Consensus participants should qualify for selection because they are: representative of their profession, have power to implement the findings, or because they are not likely to be challenged as experts in the field. It is also advisable to include potential consumers wherever appropriate (1984, p.981).

The principal concerns relating to the clinical management of study patients with persistent abdominal pain (highlighted by focus group clinician attendees) were collated and expressed

as questions for consideration at the nominal group workshops. The questions represented the issues that clinician focus group attendees considered were those that underpinned current clinical practices (mostly described as deleterious). These required considerable deliberation before subsequent improvement approaches could be identified and eventually implemented. Discussions regarding these elements of the workshops are detailed further in Chapter 7.

Gaining an appreciation of the context within which health care interventions are directed toward the study patient group and why clinicians make decisions and enact particular approaches facilitated a shared perspective among clinicians and administrators. Achieving this was assisted by the presentation of the study findings, in particular the focus group findings, prior to the introduction of the workshop activities. In addition, constructing the workshop groups to emulate the interdisciplinary groups that focus group attendees had identified as being a more appropriate form of clinician involvement. It reaffirmed the potential for a move from the traditionally ensconced siloed biomedical approach, to a shared care, collaborative interdisciplinary and multidimensional approach they now sought in order to subsequently manage the study patient group and emerging patient groups with persistent abdominal pain. It also reflected a response to their express wishes in this regard. Thus, two representatives from each clinical speciality and discipline were invited (on the basis of the above-mentioned inclusion criteria) to attend the nominal group workshops.

The key clinician stakeholders at the centre of the study phenomenon and who participated in the focus group interviews represented the clinical specialities of surgery, gastroenterology, pain medicine, anaesthesia, general practice, accident and emergency, psychiatry/psychology, dietetics, and physiotherapy. The stakeholder group was further extended (for the purpose of the workshop meetings) to include representatives from other clinical services/disciplines considered to have potential future involvement/vested interests in the development of and delivery of some aspect(s) of the revised model of care and subsequent research activities. These services/specialities included general medicine and clinical epidemiology, and primary and community network services, e.g. community postacute care services, LHD's clinical innovation and service redesign unit, centre for psychotherapy and significant health district directors/administrators, which included the director of nursing, director of clinical services

for department surgery, director allied health and the senior manager for community services.

The workshops were structured in the following way:

### **Day One**

On day one following general instructions regarding the aims and objectives of the workshops and presentation of the study findings (as per the discussion above), four groups, each with a representative from the respective clinical specialities/disciplines were assembled. Each of the groups was given a set of questions they were asked to consider and for which their mandate was to aggregate a group response in relation to the issues posed by the questions (Table 7.1 & Table 7.2). This aggregated response functioned as a collective qualifying statement(s)/approach(s) that was utilised as a catalyst position from which, upon being presented to the broader workshop, supplementary discussion was facilitated. It involved all workshop participants in a bid to work towards seeking a general consensus about each group's particular issue(s).

### **Day Two**

On day two, the initial part of the proceedings from day one was repeated. In addition, the outcomes from the nominal group workshop held the previous day were presented to the second group of participants, again with representation from the same stakeholder disciplinary/speciality groups. Eight workshop participants attended on both days as a consequence of their pivotal clinical/administrative role within the study phenomenon. Similar to the preceding day, participants were asked to consider a set of clinical concerns, posed as questions (different from those posed on day one), from which the same outcomes (group consensus statements) were sought.

At the conclusion of the 2-day nominal group workshops, the foundations of a potential new model of care emerged that could be trialled for the inpatient management of the study patient cohort in the event of a hospitalisation in response to an acute exacerbation of persistent abdominal pain. What clinicians recommended to be the essential elements of this proposed model of care are presented in Chapter 7. The model is a collation of the inductive findings generated by multiple clinician inputs during the course of the study, integrated

with those deductive findings that stem from the current literature relating to contemporary approaches directed toward, in particular, the management of chronic and complex disease entities.

At this point, it is worth noting that the proposed model presented within this thesis was conceived at the conclusion of the fourth phase of the project, and hence should be considered as a platform from which subsequent research activities and more definitive treatment approaches will be derived. Following the fourth and final phase of this study, prospective work to further refine the model would need to be examined prior to trialling/implementing the model in clinical practice. Further consultative processes, such as inputs from patients and carers, clinical governance and hospital administrative personnel as well as more detailed work with clinical speciality groups around specific details of identity, include the determination of: i) the composition of an interdisciplinary team to manage the current patient and emerging patient cohort(s); ii) the criteria for thresholds for diagnostic, procedural and surgical interventions for individual cases; iii) the implementation, maintenance and escalation and withdrawal procedures for the management of long-term opioid use in the current and emerging patient cohort(s); and iv) which health care professionals and issues affect the management of non-compliance to established practice guidelines for the management of patients with persistent abdominal pain. Without these efforts, there remains a risk of perpetrating further harm as a consequence of generating additional confusion and division regarding treatment approaches, particularly for the current patient cohort. The subject of these future activities is beyond the scope of this thesis and hence will not be discussed beyond their significance for implications regarding future research emanating from the study presented to this point.

Thus, the workshops capitalised on the momentum the study had gathered and on the expressed desire of clinician participants to further invest in identifying clinical solutions and improvements for the phenomenon under study. The purpose of the Nominal Group workshops was to offer feedback on the data collected during preceding phases of the study and to use these interpretations of the data to guide further discussion, now interdisciplinary discussion, in relation to developing and implementing a revised model of care for current

and emerging patient cohorts. In essence, this reflected a subscription to a philosophy of pragmatism whereby:

The consequences (of the research endeavour) are more important than the process and therefore 'the end justifies the means'. It advocates eclecticism and a 'needs based or contingency approach to research method and concept selection' so that the researcher is free to determine what works to answer the research questions...it is informed by the belief that the practicalities of research are such that it cannot be driven by theory or data exclusively and a process of abduction is recommended which enables one to move back and forth between induction and deduction through a process of enquiry (Johnson & Onwuegbuzie, 2004, p.17).

## **4.3 Data management, analysis and interpretation**

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### **4.3.1 Data management**

The strategies employed for data collection and management within each of the phases of the study were discussed earlier in this chapter. Each data set built upon and informed the preceding phases of the sequential design, with the aggregation of all data sets at the conclusion of the fourth stage enabling a composite profile of the study phenomenon to be viewed from a multidimensional perspective. The data sets used to inform the interpretations/explanations presented within this thesis are as follows.

#### **4.3.1.1 Quantitative data**

- Local Health district/hospital activity data (frequencies & descriptive statistics)
- Local Health district/hospital performance data (frequencies & descriptive statistics)
- APS Patient Activity Database, CPS Patient Activity Database, ED Patient Activity Database
- Chart audit data (frequencies/descriptive statistics)
- Health professional questionnaires (frequencies & descriptive statistics)

#### **4.3.1.2 Qualitative data**

- Chart audit data (themes and tensions in clinical practice)
- X 7 Individual patient interview transcripts (narratives, themes and concepts)
- X 2 Family member/carer focus group transcripts (narratives, themes and concepts)
- X 9 Health care professional focus group transcripts (narratives, themes and concepts)



- X 2 Nominal group data (consensus data re clinical management issues to inform revised model of care)
- Clinician and patient qualitative comments forwarded via letters/emails and additional comments made on questionnaires
- Researcher's reflective pieces from personal study journal.

## 4.4 Data analysis

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Demographic data were analysed using basic descriptive statistics (frequency counts, means, standard deviations), to provide group profiles and an overall composite profile of the study patient participants. All data extrapolated during the course of the study have been stored on password-protected computer files. Audiotapes will be destroyed at the conclusion of the study and de-identified transcripts stored securely for the mandatory 5 years.

The qualitative dimension of the study employed an interpretive framework, guided by the work of Thorne et al. (1997, 2004a, 2004b, 2008) and Bazeley (2013), in addition to utilising conventions within narrative enquiry guided by Riessman (2008) and Frank (1995, 2000). The product of an interpretive account aims to provide:

...a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon that is being studied and also accounts for the inevitable individual variations within them...//...which ideally out to have application potential (Thorne et al., 2004b, p.7).

As transcribed individual interview and focus group data became available, they were forwarded to the researcher in textual format for review. An initial preliminary review was undertaken to gather a broad overview, and to allow "familiarisation" with the transcribed data, so that the author could become acquainted with the stories of participants, the issues emphasised, the sequences and meanings recounted, and the perspectives of each of the participants as regards significant events, in an effort to capture 'the whole picture'. There was no prescriptive order in which the interviews were conducted. As it happens, all stakeholder transcripts were reviewed concurrently during this "preliminary familiarisation phase". The advent of these non-orchestrated events was that as the data set grew and without imposing early conventions of coding and theming, the author was able to observe an evolution of the whole picture. This added appreciation supplemented the *a priori*

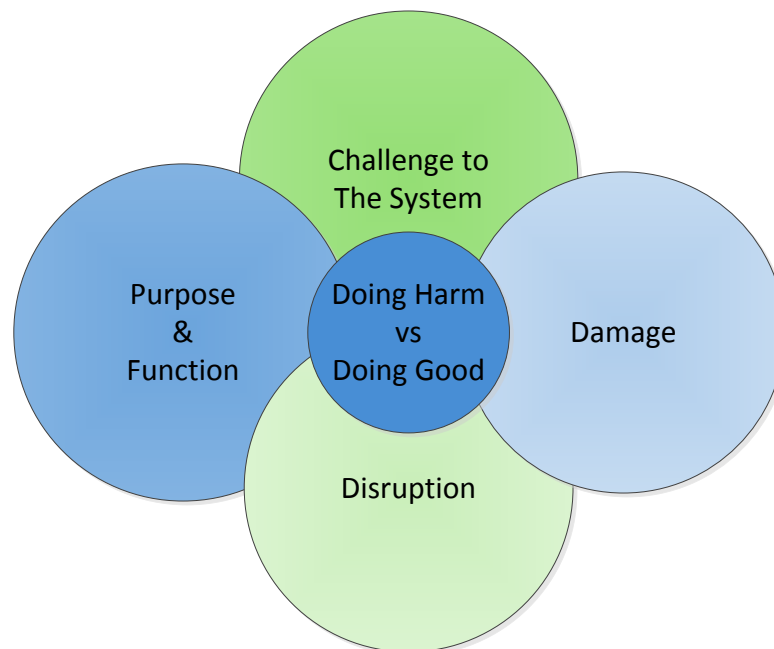
knowledge and theoretical insights that the author had gathered as a clinician, along with clinical pattern observations characteristic of clinical practice. During this initial phase, “analytical memos” were recorded regarding preliminary thoughts, interpretations and conceptualisations surrounding the evolving stories. The memos supplemented entries previously made in a research journal that contained reflections and observations gathered during the course of and following the individual patient and focus group interviews. In addition, because transcripts were reviewed prior to successive interviews and focus groups, it was possible to change the prospective interview schedules if it became apparent that previous assumptions governing question development needed further exploration. Hence, “data collection and analysis informed one another iteratively...//...evolving as new possibilities arise and are considered” (Thorne et al., 2004b, p.11).

Bazeley describes this phase as the “Read and Reflect, Code and Connect, Review and Refine” stage of initially exploring qualitative data in order to encourage researchers working with qualitative data to “gain familiarity, build a contextualised/holistic understanding, review assumptions to further shape data gathering, to develop a framework for further analyses, and to record ideas and understandings as they generate” (2013, p.7). She sees this as “a beginning task in analysing data to build a sense of the whole, to capture the essential nature of what is being spoken of or observed, before you break down the detail within it”. At this stage, grounded theorists (Straus & Corbin, 1998) would suggest “fracturing data” in order to identify the discrete elements (themes/codes) within the data, in a bid to identify their respective differences and similarities to work toward distinguishing conceptual units, and to categorise these conceptual units before moving toward the task of comparing and contrasting them. However, Thorne (2008, p.145) cautions:

In interpretive description, because the objective is rarely at the fine-tuned level of words and expression but far more often in the realm of themes and ideas, it is quite important not to derail by excessive precision in your early coding.

Hence, it is suggested that the most “broad-based and generic” coding schemes should be used. Interpretive description thus requires the researcher to undertake an “intellectual task engaging in a dialectic between theory and the data, avoiding theoretical imposition on one hand, and atheoretical description on the other” (Thorne et al., 2004b, p.11).

In acknowledging these cautions, the earliest analytical attempts in this study were concerned with identifying and working with “broad-based” data categories/concepts (Figure 4.6). Heeding Thorne’s suggestion (2008), no categories were refined until much later in the analytical process (writing-up phase). These categories were used as backdrops, and the data were checked, tested, confirmed, compared and contrasted iteratively during this phase. Differences and similarities among the data in particular situation(s) were examined, in an attempt to identify patterns and relationships within, between and across all stakeholder groups, so as to “grasp what the underlying shared intent might be within that collection of accounts” (Thorne, 2008, p.147).



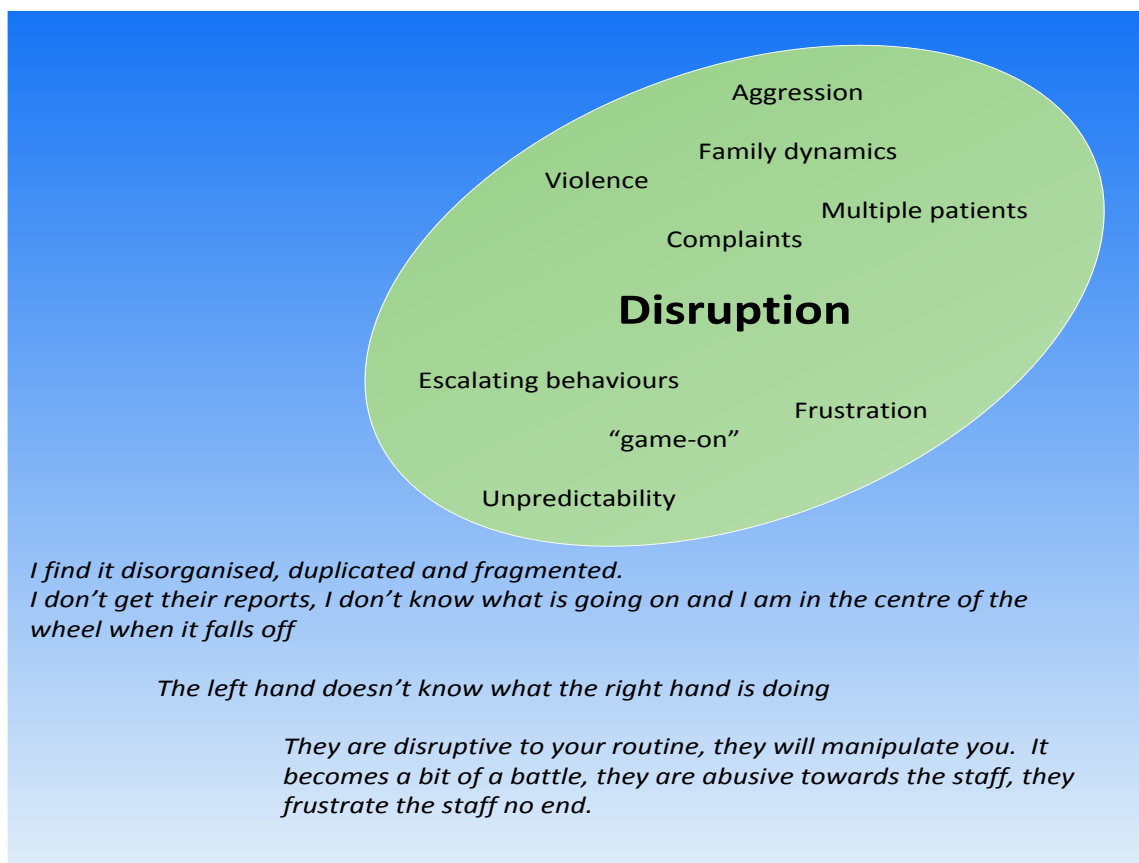
**Figure 4.6: Broad-Based Themes within the Phenomenon of Persistent Abdominal Pain**

In guiding researchers as they move toward producing more interpretive accounts, Bazeley (2013) offers a number of conventions to help manage and further distil extensive, diverse and complex qualitative data sets. Conventions utilised during the conduct of this study. During the second phase of her analytical approach, Bazeley directs researchers to “Describe, Compare and Relate”, in order to extend the interpretive work beyond “simple thematic analysis”. She encourages researchers to “break down concepts into component dimensions”, describing the approach as a pathway to “enriching data analysis” and a process that lends itself to more:

...conceptual and theoretical connections rather than organisational or taxonomic, focusing more on how things connect and what they mean in relation to each other, rather than simply sorting them into the types of things they are (Bazeley, 2013, p.9).

Figures 4.7 and 4.8 provide examples of how the two concepts of Disruption and Damage have been subjected to the conventions suggested by Bazeley (2013) and the concomitant results that would later inform the analytical and hence interpretive discussions presented in the findings chapters, i.e., Chapters 6 and 7 of this thesis. Description, she says, is about:

Making complicated things understandable by reducing them to their component parts. The process of describing categories, concepts or themes in the context of analytical writing assists in specifying their relevance, variations, dimensions and parameters as a basis for further comparative and relational analysis (Bazeley, 2013, p.5).



**Figure 4.7: Breaking Concepts Apart to Facilitate Analytical Appreciations: The Concept of Disruption**

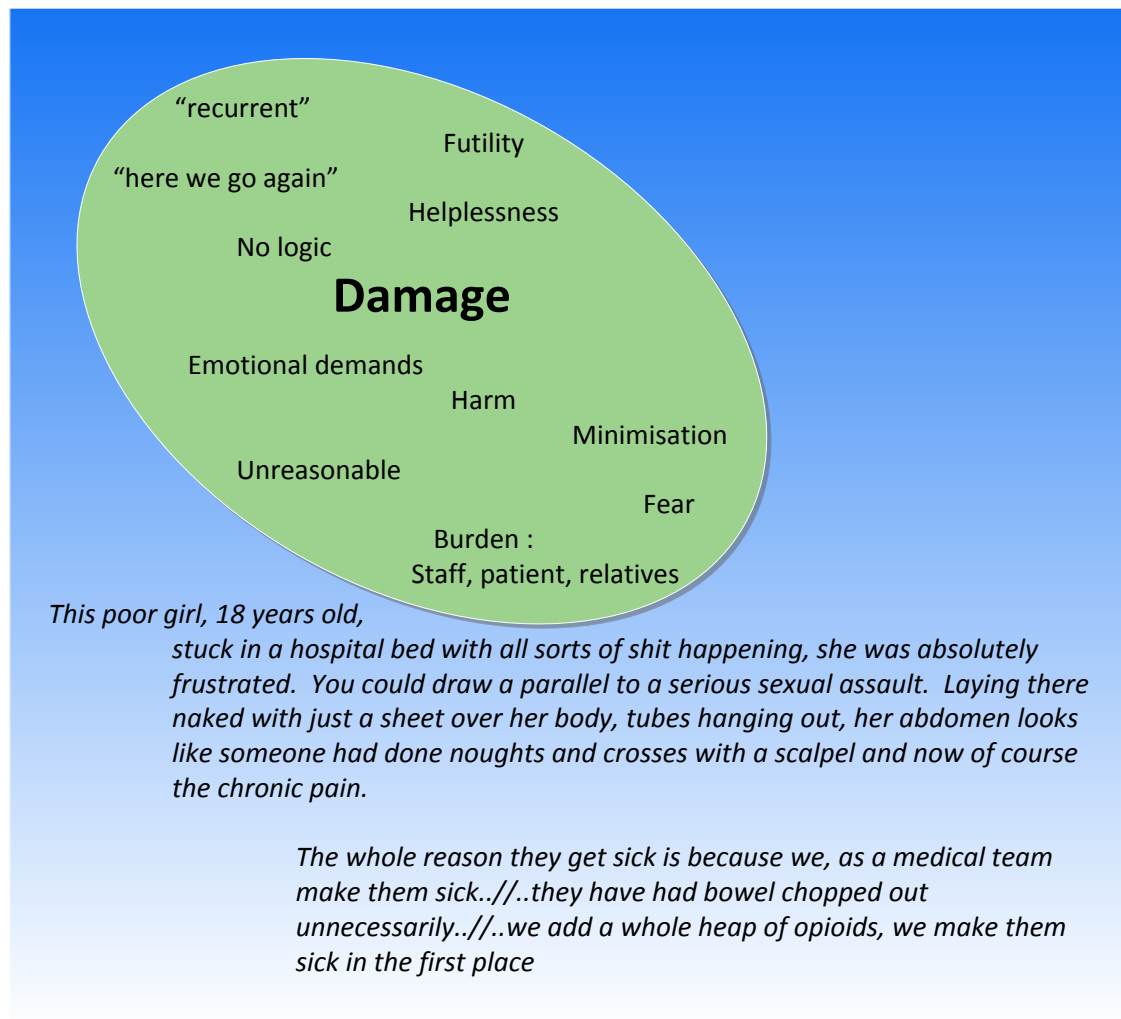


Figure 4.8: Breaking Concepts Apart to Facilitate Analytical Appreciations: The Concept of Damage

Systematically and repetitively subjecting identified concepts to this cycle offers a process to help overcome what Thorne (2008) suggests is a major threat to the credibility of any interpretive descriptive study, that is, "premature closure". Thorne proposes that premature closure, a result of "staying overlong in the microscopic view of the trees" leads to "blood-less findings" and consequently to an interpretive description that offers "nothing new or different from what we would have initially observed", or merely a "topographical summary". Similarly, Bazeley (2013, p.10) contends, "themes only attain significance when they are linked to form a coordinated picture or an explanatory model". In directing attempts toward building "coherent wholes" by attending to the above-mentioned iterative process of

analysing data and extending this to consider the conventions of identifying “patterns to relationships” that work to build coherent wholes, both Thorne (2008) and Bazeley (2013) recommend “borrowing from other techniques”. Further, Thorne (2008) suggests that within an interpretive descriptive study, an eclectic mix of a number of techniques might be required to help facilitate the journey toward building coherent wholes.

(A) robust mature program of interpretive descriptive research may ultimately draw inspiration from techniques devised from a wide range of approaches, working ultimately toward fulfilling the research agenda of “making sense of some clinical problem or issue” (Thorne, 2008, p.175).

Hence, in line with these recommendations, some of the conventions inherent within the methodological approach of narrative analysis were utilised in this study. Narrative analysis “taps the order and organisations we humans give to cognitively unstructured life experiences when we articulate them in a communicable form” (Thorne, 2008, p.152). Guided by Frank (1995) and Riessman (2008), utilising narratives to consider study participants’ constructions of their experiences by considering “extended accounts that are preserved and treated in analytical units, rather than fragmented into thematic categories”, provides a mechanism for preserving sequence and structure (the hallmarks of narrative) so that the “particularities and context come to the fore”, thereby overcoming concerns of generating interpretations out of context. Within this framework, “human agency and the imagination of storytellers (and listeners and readers) can be interrogated, allowing research to include many voices and subjectivities” (Riessman, 2008, p.13).

Similarly, Bazeley (2013, p.18) encourages researchers working with data to:

...explore the storylines (commenting that), stories and accounts reveal the embedded ways in which a particular culture or social group comprehend their world (and qualifying that)...//... analysis is as much about identifying the larger significance of object and events for a participant as it is about segmenting and coding data (going further to encourage analysts to)...//... creating an overarching narrative (thereby preventing what she describes as) death by data asphyxiation. (To achieve this she recommends researchers) identify and synthesise the story line, reduce the text to those elements that are essential...//...create a sequenced narrative, a beginning a middle and an end, and where there are several sources to inform a single case-narrative, construct a single coherent and ‘complete’ version from all available sources.

Hence, utilising the individual and composite narratives from study participants was instrumental in extending the analytical/interpretive work by taking the inductive thematic coding of the previously mentioned processes and applying and considering the codes and concepts across the broader contexts in which they were recounted; thereby:

...creating data collection pathways that challenge, rather than reinforce, the earliest conceptualisations...//... searching out alternative linkages, exceptional instances and contrary cases as a mechanism of broadening rather than narrowing conceptual linkages (Thorne et al., 2004b, p.11).

This was of particular relevance/utility when analysing the patient narratives as the main focus was the patients' individual stories, the meanings they had attributed to their situations, and the interpretations that they had made (in context) of various elements within their clinical scenario(s). The researcher made the assumption that the dialogues they constructed for themselves and the dialogues they used to 'tell the story', that is, to explain their understanding of past events, were foundational to their belief system(s), constructed, either consciously or subconsciously, about the nature of their illness. It was the researcher's supposition that these constructed stories provided, at least in part, a foundation for subsequent 'illness behaviours' that at times appeared to be unhelpful and even harmful to the patients. Hence, in considering these stories or accounts, the linguistic representations (metaphors and analogies; repetitions; indigenous typologies; and causal, conditional and contingent relations) used by participants as they attempted to convey their lived experiences were of interest and concern. This was also true of whether their conceptual developments, identified in earlier analyses, were supported refuted or consistent within the context of their propagation.

Further, the researcher was interested in exploring whether the patients' experiences, perceptions and expectations of their health care encounters were congruent with those of attending family members/carers and health care professionals. As a clinician, involved in many of the patients' clinical encounters, the researcher was acutely aware of the significant tensions that resulted from conflicting treatment paradigms within and between clinician groups, in addition to the divergent treatment expectations held between health care professionals and patients. It was assumed that the conflicting ideological platforms from which study participant stakeholders operated were instrumental in producing 'therapeutic

impasses'. Acknowledging that these ideological platforms, the consequence of powerful political, social, cultural and educational forces influencing the subjective experience of the individual at the centre of the phenomenon and situations, required due consideration beyond merely the descriptive. Hence, the narratives and in particular the composite narratives were of assistance in thinking:

...beyond the surface of the text facilitating a move toward a broader commentary...//...beyond case-centred analysis to generate categories (and in turn) conceptual inferences about a social process...//...a kind of enquiry that has a long history in anthropology and sociology (Riessman, 2008, p.13).

Hence, depicting the realist, postmodern and constructivist stands within the field of narrative analysis (Riessman, 2008). Thus making it a natural consideration within an interpretive framework that "acknowledges the structured and contextual nature of the human experience that at the same time allows for shared realities" (Thorne et al., 2004b, p.5).

These techniques were applied in a bid to enhance analysis within an interpretive descriptive context, that "none of these approaches is borrowed uncritically or used in a manner that is entirely faithful to the original tradition" (Thorne, 2008, p.153). Rather, the primacy of the process remains with "maintaining (an) obligation to account for the relationship between the technique and the underlying approach to what constitutes knowledge from which it is extracted", at the expense of being concerned with 'methodological orthodoxy'. This required the researcher to:

...navigate within and beyond the original theoretical scaffolding from which the study was launched...//... in order to advance the initial descriptive claims toward abstracted interpretations ...//... not to yield 'facts' but rather toward developing 'constructed truths' that can illuminate critical elements (within the study phenomenon) that renders them accessible to clinical application (Thorne et al., 2004b, p.14).

This approach, while attempting to retain "one's perspective on the forest" (Thorne et al., 2004b, p.14), was augmented by returning to Bazeley's approach, working toward identifying, "meta and pattern codes" within, between and across all the respective data sets and again subjecting them to the narrative accounts. Bazeley (2013), describes meta-codes as those that "represent a number of codes pulled together into a 'higher level' (more abstract) conceptual category or construct" (p.12). She identifies the utility of such codes in allowing one to "see the larger picture in your data, the key constructs that could frame your results".



She describes 'identifying pattern codes' as a level of coding that is more "inferential and explanatory", resulting from taking note of "a pattern of co-occurrence of codes". She highlighted the importance of identification of the "relational connections between codes" in a way that their interconnections help "build on the conceptual framework and contribute to theory building" (Bazeley, 2013 p.13).

As Thorne et al. (2004b, p.12) comment:

It is essential to recognise that the researcher not the recipe, is driving the interpretation...//...findings do not have their own agency, neither do participants in a study have their own voice, in the sense of representing their own interests, nor do data speak for themselves...//...it is the researcher that ultimately determines what constitutes data, which data arise to relevance, how the conceptualisations portraying those data will be structured, and which vehicles will be used to disseminate the findings .

Attending to the dimension of analysis described above requires conventions beyond simply refining and describing the range of codes and concepts emerging from the data sets. It requires "conceptualisation", a capacity that Thorne (2008, p. 170) describes as "that which makes us uniquely human and that which allows us to handle knowledge in the manner that we do ". However, theorising about concepts is inherently a process that emanates from one's ontological orientation (Thorne, 2008; Bazeley, 2013), and as such, acknowledgement of the personal biases, opinions, preoccupations/subscriptions and embedded empirically informed understandings need to be acknowledged as being inherent within and to a large degree deterministic of this conceptualisation process. Attending to this in addition to operationalising the conventions referred to above are key considerations when attempting to produce, rigorous, defensible and credible interpretive study findings.

## **4.5 Producing rigorous, credible and defensible research**

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The conceptual wrangles regarding the 'appropriateness' of the semantics used to conceive and discuss issues related to rigour in research are hotly debated from dichotomous epistemological perspectives within the contemporary literature (Tobin & Begley, 2004; Onwuegbuzie & Johnson, 2006). Qualitative researchers, dissatisfied with the positivist rationalistic terms of validity, reliability and generalisability, have popularised axioms such as credibility, transferability, dependability and confirmability, to convey

reconceptualisations directed toward more constructivist perspectives, which contribute to what Morse et al. describe as a “clutter of terms and arguments resulting in the concepts becoming obscure and unrecognisable” (2002, p.4).

Some authors argue that if we “reject the concept of validity and reliability, we reject the concept of rigor” (Tobin & Begley, 2004, p.388), while others go further and assert that “the broad and abstract concepts of reliability and validity can be applied to all research because the goal of finding plausible and credible explanations is central to all research” (Morse et al., 2002, p.3). Independent of the semantics utilised to convey and conceive the related constructs of rigor, what remains is a requirement to produce rigorous and defensible research outputs.

Discussion in the literature related to demonstrating rigor and its associated constructs within mixed methods research remains “methods centric” (Bazeley, 2004; Johnson & Onwuegbuzie, 2004; Hesse-Biber, 2010). While mixed methods components continue to nest validation of the methodology in triangulation as a consequence of convergence, corroboration, and complementarity capacities (Greene et al., 1989; Greene & Caracelli, 2003; Johnson & Onwuegbuzie, 2004), some studies are beginning to question whether such claims are more “imagined than real” and are expanding subsequent dialogues around issues of the veracity and utility of how data derived from these studies should be integrated to demonstrate and enhance validity (Bazeley, 2004). These issues have been discussed elsewhere (Chapter 3) and therefore the following discussions related to demonstrating the rigor of this study will be considered within the context of the study’s primary methodological orientation, that of interpretive description.

Thorne et al. (2004b) and Sandelowski and Barroso (2003) state that rigorous, defensible interpretive accounts are contingent upon making transparent the analytical processes that have led to findings, providing accounts/interpretations that “make sense of something that clinicians ought to understand”. Greater insights are thereby obtained through a:

...mental heuristic that make new understanding accessible to practice logic in a manner that would be consistent with the reasoning of expert practitioners for whom a similar understanding had been acquired through pattern recognition and reflective practice observations. Thus the analytical processes inherent in the conduct of the method are the essence of its utility and quality. For this reason the manageability,

coherence and rigor of the analytical processes in interpretive description are at the heart of its potential contribution to practice knowledge generation (Thorne et al., 2004b, p.8).

Embedded in the conduct of health care research is principally a mandate concerned with benefiting the individual as well as the collective. Accordingly, a moral obligation intrinsic to this agenda, underpinned by the potential for the research findings to make their way into clinical practice, highlights a responsibility, and in turn a more expansive concern toward evaluation and critique that is concerned with this moral responsibility or principled obligation:

This factor (moral obligation) inherently alters a health science researcher's disciplinary responsibility in such a way that it extends beyond the reach of traditional evaluative criteria and into the domain of how findings might reasonably be interpreted or even used. Thus, an appreciation for the credibility of qualitative research within the health sciences properly extends beyond mere consideration of adherence to the methodological rules and toward examination of the much more complex question of what meaning can be made of the research findings (Thorne, 2008, p.223).

Hence, the evaluative criteria against which Thorne (2008) proposes interpretive descriptive products should be measured, reside in demonstrating an application "in principle" to the traditional approaches of demonstrating epistemological integrity, representative credibility, analytical logic and interpretive authority. Moreover, these descriptive products extend to include moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness and probable truth, which represent the researcher's regard for the moral imperative that produces research products responsive to "the larger disciplinary, social, and historical contexts within which they are produced" (Thorne, 2008, p.223).

At the heart of producing credible and valid interpretive descriptions, is the intellectual enterprise. Guidance in relation to producing intellectually rigorous, theoretically coherent, disciplinarily informative and potentially clinically applicable interpretive accounts is beginning to emerge (Thorne et al., 2004a; Thorne, 2008; Bazeley, 2013). Thorne et al. (2004b) acknowledge that the methodological approach requires adherence to the foundational conventions (from whichever epistemological orientation they arise) of producing rigorous qualitative findings (design logic that is consistent with the aims of the investigation, purposive and theoretical sampling; concurrent data collection and analysis; constant

comparative analysis and iterative analysis). However, they caution against slavish adherence to methodological rules at the expense of producing “bloodless findings”. This departure from conventional methodological rule books, is not proposed as a licence to conduct atheoretical enquiries and in turn discreditable findings, but rather invites the researcher, intent on exploring “meanings and explanations”, to hold the messiness of the analytic process in a creative/theoretical tension. Straddling the theoretical, creative and intellectual dimensions of the analytic process enables interpretive researchers to produce findings that are “beyond the self-evident”, and as such contribute to disciplinary knowledge in a meaningful way. Thus, they describe an:

...intellectual chaos that inductive reasoning inevitably represents in the liminal space between the preliminary framework and the eventual structural decisions...//.... The intellectual task of the analyst therefore is to engage in a dialectic between theory and the data, avoiding theoretical imposition on the one hand, and atheoretical description on the other, in a quest for a coherent rich interpretation that allows a *priori* theory to be changed by the logic of the data (Thorne et al., 2004b, p.10).

Since rigorous and credible interpretive analyses are based on an analytical pathway that gives precedence to integrity of purpose over a rigid adherence to methodological orthodoxy, the procedures utilised in the production of the interpretive account bear consideration.

The foundation of interpretive descriptive work is rooted in a nursing epistemological orientation that acknowledges the individual within the particular, and also the utility of aggregated knowledge to individual cases. This orientation is crucial in directing processes (methods) toward accessing the multiple, shared and constructed realities that make up human experiences. As a consequence of accessing and interpreting “subjective accounts of multiple realities” upon which human experiences are contextually lived, and then subjecting these accounts to the interpretations of the researcher, whereby the “knower and the known become inseparable”, it follows that findings can only be based on the contingencies of their creation (Thorne et al., 2004b; Thorne, 2008). Hence, interpretive descriptive accounts become ‘constructed’ findings and at best represent what the researcher has assimilated in good faith, with reasoned theoretical guidance in an effort to fulfil the “moral imperative” to produce findings that might conceivably find their way into clinical practice through “pragmatic obligation”, and for which only “tentative” rather than absolute “truths” claims can be made.

Therefore, interpretive accounts become the product(s) of a mental heuristic, performed by the researcher, rather than being driven by methodological recipes; thus, they implicate the researchers' "honesty and prudence" in the conduct of the study as much as the findings themselves (Thorne et al., 2004b, Thorne, 2008).

According to Thorne (2008), the analytical credibility of the interpretive account rests largely with the researchers' ability to depart from prescribed qualitative conventions, by doing what she calls "letting go of the raft", being able to "navigate within and beyond the original theoretical scaffolding (of the study) in order to fully engage the process of inductive reasoning, including testing and challenging preliminary interpretations (from which the researcher's *a priori* knowledge has infiltrated) and conceptualising an ordered and coherent final product" (Thorne, 2008, p. 156). To achieve this, she recommends avoiding issues related to "going native", considering that only the researcher understands the phenomenon as an "insider". Similarly, she advises the avoidance of premature closure, which involves seeking only to confirm current understandings and provide nothing more than a "topographical" account that renders little in attempting to advance applied understandings. In addition, she cautions against "over-determination of pattern", where pre-eminence and hence biased findings are founded on compelling rather than "demographic" or "topographic" accounts of prevalence of patterns within study phenomenon. Further, over-reliance on "*in vivo* quotation" is considered to compromise "thoughtful analysis", and hence leads to "bloodless findings".

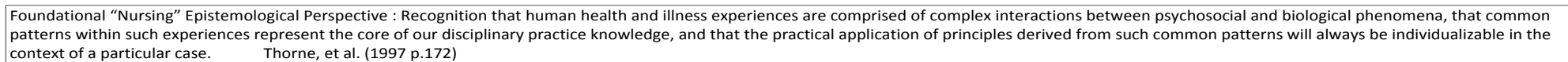
Thus, provision of interpretive accounts that are coherent, auditable, credible and potentially applicable:

...requires intellectual processes that extend beyond simply collecting and reporting data...//...it requires a representation in a form that explicitly acknowledges the analytic processes that occur in transforming raw data into findings and in constructing an interpretive account of what the themes within the data signify...//...making sense of something clinicians ought to understand...//...(by providing) a mental heuristic to make that understanding accessible to practice logic in a manner that would be consistent with the reasoning of expert practitioners...//...(that is) a tentative truth claim about how things could potentially be done better" (Thorne et al., 2004b, p.8).

To some extent, the validity and reliability associated with an interpretive descriptive account (beyond the usual conventions) become more about what is not made visible when defending the credibility and rigor of a study. Beyond demonstrating theoretical coherence and paradigmatic integrity, the defensibility of the interpretive descriptive research product is contingent upon its capacity to inform a new, or enhanced disciplinary knowledge that can translate to improved clinical practice, and accordingly its defensibility resides in passing what Thorne et al. refer to as the “thoughtful clinician test”:

...in which those who have expert knowledge of the phenomenon in a particular way find that the claims are plausible and confirmatory of ‘clinical hunches’ at the same time as they illuminate new relationships and understandings...//...Thus the integrity to the interpretative process will always generate more credible findings than will rigid adherence to the gamesmanship of rigor (Thorne et al., 2004b, p.17).

A visual representation of the process utilised to turn “raw data into findings” is presented in (Figure 4.9). Chapter 6 presents a “storied account/professional narrative” and thus represents the abstractions (interpretive findings) taken from the processes in Figure 4.9. Chapter 7 makes visible the mental heuristic of these processes by presenting and discussing the relevant features within the proposed draft alternative model of care, the product of this interpretive mixed methods approach.



**Figure 4.9: The Study Phenomenon within Context**

## 4.6 Ethical considerations:

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Ethical approval to conduct the study was sought and granted by the study sites' Local Area Health Human Research and Ethics Committee on 9 August 2006 (No. 06/07/26/5.07).

In accordance with the National Statement of Ethical Conduct in Research Involving Humans (National Health and Medical Research Council (NHMRC), 1999) the principles of ethical conduct via the protection of the welfare and rights of participants was achieved by adherence to "the basic ethical values of integrity, respect for persons, beneficence and justice" (NHMRC, 1999, p.3). Each of these issues was considered during the conception, implementation and dissemination of findings phases of the research agenda.

### 4.6.1 Voluntary participation and informed consent

All prospective participants were provided with written and verbal information regarding the study and were invited to participate on a voluntary basis. Participants were asked to provide written consent prior to being enrolled in the study. No payment or inducements were used, and participants were informed of their right to refrain from answering specific questions and to withdraw from the study at any time without penalty and without providing any reason for doing so. Participants were also assured that the decision to decline participation or to withdraw from the study would in no way affect their (patient) access to quality health care services, or for health care professionals, their condition of employment.

### 4.6.2 Privacy and confidentiality

During the course of the study, participants were asked to provide information in relation to standard demographics (patients, carers and health care professionals) (Appendices 11 & 13), and professional and service provision profiles (health care professionals). All information collected for this purpose was de-identified, as specifically designated questionnaires did not ask participants to identify themselves by name.



Interviews of individual patients, carer/family members and health care professional focus groups were conducted in a place that ensured privacy. The interviews were audio-recorded for verbatim transcription. At the conclusion of each interview, participants were asked if they wanted to review the recording and remove any comments. Recordings of the interviews were transcribed by one of two professional transcribers, each required to sign a confidentiality agreement prior to their engagement in the study (Appendix 14). All transcripts were forwarded by password-protected email to the researcher and stored in password-protected files on the researcher's computer. Audiotapes will be destroyed at the conclusion of the study and de-identified transcripts stored securely for the mandatory 5 years. All consent forms and code books linking personal information and research data were accessed only by the principal researcher and were stored securely and separately in a locked filing cabinet and on password-protected files in the researcher's office/computer. Particular care has been taken in the presentation and publication of the study findings, particularly those relating to the patient group in order to protect the identity of individuals. This has been facilitated by continuing to stress the 'composite profile' of the patient cohort rather than focusing on individual cases, and replacing any references made to individuals (clinicians, patients) with non-identifiable or generic terms.

The nature of the focus groups makes it impossible for the researcher to ensure participants' anonymity within the group. Prior to the commencement of each focus group, participants were requested to treat all information shared during the course of the interview as confidential to the group. Participants were reminded that because of the group context that the researchers could not guarantee the confidentiality of the research data if a member of the focus group chose to breach this promise. Participants were also asked to respect the privacy of any third parties (patients, health care professionals) mentioned during the course of the discussion, by refraining from using actual names or other identifiable information about them.

Finally, any reports and publications arising from the study contained no details that could potentially identify specific patients, family members, or health care

professionals, whether they were participants or third parties. As a consequence of repeatedly being admitted to the study site hospital, patients are well known by staff and sometimes by other patients. Accordingly, care will be taken not to publish any information that could potentially identify these patients or attribute any quotes from the interviews to particular individuals.

#### **4.6.3 Potential risk to participants**

Specific research conventions related to respecting participants and thereby considering issues related to beneficence and non-maleficence have been described within the context of each of the respective phases of the research project, presented earlier in this chapter. Decisions relating to the structure, conduct and inclusion criteria utilised for the study were made within the framework of attempting to maximise potential benefits of the study while minimising potential harm to participants (NHMRC, 1999).

The overall purpose of the study was to contribute to improving care for patients with persistent abdominal pain, and to develop a more efficient and effective model of care for this patient population. While there were no immediate benefits for any individual participant, it is expected that at least some of the study participants (and other patients, families and staff) may benefit in the future if the project is successful.

Given that the research project was not a clinical trial or an intervention study, it posed no physical risk to study participants. However, because of the nature of the phenomenon under study, the researcher was aware of the potential psychological and emotional distress that could result from accessing latent sensitive and emotive information. Responding to this consideration, the researcher sought professional guidance in the construction of the interview schedule for patient participants from the CPS Consultant Psychiatrist. In addition, pre-emptive requests for counselling/supportive services were arranged with the hospital's Department of Psychiatry and Psychological Liaison Service, all of whom were familiar with the patient cohort and their histories. Patients were made aware that this adjunctive service had been made available in the event they felt they required additional support

following the interviews. Staff participants were reminded of the availability of the Employment Assistance Program in the unlikely event that they felt distressed or in need of advice or counselling as a result of taking part in the study.

Patient and family participants were informed about the most relevant service to contact (such as the Hospital Social Worker, Psychiatry Liaison Department, or relevant external agencies) in case they expressed a need for support or counselling following their involvement in the research project.

## **4.7 Conclusion**

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Chapter 4 has focused on describing the processes and procedures used in order to capture the diverse data sets representative of study stakeholders' perspectives central to the phenomenon of persistent abdominal pain. Capturing multiple viewpoints has produced qualitative and quantitative data sets from which new insights and understandings have been gleaned. Descriptions regarding the conventions undertaken to ethically collect, manage, and interpret the data to produce defensible findings have been described.

This study was derived from the concerns of clinicians across a range of disciplines. Clinicians were primarily concerned with making improvements to the health care outcomes of the patients central to the study and of emerging patient cohorts. They also had an additional agenda in identifying the need to offer an alternative model of care for patients who present to acute care services with chronic and complex care needs.

Guided by Creswell and Plano Clarks' (2011) typology for conducting a qualitatively driven mixed methods research program, the study featured here represents a four-phase explanatory sequential mixed methods study. The central premise of employing both qualitative and quantitative data is to harness better understandings of the phenomenon under study. This study was concerned with qualifying patients, and care givers, including health care professionals' experiences within the context of suffering from, supporting or delivering care related to persistent abdominal pain. In

addition, the study sought to quantify where possible the impact patients with persistent abdominal pain have on the health care service they most frequently visit. The subsequent chapters of this thesis, Chapters 5, 6 and 7 are directed toward the presentation of these findings.

Potential funding authorities, however empathetic to the plight of patients, families and health care providers, operate within economic rationalistic domains and as such need convincing of the relative merits of redirecting scarce resources to patient cohorts, particularly when they are small in number. Appreciating this broader sociopolitical perspective of health care delivery, the quantitative data in Chapter 5 become instrumental in providing, not only a rationale for considering revising current treatment approaches for patients with persistent abdominal pain, but also for producing benchmarks against which clinical outcomes and fiscal implications might be prospectively measured in the event of alterations to service delivery for these patients.

Thus in Chapter 5, quantitative data are presented and highlight the impact the study patient cohort has on the hospital to which they most frequently present. Data presented in this chapter are accompanied by *notes and comments* that reveal the researchers interpretive observations, those gleaned from previous clinical encounters with the patient cohort and by consulting and auditing the patients' medical records.

## Chapter 5    Scoping the extent of the problem

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### 5.1 Introduction

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Having introduced the intent of the study and the methodological approach utilised in the study (Chapter 4), this chapter will focus on presenting the quantitative data that were extracted during the first two phases of the four-phase explanatory sequential mixed methods study. As previously discussed (Chapters 3 and 4), the utility of a mixed methods approach to conducting research, particularly health care research, resides in whether the combination of both qualitative and quantitative data sets can illuminate the phenomenon under study in a way that neither method, if utilised in isolation, can achieve. Hence, the inclusion of a quantitative dimension to the study was fundamental to providing a more comprehensive illumination of the phenomenon of persistent abdominal pain from multiple and diverse perspectives. These perspectives, although inclusive of the experiential accounts of the study patients, clinicians and family stakeholders (Chapter 6), are extended to include consideration of the impact the study phenomenon have on the health care service provider (Acute Care Sector within the study sites' LHD) and to quantify where possible the extent and scope of this impact.

As mentioned previously, the inclusion of a quantitative dimension to the study was pivotal, and was used:

- to identify the patient cohort (by virtue of their presentation/admission profiles to the study sites' hospital, and diagnosis of chronic abdominal pain (IASP, definition of pain  $\geq 3$  months), thereby facilitating purposive sampling via identification of potential study participants
- to determine the extent of the patient cohorts' health care utilisation (in terms of frequencies of ED presentations, hospital admissions and length of hospital stay)

- to assess the financial implications associated with care provision for the study cohort over a predetermined retrospective time frame (study period 2003, 2004, 2005)
- to identify the diagnostic codes (DRGs) most frequently utilised to categorise study patients' many presentation symptomologies
- to identify the types of diagnostic, procedural and surgical interventions most frequently encountered by study patients during hospital admissions
- to identify the clinical specialities most frequently involved in the clinical inpatient management of the patient cohort, and to provide an overview of clinicians' subjective appraisals of the perceived impact that managing the study cohort has on their clinical practice
- to identify the system and process issues that are most frequently recounted by patients, staff and relatives to be problematic in care provision during acute hospital admissions, that is, "wait times" for analgesia, "hands-off times" for review by specialist consulting teams, and "task times" for time taken for investigations, procedures, etc. to be completed.

Collating the above-mentioned quantitative data laid the foundation for addressing a number of key objectives. First and foremost, it enabled a comprehensive multidimensional composite profile of the study patient cohort to be compiled. Second, it illustrated the extent to which a small number of patients utilise disproportionate quantities of health care services because of unresolved chronic illnesses, such as persistent abdominal pain, highlighting the consequential impact these patients have on the health care system. Third, by augmenting qualitative data, the quantitative data facilitated broader engagement of major stakeholders at the study site (medical, health service management, administrators and funding bodies). This was particularly important given the cultural preference for a positivist or postpositivist orientation toward research activities prevalent within the medically dominated health care arena within which the researcher was attempting to engage and mobilise key stakeholders to make clinical improvements.

The more contemporary multidimensional, interdisciplinary approach to health care research agendas mobilises and engages clinicians, health care managers and administrators to adopt a change agenda that often requires significant financial and clinical resource investment. This is difficult to achieve because presenting qualitative accounts in isolation without supporting data that can demonstrate broader dimensions of the study phenomenon is insufficient to attract funding. For example, preliminary outcome measures or clinical indicators against which subsequent benchmarking activities can be directed and comparative analyses performed must derive from objective baseline data in relation to factors associated with costs, service efficiency, efficacy and resource utilisation.

Hence, in conducting the study within a mixed methods framework based on the above-mentioned motivations, the author applied rationales referred to by various other authors (Greene et al., 1989; Bryman, 2006; Creswell et al., 2006; Doyle et al., 2009). These underpin the utility of mixed methods research in providing reliable and credible research findings by being able to attain:

- triangulation of the data sets, whereby issues noted in the qualitative and quantitative data sets could be confirmed and refuted by the respective other data set, for example, delays in receiving clinical inputs (analgesia, speciality service consultation, admission from ED to a ward bed)
- completeness of the data sets, whereby the provision of both subjective and objective information considered pertinent to gaining an appreciation of all dimensions of the study phenomenon facilitated a holistic picture, one that was capable of capturing and demonstrating the multifactorial components of the phenomenon under study, complementing
- explanatory findings capable of informing the research agenda—in this case it was particularly important to attempt to explain the repeated and lengthy hospitalisations of the patient cohort, to identify the issues underpinning the protracted LOS and the hostility and frustration reported by stakeholders in relation to the current situation—thus, the provision of these explanatory

understandings informed subsequent activities directed toward developing a revised model of care

- illustration of data, whereby the qualitative data set was utilised to illustrate the quantitative data to help gain a better picture of the phenomenon of persistent abdominal pain, as it impacts on all stakeholders involved in the study phenomenon.

Despite the study being weighted toward the qualitative domain with its interpretivist/constructive epistemological orientation, the inclusion of the quantitative data in this interpretive mixed methods study has furnished expanded appreciations beyond the subjective accounts of study participants. Awareness of the quantitative dimensions as they relate to answering the research questions aimed at quantifying the impact of the health care utilisation for patients with persistent abdominal pain at the study site. Restating the research agenda highlights the requirement of a methodological pluralism that accounts for the diversity and multiplicity inherent within the study's research questions/aims.

### **5.1.1 Study purpose**

The primary aim of the study was to critically review the experiences, expectations and perceptions of stakeholders (patients, carers and health professionals) central to the construction of the phenomenon of chronic abdominal pain. In addition, the study aimed to identify clinical practices and organisational procedures, embedded within the current model of care that could be identified as constraining good patient outcomes. Finally, the study was concerned with gaining stakeholder consensus regarding an alternative treatment approach for current and possibly emergent patient cohorts with persistent abdominal pain.

### **5.1.2 Research aims**

Given the superordinate purpose stated above additional aims were to:

- Identify patients who regularly present to the hospital study site with persistent abdominal pain and to identify those clinical speciality groups and individuals most often utilised for the management of these patients



- Quantify health care utilisation for the selected cohort within a defined timeframe
- Identify system and process issues that either impede or facilitate optimal management for patients presenting with persistent abdominal pain to the study site hospital
- Qualify major stakeholders' experiences and perceptions of the suffering of, the support provided for and the care delivered to patients with persistent abdominal pain, both within the acute care environment and the community
- Identify and gain broad agreement (from all stakeholders) around the principles and essential elements of a revised model of care to better manage patients when they present with acute symptoms to the study site hospital
- Facilitate clinician engagement, ownership, commitment and mobilisation in identifying and implementing a revised model of care for the identified patient cohort.

### **5.1.3 Research questions**

- i. What are the experiences, expectations and perceptions of stakeholders (patients, carers and health professionals) central to the construction of the phenomenon of persistent abdominal pain?
- ii. What are the nature, extent and impact of repeated hospital presentations on stakeholders in response to unresolved persistent abdominal pain?
- iii. What would need to change in order to provide a more efficient and effective model of care for current and emerging patient cohorts with persistent abdominal pain?

In summary, the study aimed to build a composite cohort profile of people with similar experiences of pain, and to identify, qualify and quantify the impact associated with their experience of disease from a patient, as well as from an economic/system (health care utilisation) perspective. In addition, the study sought to identify clinical and organisational processes and procedures that stakeholders (clients, carers and clinicians) considered limited or that constrained good patient outcomes. Finally, it was anticipated that these deeper and more diverse understandings of these patient

situations and experiences, together with recommendations from the literature, would inform the provision of a more contemporary, evidenced-based model of care for patients suffering with persistent abdominal pain who regularly access acute care facilities.

The quantitative data presented within this chapter provide information that will, together with the interpretive accounts derived from the qualitative data, inform current understandings regarding the multidimensional aspects of the study phenomenon as it affects all stakeholders within a tertiary referral Australian hospital. The data sets are presented sequentially (first the quantitative data followed by the qualitative data), since doing so reflects the evolutionary and sequential processes of the study. Further, given the explanatory nature of the methodological design, first setting the scene of the phenomenon within the clinical setting, then moving toward a more explanatory discussion provided a logical approach to presenting what is inherently a complex, multifaceted clinical scenario, that has at its core, multiple, diverse and at times disparate study stakeholder views.

## **5.2 Quantifying the impact of persistent abdominal pain**

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The quantitative data presented within this chapter were extrapolated from the data gathered throughout the first and second phases of the study. The first phase of the study identified those patients who presented or were admitted to hospital and who were diagnosed with persistent abdominal pain at the study site. Further, this phase was concerned with quantifying the impact the study patient cohort had on the clinical service provisions of the LHD within which the study hospital resides, and to which the study patients most frequently attended. The patient cohort was purposively sampled during this phase and a health service utilisation profile was subsequently assembled for the group in relation to their acute care service provision when presenting and being admitted to the study site hospital.

During the second phase of the study, more detailed accounts, both qualitative and quantitative, were gathered for each of the study patients' ED presentations and

hospital admissions during the study period. The patients' clinical records for each of these presentations and admissions were interrogated in order to identify, qualify and quantify issues related to the inpatient management of the patient study group, inclusive of quantifying the system and process issues reportedly considered to be instrumental in precipitating patient, carer and clinician frustration, anger and hostility within clinical encounters.

The remainder of this chapter presents the quantitative data in a bid to highlight the disproportionate impact the study patient cohort has had on the study site facility. The quantitative data and accompanying interpretations/explanations (*notes* and *comments*) are representative of the findings extrapolated from the study site's Hospital ED, APS and CPS activity and performance databases and from retrospective hospital chart audits of patients. These data are supplemented by the researcher's interpretations derived from previous clinical encounters with the study patient group. Integration of this knowledge affords contextual insights, allowing a more-informed portrayal of the study phenomenon of persistent abdominal pain. In addition, where triangulation among data sources appeared to offer a greater potential for providing deeper insights, a number of qualitative comments derived during stakeholder focus group interviews have been integrated. This appeared particularly relevant in highlighting whether stakeholder anecdotes—at times contentious anecdotes—could be refuted or supported by the quantitative data.

### 5.2.1 Identifying patterns of health care utilisation

After receiving institutional ethics approval, the study was commenced on 9 August 2006. To consider the study phenomenon from a longitudinal rather than an episodic perspective, a 3-year study period (2003, 2004 and 2005) was identified. A retrospective approach was chosen in response to concerns surrounding anecdotal evidence that there was an increasing trend in clinical activity/health care utilisation patterns for the study patient cohort. Similarly, inpatient journeys anecdotally reported as being increasingly more problematic needed to be considered over time rather than as isolated incidents. This reduced the potential to erroneously attribute assertions of 'characteristic patterns/behaviours/outcomes', etc., to isolated events and as being the

product of an individual patient's encounter. Further, considering the study phenomenon in retrospect was instrumental in highlighting the consequential effects of applying an acute reactive, curative model to the management of a chronic multidimensional complaint. This was considered necessary (by the researcher) to help facilitate clinician ownership, mobilisation, engagement and eventually adherence to any proposed alternative model of care.

The LHD in which the study was conducted is one of seven LHDs responsible for delivering health care to rural and regional NSW. Within the study site's LHD there are 38 regional hospitals, one of which functions as the tertiary referral centre and accordingly is responsible for providing consultative services to surrounding hospitals within the district. This tertiary referral hospital was the nominated study site hospital in which the study was conducted.

As a consequence of long-standing clinical relationships, the majority of patients who regularly present to the study site hospital with persistent abdominal pain were already known to clinicians, including the researcher. However, capturing patients who may not have been referred to the local districts consulting pain service, but who nevertheless frequented the study site or other local hospitals that reside within the LHD was fundamental to identifying the scope of the problem across the LHD. Hence, questions within this initial scoping phase were directed toward identifying:

- i. How many patients presented to one of the hospitals' ED within the study sites' LHD with health care complaints related to chronic abdominal pain during the study period 2003–2005? Who were these people?
- ii. To which hospital's ED did patients with persistent abdominal pain most frequently present?
- iii. What proportion of patients who presented to EDs within the LHD required subsequent admission into the hospital ( $\geq 2$  admissions per/year during 2003–2005) as a consequence of symptoms related to persistent abdominal pain? How many people does this represent and who were these people?

- iv. How many patients required hospital admission to the study site hospital (a tertiary referral hospital within the LHD) of  $\geq 2$  admissions per/year during 2003–2005 for management of symptoms related to persistent abdominal pain, and for which patients requiring hospital admission at this rate have been diagnosed with chronic abdominal pain, i.e. “pain > 3 months’ duration” (Merskey & Bogduk, 1994). Who were these people?
- v. What is the ratio of ED presentation to hospital admissions at the study site hospital for the identified study patient cohort?
- vi. How long did these patients stay (LOS) during each of their admissions to the study site hospital within the study period?
- vii. When admitted into the study site hospital, what services did these patients most frequently consume?
- viii. What were the financial implications for the LHD for the inpatient management of this patient group?

### **5.2.2 The patient cohort profile**

Having accessed and cross-referenced the databases from the study sites’ Hospital Activity and Performance Database with the ED, CPS and the APS patient Activity databases, eight patients were identified as having fulfilled the study inclusion criteria. Seven of the identified cohort consented to their inclusion in the study and for the researcher to subsequently access their inpatient hospital patient records.

#### ***Identifying the study patient cohort (2003–2005)***

The seven consenting study patient participants are represented in (Table 5.1). Six of the seven patients fulfilled the study inclusion criteria based on activity ( $\geq 2$  study site hospital admissions/year during 2003–2005), and diagnosis (persistent abdominal pain  $\geq 3$  months’ duration). The final patient fulfilled the study criteria based on diagnosis.

Table 5.1: Patient Demographics

Patient	Sex	Age	Relationship status	Number of dependants	Employment status
1	F	28	Single	0	Disability Pension
2	F	44	Married	1	Disability Pension
3	F	35	Partner	2	Disability Pension
4	F	32	Single	0	Disability Pension
5	F	43	Partner	2	Disability Pension
6	F	40	Married	0	Full-Time Employment
7	F	55	Married	3	Disability Pension

### Notes

All seven study patient participants were female with an average age of 40 years. Five of the participants reported being married or in a long-term relationship with their partners, while two of the study participants were single and lived at home with family members. Four participants had children. Patient 2 had one child, who at the time of data collection was 20 years old. Patient 3 had two children; the youngest one was 18 months and the older one was 4 years old. Patient 5 had two children; the younger one was 2 years and the older one was 18 years old, and Patient 7 had three children all of whom were adults. All study participants with the exception of one (Patient 6), reported being on a disability pension, a consequence of long-term health issues associated with chronic abdominal pain. Patient 6 reported remaining in full-time employment despite being made “*redundant*” from a number of positions as a consequence of requiring frequent and prolonged hospitalisations.

### Comments

Five of the study patient participants recounted protracted histories with the study site hospital/LHD (for one patient, 15 years; for two patients, 20 years; and for the third patient, 30 years) and consequently long associations with a number of the hospitals’ health care professionals. For the remaining two patients, despite not having long associations with the study site hospital/LHD (for Patient 4, 1 year (2005) and for Patient 5, 5 years), each recounted long associations with other hospital sites/LHDs,

similar to those patterns described by patients who had remained within the study site's LHD.

Four study participants recounted their contact with the health care system as having begun within paediatric services before later being transferred to adult services within the study site hospital.

Acknowledging the protracted associations between study patient participants and the larger Health Care System, means that the findings presented within this thesis are merely a snap shot. The findings provide glimpses into a defined period within long and convoluted health care journeys that help inform, but do not define the whole experience of this patient cohort.

#### ***Patients' patterns of health care utilisation across the local health district (2003–2005)***

Determining the nature and extent of the health-care-seeking behaviours of this patient cohort across the LHD enabled the researcher to identify which hospitals within the region the patient participants most regularly accessed. The researcher's assumption at the outset of the study was that the study cohort received the majority of their health care inputs from the study site hospital. However, there were anecdotal reports from clinicians, particularly from ED clinicians, that study patients characteristically frequented numerous hospital services, particularly other EDs within the LHD.

Identifying whether such patterns of health care utilisation were consistent with commonly held local beliefs and reports, or conversely were refuted by such appraisals was important in highlighting the patients' health-care-seeking behaviours. This enabled the purposive sample (stakeholder groups) and study site (hospital) within which the study should most appropriately be conducted to be identified.

ED clinicians often recounted that patients were disgruntled if they were not admitted into the study hospital following their presentation to the ED unit. Clinicians' comments supporting these anecdotes became accessible during focus group interviews when they suggested that what often happens in these situations is that the patients subsequently go:

Hospital shopping, I've had one patient ring an ambulance from the waiting room to take her across to another ED just after I've discharged her! (ED Physician).

They present at multiple hospitals within a few days, and we very often don't know that they've presented at X hospital, or X hospital before coming here. Considering we are the one Local Health District, it would be nice to know that and have that better communication (Anaesthetist & Pain Management Specialist).

Data accessed via the LHD's health performance unit revealed that while study patients might at times present and be admitted to other hospital facilities within the LHD, the majority of the patients' hospital-based health care (during the study period) occurred at the study site facility, Hospital 1 (Table 5.2).

Table 5.2 represents a composite profile of the health care utilised, referred to in this instance as numbers of hospital admissions and respective LOSs, for all study patients across five hospitals within the study site's LHD during the study period 2003–2005.

**Table 5.2: Patterns of Health Care Utilisation by the Patient Cohort across the LHD (2003–2005)**

<b>Composite cohort hospital admission profile (2003–2005)</b>					
<b>Hospital</b>	<b>H1</b>	<b>H2</b>	<b>H3</b>	<b>H4</b>	<b>H5</b>
<b>No. of admissions for composite patient cohort</b>	98	1	3	3	8
<b>% of all hospital admissions to nominated hospital</b>	86.7%	0.9%	2.7%	2.7%	7.1%
<b>Total LOS/composite cohort for study period</b>	1075	1	34	8	60

### *Notes*

While patients were admitted to a number of hospitals within the LHD, Hospital 1 (H1) represents the study site hospital at which patients most frequently received medical care in response to abdominal pain and associated symptoms. During the study period, the patient group had 98 admissions, accounting for 1075 bed days at H1,



hence supporting selection of H1 as the proposed study site facility, and the hospital from which the purposive (stakeholder) sample would most appropriately be identified.

### ***Comments***

Admissions to H5 reflect the admission profile of one patient (Patient 3) into the LHD's mental health facility. Although this person required occasional admission to the facility for mental health problems, the admissions shown for H5 are those where abdominal symptoms (pain, nausea, vomiting and dehydration) were significant features of each of the admissions. Characteristic of these admissions was the transfer of the patient back and forth between facilities (study site hospital [H1] and the mental health facility [H5]) as a consequence of clinicians being challenged by the origin of the patient's symptomologies (psychological versus physiological), and difficulties in achieving clinical resolution of either.

The repeated, frequent and lengthy admissions into the study site facility for all study patient participants, highlights the disproportionate number of hospital bed days associated with the medical management of clinical symptoms related to chronic abdominal pain for this small patient cohort.

### ***Patients' patterns of health care utilisation at the study site hospital (2003–2005)***

The following data (Figure 5.1) reveal the health care utilisation patterns, described in this instance as hospital ED presentations and admissions, for each of the study patient individuals at the study site hospital (Hospital 1), during the study period (2003–2005).

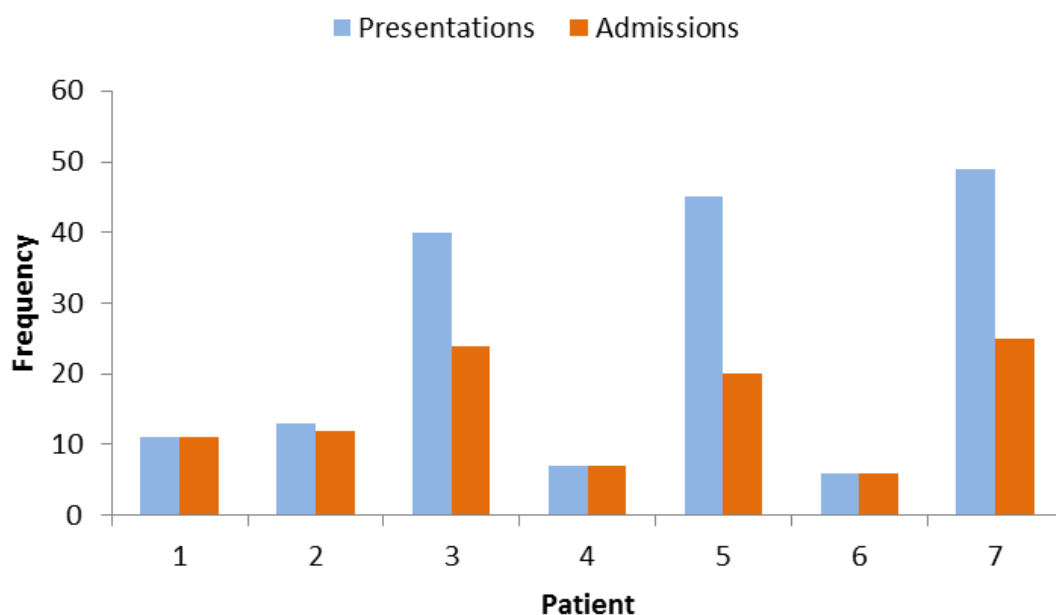


Figure 5.1: Ratio of Hospital ED Presentations to Admissions (H1) per patient (2003–2005)

#### Notes

The ratio of each study patient's presentation to the study site hospital's ED to that patient's hospital admission was calculated. Four patients (Patients 1, 2, 4 and 6) required hospitalisation each time they presented to the study site hospital's ED, a ratio of 1:1. A ratio of approximately 2:1 existed for two study patients (Patients 3 and 7), highlighting that these patients presented twice as frequently to the ED as they were admitted into hospital. The remaining patient (Patient 5) was admitted to the study site hospital on every third ED presentation (3:1).

Six of the seven patient participants were admitted at least biannually for symptoms related to persistent abdominal pain during the study period of 2003–2005. Patient 6 encountered the lowest number of admissions during the course of the 3-year study period, having six admissions during this time. Patient 7, on the other hand, required 25 admissions to the study site hospital over the 3-year study period.

Worth noting was Patient 4's admission rate. This patient required seven admissions within the study period, all seven occurring during the final year (2005). During 2005,

Patient 7 relocated to the area and became a new patient of the LHD and consequently a new patient to the study site hospital. Despite not fulfilling the study criteria on activity, the patient fulfilled the diagnostic criteria for inclusion into the study, having been previously seen by numerous chronic pain clinicians and having been diagnosed with persistent abdominal pain by the study site's chronic pain consultant.

In summary, during the 3-year study period, the composite study cohort averaged an annual ED presentation rate of 57 ED visits per year and an annual hospitalisation rate of 33 admissions per year, an average of eight presentations and five admissions per patient per year for each of the years 2003–2005. All admissions were unplanned admissions, with 34% (366) categorised as unplanned readmissions.

### *Comments*

Identifying study patients' ED presentation and hospital admission rates was instrumental in highlighting the health care utilisation patterns characteristic of the study patient cohort. Clinicians' qualitative statements, *"...they just keep bouncing back...//...you know they'll be back...//...it's like a revolving door"* (Surgical Nurse) are supported by the quantitative findings.

The recurrent nature of the study patients' ED presentation and hospital admission rates to the study site facility for the medical management of abdominal symptoms, including pain, highlights the significant impact that the patient group had on health care services and the refractory nature of their health care complaint. Clinicians use various terms to refer to patients who regularly seek health care intervention. Terms such as "frequent flyer", "high health care utiliser", "recurrent presenter" and "refractory patient", are all expressions used interchangeably both within the clinical arena and in the professional literature to describe patients who frequent the health care system.

During the initial phase of the study, a well-accepted definition of "high hospital health care utilisation" was sought. Defining health care utilisation on the basis of presentation to Accident and Emergency Departments, the numbers of unplanned hospital admissions, numbers of bed days hospitalised (LOSs) and the numbers of

avoidable hospitalisations and unplanned hospital readmissions are all determinants used within contemporary health management/administrative arenas to discuss and subsequently measure indices considered suggestive of high health care utilisation within the NSW public hospital context. Accessing the NSW Health website and health statistics for guidance yielded sanctioned terminology and associated determinants considered indicative of high health care utilisation within the State. The NSW Health Department most often refers to the terms and associated definitions of “potentially preventable hospitalisations” and “unplanned hospital readmission” as well as “length of stay” as indices most frequently used to measure system efficiencies and patient management effectiveness, particularly within the context of measuring activity associated with chronic and complex diseases:

Potentially Preventable Hospitalisations (PPH) are those conditions for which hospitalisation is considered potentially avoidable through preventive care and early disease management, usually delivered in an ambulatory setting, such as primary health care (for example by general practitioners or community health centres) (NSW Health, 2002, p.20).

Unplanned readmission is a readmission to hospital within 28 days after discharge from hospital (NSW Health, 2002, p.20).

To identify health care utilisation patterns within the context of this study, frequencies relating to ED presentations, unplanned hospital admissions, lengths of stay and unplanned readmissions were measured. To identify high health care utilisation for the study patient cohort, admission rates  $\geq 2$  admissions per year for three consecutive years (2003–2005) was considered high health care utilisation.

### ***Individual study patients' inpatient health care utilisation (LOS), H1 (2003–2005)***

Repeated and lengthy hospital admissions into the study hospital are characteristic of all study patients' health care profiles. While the patients under study have long histories of attending and being admitted into hospitals, quantifying these trends and activities within the defined study period for each of the study patients was proposed to help furnish deeper appreciations of the repetitive impact these patients have on the health care services they frequent. The study site's hospital activity and performance database was accessed in order to identify the individual study patients' admission

profiles, and to quantify the extent of the patients' individual health care utilisation, in this case, in terms of lengths of stay over the 3-year study period (Table 5.3).

**Table 5.3: Hospital 1 Health Care Utilisation (LOS) per Patient (2003–2005)**

<b>Patient</b>	<b>Total LOS</b>	<b>Min LOS</b>	<b>Median LOS</b>	<b>Max LOS</b>
<b>1</b>	183	6	14	42
<b>2</b>	174	2	11	43
<b>3</b>	184	1	7	60
<b>4</b>	142	7	25.5	37
<b>5</b>	226	1	12.5	21
<b>6</b>	28	6	6.5	9
<b>7</b>	138	3	5	11
<b>Composite Profile</b>	<b>1075</b>		<b>81.5</b>	

### *Notes*

During the 3-year study period, the seven study patient participants collectively required 98 admissions and together recorded a total of 1075 hospital bed days at the study site facility (H1). The minimum LOS over the 3 years for an individual within the composite group was 1 day, and the maximum was 60 days. The median LOS for the composite cohort for the 3-year study period was 81.5 days.

### *Comments*

Retrospective chart audits were conducted for the study patients for the 3-year study period in an attempt to account for their protracted hospitalisations. Reviewing each of the 98 admissions revealed a number of noteworthy issues related to the context of each patient's admissions and the difficult and complex clinical scenarios that appeared to underpin lengthy hospitalisations. Examination of the chart audits not only provided important contextual information from which inferences and interpretations could be made, but also helped identify those foundational issues

within the patients' inpatient journeys that seemed to complicate and prolong clinical encounters. Identifying these issues helped guide the inclusion of stimulus questions that subsequently directed focus group interviews.

Table 5.4 represents the key themes that emerged from the retrospective chart audits conducted for the 3-year study period, 2003–2005. While the substantive discussions relating to these identified themes are considered within the qualitative findings chapters (Chapters 6 and 7), their introduction at this point helps contextualise the current dialogue and presentation of the remaining quantitative data. Moreover, discussion of the key themes facilitates a sequential appreciation of the phenomenon under study.

**Table 5.4: Factors Contributing to Increased LOS**

Tensions in Clinical Practice
<ul style="list-style-type: none"> <li>• Acute Exacerbation vs New Pathology</li> <li>• Organic vs Non-Organic Aetiology</li> <li>• Fragmented/Siloed Care vs Integrated/Interdisciplinary Care</li> <li>• Acute, Reactive &amp; Episodic Care vs Pre-emptive Longitudinal Chronic Disease Management</li> </ul>
Underpinned by Challenges to (Clinician, Hospital & System) Sense of Purpose and Function
<ul style="list-style-type: none"> <li>• Variable Clinician Ownership → Delays in mobilising care</li> <li>• Patient-driven rather than Patient-centred Clinician-driven Inpatient Care → Chaos</li> <li>• Multiple and Conflicting Treatment Paradigms → Confusion</li> <li>• Underdeveloped Partnerships between Primary &amp; Tertiary Health Care Providers</li> <li>• Negligible Communications between Health Care Professionals and Service Providers</li> </ul>

The themes identified by the researcher are based on extrapolations from the medical records and represent the researcher's interpretations of proceedings that occurred during each of the respective admissions. Events documented in the patient's medical records related to care provision that could be interpreted as having influenced patient outcomes and in turn contributing to lengthy and difficult hospitalisations were considered during this second exploratory phase of the study.

Managing patients with recurrent, chronic and complex conditions within an acute, reactive, biomedical and hence largely curative paradigm will predictably expose inefficiencies and inadequacies of an acute care system that is at odds with the inherent needs of patients for whom cure would seem unattainable. Participant clinicians

highlighted this by noting that, paradigmatic divergences, system inefficiencies and misalignments, for example the siloed organisation of care and perennially deficient communication processes, represent “*weaknesses in the system*” that enable patients’ to “*expertly manipulate*” in order to meet their “*conscious or subconscious health care needs*”. As a consequence of their long associations with the health care system, patients become well versed in the health care system’s organisation, internal workings and the cultural practices, currencies and dialogues that enable care to be mobilised. At times, this may be detrimental to good patient outcomes and is reflected in prolonged inpatient stays. For example, study patients at times refuse to comply with clinical treatment regimens, which results in deleterious outcomes that lead inevitably to protracted hospitalisation (e.g. refusing enteral therapies, opioid rotations, and threatening or enacting self-harm).

While paradigmatic divergences at the system and individual health professional levels can be considered instrumental in driving repeated and prolonged hospitalisations for this patient cohort, these encounters were also profoundly influenced by patient and family member/carer expectations and health-related behaviours. Patients and families, persuaded by the wider sociological influences inherent within and seemingly synonymous with the technological and curative imperatives of modern medicine, present to health care providers expecting a resolution of their illness or at the very least, the complete abolition of their pain, distress and suffering. Trying to manage these expectations within the limitations of medicine to achieve such outcomes, produces challenging and difficult clinical encounters for which, “*the path of least resistance*” is often adopted by time-poor clinicians frustrated by the seemingly illogical and impenetrable clinical scenarios. These actions result in the continued medicalisation of the situation, which in turn requires the patient to remain an inpatient. This interpretation is supported by a comment made by a senior surgeon during a focus group interview:

I have one patient that probably spends two and a half months a year in here...//...if you try and heavy her she’ll just stay longer, she just digs in. I mean what are you trying to achieve, if you kick her out she’ll just bounce back anyway, so I’m not going to kick her out. I just bring her in, check her magnesium and potassium, she tells me when she is ready to go home. If you have a

confrontation with her it becomes a big protracted thing, and you'll have just added 5 days to her admission (Surgeon).

### ***Study patients' admitting diagnosis (2003–2005)***

If clear pathophysiological mechanisms had been easily detected, diagnosed and resolved (by attending clinicians) and medical treatment implemented that resulted in predictable clinical outcomes, these patients' journeys would not be so problematic. However, the biological and psychological profiles of the study patient cohort do not reflect such reductionist appraisals and thus challenge prescriptive, standardised treatment approaches. Consequently, because patients' presentations are atypical in nature and patient responses appear to clinicians to be "*disproportionate*", and at times seemingly "*illogical*" and "*unfounded*", the fundamental issue that consequently pervades clinical encounters in these situations appears to reside in the following questions:

- i. Is the patient presenting with new acute intra-abdominal pathology?
- ii. Is the patient experiencing an acute exacerbation of their chronic underlying condition?
- iii. Is the patient presenting with somatic symptomologies in response to psychological stressors?
- iv. Is the patient being motivated for other reasons—social, opioid seeking?

In the absence of suitable diagnoses that can adequately reflect these patients' presenting symptoms, clinicians are confronted with the deficiencies of diagnostic categorisation. No appropriate label seemingly accounts for their atypical presentations; hence, these patients become diagnostic "*outliers*". This issue represents the first of many tensions characteristic within study patients' illness trajectories and hence encounters with health care professionals. The tensions related to accessing suitable diagnoses for study patients reflect a system and its proponents' discomfort with operating outside the prescriptive jurisdiction of diagnoses and treatment.

These situations present significant difficulties for clinicians, particularly junior clinicians and often result in past diagnoses being reapplied. Thus, assigned DRGs are



perpetrated on the basis of historically assigned diagnoses, despite in some cases little or no diagnostic evidence being available to suggest that assignment of such diagnostic labels is appropriate. Hence, clinicians are frequently challenged by the question, *"What is the underlying diagnosis?"* for which, in the most part, they are unable to provide definitive answers. This is particularly relevant in the frequently occurring scenarios where patients whose past histories are unavailable have been seen by multiple clinicians over many years and been offered numerous diagnoses.

The difficulties associated with the ambiguity that surrounds diagnoses for the patient cohort cannot be underestimated. The prominence of these difficulties and the importance clinicians place on reconciling the ambiguities surrounding issues related to diagnosis in the context of better managing chronic abdominal pain is reflected in an email forwarded to me by a senior surgeon following his attendance at the surgical clinicians' focus group:

Within the chronic and relapsing abdominal pain group, there is a sub group who have clearly documented evidence of chronic Pancreatitis, and some of our strategies need to be a little different for them, than for other patients with chronic abdominal pain without evidence of organic disease. There are those who present just with pain and those who present with nausea and vomiting and abdominal distension. Our terminology should be objective and consistent. Therefore "Pancreatitis" should only be used with patients who have clear objective evidence of that condition. Similarly, unsupported references to "Obstruction", "Pseudo-Obstruction" and "Adhesions" should be avoided...//...Some of the patients who have been given organic diagnosis (e.g. Pancreatitis, Bowel Obstruction) need to have their data and imaging studies (past and present) reviewed by an experienced surgeon who can declare the appropriateness of the diagnostic label that can be presented to the patient and recorded in the clinical record, and communicated to other involved clinicians. This requires a significant level of comfort about saying; "I do not know the cause" and let's just see what we can do about the pain itself (Surgeon).

Therefore, it is not surprising that in the absence of DRGs that adequately capture the vague, inconsistent, inconclusive and overlapping characteristics of study patients' presenting symptomologies, historically assigned DRGs continue to be applied. In addition, diagnostic descriptors such as nausea and vomiting, volume depletion, and pseudo-bowel obstruction are regularly utilised to describe associated symptoms, but are not in and of themselves diagnoses. Similarly, it is not clear whether DRGs

assigned to patients for anxiety and depressive illness are based on patients meeting the objective diagnostic criteria for such disorders, or whether they represent attending clinicians' subjective appraisals of patients' associated symptomologies which have made their way into the clinical notes and as such have gained sanctioned validity. Identifying this shortcoming highlights the significance of potential efforts being directed toward making available a diagnostic category that better reflects the clinical characteristics of the study phenomenon. Doing so would make accessible clear understandings rather than erroneous appraisals of patients' conditions so that this can be better communicated among all stakeholders, including patients. These difficulties at the clinical frontline are well represented by the dialogue that occurred between two surgeons as they discussed this issue during the focus group interview:

The secret to managing these patients is not to be talking any diagnosis...//...it just complicates the care, it makes it impossible, you've got to get the conversation away from the diagnosis and talk about managing the pain (Surgeon A).

They can't write dickhead on the form can they? The intern has got to have a diagnosis so he comes up with one and then the patient just grabs it and says but doctor says I had a bowel obstruction (Surgeon B).

Given that diagnostic categories are formulated on the basis of patients fulfilling criteria under the International Coding for Diseases (ICD), chronic pain, by virtue of it being considered a symptom rather than a disease, has no corresponding DRG. Hence, what remains is an inconclusive description of the existing primary and secondary diagnoses assigned to study patient presentations. Table 5.5 represents a composite summary of the various diagnostic criteria used to classify a study patient's hospital admissions within the study period 2003–2005. The summary was extrapolated from the study site's hospital activity and performance database by identifying the top ten diagnostic categories for each of the study patients' admissions during the 3-year study period.

The Diagnosis Related Groups (DRGs) used to classify patients' hospital admissions offer some insight into the historically assigned diagnoses of patients' underlying

abdominal complaints, and, in addition, highlight associated physiological and psychological co-morbidities identified by various attending clinicians.

**Table 5.5: Admitting Diagnosis Related Groups (DRGs) for Study Patients (2003–2005)**

Primary Diagnosis	K50.9	Crohn's Disease Unspecified (Patients 1 & 2)
	K51.9	Ulcerative Colitis Unspecified (Patient 1)
	K58.9	Irritable Bowel Syndrome (Patients 1, 4 & 5)
	K86.1	Other Chronic Pancreatitis (Patients 3 & 7)
	K 86	Acute Pancreatitis (Patient 7)
	G93.3	Postviral Fatigue Syndrome (Patient 4)
	K55.1	Chronic Vascular Disorders of the Intestine (Patient 4)
	K91.5	Post Cholecystectomy Syndrome (Patient 6)
Secondary Diagnosis	K83.0	Cholangitis (Patient 6)
	Z98.0	Intestinal bypass and anastomotic status (Patient 1)
	K04.7	Peri-apical abscess without sinus(Patient 1)
	Y83.3	Surgical operation with formation of external stoma (Patient 2)
	K56.6	Other/Unspecified Intestinal Obstruction( Patients 1 & 2)
	K56.5	Intestinal Adhesion with Obstruction (Patients 1, 2 & 4)
	E46	Unspecified protein-energy malnutrition (Patients 1,2 & 3)
	E86	Volume depletion (Patients 1, 2 4, 5 & 7)
	R11	Nausea and Vomiting (Patients 2, 4, 5)
	R10.4	Other and Unspecified abdominal pain (Patients 1, 2, 3, 4, 5, 6 & 7,)
	N17.9	Acute renal failure unspecified (Patient 1)
	Y92.22	Health service area (Patients 1, 2, 3, 4, 5, 6 & 7)
	K83.8	Other spec diseases biliary tract (Patient 6)
	G40.90	Epilepsy unspecified (Patient 3)
	E10.9	Type 1 diabetes mellitus w/o complication (Patient 3)
	I45.6	Pre-excitation syndrome (Patient 3)
	J45.9	Asthma unspecified (Patient 3)
	G82.20	Paraplegia, unspecified (Patient 1)
	Y45.0	Opioids & related analgesic adverse effects in treatment use (Patient 1)
	F60.31	Emotion unstable person disrd borderline (Patient 3)
	Z43.2	Attention to ileostomy (Patient 2)
	Z93.1	Gastrostomy status (Patient 2)
	Z93.2	Ileostomy status (Patient 2)
	Z93.3	Colostomy status (Patient 2)
	K56.5	Intestinal adhesion with obstruction (Patients 1, 2 & 4)
	Z50.3	Drug rehabilitation (Patient 6)
	K52.9	Non-infective gastroenteritis and colitis (Patient 4)
	G43.9	Migraine unspecified (Patient 4)
	F41.2	Mixed anxiety and depressive disorder (Patients 3 & 4)
	F11.2	Ment/beh disrd opioid use depressive syndrome (Patients 1, 2, 3 4 & 5)
	K59.0	Constipation (Patient 4)
Source: LHD's Hospital Health Performance Unit		

### Notes

Two patients (Patients 3 and 7) within the cohort had previously (prior to the study period) been diagnosed with pancreatitis. Patient 7's initial acute pancreatitis was diagnosed following a motor vehicle accident. There was no documented precipitant in Patient 3's medical records for her diagnosis of pancreatitis. Despite the initial diagnosis of chronic pancreatitis "*allegedly*" being supported by elevations in

pancreatic enzymes (amylase and lipase), upon closer interrogation of these patients' inpatient notes, considerable debate among clinicians regarding the appropriateness of the diagnosis, in particular for one of the patients (Patient 3), highlights the potential that such a diagnosis might be propagated on the basis of historical accounts rather than on that of diagnostic criteria. This was later highlighted and supported by surgeons' dialogues during their focus group interview when discussing diagnoses of the study patient cohort:

Nearly always none of the parameters (diagnostic criteria) are fulfilled; all we have to rely on then is the patients' complaints of pain (Surgeon).

Nevertheless, these patients were categorised as having chronic pancreatitis. Secondary diagnoses used to categorise both patients' presentations revealed a combination of physiological and psychological co-morbidities. A combination of co-morbid physiological conditions applied to these two patients (for Patient 3, asthma, epilepsy and type 1 diabetes, and for Patient 7, hypothyroidism, primary hypertension, splenomegaly, nephrectomy and hip implant). In addition, co-morbid psychological conditions for both patients were noted, relating to categories of mental behavioural disorders, panic and anxiety disorders and being categorised as emotionally unstable patients. This situation illuminates the clinical complexities that confronted attending clinicians when these patients presented for medical care.

Patients 1 and 2 had both been diagnosed with Crohn's disease. Patient 1 had additional diagnoses of ulcerative colitis and IBS. As a consequence of these diseases, both patients had previously undergone repeated and extensive surgeries, with Patient 2 having had an ileostomy placed in late 1990. These patients' presentations to hospital are characterised by complaints of nausea, vomiting, dehydration, reports of altered gut motility and increased abdominal pain. These patients are often given provisional diagnoses of "pseudo-bowel obstruction", "intestinal adhesions" with or without "bowel obstruction", for which, in the main they are subsequently managed conservatively, but in the past have undergone numerous laparotomies in order to, "divide adhesions" and relieve "pseudo-obstructions". Attempting to discern whether a patient's abdominal symptomologies are a consequence of opioid and other analgesic

medications or triggered by other intra-abdominal pathology is challenging, particularly if patients are distressed by pain and any suggestion of reducing or rationalising opioid therapy to regain gut function are hotly contested by patients and accompanying family members/carers.

Patient 4 arrived at the study site LHD with an extensive past medical history. The patient had been previously diagnosed with postviral fatigue syndrome, including unspecified paralysis and chronic vascular disorders of the intestines, for which she had previously undergone a colectomy. The seven admissions encountered by the patient within 2005 were categorised by DRGs related to unspecified abdominal pain, nausea and vomiting, non-infective gastroenteritis, volume depletion, unspecified protein-energy malnutrition and pseudo-bowel obstruction. In addition, co-morbid psychological states, anxiety and depressive disorders featured within the top ten admitting DRGs for this patient during each of her hospital admissions.

Patient 5 was diagnosed with IBS, and Patient 6 was diagnosed with post-cholecystectomy syndrome and cholangitis. They were both most frequently admitted into the facility under DRG categories of unspecified abdominal pain, nausea, vomiting, and volume depletion. Similar to all other patients in the cohort, both these patients also had DRGs related to depression and anxiety within their top ten admitting DRGs during 2003–2005.

### *Comment*

The conundrum of deciding whether patients' presentations are the product of competing aetiologies, that is, biological versus psychological, produces significant tensions during therapeutic encounters for both patients and clinicians. In these situations, clinicians may seem suspicious and dismissive of patients' complaints. The clinicians are met by well-versed, invested and emotionally distressed patients and families who seek to gain validation of their symptoms, in order to legitimise access to the care they believe they need. These difficult and tense clinical situations, characteristic of many of the inpatient encounters recorded within the patients' hospital records do, in part, provide explanations about protracted lengths of stay.

Patients challenged by assertions of their lack of authenticity as reliable and trustworthy historians of their illness and the primacy of psychological mediators for their condition respond by escalating illness behaviours (refusing to comply with treatments, threatening self-harm, etc.). This in turn mobilises clinicians, particularly junior clinicians, and thus the medicalisation continues.

### ***Study patients' inpatient health care utilisation (interventions/treatments), H1 (2003–2005)***

In addition to considering study patients' health care utilisation from a health-seeking perspective (number of presentations to an emergency department; number of hospital admissions; and LOS), the study cohort's consumption of health care services, in terms of diagnostic, procedural and surgical interventions was also considered within the context of the study. Considerable anecdotal material surrounding the inpatient management of the study patient cohort highlighted the fact that clinicians considered that the patient group received unnecessary and often duplicated clinical inputs during the course of their inpatient stays:

These people, they know the weaknesses in the system, they always arrive at night, they know what to say in terms of symptoms to report, they know what to do and say to get into hospital ...they'll lock up an intern who will easily spend a couple of thousands of dollars on tests, the surgical registrar going back and forth from theatre...//...it's difficult, you try and save money, if you discharge them they'll be back in two nights then they'll spend another couple of thousand again on scans and tests...you try and save money, you do (Surgeon).

One senior clinician had attempted to overcome these situations by mandating that he be contacted in the event that one of the study patients presents to the hospital's ED and prior to any intern, resident or clinician requesting diagnostic tests, procedural interventions or admission into the hospital. This directive had been documented in one of the multiple volumes of the patient's medical records and was not readily accessible for attending ED clinicians. Communicating treatment recommendations in this manner is not only unreliable but also sabotaged by customary practices within the clinical environment, for example when patients present to the ED the most recent volume of their medical record is forwarded to the department unless attending clinicians make a special request to have all volumes pulled from the archives. Further,

relying on clinical staff in busy, time poor and acute care environments to trawl through volumes of patients notes to unearth treatment protocols is unrealistic. Typically, clinicians working in these environments rely heavily on the most recent summaries of the patient's health issues in order to expedite care. Hence, it was not surprising that focus group participants highlighted the lack of reliable and consistent communication processes as being instrumental in driving inappropriate and unnecessary diagnostic and treatment interventions being, at times, directed toward the study patient cohort.

It's very difficult in these situations...//...they're not like other patients with chronic conditions, there's the acute abdomen stuff...it's difficult when it's three o'clock in the morning, and they've got 4 or 5 kilograms of notes that say they've presented with acute abdomen for the past three or so years...//...in reality it's difficult. There's always that lingering question of whether there's something acute going on and so there's the next CT or another laparotomy, and they look unwell (ED Consultant).

We need them to be able to flag them in the system and a treatment plan needs to be up-to-date and accessible. It just locks up clinicians, particularly junior ones, it can take hours...//...but not all the patients will stick to a plan, they'll demand that things have changed and they can have more morphine and then you find out they haven't. There's no point in a plan if everyone isn't going to stick to it (ED Nurse).

Additionally, other clinicians relayed their individual attempts to prevent inappropriate diagnostic, procedural and surgical inputs being directed toward the study patient cohort. This mostly related to admitting clinicians making value judgements about the relative merits of discharging the patient or admitting them on the basis of considering where the patient was most likely i) to consume the least amount of health care services, and ii) to escape being subjected to inappropriate or unnecessary diagnostic, procedural or surgical interventions. In these situations, the admissions became a "*containment*" approach. Such "*containment*" approaches were not only mobilised in response to clinicians' awareness of inappropriate resource utilisation and the subsequent financial implications for the health care service, but also from a position of appreciating the potential harm through iatrogenic events and the reinforcement of unhelpful messages to patients' regarding their symptoms.

Quantifying the degree to which inappropriate or unnecessary duplications of diagnostic, procedural and surgical interventions were directed toward the treatment group was beyond the scope of this study, but is central to the study phenomenon. Discussions about the potential of prospective studies to contribute to understanding the specific diagnostic and treatment issues in this clinical context would be invaluable in directing efforts toward improving the management of not only the current patient cohort, but also emergent patients with persistent abdominal pain.

Thus, attempts to quantify unnecessary and duplicate interventions within this study gave way to more descriptive accounts of the diagnostic, procedural, treatment and surgical interventions directed toward study patients at H1 during 2003–2005. Table 5.6 details the ten most frequently provided clinical interventions for the composite study patient cohort during 2003–2005. It must be noted, however, that the study interval reflects a time period that occurred late in the illness trajectories for all patients involved in the study. Thus, the extensive and numerous diagnostic, and, in particular, surgical procedures that all patients have encountered as a consequence of their chronic pain and underlying abdominal aetiologies are not reflected in Table 5.6. Hence, these interventions reflect those utilised in what could be considered the ‘maintenance phase’ of their chronic and complex abdominal pain illness trajectories.



**Table 5.6: Diagnostic, Investigative and Procedural Interventions for Chronic Abdominal Pain (2003–2005)**

Diagnostic investigations	Treatments directed toward the resolution of symptoms	Procedural interventions for symptom management
<ul style="list-style-type: none"> <li>• Abdominal X-ray</li> <li>• CT abdomen with and without contrast.</li> <li>• MRI</li> <li>• Fibre-optic colonoscopy to caecum</li> <li>• Opaque enema of small intestine</li> <li>• Dynamic blood flow studies</li> <li>• Bone density studies</li> <li>• Bladder scans</li> <li>• CT kidneys</li> <li>• IVP</li> <li>• Haematological studies including pancreatic enzyme assays</li> </ul>	<ul style="list-style-type: none"> <li>• Injection/infusion of thrombolytic and prophylactic substances</li> <li>• ERCP</li> <li>• Intra-operative cholangiography</li> <li>• Laparoscopic cholecystectomy</li> <li>• Suture of small intestine</li> <li>• Laparoscopy</li> </ul>	<ul style="list-style-type: none"> <li>• Insertion of central venous catheter (CVC)</li> <li>• Insertion of percutaneous endoscopy gastrostomy tube (PEG)</li> <li>• Administration of TPN via CVC</li> <li>• Infusion of enteral therapy via PEG</li> <li>• Injection or infusion of electrolytes</li> <li>• Removal of gastrostomy tube</li> <li>• Sedation and general anaesthesia (to perform procedures)</li> <li>• Injection of antibiotics</li> <li>• Injection of botulinum toxin</li> <li>• Transfusion of packed cells</li> <li>• Drug detoxification</li> <li>• Management of neuraxial block</li> <li>• Insertion of rectal tube</li> <li>• Enteral feeding via percutaneous feeding catheter or central venous catheter</li> <li>• Repeated insertion of percutaneous endoscopy gastrostomy tube</li> </ul>

Patients' clinical resource consumption during ED presentations and hospital inpatient stays mostly involved diagnostic investigations to identify and diagnose physiological problems associated with presenting symptoms, including reports of increased pain. The diagnostic investigations most frequently encountered by the patient group were abdominal X-rays, abdominal computerised tomography (CT), abdominal ultrasound, intra-operative cholangiography, bowel studies and on occasion nuclear magnetic resonance imaging (MRI). These procedural interventions along with occasional (mostly diagnostic) laparoscopies and laparotomies were implemented by clinicians to identify and "treat" abnormal gastrointestinal function.

In addition, all patients received haematological screening to assess fluid and electrolyte imbalances, and for patients with histories of pancreatitis, pancreatic enzymes were assayed. These tests amounted to the standardised approaches utilised in the management of patients presenting with nausea and vomiting, particularly in the presence of fast gastro-intestinal transit times and for patients with ileostomies.

Clinicians responding to individual patients' particular clinical issues inevitably utilised additional diagnostic investigations. Bladder scans, CTs of kidneys, intravenous pyelograms (IVPs) and gastroscopies were frequently undertaken during the course of the study patients' hospitalisations.

However, when reviewing the procedural and diagnostic investigations (retrospective chart audits and examination of the hospital performance unit database), what became apparent was that the most frequently undertaken procedural interventions, were those conducted not only to manage symptoms related to dehydration and pain, but also symptoms arising from previous medical interventions.

To this end, considerable resources were allocated toward securing venous access to deliver intravenous treatments for these patients. As a consequence of repeated and extensive medical procedures, accessing peripheral veins for these patients produced significant clinical challenges. As a result, some study patients required the implantation of percutaneous catheters for the long-term management of this aspect of their care; for others, repeated and extensive procedural interventions were necessary to secure venous access during hospitalisations. The repeated and invasive approach to securing venous access in these difficult clinical scenarios often necessitated considerable specialist medical and nursing input. Additionally, the placement of invasive intravenous lines as well as repeated and frequent venous catheterisation increased the patients' risk of line infections. For two of the study patient cohort, line infections resulting in generalised sepsis culminated in lengthy ICU admissions that complicated and prolonged their respective hospitalisations.

Further, procedural interventions for managing patients' malnutrition and dehydration status (nasogastric catheters, percutaneous gastrostomies and central lines for TPN) required significant inputs, not only in terms of the extensive (long-term) use of the required equipment, but also in terms of the initial and ongoing assistance of health care professional specialists. In addition, diagnostic and procedural interventions directed toward maintaining and managing equipment failures, integrity and function inevitably resulted in increased procedural and surgical interventions. For example,

diagnostic CTs and intra-operative replacement of catheters featured highly within the study patients' profiles of their top ten procedural interventions.

### ***Patients' inpatient health care utilisation (admitting specialities), H1 (2003–2005)***

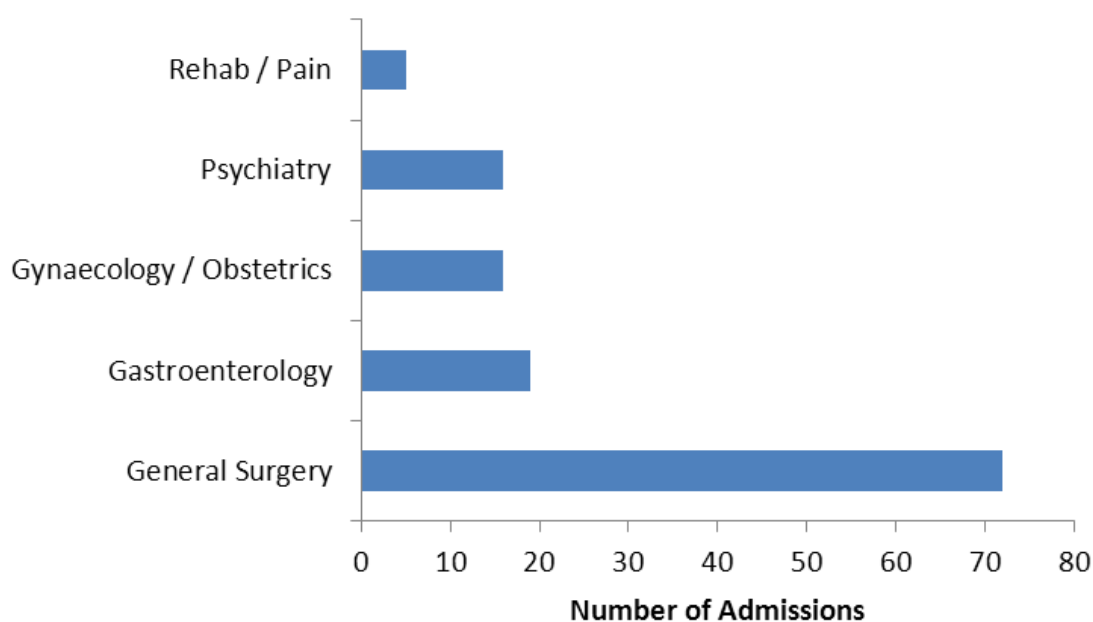
A legacy of past “difficult” and “futile” encounters with the study patient cohort has left the majority of hospital specialist inpatient teams guarded about what they feel they can offer to study patients when admitting them into the hospital under their, and their speciality teams' care. When patients present with compelling and clinically straightforward symptoms for which clinicians feel they can implement standard therapies to seek resolution, accessing appropriate specialist teams prepared to take on the responsibility of overseeing these treatments and admissions does not typically produce difficulties. However, on the occasions when patients' presentations and symptoms are vague, seemingly clinically illogical and predominately pain focused, accessing medical teams prepared to take on the responsibility of being the admitting speciality produces significant challenges:

No one wants to look after these people because they're very unlikable and they don't have a physical problem that anyone can find, so the ED gets stuck with arguing between the surgeons, the gynaecologists, the gastroenterologists and anyone else who might be involved about who is going to look after the patient...//...and they keep coming back again and again and again and the clinician that had them last time won't look after them this time...//...I can speak to surgeons, like I have today (referring to one of the study patients currently in the ED ward) and they'll say look we've looked at her, we can't find anything wrong with her—it's not surgical—get a physician to admit her and I said well physicians won't take her because she's got abdominal pain—gynaecologist won't take her because she's got no clear gynaecological pathology, and we can't admit her directly under the pain team...//...so I have to find ownership somewhere even though there's no clear cut surgical pathology simply to access the other services this woman really needs...//...it requires the staff specialist to be involved, trying to get something to give in the system, it's usually one of the nice guys and that's not fair ...//...it can take 48 hours or so to sort out (ED Staff Specialist).

The difficulties and clinical implications associated with not being able to successfully access admitting specialist teams featured strongly in focus group discussions, particularly those involving ED medical and nursing staff. Securing an admitting team was renowned to be a difficult and protracted encounter (up to 48 hours) and

characteristic of the study patients' pathway from presentation to admission at the study site facility. These clinical scenarios are typically referred to the most senior medical ED clinicians to manage, as the perception amongst the majority of clinicians is that it is these individuals who are most successful in exerting pressure on the system until "*something* (by which they meant, someone) *gives*".

Figure 5.2 identifies the medical teams documented as the 'admitting speciality' for the study patient cohort during 2003–2005. The surgical and gastroenterology teams account for the speciality services who most frequently accepted responsibility for the hospital admissions and the subsequent inpatient management of the patient cohort during the study period. Admissions recorded under the gynaecology/obstetrics teams reflect admissions encountered by Patient 3. These admissions, associated with chronic abdominal pain, and complicated by pregnancy required simultaneous medical team inputs (surgical and gynaecology/obstetrics). Admissions highlighted under the authority of the psychiatry, rehabilitation and pain teams reflect admissions that occurred in the final year of the study period for treatments directed toward drug (opioid and other pain medication) withdrawal, rotation and functional rehabilitation. Whilst the pain and psychiatry teams did not have admission rights to H1, these teams began enlisting the help of the rehabilitation team in order to redirect hospital admissions toward more pre-emptive approaches for managing study patients with persistent abdominal pain.



**Figure 5.2: Admitting Medical Specialities (H1) of Study Patients (2003–2005)**

When attempting to organise care for study patients upon presentation and subsequent admission into the hospital, ED clinicians regretted the circumstance that no identifiable specialist clinician/team had been made responsible for the ongoing management of these patients. As a consequence of this lack of ownership, ED clinicians reported having to invest considerable time into attempts at securing a medical team prepared to take on the responsibility of the inpatient management of these patients. Often this required numerous attempts with different teams, until, as they suggested, something “*gives*” in the system, and, by their own omission, “*usually one of the nice guys*”.

As such, ED clinicians made repeated references to the “*lack of ownership*” being foundational to the significant difficulties encountered during these situations. Patients, relatives and carers become frustrated and angry when they perceived that the health care service responded neither appropriately nor in a timely manner. Patients could spend significant time in the ED (up to 48 hours) while debate continued about whether they should be admitted to the facility and under which team. Until this detail was sorted out, the patient could not progress further into the hospital. This produced significant tension among clinicians, patients, family members and carers, as

staff in these areas often direct their attention to the needs of patients with life-threatening conditions. This means, of course, that their time may be directed away from the study patients' significant demands:

One of the big problems is there's no ownership of these patients...//...if someone could own them and actually know their histories, instead of us weeding through the history very quickly, relying on memory or relying on incomplete notes, or when you can't get the notes (previous notes from medical records) relying on patients' manipulative stories and you're faced with a patient who is in severe pain, who looks really unwell, we have to do something—so we start doing something, then at the end of the day you find out this is a recurrent theme...so having someone who knew their histories would be huge (ED Physician).

### ***Notes***

In response to the above and as a consequence of presentation symptomologies, the general surgical team provided the bulk of inpatient services for the patients during the 2003–2005 study period. Generally, patients presenting with increased pain associated with nausea, vomiting, abdominal distension and changes to gut motility were often given a provisional diagnosis of abdominal pseudo-obstruction, thereby implying that surgical teams were responsible for their clinical inpatient management. This reflects historical local clinical practices:

It's established historical practice to have these patients come in under General Surgeons or Gastrointestinal Surgeons...//...desire to avoid overlooking significant acute intra-abdominal pathology...//...however it does mean these patients are placed in wards where the focus is on preparing for and recovery from surgery...//...with junior staff who focus on managing the "acute abdomen"...//...the disadvantage of this is that a surgical intervention is at least on the menu of options (Surgeon).

Difficulties arose during these clinical encounters when clinicians made attempts to validate or refute this provisionally assigned diagnosis. This was particularly so if symptomologies were considered to be a consequence of opioid therapies and when subsequent treatment strategies were directed toward rationalising analgesic therapies so as to restore gastrointestinal function. Having repeatedly encountered these clinical scenarios, surgical teams became cautious in committing to overseeing such impending admissions, given that their previous experiences had been characterised by the

cohorts' inpatient journey being *"difficult, futile and protracted"*. These admissions, as they saw it, not only resulted in variable therapeutic gains, but also impacted significantly on ward staff, *"they give the girls (nurses) hell down there, you can't have more than one of them [patients] on the ward at any given time"*, and hospital function *"blocking surgical beds that might otherwise be utilised for patients awaiting elective surgeries"*.

Infrequently, other consultative services (gastroenterology, gynaecology/obstetrics) have overseen the admission of these patients. However, many clinicians within these clinical disciplines recounted that in doing so, they were:

Simply providing a name over the bed so they (patients) can get access to some of the services they need (Consultant Gastroenterologist).

Clinicians adopting this pathway for the clinical management of the study patient cohort did so in order to access the inpatient services of both the chronic pain service and the liaison psychiatry services. These services operate as consultative services to inpatient specialist teams and do not have the authority nor the necessary infrastructure required to oversee the admission and inpatient management of patients, including the study patient cohort, into the study site hospital. Accessing these services on an outpatient basis is difficult, and to expedite patients getting access to these services some clinicians are prepared to admit the patient in order to help resolve issues related to pain and psychological distress.

When the study patients required admissions to manage issues related to optimising and rationalising long-term opioid therapy, these admissions were 'trialled' under the rehabilitation/pain admitting speciality. These admissions began to appear during 2005, coinciding with the transfer of CPS into the study site facility. This move enabled a more pre-emptive approach to managing patients on long-term opioid therapy because rotations and analgesic regimes were being optimised under more controlled conditions, within a rehabilitative rather than a surgical framework. Since this change to the clinical management of these patients was introduced in the latter stages of the study period, a relatively small number of inpatient stays (5/98 admissions) are

attributed to these clinical approaches and show the admissions of the two study patients who have encountered such admissions.

### ***Study patients' inpatient resource utilisation (treating teams) H1 (2003–2005)***

Once admitted into the hospital, the study patient cohort had numerous clinical specialties that became involved in providing inpatient care. Reflecting the complex and diverse nature of the patients' presenting problems, numerous teams were mobilised to address and support the inpatient management of these issues. Examination of the retrospective chart audits revealed that during any given admission, up to ten individual inpatient specialist teams could be mobilised to deliver inpatient care to the study patient cohort. Figure 5.3 shows the seven most frequently accessed clinical specialties during admissions between 2003 and 2005 involved in providing inpatient care for the study patient cohort.

While the multidisciplinary approach facilitates the provision of specialist services to meet diverse and challenging care requirements, difficulties can arise as a result of having so many clinicians involved. This is particularly so when attending clinicians might have competing or contradictory treatment/paradigmatic approaches and thus potentially conflicting appraisals of the situation. Such situations have been reported by participants, including patient and carer participants, as producing significant tension, frustration and hostility, between patients and health care professionals and between and within treating teams, leading to difficult and at times "*chaotic*" clinical scenarios.

In addition to identifying the numbers of clinicians and clinical specialist representatives involved in the inpatient care of the study patients, and the inherent extensive resource utilisations, identifying these treatment specialties facilitated the purposive sampling approach to identifying potential focus group clinician participants.



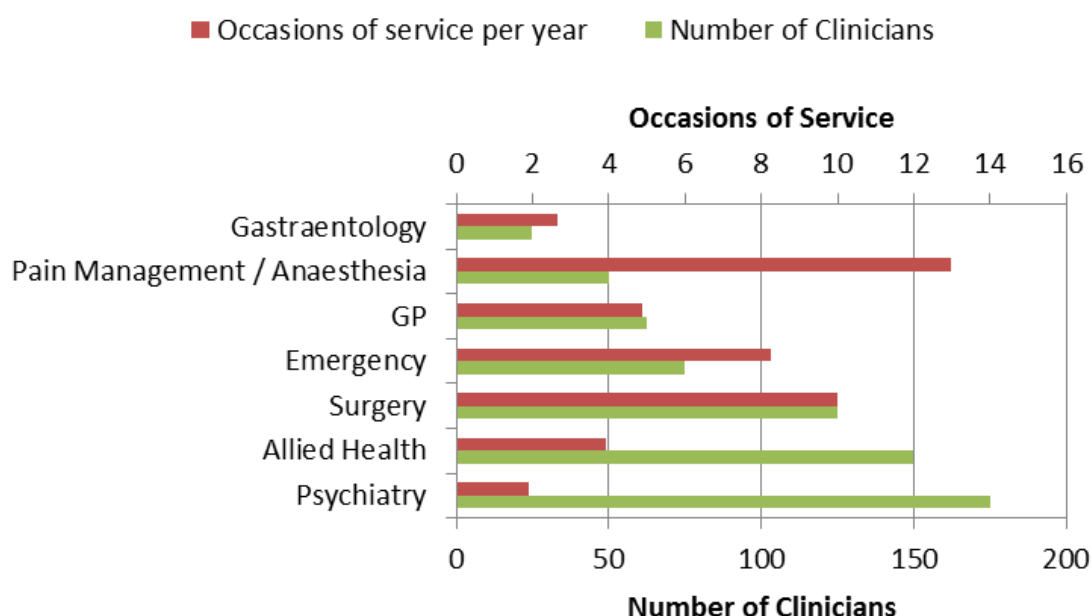


Figure 5.3 Clinical Specialties –Occasions of Service per Year for Chronic Abdominal Pain (2003–2005)

### Notes

Clinician focus group attendees were asked to give some indication of the numbers of patients (not necessarily study patients) they had seen with persistent abdominal pain in the 12 months and the 4 weeks prior to attending their focus group interview. Clinicians from the pain management/anaesthesia specialism reported the most frequent encounters with patients suffering from persistent abdominal pain (4 clinicians provided approximately 162 occasions of service/year), followed by surgeons (14 clinicians provided 125 occasions of service/year) and ED clinicians (10 clinicians provided 103 occasions of service/year). The GP group reported seeing at least one patient per week with problems associated with persistent abdominal pain.

### Comment

Having multiple clinician involvement, particularly for the inpatient management of the patient cohort, would appear, on the surface, to be appropriate given the patients' multidimensional complaints. However, significant difficulties in the clinical arena often arose as a consequence of these situations. As a product of the vast and diverse numbers of clinicians involved, patients frequently recounted occasions when

significant tensions within and between treatment teams and between health care professionals, patients and families ensued because conflicting diagnostic and treatment information had been given. Given the diversity of clinicians' professional orientations, paradigmatic divergences often make their way into clinical practice; this represents professionally siloed, conflicting and hence counter-productive care. In addition, these scenarios contribute to what clinicians report as the occasions when patients, if they are unhappy with one treatment approach, will *"manipulate and play one team off against the other"* in order to access more agreeable treatment pathways—pathways that are typically characterised by increased medicalisation rather than conservative treatment approaches.

### **Quantifying study patients' impact on speciality clinicians' activity (2003–2005)**

Table 5.7 lends support to anecdotal reports that care provision directed toward the patient cohort was *"time consuming"* and highlights clinicians' responses to a questionnaire given at the close of the health care professionals' focus group interviews. The questionnaire asked attending clinicians to estimate the extent to which they were exposed to patients with persistent abdominal pain per year (measured in terms of occasions of service). In addition, clinicians were asked to compare their inputs (measured in units of time) when managing patients with persistent abdominal pain in comparison with other patients they encountered within the scope of their clinical practice(s).

**Table 5.7: Comparative Time Allocated to Chronic Abdominal Pain and Other Cohorts per Clinical Speciality**

	Less time	Same time	25% more time	50% more time	75% more time	Twice as much
<b>Emergency (n=12)</b>	--	8.3%	8.3%	41.7%	8.3%	33.3%
<b>General Practice (n=5)</b>	--	--	--	40.0%	--	60.0%
<b>Gastroenterology (n=6)</b>	16.7%	50.0%	33.3%	--	--	--
<b>Pain Management (n=12)</b>	8.3%	16.7%	25.0%	--	8.3%	41.7%
<b>Surgery (n=10)</b>	10.0%	20.0%	--	70.0%	--	--
<b>Other (n=8)</b>	25.0%	--	--	50.0%	12.5%	12.5%
<b>Total (n=53)</b>	<b>9.4%</b>	<b>15.1%</b>	<b>11.3%</b>	<b>34.0%</b>	<b>5.7%</b>	<b>24.5%</b>

### *Notes*

For the clinicians who chose to respond to the questionnaire (53 clinicians), over half (34 clinicians) reported needing to invest at least twice as much time with the patient cohort than with other patients they most frequently encountered in their clinical work. While some clinical specialties could more readily access the large portions of time required to engage with and manage the patient study group (pain specialists, psychologists, and to some extent gastroenterologists and nurses), this was not the case for others (ED clinicians, surgeons, anaesthetic registrars), who often are confronted with competing situations that required their urgent and immediate attention.

### *Comment*

Quantifying the degree to which clinicians feel they need to invest in the patient cohort in comparison with other cohorts within their areas of expertise was important. Identifying the impact (perceived by attending clinicians) that the study patients represent, in terms of the time required to manage their health care complaints, highlights the difficulties and complexities that clinicians are confronted with in these clinical scenarios. Clinicians in these situations reported that they needed to invest disproportionate amounts of time to achieve therapeutic outcomes. This was certainly a point of discussion within focus groups: clinicians who worked in acute emergency arenas reported having no time to invest in such encounters. A similar view was noted for clinicians in private practice where inadequate financial reimbursement and scheduling issues made it difficult to “*meaningfully invest in the patients to the degree that their condition required*”, and for which they recognised they had “*limited skills*”; and for other clinicians who in the past had made numerous and significant efforts only to be subsequently confronted by the “*futility*” of their efforts when patients re-presented with the same and at times more debilitating issues.

The degree of commitment required to participate in these clinical scenarios is difficult to assess for the majority of clinicians within the acute care environment. Clinicians in these situations spoke of occasions where it was “*all too hard, and futile anyway*”, “*we never get anywhere with these patients...it’s just not worth it*”. A sense of helplessness and resignation pervades clinical encounters for clinicians in these situations, and often

translates into clinicians being primarily concerned by not wanting to aggravate already emotive and challenging situations for patients, families, nursing staff and other patients. Thus, clinicians frequently reported that in these situations they were more inclined to *"take the path of least resistance"*, by giving into patients' demands for more analgesia, reducing gastrostomy feeding, etc., despite such inputs consequently stalling therapeutic advances.

The degree to which clinicians need to invest both personally and professionally in these therapeutic encounters, and for which they reported variable success presented significant challenges for participant study clinicians. These challenges brought into question their sense of purpose and function as health care professionals. It also ultimately challenged their therapeutic intent when dealing with the patient group. The tension these situations produced for health care professionals, patients and family members or carers is discussed further in Chapters 6 and 7.

#### ***Cost attributed to the inpatient management of the study cohort (2003–2005)***

One aim of the quantitative dimension of the study was to estimate, as far as possible, the financial implications of caring for patients with persistent abdominal pain for health care service providers, in this case, the study site hospital and the LHD. Although this patient group is small in number, they consumed considerable health care resources.

Health care professionals responsible for overseeing the hospital inpatient management of the study patient cohort had conflicting opinions about the costs associated with caring for the patient group. While some clinicians considered the patients financially burdensome for the LHD, *"they're costly for the health care service at every point"*, others believed the costs to be *"insignificant"*. Clinicians, who considered that costs were negligible, qualified such appraisals on the basis of their understanding that the costs were *"relative"* to what would otherwise be incurred if patients were not admitted and left to seek health care services elsewhere, with unacquainted clinicians likely to continue the relentlessly pursuit of organic pathologies. These clinicians reported their containment strategies to be a means of not only protecting patients

against potential iatrogenic harm, but also protecting the health service at large against escalating and potentially more extensive costs associated with the health care management of the patient cohort.

Costing data retrieved from the LHDs' performance and activity databases relating to the cost associated with caring for the study patient cohort during the 2003–2005 study period are presented in Table 5.8.

**Table 5.8: Costs of Inpatient Care for Patient Cohort (2003–2005)**

<b>Patient</b>	<b>Total Cost</b>	<b>Mean Cost</b>
<b>1</b>	\$107,397.00	\$9,763.36
<b>2</b>	\$77,212.00	\$6,434.33
<b>3</b>	\$76,409.00	\$5,877.62
<b>4</b>	\$69,298.00	\$9,899.71
<b>5</b>	\$53,298.00	\$2,664.90
<b>6</b>	\$52,905.00	\$8,817.50
<b>7</b>	\$8,626.00	\$345.04
<b>Total</b>	<b>\$445,145.00</b>	<b>\$6,257.49</b>

### *Notes*

A total of \$445,145.00 was incurred by the study site LHD in response to providing inpatient care for the composite patient cohort during 2003–2005.

### *Comments*

The costs attributed to these patients' hospitalisations were generated from the assignment of patients' presenting symptomologies and diagnoses according to the Codes from the International Statistical Classification of Diseases and Related Health Problems (ICD-10). The ICD-10 codes underpin and inform the assigned Australian Revised-Diagnosis Related Groups (AR-DRGs). AR-DRGs are defined as the "patient classification system that provides a clinically meaningful way of relating the types of patients treated in a hospital to the resources required by the hospital...//...each patient is classified based on their diagnoses, surgical procedures and other routinely collected data." (National Case Mix and Classification Centre (NCCC) University of Wollongong, Australia) <http://nccc.uow.edu.au>.

AR-DRG-associated “cost weightings” are utilised by the Australian Government to report, measure and distribute funding according to the service provision profiles of LHDs and hence individual hospitals. These “cost weightings” are essentially service weights/costs and are mainly measured in terms of service utilisation, for example, LOS. Within these cost weightings, specificity regarding the relative costs for a given DRG are limited to pathology, diagnostic imaging and operating theatre costs, and thus do not account for non-characteristic service utilisations, for example, the provision of specialist psychiatric nursing to prevent episodes of threatened self-harm. Thus, the DRG categories offer little potential to capture the increased health care resources consumed by ‘outlying patients’, or patients who do not fit the prescriptive criteria of the specific ICD-10 codes from which costings are derived. Therefore, because individual variations and utilisations within specific classifications, lack the specificity required to account for individual variations to ‘normalised’ treatment pathways, the costs associated with the DRG used for categorising patients such as persistent abdominal pain patients, can at best be considered ‘conservative estimates’.

Interrogating the inadequacies of the current funding model by capturing the costs associated with patients who do not fit the normalised diagnostic categories (outlying patients), was beyond the scope of this study. Capturing the available costing data for the study patient cohort, made available base line information that could provide a reference point for comparison for subsequent studies concerning health care utilisations and costing associated with the study patient group. The costing data presented here for the patient cohort, being conservative in nature, highlight the issues associated with the inadequacy of the costing model. This has made apparent the importance of future work that could be directed toward studies of this patient group. Studies directed toward capturing more accurate and representative costings associated with the care provision for patients with persistent abdominal pain would identify the real extent of their financial impacts on the acute care health sector.

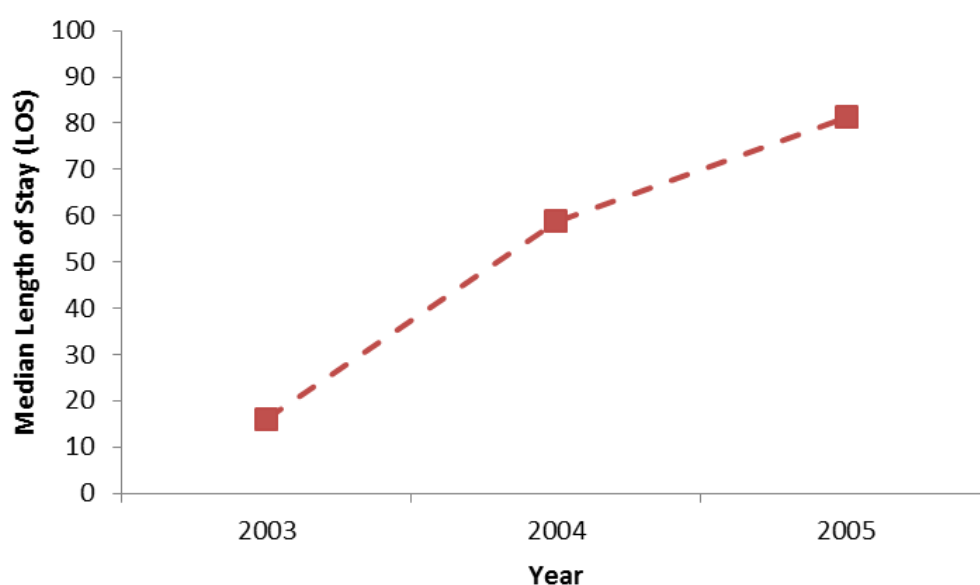
#### ***Composite patient health care utilisation (as LOS) trend data at H1 (2003–2005)***

The majority of the study patient participants (five of the seven) reported long associations with the study site Health Care District, the study site hospital and

resident clinicians. For three patients, their association stretched over two decades. Anecdotally, clinicians reported the patient group as having been in the system “forever”, and that their presentations were becoming seemingly more frequent, admissions more prolonged and their clinical presentations more difficult to manage. Acknowledging such anecdotes required the researcher to consider the composite group’s health care utilisation trends over the course of the study period. The trend data represent the median LOS for the composite group over the 3-year study period, inclusive of a time frame during which no patient underwent significant surgeries. The LOS values represent the hospital bed days associated with the management or maintenance of patients’ chronic abdominal conditions and pain symptomologies (Figure 5:4).

### Notes

The median LOS for the composite group rose exponentially over the 3-year study period, as shown in Figure 5.4.



**Figure 5.4: Median LOS per Year (2003–2005) for the Composite Study Cohort.**

In 2003 the median LOS for the seven study patients was 15 days, in 2004 the group’s median LOS increased by 27% to 55 days. In 2005, the composite patient group’s median LOS peaked at 81 days, reflecting a 68% increase from 2004. During the 3-year study period, each patient averaged 52 days/year or 7.5 weeks as an inpatient at the

study site facility per year for 3 consecutive years as a consequence of their chronic abdominal pain symptomologies.

### *Comments*

It is difficult to draw inferences regarding this trend; however, a number of potential explanations can be offered. The explanations offered are derived from the researcher's experience as a clinician at the study site, as she is cognisant of the contextual situations that surrounded the clinical activities related to the medical management of the patient cohort at the time. In addition, findings extrapolated from the retrospective chart audits and closer interrogation of the activity data from the study site's hospital health performance unit database for 2005 helped illuminate possible precipitants to the increased activity of the composite study patient cohort.

One potential explanation involves a new patient who joined the study patient group during 2005. This patient relocated to the LHD during the final year of the study period and presented with a long-standing history of persistent abdominal pain for which she had been managed by a neighbouring Metropolitan Local Health District. During this patient's first year of contact with the study site hospital, she required seven hospital admissions, accounting for 161 hospital inpatient days, representing an average LOS of 23 days per admission, three times the previous year's composite average LOS.

Another potential explanation is that during 2005, Patient 3 became pregnant with her second child, and while admissions directly related to her pregnancy were not included in the frequency counts for the 2005 hospitalisations, each of her other admissions (for persistent abdominal pain) during that year were complicated and prolonged as a result of the contentious issues surrounding the management of pain, including optimising opioid analgesic regimes in the context of ensuring foetal wellbeing. Reviewing the hospital records of this period revealed that significant and difficult clinical encounters (discord between patient, families and clinicians surrounding perceptions of suboptimal pain management), particularly related to the cautious administration of opioids was directly responsible for producing therapeutic



impasses that seemingly underpinned prolonged hospitalisations (in excess of 60 days) and repeated presentations to the study hospital and other hospital EDs.

One final explanation resides in the fact that, during 2005, improved clinical understandings regarding the management of chronic pain, particularly within the context of acute exacerbations requiring hospitalisation were beginning to make their way into clinical practice. The introduction of the CPS and subsequent alterations to the inpatient management of the study patient cohort began to impact on clinical practice activities that could conceivably be reflected in the activity data (LOS) during this period. One would assume that by improving clinical management approaches, reductions in health care consumption would follow. However, the changes to clinical practice that characterised this period for the study patient cohort (at that time, four of seven patients), represented clinical approaches that challenged historically embedded biomedical paradigmatic approaches. This saw a reduction rather than an escalation of pain management treatments, particularly opioid medications, in a bid to re-establish effective analgesic pathways and reduce side effects, such as gastrointestinal dysfunction.

One of the most compelling issues discerned during the retrospective patient chart audits was the degree to which patients were physiologically compromised when presenting to the hospital, and how that became a direct indication of how difficult and protracted the ensuing admission would be. For example, if patients, particularly those relying on supplemental feeding via percutaneous gastrostomy/nasogastric tubes (two patients) presented in a significantly dehydrated state, with considerable electrolyte imbalances, their inpatient journeys tended to be characteristically prolonged. Generally, these inpatient stays are complicated by the difficulties associated with gaining peripheral venous access (for the purposes of fluid resuscitation). Patients with vascular insufficiencies resulting from numerous and repeated vascular catheterisations over many decades of hospitalisations present clinical challenges for clinicians, particularly junior clinicians, who most typically manage these patients upon their presentation to ED. Although accessing a patient's vasculature in a tertiary referral centre should be a technically straightforward procedure, particularly with the

advent of supportive services such as ICU whose staff are regularly called upon for procedural assistance in these situations, clinicians, even senior clinicians, remain hesitant about using invasive procedures on these patients, considering that the risk-benefit ratio is considerable in the context of repeated and what they largely consider avoidable admissions.

These clinical scenarios become complicated when patients elect, for whatever reason, to cease taking medications, refuse to administer their enteral therapies; refuse to eat and drink (problematic in the case of patients with high-output ileostomies and fast gut transit times); delay presentations to the hospital until they are significantly unwell (partially in a bid to appear authentic); and self-medicate excessive doses of opioids (in response to increased pain and distress), such that side-effect profiles (decreased gut motility, constipation, gut distension, etc.) become so deleterious as to require significant medical intervention. These actions typically result in the patients appearing to the ED significantly unwell and in need of medical intervention to address physiological problems that could have largely been avoided if managed preemptively in the primary care setting. Patients' motivations for resorting to such actions are significant here. Patients generally reported:

I have to almost be dying before I'll go in there, I just hate the place (study site ED)...I'll leave it to the absolute last minute (Patient).

I used to go to X (General Practitioner), every couple of days for a pethidine injection...it would just get me over the hump...now they've got me on these slow release things and I can't manage these flare ups like I could with the injections or the endone...so now when it flares up I'll put a patch on...then when that doesn't work I'll put another one one...In the end I'll end up with four patches on just trying to get on top of it (pain) (Patient).

I'm usually so ill when I arrive (to the ED) I really push the boundaries until I absolutely have to go in...//...I'll also decide to go because of pressure from my parents. I get to the point where I'm so drained because of the pain, I can't walk, I can't go to the toilet, I'm so dehydrated and the lack of food intake stops my bowel working, but eating causes so much pain (Patient).

I don't go outside, I can't be bothered anymore ...//...I'm just sick of being sick...//...I just want to die...//...so I stop feeding myself (via gastrostomy) and I stop eating...//...I try to stay out of the emergency for as long as I can 'cause I just know it will be sheer hell (Patient).

### *Identifying system and process issues contributing to LOS at H1 (2003–2005)*

In addition to the distinctive clinical complexities that appear to act as precipitants to numerous and lengthy hospitalisations for this cohort, are the perennial hospital system and process issues that are well recognised for impacting on the efficient and effective management of hospital inpatient care. Despite hospital mandates of providing “the right care, to the right patient, at the right time” (NHS Health Care & Modernisation Agency, 2005, p.4), the provision of such outcomes remains seemingly difficult to achieve. Patients who challenge system efficiency and efficacy are typically those who do not fulfil prescribed diagnostic and treatment pathways and who challenge the purpose and function of the operationalised procedures implemented to manage ‘typical’ rather than ‘atypical’ clinical scenarios. Patients with persistent abdominal pain represent such a patient group. As a result, their inpatient pathways are characterised by delays in care provision. The causes of delays in care provision are many and varied and are discussed in Chapter 6. Most frequently, they relate to problems associated with ED clinicians being able to initially identify Specialist Medical Services prepared to take responsibility for the clinical management of the patient, including authorising and overseeing subsequent hospital admissions. Further, once the patient is admitted into the hospital, delays in expediting inpatient clinician consultative services also follow, resulting in care effectively being stalled until specialist clinician input is forthcoming.

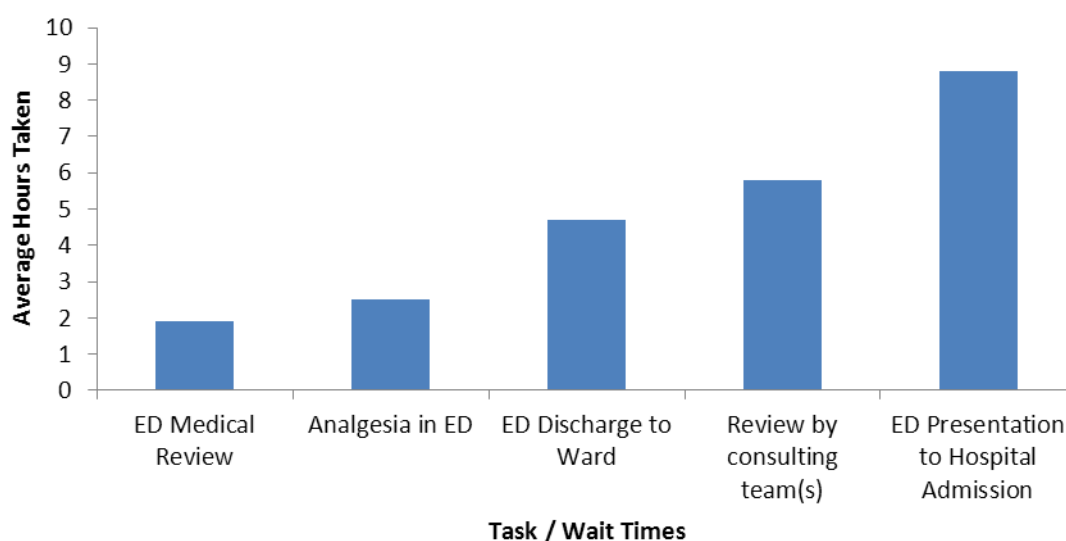
In addition to these delays, clinicians are often confronted with little or conflicting clinical information, which makes contextualising clinical presentations within the patient’s past medical history difficult. For most of the patients, initial diagnoses and supporting documentation were buried within volumes of inaccessible past medical records. Accordingly, diagnostic labels appear to have been perpetuated on the basis of historical accounts reiterated by patients, including historically assigned diagnoses and treatment strategies, some of which attending clinicians have difficulty in reconciling because of the conflicting current clinical presentation(s) and diagnostic evaluation(s). Similarly, for those patients who transferred from other health care providers, little in the way of supportive or definitive documentation relating to underlying diagnoses

was made available. Further, even if efforts were directed toward formalising treatment approaches, particularly in relation to the analgesic management of patients' acute exacerbations, such treatment plans were often obscured in voluminous editions of patients' records. Finding and identifying the most suitable plan was a difficult task, which stalled the well-intentioned attempts to improve the clinical management of these patients.

Collectively, these issues appeared to provoke tensions during clinical encounters, whereby patients became increasingly frustrated by what they described as the inertia of clinicians, perceiving such delays in care as representative of clinicians' suspicion of their authenticity as deserving and legitimate patients who required care much like every other patient:

I just want to be treated like every other patient (Patient).

The system and process issues most often identified by stakeholders as problematic in these scenarios (Figure 5.5) were closely examined during the retrospective chart audits. ED clinicians most often complained about delays they faced in securing a treating team prepared to accept the care of the study patient cohort. Patients, on the other hand, most frequently complained about delays in receiving analgesia, the time it took for them to transit through the ED and subsequently be admitted in one of the hospital wards, and the delays they experienced in being assessed by either the medical team in the ED or the chronic pain service on the occasions they were admitted into the ward.



**Figure 5.5: Hospital System and Process Issues Contributing to Increased LOS (2003–2005)**

### *Notes*

On first presenting to the study site hospital's ED, patients waited on average 2 hours before being reviewed by a medical representative within the ED. In these situations, the medical review is instrumental in mobilising the pain medication that the study patients most often sought at this stage. Delays in having an ED medical review consequently translated into delays in the patient receiving analgesia. Once patients were medically reviewed in the department, it took an average of 2.5 hours until the patients' prescribed analgesia was administered. Issues complicating these delays relate to clinicians having difficulties locating pain management treatment plans that may have been formulated during past admissions by the chronic pain specialist, difficulties achieving venous access for the administration of parental opioids and issues related to staff being unable to locate PCA devices, and being unfamiliar with implementing and managing the modality.

When ED medical staff sought consultative medical opinions from inpatient specialist teams, they waited an average of 5.8 hours for such reviews to take place. These delays were often complicated by consulting teams, most often surgical teams being delayed in theatre, attending to competing clinical responsibilities, or resisting the responsibility for such admissions. Specialist consultative reviews are critical on these occasions, as ED staff often rely on such reviews to help eliminate the suspicion of

acute intra-abdominal pathology, to help coordinate treatments, or to support conservative management approaches.

In general, in the event that a patient is required to be admitted into the hospital for ongoing clinical management, this process takes on average 4.7 hours from the time of initial ED presentation until the patient is transferred to an inpatient ward bed. For a patient from the study cohort (during the study period of 2003–2005), from the time she presented to the study site hospital's ED, was attended to by medical personnel, and subsequently was admitted into a ward bed, the process required an average wait time of 8.8 hours. Once in the hospital, if the admitting team requested the patient be reviewed by the consultant CPS service, this consultation represented an average delay of 6 days.

These system and process issues appear to underpin some of the situations documented in the patient notes where frustration led to anger, hostility and on occasion violence toward staff. These emotive situations where patients and family members felt they were being dismissed as ill-informed, or worse, suspicious patients, took on an added dimension when hospital complaints staff, security personnel, hospital management and on one occasion the media were mobilised by dissatisfied patients and family. These are circumstances that compounded and complicated already difficult and complex clinical scenarios.

### **5.3 Conclusion**

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Past experience as a clinician and service manager have taught the researcher that service providers, no matter how sympathetic to the unfortunate plights of patients, require evidence that alterations to clinical practice will work in order to be persuaded to mobilise the necessary funds and infrastructure required to enact any improvement strategies recommended. No matter how altruistic the agenda of researchers may be in highlighting the inadequate management of a patient or group of patients, the reality is that there are many patients, equally deserving, who require access to the same limited funding from which health care service provision is delivered. As clinicians and

researchers, we have a professional, moral and ethical obligation that is not restricted to the human dimension of providing health care, but a broader social imperative and responsibility to provide ethical and socially responsible health care services to patients, including making recommendations in relation to what these health care services should offer. For this reason, and in addition to recognising the prevailing positivist research culture within health care, based on which many of these decisions are made, the inclusion of the quantitative data was necessary. This inclusion was not a cursory attempt to 'negotiate' the system to best fulfil the research agenda, but rather it was central to highlighting important aspects of the study phenomenon that would not have been accessible via the qualitative data alone. It demonstrates the methodology's propensity toward data sets being mutually informative rather than being exclusive of one another. In addition, the quantitative data have contributed to the provision of a comprehensive account of the multidimensional aspects of the research phenomenon, from which measurements relative to a newly created baseline can be achieved in the future. Finally, conducting research that concerns multiple disciplines and multiple philosophical orientations requires an approach that not only makes the conduct of the study and its practical implications 'accessible' for all, but also reflects the reality from which clinical concerns that become the subject of research agendas originate.

Having presented the quantitative data and thereby highlighting the nature and extent of the resource implications in providing health care (hospital resources) to patients suffering from persistent abdominal pain, the following chapter, Chapter 6 is directed toward providing the qualitative accounts from all stakeholders (patients, family members/carers, healthcare professionals) at the centre of the study phenomenon. These qualitative findings are presented in an attempt to better illuminate and critically appraise how and why this situation exists for patients' and the concomitant impact it has for all stakeholders central to the experience of persistent abdominal pain.

## Chapter 6    Becoming and being a patient with persistent abdominal pain

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### 6.1 Introduction

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Chapter 5 quantified hospital-based health care patterns of utilisation, the characteristics of the patient cohort and the nature and extent of the concomitant extensive resource implications for the identified cohort. This present chapter aims to provide deeper appreciations derived from both the findings and relevant literature relating to: i) the experiences of patients, family members/carers and health care professionals at the centre of the study phenomenon; ii) the identification of factors contributing to the maintenance of unhelpful health-related behaviours; and iii) the provision of insights into potential improvements in clinical management that might translate to better health outcomes for current and emerging patient cohorts with persistent abdominal pain.

This chapter centres on the qualitative data from patients, their family members/carers and health care professionals who participated in the study. The data sets primarily focus on the experiences recounted by patients over their life spans: Part One – *Lives before chronic pain*; Part Two – *Lives interrupted by chronic pain*; and Part Three – *Lives dominated by chronic pain*. The sequential presentation of the patients' stories, around the central plot of persistent abdominal pain, makes accessible patients' constructed realities of events leading up to, during and subsequent to the development of their persistent abdominal pain states.

Narratives allow patients to make sense of their illness journeys. Riessman refers to this as the "meaning-making function of narrative" (2008, p.10). Appreciating how patients have come to make sense of their journey of becoming and being a patient with unresolved abdominal pain, provided an opportunity to gain better insight into the genesis of the patients' understandings, beliefs and conceptualisations surrounding their "constructed identities" as people with persistent abdominal pain. When peoples'



“imagined biography”, “maps and destinations” are disrupted by misfortune and illness, particularly chronic illness, the human interpretive practices and consequential “embodied narratives” represent attempts to “reconstitute and repair ruptures between body, self and world” (Frank, 1995; Riessman, 2008). Similarly, appreciating the narratives that family members/carers and health professionals recount also makes accessible their respective constructed realities and hence their assembled identities as carers/supporters of loved ones with ongoing health care issues and as health care providers for patients suffering from persistent abdominal pain. Within this context, Lupton (2012) refers to the sociocultural context or “life-world” in which meaning is generated regarding the “understandings, concepts and beliefs that lay people bring to the medical encounter” (2012, p.vii), and that doctors and other health care professionals possess as not only a product of their “scientific training but other aspects of their own life-worlds” (Lupton, 2012, p.vii).

Accessing the constructed realities of major stakeholders (patients, carers and health professionals) was fundamental to ‘unpacking’ the complexities surrounding the psycho-pathophysiological and social causes and implications inherent in developing their interpretations of the reality of living with, and attending to debilitating chronic illnesses and associated symptoms of pain.

As noted in Chapters 3 and 4, the stakeholders’, particularly patients’, at times lengthy stories are presented in a way that reflects their constructed reality, an approach referred to by Riessman as “mapping the contours of the interpretive process that happens with biographical disruption – *telos*” (2008, p.57). Approaching the data in this way makes apparent some of the interpretive beliefs that stakeholders have accumulated as a consequence of historical interactions and experiences as they have occurred for:

- patients who live with chronic abdominal pain and frequently seek medical attention
- family members or carers who live with, support and care for patients with chronic abdominal pain, and

- the health care professionals who encounter these patients when they seek medical assistance, in particular GPs and hospital-based health care professionals such as emergency department clinicians, doctors across a large number of specialisms and nurses in the various wards where these patients are repeatedly admitted.

Consequently, each of the following three parts within this chapter includes narrative accounts (experiences and their impact) for all study stakeholders. The consequences of the patients' experiences however are central to the experiences of all stakeholders. Hence, the responses to the patients' experiences are presented after the patient stories. Parts One, Two and Three are presented below and key themes and patterns are identified and the concepts discussed.

## **Part One: Lives before chronic pain**

Interviews with the study patients commenced by asking participants to reflect on 'growing up', and to describe what they remembered as major features of their lives before becoming unwell. For all participants, early adolescence appeared to be a turbulent time characterised by life events that they described as having significantly impacted on them as they grew into adulthood. For five of the seven study participants, adolescence marked a juncture between a life before and a life after pain. The events during this phase of their developmental histories were recounted with marked vigour and emotion, appearing to highlight the ongoing prominence these events have for patients recounting their stories of developing persistent abdominal pain.

Whether patients had decided that these early childhood events were inherently significant within the context of their pain stories, or whether the prominence these events attain within the patients' narratives are a consequence of repeated exposure to questioning by health care professionals required some consideration. Curiosity surrounding this issue was prompted by a number of features emanating from the interviews: i) the consistency with which all study patients chose to begin their stories

with their respective accounts of their developmental difficulties; ii) the seemingly rehearsed, lyrical and almost scripted nature of how the stories were presented; and iii) the propensity of all patients to return repeatedly to these events during interviews and to direct significant and often exhaustive explanations (with detailed anatomical and physiological explanations) toward discounting any association that might be made between their developmental histories and their persistent pain complaint(s).

Highlighting these features of the patient interviews is not intended to trivialise, discredit or question the veracity of the patients' accounts. Rather, reporting on the notable characteristics of the patients' interviews is intended to emphasise the way in which these patients have come to know how and what health care professionals are seeking during information exchanges related to their illness histories. Acknowledging this reveals the significance of such influences on patients as they set about constructing their illness stories (whether for researchers or clinicians), in deciding what is and what is not important in the context of these stories (Frank, 1995; Kleinman, 1995) for the purposes of having their needs met. Riessman makes the following comment regarding attention to such conventions, stating, "a good narrative analysis prompts the reader to think beyond the surface of the text, ...//...there is a move toward a broader commentary ...//...making conceptual inferences about a social process is an equally 'valid' type of enquiry" (2008, p.13).

Regardless of the basis of their prominence within the study patients' narratives, the patients' developmental histories and the difficult life events that they recounted as having impacted on their wellbeing featured significantly within all patients' illness stories. All patients, given an opportunity to relay their story from any point in their illness trajectories, elected to commence their stories by recounting their respective difficult developmental histories. The difficulties described by participants were, for the majority of participants, the result of a combination of major physical, cognitive and socio-affective challenges during developmental years.

## 6.2 Developmental histories: Difficult life events affecting wellbeing

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Patient participants' developmental histories were characterised by considerable challenges. These were marked by difficult life events that included: i) significant changes to the structure of family units, ii) disruption to social development opportunities, and iii) marked alterations in physical and /or psychological wellbeing.

### 6.2.1 Changes to family structure

Discussions regarding life before ill health for study participants featured themes associated with changes to their respective family structures. Disruptions to study patients' family structures were particularly prominent for four of the seven patient participants.

Three participants volunteered information about being adopted as young children. While stating that they had been relatively happy within their adoptive families, each recounted stories of having made attempts during early adolescence to make contact with biological parents and siblings. These attempts had been unsuccessful for all three participants, with each describing the events as a "*phase in their life*" or as something they had "*disregarded*", or had rationalised "*what's gone is gone*".

One participant recounted the volatile circumstances surrounding her parents being divorced and her subsequent estrangement from her father as a consequence of her mother's and later her stepmother's interference:

...mum and dad divorced when I was young...//... there was a war of words and mum refused to let my father have access visits to us if my stepmother was around...//... I was pretty close to my father but then when I was about 13 he married my stepmother and she hates any female intervention, even his own daughter. She eventually pushed him away from me (Patient).

Although not reporting physical disruptions to family structure, the remaining three patient participants reported accounts of being emotionally estranged from parental figures, particularly mothers. For these participants', difficult relationships with parental figures often resulted in these participants being estranged from their

immediate family, and spending protracted periods during their formative years with extended family members.

I had a lot of trouble with mum, we went through a really bad stage where I just hated her and she hated me...//... then I went to live with my pop, he helped me through the rough times (Patient).

When I was 16 she (mother) kicked me out of home,... //...I went to Sydney and got my first job...//...I stayed there till I was 20...//...I didn't have much to do with her (mother) after that (Patient).

In contrast, one patient recounted how highly attentive her mother was when she became unwell during her early teens. In the early stages of this patient's illness, the patient was often admitted into the hospital/ward in which her mother, a nurse manager, was employed. The patient reported these occasions as ones where she received the most supportive and facilitative care. The patient reported her mother's ongoing attentiveness to her illness being fundamental to her being able to endure the hostilities she at times encounters in the health care system. The mother, now in her 60s, is the patient's full-time carer.

I'd be going in and out of hospital every 6 weeks, ...//... it became sort of very routine...//...they'd only let me home when I could cope without pain relief (pethidine injections) and my bowel was functioning ...//... I'd be on the ward where they knew me on the oncology ward where they knew mum. They were extremely compassionate. Their thoughts around pain relief were extremely liberal compared to other wards. If I was on a different ward and I asked for pain relief there might be a bit of a funny look...//... but on mum's ward when I was in such agony, they (nurses) would be asking the doctors and saying for goodness sake give her more pain relief, she's in agony...//... so I didn't have major problems then, except if they put me on a different ward then the whole time would be horrific, I would be treated terribly (Patient).

Dialogues regarding patient participants' relationships with their fathers did not feature as prominently as those discussed regarding mothers. All but two patient participants gave accounts of strong and supportive relationships with fathers, except in one case where the patient participant referred to her father as being "*physically abusive*". One participant discussed her relationship with her father only within the context of being estranged from him, and the lost opportunities surrounding this as a consequence of divorce and later interference from her stepmother. The remaining

participant never mentioned her father or his involvement during her developmental years or during periods of ill health beyond passing comments relating to his occasional visits when she was hospitalised, or his limited input in supporting her mother in the provision of her daily care requirements.

Whether adopted or raised by biological parents, participants' accounts of difficulties within formative relationships appeared to be permeated by a theme of estrangement. Whilst this estrangement was largely discussed in relation to the fractured relationships patients have with parental figures, these estrangements also extended to include siblings for five of seven participants.

I don't speak to her she's a b.... I don't even bother with her anymore (Patient).

As patients' stories unfolded, difficulties encountered within relationships became a recurring theme. Relationships with parents, siblings, school, university, work and other social and friendship groups as well as health care professionals were consistently plagued with themes of opposition, hostility and tension, frequently resulting in fractured connections, estrangement and ultimately isolation.

I haven't yet had a relationship that wasn't abusive in some way (Patient).

A significant and recurring theme across all participant narratives was the difficulties they encountered connecting with their respective peer groups, particularly during early developmental phases. Compounding these situations was the isolation patient participants experienced in regard to their peer groups as a consequence of ill health.

### **6.2.2 Disruption to social development opportunities**

As ill health increasingly interrupted patients' studies, and their lives as pre-teens, adolescents and then young adults, participants recounted becoming progressively more isolated from peer groups. As a consequence of frequent and extended hospitalisations as well as protracted recovery periods spent in isolation at home, the majority of the study patient group had limited opportunities during these formative years to cultivate social skills and develop friendship groups. This pattern of estrangement from peer groups continued for the majority of patients into young

adulthood, where they recounted ongoing and extended absences from their workplaces, resulting in their eventual departure from paid employment (for six of seven participants), and reports of having limited or no social networks or friendship groups.

My life completely changed, I missed a lot of school, quite a chunk of school at the end of primary, about half of year seven and then throughout the rest of high school. I missed a fair bit between ages 11 and 22. I was constantly sick, constantly going in and out of hospital (Patient).

For all patient participants, the onset of their ill health marked the beginning of a slow and then eventually a complete withdrawal from peer and social group(s). As they became progressively unwell and remained unwell, their lives were frequently punctuated and dominated by long periods of hospitalisations and protracted recovery periods at home. For the majority, five of the seven patients, transitioning from childhood into early adulthood marked the beginning of a slow and steady physical decline in response to a series of episodes of ill health, repeated hospitalisations, and protracted recovery time, all of which appeared to be disproportionate to what the expected trajectory of such illnesses would follow, for example, glandular fever. Patients' self-identities appeared to be shaped by these events, a concept that Riessman illuminates by stating:

Identities are narratives, stories people tell themselves and others about who they are (and who they are not). But the identity is fluid, always producing itself through the combined processes of being and becoming, belonging and longing to belong...//...in a word, narratives are strategic, functional and purposeful (2008, p.8).

These constructed personal identities are reflected in the following statements:

I was the kid at school who was always sick (Patient).

So everything that was supposed to be normal wasn't normal and that's how it's been for as long as I can remember (Patient).

I was 11 when I got sick and from then my life has been limited by A LOT of physical illness (Patient).

### 6.2.3 Changes to physical and psychological wellbeing

For five of the seven study participants, poor physical health was a recurring theme during early adolescence. Although the majority of these patients did not perceive these early illnesses to be directly related to their current abdominal pain condition, all noted the unusual and atypical trajectories that characterised their early childhood illnesses. They rationalised these unusual pathways as a consequence of being “different” to others with similar conditions. These conceptualisations became apparent through patients repeated references to their historical and ongoing propensity to challenge and confound attending medical personnel with their uncharacteristic symptomologies and atypical illness trajectories.

I have always pushed the boundaries of medicine (Patient).

I just don't fit into their nice little box...//... you can't put me in the same box as everyone else. I can't be treated the same way (Patient).

They don't know what to do with me, they don't know how to treat me, I'm too hard a case, I've got too many complications...//...I've always been in the too hard basket for them (medical professionals) (Patient).

My condition was so bad I have pushed medicine and the doctors to the limit (Patient).

For these patients, recurrent illnesses resulted in frequent and protracted hospitalisations and in two of the cases multiple and extensive explorative surgeries. For five of the seven study participants lingering engagement with numerous and diverse groups of health care professionals was a characteristic feature of their early developmental years. What was consistent across participants' early illness narratives was the extreme and disproportionate responses they had to complaints usually considered within the 'normal spectrum of childhood illnesses'. For example, one patient required multiple explorative surgeries for queried bowel obstructions and adhesions following an appendectomy, and another had total body paralysis following a flu injection. These earlier responses to ill health and the accompanying conceptualisations are foundational to the patients' understandings and belief systems surrounding these events:



Lots of other ill health came before the chronic abdominal pain. When I was 11 years old I had Ross River Fever and because I was SO very, very sick and had lots of immune-related problems they gave me a flu vaccination and that caused paralysis and caused my total body to be paralysed as well as my gut...//... following that I had a lot of nerve pain from all the nerves in my gut being paralysed in the same way...//... prior to that I did have some abdominal pain but it was different...//... they diagnosed it as Crohn's disease then but now the pain is different (inferring the paralysis is now the underlying mechanism of her abdominal pain)...//... the pain then was nothing to what I have now (Patient).

For the one participant who identified her initial childhood illness as the precipitant to ongoing chronic abdominal pain, the basis of this resided in her belief that initial medical management of her physical complaints was characterised by misdiagnosis, inappropriate medical treatments and interventions, including unnecessary surgeries:

Before I became unwell my life was fantastic...//...I got sick at 14...//...at 14 the rot started setting in and from then on I just went down, down, down....//...they said I had appendicitis and they did an appendectomy, after that I was going into hospital every month ...//...they misdiagnosed me ...//... it was malpractice...//...it was misinformation...//...so it was complete incompetence, incompetence by these doctors...//...if they'd given mum and dad the right information at the right time I reckon, I reckon I would have been alright. Instead they just took feet and feet and feet of bowel away...//...I had 13 operations for gangrene in the bowel, obstructions, adhesions and strangulations; they just kept cutting, cutting and cutting...//...if they would have looked further in the first place (referring to misdiagnosis) I wouldn't have all this trouble now (Patient).

For the remaining two participants, initial contact with the health care system occurred following encounters with mental health services. These followed traumatic and psychotic events that occurred for both patients during early adolescence (sexual, physical abuses; anxiety, depressive and personality disorders). Both patients developed chronic illnesses (pancreatitis and chronic low back pain) for which they then proceeded to require extensive and prolonged engagement with the acute care system. Both patients underwent extensive surgeries, treatments and diagnostic procedures for these conditions, before eventually being diagnosed with chronic abdominal pain. Both patients have remained engaged with and continue to move frequently between the mental and general health care systems within the local health district. They also reported having used these services elsewhere.

Despite not being directly questioned in relation to histories of abuse, five of seven participants volunteered having encountered significant physical, psychological and sexual abuse.

I was sexually assaulted when I was younger and I think that has had an effect on me as I've gotten older. I went to court over it and I lost my court case and ended up in the psych unit. That sort of started the whole rigmarole of me having sort of lots of problems with mental illness and not being able to cope, I was 16...//...he assaulted me and took advantage of me. I didn't tell anybody for about 4-5 days I was taken to the hospital because I was found unconscious at the bottom of the railway station stairs, I'd been threatened by him (not to tell anyone). He already pushed me down the stairs so I was worried what he would do to me if I opened my mouth...//... eventually I told them, it did go to court but because of lack of evidence he got off. Then I went into the psych unit for 3 months because I couldn't cope...//...I tried to take my life in there...//... it was the beginning of everything sliding down hill (Patient).

For some, these were not isolated incidents but were repeated and at times concurrent events during their adolescent and early adult lives. Characteristic of all patients' accounts were the significant and lasting effects these events had had on their lives and their wellbeing. Compounding these experiences was the variable and "*unhelpful*" encounters patients reported having had with psychologists and psychiatrists in the aftermath of trying to manage the consequences of these events. These variable early encounters with mental health services appeared to underpin patients' ongoing suspicions of, and subsequent reluctance to engage with, health care professionals from within this clinical domain.

It all sort of spiralled out of control. I just had admission after admission into the psych unit. Then I tried to kill myself again. This was between the ages of 16 to 21...//...All the psychiatrist did was medicate me to the point I had to be spoon fed by my own mother...//...they had me that drugged up and I don't want to go down that road again (registering refusal to engage with psychiatrist/psychologist when admitted as an inpatient at the study site)...//...I don't want to be put back on truck-loads of medication, they wanted to do shock treatment, but I wouldn't be part of that because I've seen the damage that can do. I didn't have any really close friends that I could turn to for help or anything really... //...just as I started to get my relationship back with my mum my back went and then they transferred me from the psych hospital to X (study site) and that's when I had my first surgery (Patient).

#### 6.2.4 Generational influences on health and wellbeing

A family history of chronic physical and psychological illness was a consistent feature of participants' stories. Five patients reported having at least one parent with a chronic illness, while one reported that both parents suffered from chronic illnesses. As a consequence, patient participants recounted extended absences of the parent as a result of hospitalisation or withdrawal from the family. In addition, two reported a parent whose chronic illness required the long-term administration of opioids:

Mum really wasn't that understanding (about my illness) cause my dad was also in X (private hospital) with back pain as well, because he's got a bad back as well (Patient).

In addition to these histories of parental challenges with physical illnesses, participants reported having at least one parent who had additional challenges with their psychological wellbeing. Six of seven patient participants recounted having a parent with a mental health illness. These were mostly described by participants as depressive and anxiety disorders. The patient participants described the affected parent using phrases such as, "*mentally unstable, mentally labile and mentally fragile*", most often within the context of explaining why the parent was "*not (physically or emotionally) available*" to them.

I think mum was mentally unstable. I spent a lot of my life at Nannas because she (mum) just couldn't cope. She was too sick mentally, she was just stressed and it made her sick. She just wasn't around, she'd go to bed and Dad and I would cook tea every night, and whenever I was sick she was a fanatic screaming mess (Patient).

Having worked with the patient participants for a number of years, I was aware of the difficult developmental histories and complex psychosocial issues these participants brought to clinical encounters. However what became more apparent during the course of the interviews was that their whole lives had been dominated by these challenges. The recurring feature of abandonment and estrangement were characteristic features of the many and varied relationships they encountered, not only during early childhood and adolescence, but also extending into adulthood and even now as older women. This was a recurrent and consistent theme within their stories.

I didn't ever have many relationships...//...I've only ever had bad, and mostly abusive relationships, you know physically abusive, psychological and lots of sexual abuses (Patient).

A reflective statement entered in my research journal following the interviews of patient participants illustrates my considerations on these issues:

There is a profound sense of abandonment for each of these people. They recount numerous relationships that can only be described as fractured. The mother daughter relationship (whether biological or adoptive) appears to be the most fractured relationship recounted by all but two people. Despite articulating they had "let go of these bad relationships" they talked animatedly repeatedly returning to them, using emotive and metaphor laden language to describe what had characterised their collapse. It was interesting to note that any positive references related to male influences. What was not obvious to me as a clinician, but has become more evident as a researcher are the similarities of the characteristics, dimensions and consequences of these difficult life events for all participant patients. The most profound feature: repeated and extensive abandonment. In these situations it seems pain has become a displacement mechanism, and the stories surrounding its intrusion into the patients' lives a means of making sense of difficult life events (abandonment, estrangement, abuse). In the absence of having been able to adequately reconcile these experiences, maybe pain with its biological manifesto, mobilises and engages people toward unmet needs (emotional and physical), provides by default, an "identity" a "connectedness" a "belonging" that has otherwise been lost in the messiness of a "difficult life".

Freeman offers some insight into how the work of narratives clarifies even "obscure objectives":

This is not to claim that intentionality of narratives is always conscious and deliberate; the ends that are being achieved maybe utterly obscure to those whose narratives they are. Rather, the claim is simply that narratives as sense making tools do things – for people, for social institutions, for culture and more (2002, p.9).

Gaining an appreciation of the significance of the developmental histories and events that led up to patient participants developing persistent abdominal pain was important to allow their associated beliefs and understandings about their illness and illness experiences to be examined, unpacked and contextualised. In addition to patients' accounts, family members'/carers' and clinicians' conceptualisations regarding these

socio-affective influences were considered instrumental in informing the research purpose.

Semistructured focus group interviews enabled access to stakeholders' understandings regarding their loved ones'/patients' journeys, including past encounters with the health care system and health care professionals, and events leading up to and instrumental in the development of the patients' persistent abdominal pain conditions.

These experiences of supporting and caring for someone with persistent abdominal pain are presented in the following sections. First, as they relate to the family members'/carers' perceptions and understandings, and second as they relate to study participant health professionals responsible for delivering health care to the patient cohort.

### **6.3 Family members'/carers' insights into events leading to the development of persistent abdominal pain**

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Of the family members/carers participating in the study, four were husbands, one was a partner and the other was the mother of one of the patients. All family members/carers were the principal carers, and had extensive experiences traversing the health care system with and on behalf of their loved ones for at least the past two decades.

The tone of the initial focus group was quite melancholic as participants reflected on what they described as lost opportunities, ill-fated plans and an altered life course for themselves, their children and their loved one as a consequence of loving and caring for someone with a chronic pain condition. There was a sense of heavy resignation surrounding their circumstances, particularly for those attending the focus group who had endured the situation for longer (over 20 years) than for other participant carer/family members.

It is very, very difficult; it's a huge drain it (caring for a loved one with persistent abdominal pain) just takes over your life (Family Member).

We'd come to the conclusion many, many years ago that my wife would not live to be an old woman, so we just take each day as it comes, that is all we can do (Husband).

X (patients' name) has no quality of life, neither do I and neither does our son (Husband).

The interview commenced by asking participants to reflect on life with their partners or daughters prior to them becoming unwell and developing their chronic abdominal complaint. Three of the six carer participants described coming to the relationship aware of the various health challenges their partners faced, albeit stating these were not originally as significant and debilitating as they had become over subsequent years. For the remaining two participants, their partners became unwell later in the course of their relationship/marriage. Both perceived these events to be the result of medical mismanagement. The participant mother recounted her daughter's normal childhood up to the age of 11, before repeated illnesses became a significant feature of her early adolescence, which then continued to "*dominate her life*". The following composite narrative of participant family members/carers introduces these events and associated conceptualisations, as perceived by them.

She started (being unwell) when she was 15, one of her ovaries turned into a cyst, then she got gangrene of the bowel, the surgeons didn't find it in time, then she got endometriosis, then she had a hysterectomy...//...I think it's been her bowel that's been the critical thing. In 1985 the chronic syndrome sort of settled in, so it's been in and out of hospitals for long periods of time, 6 month stints, 3-month stints, 6-week stints. She's in hospital at the moment, this Friday it will be 6 weeks that she has been in here. It's just an ongoing thing all the time – but it started a long time ago (Husband).

She was in reasonably good health when I met her...//... she'd had 13 operations in just over 12 months so once a month they were opening and closing her...the scar on her stomach is like a zipper...//...we did have a period where things were good then things got worse straight after our son was born, within 2 months of his birth (Husband).

...we've been together for 5 years, for the first year she was perfect she told me everything right from the start, her back pain, her Hep C, the slashing (referring to history of self-harm), and the abdominal stuff, so I knew what to expect. Things started to go downhill when they put her in hospital for back pain; she went in had some traction and then came out in a wheelchair. I had to do everything for her take her to the toilet, everything. Now her abdominal pain is the problem, we don't do anything we don't go anywhere (Partner).

My daughter was a healthy girl till she was 11 then she got Ross River Fever, but also we have a lot of immune system problems in our family, a lot of colitis and inflammatory bowel problems, she had so many immune problems she would just get everything. So she has been sick since she was 10, 11 we gave her a flu injection and that just paralysed her. After that, she could just move her hands and only just move her head. The paralysis just took over her body, it took out all function, and all motility of her bowel and so she has been in and out of hospital every 6 week for a very long time. Eventually there was nothing they could do so they took out her large bowel. Now the small bowel is starting to do the same thing (referring to it being paralysed)...//... we sit for weeks (before presenting to ED) expecting any day or night to have to come in. The whole thing is a real torment for the carer (Mother).

Consistent across carer narratives was the opinion that medical mismanagement had featured strongly in the development and maintenance of their loved-ones' ill health. While this was considered by two patient participants to be the precipitant to their loved ones' ill health, all carers commented on the varying degrees to which they attributed medical inputs as having been instrumental in the subsequent deterioration within illness trajectories. The theme of damage associated with medical mismanagement was discussed more vigorously and with more emotion (anger) by participant family members/carers than had been expressed during patient interviews.

This all started for us when she went in for an operation – the doctor stuffed something up and now she's just a mess. This has been a good year – she has only been in twice. Usually it's about every month. I forget what she went in for originally but the doctor did something...//...something didn't work. It was about 16 years ago, we never thought she'd come out of it (referring to an initial and turbulent intensive care admission). She was in that much pain, it's just been mind-blowing, the whole thing (Husband).

In contrast to the emphasis with which patients elected to discuss their developmental challenges (physical, psychological and sexual abuses), participant family members/carers did not direct discussions to include such information. Whether this was a consequence of the group settings in which interviews took place, or as a consequence of participants not considering the information important is unclear. For the participant who did elect to mention her daughter's history of sexual abuse, she did so within the context of justifying the care requirements (requesting a single room)

during her daughter's hospitalisations, and the need for considerable psychological support.

Look there is so much multiplicity with her. There's a history there you know. It's very personal and I don't think they (health care professionals) care or have time to worry about it (referring to the sexual abuse), she has so much anxiety (invasion of privacy) so she has become completely dependent upon me, her fears and her anxieties have become really exposed, I feel I have to be there to protect her (Mother).

Similar to patients' accounts, carers noted the social isolation their loved ones encountered, initially as youngsters and then later as adults. Carers stated that the consequences of their loved one being socially isolated had significantly limited opportunities to develop social networks, preventing the development of friendship groups that might have provided a sense of wellbeing and support, not only for patients, but also for the family.

She is very isolated, very isolated; she has no friends and anyone who does come to see her are more my age. They usually end up leaving in tears because they can't stand to see her like this (Mother).

It's difficult 'cause she's not a pretty sight hanging over the bowl vomiting all the time and the pain is such an intrusion, people just stopped coming, who we thought were friends turned out not to be friends (Husband).

We just stay at home (Partner).

Family member/carers discussions featuring histories of fractured relationships and ongoing family estrangements were cursory. Apart from brief comments referring to the lack of support they received from the patient's family (parents and siblings) in caring for their loved ones, carer participants did not focus attention on these fractured relationships. In contrast to this were health professionals' perceptions that such extensive psychosocial challenges were foundational to the *"difficult and complex"* profiles they attributed to the patient cohort.



## 6.4 Clinicians' insights into the primacy of patients' developmental histories

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The majority of clinicians interviewed recounted long associations with four of the seven study patients and their families (for some 10–20 years). These clinicians offered extensive insights into their perceptions of the primacy of difficult developmental histories in the genesis and maintenance of the patients' ongoing pain, dysfunction and disability, feature(s) they considered to be 'characteristic' of the study group.

These patients have typically been abused, they've often had really horrible, horrible lives and they have unhelpful relationships, they've had pretty sad lives...//... I can't fix that (Surgeon).

One GP caring for the family of one patient (as indicated in the quoted material in the following paragraph) offered details regarding the difficult, complex, 'whole of family' medical histories, stating:

I have three patients that fit this profile...one is quite young in her early twenties...//...she actually comes from a very pain orientated family – dad's got chronic pain, mum gets chronic headaches, dad's been under the chronic pain team, he gets the regular endone, he is the distributor of the endone for everyone else in the family (GP).

The difficulties that patients encountered as a result of, or related to disrupted childhoods, patterned/socialised health behaviours, physical, psychological and sexual abuses, in addition to a number of medical mistreatments or misadventures were considered by all health professionals to be instrumental in producing and maintaining some of the aberrant health behaviours frequently displayed by these patients.

The ones I'm seeing just want a holiday, to get out of whatever is going on around them, an abusive relationship or whatever, they're not in pain...//...but what is pain? They escape to come here, they interact with people, people are nice to them sometimes, they get fed and it's a holiday from the horrible things (Surgeon).

A lot of their problems are tied up with outside issues, when these people present it's usually an outside incident precipitating it, so then they take more opioids and that contributes to their problems. Let's not forget these people have complex personal, home and family dynamics that we are not going to be able to fix in a million years. We can only treat them as they come and we'll never fix these problems, they always come back, again and again and again (Surgical Nurse).

You have to think about what causes these people to present. Is it a learned behaviour because there is some sort of secondary gain, whether they've been sexually abused which is a big issue for the group with functional abdominal pain and refractory irritable bowel...//...it's impossible to answer, there are environmental factors and then the medical profession comes in and I suspect worsens the situation (Gastroenterologist).

In addition to clinicians' observations of associations between negative socio-affective features and deleterious health outcomes, they also noted the considerable part iatrogenesis plays in these situations. While many acknowledged the difficulties in identifying these patients prospectively, they were emphatic about the role that inappropriate medical input had played for these patients in the early stages of their illness trajectories and the ongoing propensity to perpetrate harm in this way by continuing to adopt a medicalised approach to subsequent management strategies.

The reason they get sick is because we, as a medical team, make them sick. If you think about it, they got sick because they had bowel chopped out unnecessarily; we're making them sick because we add a whole bunch of opioids – the reason they are sick is we make them sick in the first place (Anaesthetists/Pain Specialist).

Clinicians recounted being confronted by difficult clinical scenarios where they needed to, *“work out how much (of the patients' presentation) is psychological and how much is physiological”*. The perceptions of many clinician participants were that delivering effective, non-harmful treatments was dependent upon having some appreciation of the relative contributions of the biopsychosocial domains of the patients' presentations, a mandate that few reported feeling adequately equipped to manage.

There might be some physical cause of their pain, but there is ALWAYS some psychosocial driver. I don't feel equipped to deal with all the issues they present with. I can screen for all the physical issues but the psychological issues, I am way out of my depth (Gastroenterologist).

The battle is for them to get the psychiatrist to say it ( the pain) is all in their head, and that it's all psychiatric, usually the referring team are asking is there a psychiatric component or a psychological component, you know if it is a specific psychiatric morbidity that if you turned it away they'd be able to deal with the patient better, and the answer to that question is always yes there is a component, but they're sort of asking the wrong questions, yes we should exclude the major psychiatric morbidity, but these people have been in and out of the system and you're not

going to find anything new, it's about re-educating about the mind body interaction and working with patients and staff so they all actually believe it (Psychiatrist).

These difficult, complex clinical scenarios represent contexts and platforms from which initial and ongoing encounters among patients, families and health care professionals transpire. From consideration of events and effects of these situations, deeper appreciations of the study phenomenon become apparent. As patients' illnesses progressed toward chronicity, their narratives became progressively denser with recurrent accounts of difficulties experienced in accessing, negotiating and enduring the health care system. Clinicians' responses to these situations focused on the difficulties they face in balancing the potential to harm, and the potential to do good for patients in these circumstances. For family members/carers, the progression toward chronicity represents a reorientation of life toward the need to repeatedly engage with the health care services and a responsibility to advocate on behalf of and to protect their loved ones during encounters with health care professionals.

You just feel like you have to be there all the time to protect her. I'm scared to leave her there just in case they do something stupid, which they have done. I've been escorted from the hospital by security; I've had people fired because they're just incompetent, just absolutely incompetent (Husband).

These issues are further explored in the following section.

## **Part Two: Lives interrupted by chronic pain**

What becomes apparent from the patients' narratives is that people did not suddenly arrive at a diagnosis of persistent abdominal pain. There are long histories of repeated and complex episodes of ill health, characterised by atypical clinical presentations, disproportionate and refractory responses to conventional medical treatment(s), and variable interactions with health care professionals throughout their journeys.

Thorne, in her book *Negotiating health care: the social context of chronic illness* (1993, p.16), described similar journeys for patients leading up to their diagnosis of a number of chronic illnesses, referring to these trajectories as an "illness odyssey". For patients with persistent abdominal pain, this too is the case. The illness odyssey becomes a life

of accessing, negotiating and enduring the health care system. As previously noted, integral to these journeys are numerous and lengthy associations with health care providers. It is not surprising that encounters with health care professionals dominate patients' narratives of their 'illness odysseys'. Clinicians become central characters in patients' life stories, and become pivotal to how individuals come to make sense of, articulate and imbue meaning to life events associated with becoming and being a patient with persistent abdominal pain. Implicit in patients' constructed illness narratives are the sociocultural influences that permeate encounters with clinicians. Arthur Frank describes the development of these illness narratives in the context of being unwell in the following excerpt:

...the ill body's articulation in stories is a personal task, but the stories told by the ill are also social...//...the less evident social aspect of stories is that people do not make up stories by themselves. The shape of the telling is moulded by all the rhetorical expectations that the storyteller has been internalizing ever since he first saw some relative describe an illness, or she saw her first television commercial for a non-prescription remedy, or she was instructed to "tell the doctor what hurts" and had to figure out what *counted* as the story the doctor wanted to hear. From their family and friends, from the popular culture that surrounds them, and from the stories from other ill people, storytellers have learned formal structures of narrative, conventional metaphors and imagery, and standards of what is and is not appropriate to tell. Whenever a story is told these rhetorical questions are reinforced in some ways, changed in others, and passed onto affect others' stories (Frank, 1995, p.3).

An entry in my research journal details early reflections on the nature and tone of the individual study patient interviews and highlights my considerations regarding the notion of a medically socialised illness narrative.

*A notable feature of patient interviews resides in the tone of the conversations. Patients articulate their stories with considerable emotion, all events and situations described as dire, extreme and "very, very rare". The language is strong, compelling and technically sophisticated. Medical terminology and jargon are used in the correct contexts. Conversations regarding medications, diagnostic procedures, interventional procedures and surgeries are not stilted, but rather flow easily, at times leaving me feel as if a clinician was briefing me on the history of a new patient at 'hand-over'. In this way conversations appeared rehearsed even calculated, with patients often appearing to be cautious about what*

and how they recounted their stories, possibly the result of past experiences or the fear of misinterpretations being perpetrated, an issue highlighted in the following exemplar.

When I used to tell clinicians that (leading up to an acute exacerbation of abdominal pain) I had an 'aura', they'd just dismiss me and say, "oh you're ok, you've just got abdominal migraines", so now I try and stay away from using the word 'aura' (Patient).

Appreciating the constructed realities that patients come to understand and imbue in relation to the genesis, maintenance and expected consequences of their symptoms, including chronic pain, offers some insight into the possible foundations of patients' illness behaviours. From patients' illness narratives highlighting sociocultural and medical influences within their construction, it becomes apparent that patients appreciate the inherent power of a well-constructed illness discourse. Possessing the social capital required to negotiate the terrain of the health care service appears for many patients to have facilitated their access to intervention pathways. With repeated exposure to the service, they have acquired considerable biological knowledge, medical terminology and jargon. They possess considerable skill in negotiating the system by identifying its inherent weaknesses and cultivating relationships with key health professionals, consequently facilitating their ability to, as clinicians see it, *"expertly navigate and manipulate"* to achieve care requirements.

I don't fit the stereotypical profile of an opioid seeker. I am well dressed I work, I'm well spoken. I know everything there is to know about my condition, I know probably more than they do. I know all about the drugs, what the drugs can and can't do and which ones I can and can't have and I speak confidently about it (Patient).

At least one of them is a complete psychological problem, and she is extremely clever, she manipulates the ED staff against the surgical staff and whoever else is involved and gets in (admitted into the hospital) no matter what. I've had one of them ring the bed manager from the cubicle or the patient complaints officer; they know how to make the system respond to them (ED Physician).

These people know the system, they know to arrive at night or on the weekend when there are few senior staff on, they know the symptoms they need to have to get into hospital, they know what to do to get into the place (Surgeon).

While patients appeared to invest significantly in these undertakings, seemingly in a bid to strengthen their veracity, paradoxically clinicians reported feeling disconcerted by and even suspicious of such exchanges with patients.

It's bad news when a patient can rattle off everything and can tell me the dose of everything they can and can't have (Anaesthetic Registrar).

I don't like patients telling me what dose of narcotic they want, it's just not right (General Practitioner).

Two patients' illness narratives (given in the next subsection) illustrate the powerful socialisation and dynamic processes instrumental in influencing patients' construction of narratives. Their subsequent beliefs and understandings regarding the development of their persistent abdominal pain and their trajectories become evident.

## **6.5 Patients' illness odysseys: The 'illness narratives' of two patients**

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*Because I was so immuno-compromised they gave me a flu vaccination, the problem was that I had glandular fever at the same time that they gave me the injection, so my immune system was already overwhelmed. As soon as they put that injection in me I started to get symptoms – it built up over 2 weeks to the point where I was falling over all of the time, I was just a mess, I was getting increased weakness and it got to the point where my legs weren't working anymore and I couldn't lift my head up, I could only just lift my hands slightly...//...they think that the vaccination and the glandular fever antibodies overwhelmed the immune system and that's why I ended up paralysed. ...//...they theorised that's what has happened to my gut ...//...my neurologist said that it will always be a problem...//...it will probably be this way forever...//...always this background of damage and weakness...//...Prof X said it seems like the bowel needs a pace maker...//... it basically had no peristalsis left whatsoever...I went to see Prof X about having the large bowel resected and he said definitely you've put up with it this long let's get rid of it...the reason they didn't do it in X (hospital) was because they said the paralysis was all the way through and if they took out the large bowel I'd still have problems...//...but eventually I had the large bowel resected and that helped for a while, but now the small bowel is becoming more flaccid and enlarged just like the large bowel and we can't do anything about it...//...so what they said would happen and what we feared would happen has happened. After I had the colectomy I was still in pain and they needed to take my gallbladder out, but I had to wait a couple of months and because they waited so long there was so much scar tissue and so much swelling inside all the cavities they could barely work around it, I was on the table for 4 hours because there was lots of stenosis of the bowel, adhesions and scar tissue, it took a long while for them to free up the bowel. Following the colectomy I have continuous problems with the bowel because it is such a flaccid sack with no peristalsis every bit of food I try to eat I vomit up, it just won't pass through my stomach, I am back and forth in and out of hospital for this, they put a nasogastric tubes down and try and feed me that way but it's*

*agony and I scream and beg them to stop feeding me because if you put any sort of volume or liquid down into the gut then of course it's going to stretch and cause pain especially when there is so much neuropathic pain and sensitivity in the nerves of the gut ...//...the greater the volume the worse the pain, so they feed me get me back on solids send me home. When I go home I start vomiting everything I eat up again, I get weaker and weaker and then I go back in (hospital) again. It happens over and over and over again (Patient).*

*I woke up one morning and couldn't move my legs from the waist down, they did a myelogram and an MRI and lots of other stuff, apparently they used the wrong chemical for the myelogram after that I had serious problems with my back, they did three lots of surgery and when I changed surgeons and he took me to theatre he said "who did this to your back?", apparently it was a mess and they said my back will never be the same, and my back has never been the same since that first surgeon attacked it. It was such a mess they had to do a double spinal fusion, it worked for a while then my sacro-iliac joints started to collapse, so I had to have them operated on as well, then they put me on opioids. I managed for a while then they put me in traction and then the last time I went in for my back I came out in a wheelchair because I couldn't use my legs and needed full time care, had to be taken to the toilet and stuff, eventually I got back on my feet...//...I went to sue the first doctor but couldn't bear going back to court after the sexual assault case...//... after the last lot of surgery (back surgery) he (orthopaedic surgeon) said eventually I will end up in a wheel chair, because the whole lot will just go and the spinal cord will just give way and collapse...//... he said I will be confined to a wheelchair – it's played on my mind ever since he told me that ...he told me that by the time I was 35 it would probably happen...//...I know how bad my pain is now, so I dread the thought of it happening...//...I don't let it rule my life and say 'shit I'm going to be in a wheel chair soon', but it's in the back of my head it's not something that's easy to live with knowing you're going to get worse and be in a wheelchair...//...then about 3 years after that I developed all this abdominal pain and it's just been getting worse and worse, they've done biopsies gastroscopies, colonoscopy and laparoscopies, I'm just not getting anywhere with it., it just keeps getting worse and worse. The gastroenterologist I saw originally, he told me exactly what the problem was and that all I need to rectify the problem was to just "nick" the gut and widen it so the food could pass through the gut and I wouldn't have all this nausea, vomiting and pain. He was in the process of organising this and then he left the hospital ...I know I'm never going to be completely cured because things are just deteriorating all the time, my thoracic spine is starting to collapse now so it's just not the lower spine for me it's the whole spine and plus the abdominal pain (Patient).*

Using the above patient narratives as a representative backdrop for study patients' experiences in becoming and being a person with persistent abdominal pain, makes accessible the influences of the governing "macro-level socioeconomic and political forces" inherent in their construction. Within these narratives, the powerful influences of the medical 'high priest' providing declarations regarding disease progression and expected outcomes feature significantly. Powerful predictions made by clinicians who patients deem to be prominent, such as "there will always be a background of damage and

*weakness; the bowel is a flaccid sack with no peristalsis”, or “eventually you will end up in a wheelchair because the whole spinal cord will just collapse”,* become instrumental in how the patients interpret, understand, explain and embody their ill health and what they perceive to be their future illness trajectories. These suggestions, when reinforced, *“he said the gut just needed to be ‘nicked’ to allow the food to go through; if we take the small bowel out the same thing will happen to the large bowel; so what they said would happen has happened”* are particularly powerful in helping strengthen these beliefs and conceptualisations, and thereby function to help patients rationalise and understand their suffering, *“Professor X said this would happen, and he’s the expert in this field”*.

Additionally, these powerful narratives, dense with medical terminology, *“paraplegic; flaccid; peristalsis; resection; collapse; immuno-compromised; neuropathic pain”*, not only invoke compelling imagery and reinforce the notion of deficient and abnormal biology, they also conspire to provide authoritative, explanatory and justificatory accounts. It appears that patients utilise these conventions in order to help validate not only their symptomology and their extreme situations, but also to sanction their realigned “maps and destinations”, and consequently their self-identities.

I wanted to be a social worker but now I’m just too sick, I need full-time care and need a lot of physical support (Patient).

Kleinman (1995), in his discussions on human suffering, its sources and consequences, encourages researchers studying chronic pain patients to consider seeing beyond the macro-level socioeconomic and political forces that influence patients’ pain experiences, to also consider the “micro-moral settings that are particular, inter-subjective and constitutive of the lived flow of experience” (1995, p.123). He emphasises the moral processes because he asserts that it is in the “micro-moral contexts of daily life” that beliefs and behaviours are constructed in response to the illness experience and that which in turn “mediates the relationship between societal and personal processes” (Kleinman, 1995, p.123).

Our family has a lot of bowel problems. Crohn’s disease, ulcerative colitis, and a lot of immunological compromise, it’s not surprising that X (patient’s name) is where she is (Mother).



Kleinman stresses the importance of considering the moral context of peoples' experiences because it is here that one can appreciate that such experiences are not entirely subjective, given that they are shaped by the "moral sensibilities" instilled by families in response to "contested preferences and differing priorities", resulting in what Kleinman terms a:

...socio-somatic linkage between symbol systems and the body, between ethos and the person, a linkage that allows cultural meaning to provide structure for attention, memory, affect, their neurobiological correlates, and ultimately experience (1995, p.124).

Hence, the "generative matrix of ordinary processes through which chronic pain becomes experience...contributes to the further becoming of experience" (Kleinman, 1995, p.125) provides a platform for exploration of the patients' journeys.

## 6.6 Seeking medical intervention: The difficulties and complexities within the clinical encounter

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All patients recounted convoluted histories of ill health resulting in extensive and long-term engagement with the health care system, in particular with professionals within acute care facilities. Some (2/7) patients' drew causal links between their early (occurring during developmental years) illnesses and their subsequent chronic pain condition, while others (3/7) recounted a "*lifetime of ill health*". Two patients reported that their chronic abdominal pain developed later in life. For one patient, this was seen as a consequence of developing pancreatitis following a blunt trauma to the abdomen, and for the other it was the result of cholangitis following an uncharacteristic and turbulent postoperative course after a cholecystectomy.

In addition to physical health challenges, five patients recounted significant mental health issues that emerged during their formative years. Three of these patients reported having frequent depressive episodes requiring medical and pharmacological intervention. Two patients recounted more significant mental health challenges, where frequent and lengthy admissions to mental health facilities for depression, anxiety, panic and personality disorder, drug and alcohol abuse, self-harm and suicide attempts represented their initial encounters with health care services.

Clinical encounters with the patient group were described universally by clinician participants as *"difficult and complex"*. One of the most challenging and difficult issues recounted by clinicians, particularly doctors, was that characteristically the patients presented to them late in the course of their natural histories. Consequently, clinicians reported *"inheriting"* the legacies of past, at times *"questionable"*, medical encounters, delivered by numerous and diverse health care professionals over significant periods of time.

One of the big problems with these people is we are seeing them very late in the course of their natural histories, they have been given opioids for their abdominal pain early in their history and it's a disaster. It creates an insoluble situation because you're dealing with things like narcotic bowel syndrome, narcotic withdrawal, the underlying problem and it quickly escalates into an insoluble position. I think it goes back to prior hospitalisations, I can understand why people do it but it's a disaster when they do (Gastroenterologist).

Compounding these scenarios are the difficulties clinicians face in attempting to access and collate the extensive and complicated past medical histories of these patients. Typically, patients engage numerous clinicians concurrently, both in the primary and tertiary health care sectors; an integrated and sequential account of their health histories is therefore not accessible. These situations are further compounded by patients' tendencies to move between GPs and to elect to employ the acute care sector as their primary health care provider. When these patients present to EDs with acute episodes of illness, appraising their chronic conditions is difficult. Acute care clinicians rely on patients' accounts of their past medical histories and are guided by presenting symptomatology and reports of past management strategies recorded in the patients' hospital medical records. Hence, the current medical management for these patients appears to be largely delivered from an acute reactive episodic perspective.

The problem is no one owns these patients, there is no ownership, if someone actually knew them, knew their history we could sort them out. At the moment you're relying on memory, you're weeding through volumes and volumes of past mostly incomplete notes, the patients might manipulate the history so you're faced with a patient who comes in looking terrible, we have to do something, so we start to do something, then eventually we find out it's a recurrent theme (ED Consultant).

I still haven't got my head around her history, it's very long, I've inherited her by default, I get the feeling that's what she does, she sees two surgeons, and has told me that if she has a fight with one then she moves onto the other, she's certainly done the rounds of the medical system (GP).

Just as patients construct illness narratives, clinicians construct care narratives. The purposes of the two narratives are not dissimilar; both seek to make meaning of and hence assign explanatory propositions to patients' illness behaviours. This is particularly the case when illness behaviours appear not to satisfy objective biological indicators. Consequently, clinicians are challenged by their inability to assign biological constructs to explain the patients' presentations and symptoms, a practice to which they have been 'socialised' to achieve. These situations prove characteristically difficult for clinicians.

These patients are just so difficult they tend to come from pain orientated families, they have terrible abusive histories, they all have multiple allergies, they can't take this they can't take that, they can only have the needle (referring to patients' preferences for injectable opioids, particularly pethidine). They've all seen hundreds of people, no one has been able to put a label on them or if they have it's a wishy washy label. Most of them have had multiple operations, laparoscopies and laparotomies, now they have adhesions that cause pain. They're just a bloody mess (GP).

Hence, the central plot presented by clinicians during focus group interviews was that of the *"difficult and complex"* patient cohort. The challenge generally related to challenges arising from patients' atypical, uncharacteristic and at times seemingly illogical clinical presentations and symptomatology. Complexities related to the pervasive psychosocial issues of the clinical encounter. Clinicians generally described having to negotiate difficulties in not having adequate objective diagnostic criteria or category/label to apply to patients and their symptom constellations and hence the propensity for attending doctors, particularly junior or unfamiliar clinicians, to reinforce previous *"unsubstantiated diagnoses"*, or offer new seemingly implausible diagnoses that, *"invariably do not fulfil any of our diagnostic criteria"*. Some difficulties and complexities of diagnosis include:

- the dubious nature and appropriateness of past medical diagnoses, interventions and treatments

- the questionable appropriateness of current treatment approaches, particularly in relation to long-term opioid maintenance therapy, in addition to sanctioning supplemental and escalation of maintenance opioid dosing during acute episodic events
- questionable therapeutic benefits of these patients' ongoing engagement with the acute care health sector/clinicians, including repeated and lengthy hospitalisations
- difficulties in identifying these patients early in their illness trajectories as being likely to progress to chronicity, and thus circumventing ongoing pursuits of trying to identifying causative biology, and
- characteristic delays in identifying underlying pathological causes and significant psychosocial mediators considered by clinicians to be the juncture between these patients having good clinical outcomes, or conversely, developing significant physiological consequences, including a life disrupted by chronic pain.

Having presented the context of these difficult and complex therapeutic encounters, clinicians' responses to caring for these difficult and complex patients are now discussed.

### 6.6.1 Difficult and complex patients: The diagnostic challenges

When patients present to health care facilities with complex psychosocial histories, in addition to equally complex biological conditions, symptoms and histories, they present significant challenges for clinicians. The patients' symptoms are not always characteristic of and concordant with many of the previously applied diagnostic labels. Despite this, all study patients had previously been assigned diagnoses which they and their families/carers had understood to be the source of their ongoing health issues, including persistent pain.

She thinks she's got a label (diagnosis), but I'm not sure that anyone else agrees with that label so there is this constant battle when she presents to hospital, because no one buys her story and it's a story that was given to her by another surgeon in X (capital city), many, many years ago, but none of the tests seem to support her story (GP).

Having persistent abdominal pain was reported by patients, relatives and some clinicians to be a consequence of patients being affected by symptoms of diseases such

as pancreatitis, Crohn's disease, cholecystitis, and inflammatory and short bowel syndromes. For others, having persistent abdominal pain describes a constellation of signs and symptoms characteristic of abdominal adhesions, pseudo-obstruction, malabsorption and narcotic bowel syndrome, largely iatrogenic in origin, due to repeated surgical and pharmacological, mostly opioid, interventions. Clinicians interviewed did not appear to consider persistent abdominal pain to be a diagnosis in and of itself. Rather, they used it as a descriptive term in order to orientate discussions about the patient cohort and in part to encapsulate what they believed represented a *"very homogeneous"* group, mostly described in terms of the patients having:

- vague and unsubstantiated diagnostic labels
- unexplained and disproportionate physical signs and symptomatology
- disproportionate responses to pain and any stimuli
- frequent presentations to tertiary health care facilities
- frequent and extensive admissions to tertiary health care facilities over numbers of years
- numerous health care provider involvements, both primary and tertiary
- extensive investigations, surgeries, pharmacological interventions and treatments with no resolution in symptomatology
- complex and difficult physical presentations that frequently conflict with usual presentations/pathologies
- difficult developmental histories including abusive histories
- +/- diagnosed psychiatric, psychological illnesses, and
- disproportionate distress and disability.

As a consequence of clinicians not being able to apply appropriately sanctioned diagnoses for the patient group, clinicians across all clinical specialties employed variable and interchangeable diagnostic labels (*functional bowel syndrome, pseudo-bowel obstruction, persistent/chronic/refractory abdominal pain, pancreatitis, cholangitis, narcotic bowel syndrome and personality disorder*). These terms were used by clinician participants to convey a shared understanding, help define the population, and hence focus discussions during interview sessions. Conceding these patients are *"medically difficult*

*to identify and assign diagnostic labels*", clinicians appeared to find a more unifying space from which to orientate discussions using terms such as *"frequent flyer, heart sink patients"* and *"frequent attenders"*, patients with *"similar demographic profiles"*. This appeared to help clinicians scope the patient cohort, based on characteristics of the patients' presentations and histories rather than by giving them discrete diagnostic labels. The following two excerpts highlight clinicians' attempts at reconciling the difficulties associated with procuring a distinct diagnosis that adequately encompasses the patients' clinical picture, and they represent the extent of clinicians' clarity on this issue.

These people get lost in a cloud of diagnoses where there are recurrent acute abdominal pain syndromes, like inflammatory bowel disease, ulcerative colitis and Crohn's who present looking fairly similar to the way a lot of these people present, and some of them may even have a background of one of these organic based syndromes as well (Anaesthetists/Pain Consultant).

In my experience there are three groups, the group that get the pancreatitis label, those that get the recurrent bowel obstruction label, and the third group is post-traumatic and what they all have in common is their demographic features (referring to difficult developmental and psychosocial histories) (Surgeon).

The extensive and somewhat inconclusive discussions based on diagnoses, exemplify what is characteristic of clinical encounters during hospitalisations of the patients: a lack of and inappropriate, unsubstantiated diagnoses being variously and interchangeably applied. These situations are difficult for clinicians, as they contravene approaches to clinical practice with which they are traditionally more comfortable and familiar.

I'm always thinking, What is being missed? What is the diagnosis, quite often I don't know what I'm treating, and nobody else seems to know and so we tend to feel totally helpless about contributing anything worthwhile other than reinstituting the regime that was used last time. That's my overwhelming feeling – *I have no idea what I'm treating (increased emphasis)*. Everyone just ends up throwing their hands up and calling the pain team to come and rescue you (the clinician), so you can stop thinking about it (Gastroenterologist).

Lack of clarity regarding study patients' diagnoses produces a tension in clinical practice that clinicians find difficult to reconcile. Vigorous dialogue across all clinician

focus groups highlighted the ambiguity that characterises diagnoses for this patient group, and the consequential deleterious outcomes that can arise. When no scientifically sanctioned diagnosis appears to be relevant for these patients' presentations, the potential for clinicians (particularly junior clinicians) to assign inappropriate diagnostic labels follows. Clinicians see these applications as largely an attempt to satisfy the cultural norm of the biomedical environment.

I think it's a mistake to label something with a diagnosis when it's undifferentiated, you can't do it. But people rush to make a diagnosis and put it into the charts and it just gets perpetrated (Surgeon).

This produces difficult therapeutic tensions as clinicians wrestle with questioning the validity of previously stated and documented diagnostic labels, while attempting to eliminate or rationalise biological presentations, both subjective and objective, that appear to contravene usual clinical pathways in the midst of a considerable psychosocial patient clinical milieu. This was well described by two experienced local surgeons, who cared for these and similar patient groups in other acute care hospitals during their extensive careers. In their accounts, both surgeons alluded to the powerful influences that semantics, in the form of diagnostic labels, have in influencing any clinical scenario for these patients. However, this insight is powerfully offset by the practical realities and the socialised patterns that underpin the applied approaches taught in medical schools. Such approaches are applied by clinicians, particularly junior ones, "*in the trenches*" of an acute care environment in an attempt to manage acutely unwell patients.

By the time I get to see them someone has already plugged a diagnosis on them. I think the secret is not talking diagnosis to these people, it just complicates the care. It makes it impossible, because once these people are on the round-a-bout it's difficult to get them off it. You've got to get the conversation off the diagnosis and onto pain management. I think our clinical terminology should be objective and consistent; any unsupported references to 'obstruction' or 'adhesion' should be avoided (Surgeon).

Well they can't write dickhead or frequent flyer on the chart can they? The intern has got to have a diagnosis so he comes up with one. Then the patient just grabs it and says 'doctor told me I had a bowel obstruction'. It gets written in the notes and it just gets perpetrated from there. We all feel

inadequate if we just write pain on the chart, and we shouldn't feel inadequate, but we do because it's not a diagnosis. It was not what we were taught to do in medical school (Surgeon).

Despite their appreciation of the situation, clinicians reported being confronted by the patients' "*variable and wishy washy*" diagnostic labels. They considered the plights of some patients to be difficult, and, in part, to be compounded by the attachment of these often "*unsubstantiated labels*", with the clinical consequences arising from these historically embedded labels. Patients had undergone numerous investigations, treatments (including long-term opioid therapy) and for the majority, significant and multiple and at times "*unnecessary*", surgery.

It's always the same; the next scan will find the problem better, the next surgeon will be able to do something that the last wasn't able to do. He'll find that little bit that's hurting and pull it out and I'll be better, it can end up in an absolute disaster. One of the ladies that I see is now seeing 'St Peter' (referring to another surgeon), she had post-traumatic pancreatitis following a car accident, she has had three attempts of an ERCP, has never a rise in amylase, CT scans are always normal, but then when St Peter did a scope he saw her superior mesenteric artery pulsating on her jejunum (inferring this was the source of her pain), so she had an intestinal bypass for the pseudo blockage then ended up on TPN was in hospital for 6 months and is still no better; she's an absolute mess. There is a real lesson for us in medicine... not to meddle, you know there might be a segment of Crohn's or whatever but if it hasn't perforated leave it alone! (GP).

Despite having intellectualised appreciation of the powerful influences that reside within the semantics of biological diagnoses and acknowledging the damaging effects that result when these are erroneously applied, many clinicians were additionally defensive of the difficult and practical realities from which these situations arise. What becomes apparent within these dialogues is that clinicians in these situations operate from firmly embedded biomedical ideological practices; however, they are also motivated by fear. This presentation is where "*something organic might be declaring itself*" and hence their actions are subsequently directed toward ensuring that patients do not suffer significant morbidity or mortality. They do not wish to be "*associated with being the boy who cried wolf*", and nor to being exposed professionally to claims of "*malpractice or negligence*".

It's not that easy when you're in the trenches. I have one that comes in with near fatal potassium levels, and if you miss it it's not good. These people start out with some sort of surgical condition,



then they keep bouncing back, so there is always that suspicion that there is something organic going on. You've got to eliminate the acute things, there's a series of things you go through, and then inevitably you go 'oh well, it's just like the other 25 admissions'. The real hard cases, I don't want to be too philosophical here but how do you define pain in these situations, most of the time the pain is psychological pain, they're escaping from something terrible at home or just not coping (Surgeon).

### **6.6.2 The paradigm challenges: Biology versus psychology**

As clinicians negotiate the vagaries of unsubstantiated diagnoses in the midst of patients' reports of increased pain, distress, and disability in addition to symptoms of nausea, vomiting, abdominal distension, dehydration, and electrolyte imbalances, they are attempting to discriminate between potentially life-threatening biological event(s), i.e., the likelihood of an acute exacerbation, or whether the patient is *"somaticising in order to have other needs met"*. This dualistic appraisal of patient presentations illustrates the prevailing clinical and sociological constructs that we have come to understand as the pain experience, that is, *Is the pain coming from the body or the mind?* Clinicians say, *"the trick is to try and work out how much of the patients' presentation is physical and how much is psychological"*, and similarly patients say *"this pain has got to be coming from somewhere"*.

Arthur Frank writes of the Cartesian approach of appraising illness, commenting:

Only a caricature Cartesianism would imagine a head compartmentalized away from the disease, talking about the sick body beneath it. The head is tied through that body through pathways that science is only beginning to comprehend, but the general principle is clear: the mind does not rest above the body but it diffuses through it (Frank, 1995, p.2).

#### **6.6.2.1 Damage and the biomedical model**

Medicine has a long history and much has been written about the Cartesian model of illness from which it emanates. The dualistic approach of appraising illness from a reductionist mind/body divide is firmly entrenched in health care delivery, and in particular within acute care contexts. However, approaching illness from a dichotomised orientation can prevent patients with chronic and complex care needs receiving the health care they require. This is particularly marked when clinicians,

services and sociopolitical inclinations are aligned to (and thus represent authority derived from) a prevailing biological/scientific agenda.

One of the key issues with this patient group is they come into a medical hospital and they expect a medical intervention, they are caught up in a physical journey, and they come into an environment where medical clinicians are valued highly and are experts in the physical journey. In chronic pain we are trying to encourage a shift to a more holistic model, but the whole hospital is medically run. So the whole system, the administration and the clinicians reinforce the medical approach right from the beginning (Psychiatric CNC).

These sociopolitical inclinations are further reinforced and hence derive comparatively more legitimacy, due in part to the ability to quantify and measure outcomes, a process that facilitates what some commentators describe as the rising industrialised and hence capitalist politicisation of health service provision (Illich, 1975, 2010; Bortz, 2011; Lupton, 2012). Nevertheless, the practical out-workings of these powerful sociopolitical forces, particularly as they relate to pain, are palpable in clinical settings. Clinicians confronted with patients who require an alternative approach beyond the acute biomedical model are frequently challenged by the lack of available services to which they can refer the current patient cohort or who they can engage for patients that they identify as at risk of progressing down unhelpful chronic pain trajectories, *“they’re here by default, what’s the alternative, there is none”*.

Chronic pain until recently hasn’t been much of an entity, all our training was ‘you’ve got acute pain – we diagnose it – we fix it’. During my medical training we didn’t even talk about chronic pain. It is slowly getting better. There are people who have now got the skills for managing chronic pain. But you can’t get to them, the waiting list is miles long and you’ve got no chance getting them seen by liaison psychiatry unless they’re (the patient) an inpatient. Quite often I will send my patients in (ED presentation) just so I can access the services they need. So by default they end up in the acute care system (GP).

The acute care environment into which these patients present and from which their care over the past two decades has been predominantly delivered, reflects powerful sociocultural and political influences and alignments to the prevailing biomedical model. These cultural orientations underpin the prioritisation, organisation and delivery of services. Consequently, these paradigmatic orientations govern care

mandates and hence underpin and direct the purposes and functions of those responsible for fulfilling the prescribed acute biomedical agenda within, in particular, hospital environments.

The thing is they come into an acute care hospital, under a surgeon, and so there is always this expectation that if all else fails there is an operation around the corner, you have to try hard to not get sucked into operating on them, because you know it's going to make their situation worse in the short term and in the long term (Surgeon).

It is not surprising therefore that clinicians recounted that when delivering care within these contexts, particularly care delivered on occasions when patients presented with an acute exacerbation, they needed to marshal considerable *"discipline"* in order to act *"counter-intuitively"*. During these encounters they are frequently challenged by disconcerting questions such as *"What are we trying to sort out?"* and *"What is my therapeutic intent?"*

Our system is geared toward ruling out emergencies, so the presumption is always that someone has got something terribly wrong, until you prove otherwise. So with these patients because of that presumption they consume a lot of resources until you actually purposely stop that from happening (ED Consultant).

Although the majority of clinicians reported an 'intellectualised academic' appreciation for the inherent power and hence potential harm of the practical out-workings of the biomedical model, it appeared that the study patient cohort exemplifies the dilemma, both professional and personal, that exists for clinicians as they attempt to navigate these paradigmatic divergences in the midst of socially, politically and professionally embedded ideologies underpinning traditions within health care delivery. This tension fundamentally challenges clinicians' sense of purpose and function and consequently results in them feeling distinctly uncomfortable.

We have nothing to offer these people. It's hard enough trying to differentiate people with significant abdominal pathology. They have a chronic illness and we're not very good at managing that, they are very complex people and have multiple issues to address, and in our department we offer a particular service focusing on acute problems. So I don't know that we can really offer them what they want, we actually become a default place for them and they don't really need emergency services. They need primary care – there you assume that there is probably nothing majorly wrong

whereas here we see that there is something majorly wrong. So the system, the model here is a bad fit for these people (ED Physician).

While acknowledging the issue of iatrogenic mediators within the patients' health conditions, clinicians' dialogues were sensitive to the influential role that sociopolitical and "*medicalised*" environments play in propagating "*harm*". They recognised that within these environments both they and the patients had become embedded in the prevailing biomedical model. Occasions requiring a departure from these well-rehearsed and historically embedded ideologies represent unfamiliar, uncomfortable and hence difficult terrain for both parties to navigate. In these situations, clinicians reported deferring to what they termed, "*the path of least resistance*", by which they most generally referred to continuing to adopt a biomedical approach despite recognising this was not always entirely appropriate. In recognising these difficulties within their own clinical practice, clinicians used these understandings to help rationalise why health care professionals previously responding to these patients' health (pain) crises might have acted "*counterproductively*".

She had a total colectomy for opioid induced constipation, she was on three different opioids in a totally non-optimised way, the surgical person made a decision, and I think responding to her distress and not playing by the team approach and just responded by chopping out the bowel. There's also the other patient that the surgeon said he "just operated on her to shut her up". But you know it's no different to me giving in on a Friday afternoon when I'm tired, feeling a bit isolated, feeling down she's got you backed in a corner and so I up the morphine dose, it's just so hard (Anaesthetist/Pain Consultant).

The central theme of 'doing harm' that resides within and is fundamental to the tension clinicians describe concerning the use and misuse of diagnostic labels, is a consequence of the ideological platform and therefore the paradigmatic approach from which clinicians derive their understandings of these patients' ill health, and from which they direct subsequent treatment(s). Clinicians repeatedly and powerfully described how assigning an acute care framework to the management of patients with chronic and complex health issues can cause harm. This harm, mostly expressed in relation to iatrogenesis, was considered by participants to be the consequence of patients in these care contexts being medicalised.

So then, this poor girl 18 years old ends up stuck in a hospital bed with TPN (total parenteral nutrition) going and all sorts of other shit happening to her. So she was absolutely brutalised, you know you could draw a parallel to the serious sexual assault that she had already experienced. There she was totally lost all her modesty, lying there naked under the sheets, bloody tubes hanging out of her everywhere, her abdomen looking like someone had done naughts and crosses on it with a scalpel, and now of course the chronic pain settles in (General Practitioner).

While some clinicians and patient stakeholders considered such events to border on “*negligence*”, others saw these events as the product of a broader sociological construct representative of a society that has come to expect, as a consequence of its current curative and technological imperative, a conceptualisation of contemporary medicine that was incongruous with what it can deliver.

These patients are a great lesson on how useless we are at treating a lot of things. If you watch TV and see programs like House and he manages to fix everyone and then you hang around hospital and watch us do operations and everyone seems to go home, you get a false impression of just how fantastic we are as doctors and surgeons, it’s crap, you don’t come to outpatients and see the people that end up incontinent and the chronic pain issues. We’re not really good at all really we are quite impotent against a lot of things, problems like chronic pain and it really isn’t a bad thing, it’s about how limited we are as Doctors, and especially as Surgeons (Surgeon).

While study participant health care professionals largely referred to “*damage*” in the context of iatrogenesis, other stakeholders also referred to damage from within their respective experiences. The strongest emergent theme was the concept of damage, seen differently by each of the stakeholder groups:

- For patients, damage was seen largely to result from scenarios surrounding medical misadventures, including “*misdiagnoses, malpractice and hostile and abusive*” therapeutic encounters with many health care professionals.

The last experience was a harrowing experience, you just get the ones (health care professionals) that have it in for you. You just feel so violated (Patient).

- For family members/carers the theme was embedded within accounts relating to the lasting and damaging effects the condition has had on relationships, particularly those negative effects on the children at the centre of these families.

He (son) has had five suicide attempts – he just couldn't cope anymore, he couldn't cope with X's (mother's) illness. Now he's on dope at the moment it just helps him cope with things (Husband/Father).

- For clinicians, the theme was reflected in dialogues regarding damage stemming from inappropriate medical inputs, and was largely articulated in relation to paradigmatic divergences in approaches utilised in the assessment, treatment and management of the patients with persistent abdominal pain states.

The reason they are sick is we, as a medical team made them sick. If you think about it they had bowel chopped out unnecessarily, we're making them sick by adding a whole bunch of opioids, the reason they are sick is we make them sick (Anaesthetist/Pain Consultant).

The recurrent and pervasive theme of damage expressed by clinicians underpinned their extensive dialogues regarding the confronting clinical dilemmas they face when managing the study patient cohort, particularly during acute exacerbations requiring hospitalisation. The main dilemma clinicians described is that of balancing the potential 'to do good and to do harm' in the midst of providing medical care to these patients. Clinicians described these clinical encounters as particularly demanding because of their self-proclaimed limited capacity to resolve the issues at the core of patients' complaints (chronic pain/suffering), *"I have nothing to offer these people"*.

In addition, these clinical encounters occurred within highly emotive contexts characterised by conflicting patient and clinician treatment aims, high patient and family expectations (the complete amelioration of pain), amidst the pervasive threat that patients and families would mobilise additional powerful administrative (patient complaints officer; hospital administration) and political (local members of parliament, television networks) resources in order to agitate and to have their needs, their perceived unmet needs, met.

These people are draining, so draining, they need lots of attention, and they know the system over and over. They know how to get what they want. They and their families have the expectation that all their needs are going to be met. You have them begging, having tantrums pounding the floor demanding pain relief, you have the relatives chasing you down the corridor, they're aggressive, you want to be on the other side of the desk, it's just easier to give into them. The begging, screaming and the tantrums, it's all so emotionally draining, and they're here for weeks and weeks

on end! They can count the footsteps to the customer complaints unit, you start to get the threats, they're writing down everything in their little books, we've had one that threatened to get Today Tonight (a current affairs program) involved to do a story on how we were refusing her right to pain control, and it is just so difficult (Surgical Nurse).

These situations produce for clinicians "*the most difficult clinical encounters*" they experience in practice. Difficult because despite considerable individual and collective efforts these patient appear not to improve, and in most cases progressively deteriorate. In these situations, clinicians recount engaging with the patient cohort from a position of "*helplessness*", a position they find personally and professionally challenging.

### **6.6.3 The personal and professional challenges for clinicians**

The consequence of inappropriate diagnostic labelling and subsequent treatments was fundamental to clinicians' concerns in relation to the ongoing clinical management of the patient cohort. In addition to the ethical dilemmas this produces for clinicians, many participants also reported feeling complicit in the harm produced by the continuing subscription to a biomedical approach for managing patients in these situations.

You feel like you've contributed to the problem, not only as a profession but as an institution. They were all given narcotics here, then given them again and again, so you feel involved in the course of the problem – and you don't know how to break out of that because it's so much easier to just do it again, and often the patient will be quite satisfied with some more narcotics for a while and you accept that as some sort of gain and in the meantime you're perpetrating the problem (Gastroenterologist).

Further complicating these clinical encounters is the reality that within the patient cohort, there are individuals (as a consequence of side effects from previous surgeries and ongoing pharmacological treatments), who clinicians recognise, who present to the ED significantly unwell. The catalyst for these encounters is universally increased pain, followed by nausea, vomiting, dehydration and consequently increased distress and dysfunction. What clinicians find extremely challenging in these situations is that these symptoms (largely iatrogenic) are often the result of patients not complying with their

home (mostly enteral) treatment instructions, in addition to the rapid escalation of opioid doses being self-administered, administered by relatives and GPs responding to increased reports of pain and distress. Consequently, patients present to the ED requiring medical assistance in order to redress physical issues primarily related to opioid side effects (nausea, vomiting and abnormal bowel function) and to the patients' decisions to cease enteral therapies either by jejunostomy feeding, and their refusal to eat or drink, reportedly due to pain being exacerbated by these activities. Prolonged anorexia in patients with limited physical reserves characteristically results in patients presenting with clinical issues associated with significant dehydration, vomiting, electrolyte imbalances and cachexia resulting in reduced physical function, increased disability and distress and on some occasions significant physiological consequences, e.g. acute renal failure.

The problem is that the majority of these people start off with some sort of surgical condition, and we never seem to shake off this ownership. They're with us long after the surgical issue has occurred because they keep bouncing back. There is always this suspicion of a surgical condition causing the pain. You learn from day one that just because someone is unusual, it doesn't mean they can't be unusual and sick (Surgeon).

Patients' responses to questions regarding events leading up to and circumstances surrounding decisions to present to a hospital ED for medical treatment are particularly informative here. All patients reported delaying their presentations for a number of reasons. Patients mostly reported delaying presentation because they were fearful of having to endure the hostilities of the system, including suspicious clinicians who might potentially dismiss their legitimacy on the basis of being considered a drug seeker, malingerer, or worse still being "*psychologically deranged*". Thus, to overcome potential stereotyping and to secure legitimacy as a sick patient who gets "*treated just like everyone else*", patients recounted the physiological parameters they thought would secure their passage into the system.

You just get sick of being sick and you can't be bothered anymore. I start to feel like a waste of space and a burden and I just want to die so I just stop feeding myself and stop everything (referring to medications). I try and stay out of emergency for as long as I can, because I know it will be sheer hell in there. You're totally at their mercy, you're full of fear, trying to say the right



thing being compliant, some of them just have it in for you they call you a frequent flyer, I've had one nurse call me a drug addict to my face. She said 'back in for another hit are we...that didn't last long'. When I decide to go to hospital two things happen, the severity of the pain increases, that used to be my guide to go to hospital, now it's increased pain, dehydration, vomiting, no bowel movement or wind – they're the key now. I fight and fight not to go (to hospital). I'm so ill when I arrive, and this last time I really pushed the boundaries, I ended up in ICU (Patient).

Consequently, the clinicians required to manage these clinical encounters, particularly clinicians whose responsibility it is to diagnose potential life-threatening/biological mediators for the presentation(s) continue to operate with an index of suspicion directed toward excluding an acute biological event or intra-abdominal pathology. Hence, within this reductionist medical paradigm, the underlying assumption that pervades the clinical encounter is the potential that *"something life threatening might be declaring itself"*, despite being *"unlikely"*, but the consequences of which, *"if overlooked as just being chronic, would be catastrophic both for the patient and the clinician professionally"*. It is these assumptions that have continued, over the past 20–30 years for the study patient cohort, to underpin the context of the study patients' hospital inpatient journeys.

The first thing I have to do every single time is make sure there is no underlying abdominal problem, eliminate the acute things, even though this might be the 25th admission this year, and then try not to get sucked into operating, because you know that it's only going to make things worse (Surgeon).

Clinicians reported that such clinical encounters required considerable *"discipline"* and *"courage"* in order to achieve therapeutic outcomes that not only overcome the ability to *"perpetrate harm"*, but additionally safeguard patients against the potential for *"suffering morbidity associated with pathology being overlooked because it is considered chronic"*.

Discipline was described in terms of the need to attend to each clinical assessment with an index of suspicion that still allowed for the possibility of organic pathology, while concurrently contextualising the presentation within the chronicity of the patient's history, both physical and psychological. Courage was described in terms of the clinical resolve required when, in the absence of definitive diagnosis but in the

presence of escalating patient illness behaviours, both subjective and objective, one could be comfortable in treating the patient *“conservatively, and not giving in to their demands for more narcotics, and not getting sucked into operating on them”*.

The ability to achieve such outcomes was considered by the majority of clinicians to be the domain of the very experienced. Experience implied seniority, enabling clinicians to provide the authority required to manage such scenarios. Such experience suggested a significant understanding of individual(s) (mostly through repeated exposure), to be able to contextualise their presentation across its life course (for that individual) rather than from the acute episodic encounter.

The value of having these patients under the care of an experienced and patient Surgeon is really to minimise the chance that they will have surgery, as well as minimise that they will be investigated as though they may require surgery. The disadvantage is the expectation that a surgical intervention is at least on the menu of options (Surgeon).

It was agreed by all clinicians that *“these patients are medically difficult patients to distinguish initially”*. Identifying patients prospectively rather than retrospectively was a much sought after outcome that participant clinicians wanted to achieve through their input into the study. Many thought that there was little that could be offered in terms of helping the current cohort, but rather saw that early identification of emerging cohorts was where the utility of the study resided.

For the current cohort we could start with a fairly defined starting pathway that would mean that we investigated them, ruled out any pathology and then didn't do any of the rest of the stuff anymore. Because once they've been on the round-a-bout for 3 or 4 years it's hard to move them off it. Your best chance for intervention is to actually get them early (Gastroenterologist).

The ability to identify emerging patient cohorts at risk of progressing to a chronic pain condition has been the subject of significant research in the pain management arena, particularly within the past two decades. While considerable research has been directed toward the biological domain of interrupting pain pathways activated in response to nociception (trauma, tissue damage), principally in acute post-trauma, postoperative and acute-malignant settings (Shipton & Tate, 2005; Perkins & Kehlet, 2010; Schnabel, Pogatzki, 2010), work in relation to considering additional

psychological vulnerabilities and environmental risk factors is beginning to emerge (Granot et al., 2005; Kehlet et al., 2006). Considering risk factors that might extend beyond the biological domain to include the psychosocial components inherent in the chronic pain experience represents a paradigmatic shift in appraising the phenomenon of pain (in particular, persistent pain) away from a competing dualistic construct of biology versus psychology toward a multidimensional conceptualisation of the experience of pain. However, this paradigmatic advance is still in its infancy, and as such its integration into the clinical 'coal face' lags behind research advances. Illustrative of this are the patients' illness trajectories, which expose their treatments as still being delivered from a historically embedded biomedical reductionist approach.

#### 6.6.4 Sabotage and challenges in improving the situation

When clinicians feel they have limited resources, either personally or professionally, and the system/colleagues do not support attempts to alter the treatment courses of these patients, the situation is most often considered *"too difficult"*. This is particularly true in the context of significant competing clinical demands of other critically ill patients. In addition, the frequent and repeated relapse of these patients leaves clinicians feeling professionally and personally *"frustrated and challenged"*, and they perceive any potential efforts to be *"futile"*.

They're heart-sink patients, despite all the intellectual effort they still keep bouncing back, everything has already been done. We never seem to get anywhere with them, it's like a revolving door. You know you should do the right thing, but you know you're not going to come up with anything. It's frustrating, so then you take the path of least resistance and it's the easiest way out, but it's the wrong approach to it (Gastroenterologist).

In the face of these difficult and complex clinical encounters, clinicians reported surrendering to a *"path of least resistance"*. They referred to the need to expedite clinical encounters with the patient cohort in a way that maintained and preserved the status quo of the clinical environment. Adopting this approach meant that clinicians either gave in to patients' *"demands"* (referring to the administration of increased doses of opioids), or continued to support a medicalised approach to the patients' ongoing clinical management. What followed was a cascade of diagnostic, interventional,

surgical and pharmacological activity, all potentially harmful for this patient cohort. For the majority of patients, this has continued for over at least 20 years!

Can I be honest and tell you, as a Registrar looking after these people I have a 30 to one rule and it works like this. If you go and see them and you want to get out of there in a timely manner you spend 1 minute and increase their opioids, everyone's happy. If you want to turn them down, or leave them on the same dose you have to spend at least 30 minutes before you can get away with it. Any less and you're going to get continually hassled all day, they'll be complaining, the family will be complaining and the nurses will be ringing and I will be in the theatre gassing someone. It's not easy but they're not a priority in this environment (Anaesthetic Registrar).

Hence, in referring to these situations, clinicians made repeated reference to the inherent "*saboteurs*" that perpetually infuse clinical encounters involving the patient cohort. Clinicians largely referred to these acts of sabotage as: i) the patients' conscious and subconscious agendas, "*I think part of her wants to die*", and at times, ii) competing family/carer agendas, "*her family have asked for a 'not for resuscitation order', even though she's only in her 30s!*", iii) isolated clinicians' decision making "*problems arise when people (clinicians) don't play by the team rules*", and iv) the cultural environment to which they are repeatedly exposed, "*they get put into a surgical ward, everyone is sick, there are machines everywhere, there are disadvantages to this, it sends conflicting messages to these patients about what we are trying to achieve*".

Despite these challenging clinical circumstances, many clinicians, particularly senior clinicians, had seemingly worked to reconceptualise their therapeutic intent in dealing with the study patient cohort. These reconceptualisations or "*containment measures*" were described as approaches directed toward an orientation of "*harm minimisation*". Within these approaches, clinicians mostly referred to their role and purpose as being instrumental in preventing "*unnecessary medical intervention*" and as a conceptual move away from an intent to diagnose and cure to one that attempted to support and facilitate a "*worthwhile life*".

These people keep coming back to us for whatever reason, we have to stop seeing that as a sign of failure, they accept and extract whatever benefit they get from us and we can't dislodge them. It's very powerful, it's survival – it's a survival instinct. These people get attention; I think the system helps them in some strange way. We get irritated because it costs us money. They get something

out of being in hospital, otherwise they wouldn't keep coming, they are voting with their feet (Gastroenterologist).

It's a matter of minimising the damage to them, minimising the impact to the health care system and maximising their chances of them having some hope of some sort of life that doesn't revolve around hospitals and outpatient clinics (Surgeon).

It can be very, very difficult to know when to investigate their chronic abdominal pain and when to stop and say 'look everything is fine'. It really comes down to clinical sense, clinical nonce. I know that smacks of medical paternalism but there is no doubt that that is what we do. Sometimes we can be wrong doing that, but I think we all decide at a certain time when we think it's going to be worthwhile taking the investigations further. There isn't much in the literature about what constitutes evidence based treatments for these people because they're such a diverse group (Gastroenterologist).

In addition to the clinical complexities, the psychosocial complexities of the presentation complicate the clinical encounter further and disrupt the social order of the acute care environment. The fact that these patients, well known to many clinicians, as having documented opioid dependence, manipulative behaviour, personality disorders and psychiatric problems coupled with, at times *"aggressive and abusive families"* means that clinicians find themselves in situations where they find it difficult to discern whether the patient's presentation is motivated from *"legitimate"* physiological sequelae or something else. Further, the ability of these patients to *"expertly navigate the system"* in order to satisfy their demands leaves clinicians feeling *"manipulated and disrespected"*.

## **Part Three: Lives dominated by chronic pain**

Arriving at a diagnosis of persistent abdominal pain has not been part of a direct and uncomplicated route for the patients, but rather an end point of difficult, complex and circuitous pathways toward attempts to unravel the problems associated with unresolved abdominal symptomology, including persistent and at times escalating pain.

These patients have conditioned responses, they didn't become chronic pain patients overnight, so whatever has happened along the way within the health care system, in one way or another it has contributed to why they remain here now (Anaesthetist/Pain Consultant).

Remaining entrenched in the acute biomedical model for the ongoing management of their ill health means that the patients, their families and carers have an ongoing need to access, negotiate and be sustained within the health care system in order to have their perceived needs met. The ongoing lack of an adequate diagnostic label from which consistent, reproducible and shared understandings can be conveyed in a single descriptor produces fundamental tensions in clinical practice. Clinicians operating without such familiar constructs, having exhausted their intellectual energies in attempting to assign possible biological causes reported feeling challenged, frustrated and distinctly uncomfortable negotiating the vagaries of inadequate biomedical explanations, *"I don't know what I'm treating"*. These frustrations are further intensified when biological treatments are implemented and maintained in the patients' management, *"I find it increasingly curious that these patients are given opioids at all, it just makes their situation worse"*. This is particularly heightened in the context of long-term opioid administration and is intensified when patients repeatedly present to the ED reporting pain exacerbations and requesting additional opioid analgesia, *"from our experience these patients are much happier with narcotics in their systems than they are without them"*. Consequently, in the midst of these challenging clinical scenarios, clinicians reported finding these patients *"difficult"*.

If we have a diagnosis within the medical paradigm, we're happy. If the patient's got X or Y then they're not wasting our time, but if we can't make a diagnosis then we are out of our comfort zone, if they don't fit into our cure box – then we start to find the patient difficult, the attitudes you pick up from people (referring to medical colleagues) it's terrible, it's just a redefinition of their frustration (Gastroenterologist).

In these situations, clinicians invariably question the reliability of the patients' views on their complaints, the precipitating factors (psychological versus biological) and consequently the motivation(s) for their presentations.

These people seek out emergency departments because of the rapid turnover of staff and therefore the chance of them manipulating is greater in these settings (inference being the patient is seeking

opioids). There are heaps of times I'll walk on duty, I'll say hello to them in the waiting room and then you notice them leave, because they know they're not going to be able to manipulate me. Then, when you go home and come back in the morning you'll walk in and see them sitting up in the bed and it's like, *GAME ON* (ED Consultant).

Although the clinician in this instance refers overtly to the tensions that result in clinical practice between clinicians and patients as well as family members and carers, by referring to it as *"game on"*, his account aptly represents the consistent and recurrent theme (presented by all stakeholders) of the tension that resides and dominates clinical encounters within these contexts. The game appears to centre on clinicians wanting to expedite clinical encounters with these patients, *"if you can convince them to get up out of the bed, rise and walk and keep on walking than there is intense satisfaction with being able to discharge one of these people"*, while the patient is invested in seeking answers and treatment to ameliorate their symptoms and suffering, *"I just want to receive care like everyone else"*. These tensions appear to principally arise from the disruption of order; these patients disrupt the normative expectations and hence those processes historically and socially embedded within the acute care environment.

These patients really impact on the system; they can take 24–48 hours to sort out and that really impacts on bed block in the department. No one wants to look after them, we can't get a team willing to take ownership for their care, so they get stuck here. They are incredibly labour intensive in an environment where you are caught up with resuscitating someone fighting for their life and these people are walking around the ED putting their head inside the curtains demanding attention and narcotics (ED Physician).

Integral to this are the challenges clinicians face in these circumstances when their purpose and function as health care providers are disrupted and they are challenged by needing to *"act counter-intuitively"*, in order to engage with these patients. Hence, the most fundamental orientations of the health care service and its providers continue to be repeatedly challenged. This is exhibited when the normative basis of engaging with patients (diagnosis) appears tenuous and biomedical treatments seem impervious to understanding and improving patients' situations. As a consequence, clinicians reported feeling that they *"have nothing to offer these patients"*, with patients

consequently reporting feeling “*abandoned*” in these situations. The impact and consequences of these encounters are apparent within the following patient excerpt.

I was going in and out of hospital saying “hello” something is there, this pain has to be coming from somewhere, this is not something I’m doing because I’m in an unhappy marriage, or I’m attention seeking or drug seeking. I wasn’t getting anywhere so I got the shits with them all and went to see this new ‘wonder boy’ who had come to town offering cures for chronic pain. I went through a lot of treatments with him. But when his treatments didn’t work he refused to come and see me and I would be begging him and screaming at the nurses that it’s not working, I had an absolute meltdown in there, they had to have two nurses looking after me all the time. It was the biggest mistake of my life (Patient).

Patients’ and family members’/carers’ responses to these events can at times be extreme. When patients or their relatives feel that they are being treated unfairly by clinicians, stigmatised by their (clinician’s) responses, or questioned regarding their veracity as a rightful and deserving patient, the tensions in clinical practice quickly escalate. When patients’ and families’ expectations are not met, particularly in relation to opioid administration, conflict often arises. Tired, exhausted and hypervigilant family members/carers wanting to quickly relieve their loved one’s suffering and distress are often met by suspicious and frustrated clinicians attempting to manage difficult and complex clinical scenarios that they feel “*ill equipped to manage*”. Ethical dilemmas confront staff and are difficult to reconcile in the midst of the mandate to ‘do no harm’. In providing diagnostic procedures, clinical interventions and pharmacological treatments, clinicians are ever mindful of the consequence of missing a life-threatening condition. At the same time, clinicians attempt to minimise any further damage to the patient by not reinforcing deleterious “*illness behaviours*”, by not reinforcing opioid and medical dependence, and by not engaging in unnecessary and potentially dangerous investigations and treatments.

I think one of the issues is the attitudes that institutions take with these patients. Institutions at times can be quite hostile to these patients’; a negative environment is built up toward these patients. It’s interesting to see the responses of staff to these patients, a lot of assumptions are made. Staff get irritated attitudes pick up, and there is a breakdown in the therapeutic relationship. You can say there is one definition of medicine; that is ‘to comfort always, to relieve often and to cure rarely’, but in modern medicine we have gone the other way. We have great difficulty with



this definition and so we manage chronic pain very badly because they (patients) don't fit into our cure box and we as clinicians don't feel powerful in the mid-zone so we become suspicious of the patients (Gastroenterologist).

The following stakeholder excerpts represent the differing perspectives within these circumstances. Again, although the responses are extreme they are nevertheless characteristic, with four of the seven patients reporting having to mount considerable efforts in order to have clinicians "*listen to me*". By this they mean having clinicians validate their complaints, "*you have to believe me*".

One of the patients we are involved with has stabbed two staff members and stolen a baby from the nursery (her own baby). She has gone to the HCCC, she's got a case manager with the HCCC and she's also gone to the antidiscrimination board. These people are ringing and questioning why we put such boundaries around these patients. The system is not supportive of us when we have these difficult patients, she has stabbed two of our staff and she is complaining that we ask her to be searched before she comes into the ED, so then it goes to the HCCC and she has a case against us and if she wins the 40,000 dollars it comes out of the ED budget, so you can't blame staff for giving into these patients and letting them do just want they want. Sometimes you can't be bothered you're in a busy department and they're just not your priority (ED Consultant).

They just won't listen to you they don't believe you they just slush you off. The last time they were just terrible to me in there – that's the time I swallowed all the thumb tacks, just to get someone to listen to me and they wouldn't take me serious. Then they just treated me worse after that (Patient).

I have to always be there to protect her and to look after her interests so she gets treated right otherwise the wheels just fall off. I feel like I have to protect her because they do stupid things and they won't listen to X or me and we know her condition better than anyone. They just won't listen, like she has a port-a-cath and they insist on trying to put a catheter in her veins and I get there and she's black and blue from the intern making umpteen attempts, if they'd just listen and access the port-a-cath. It makes me really angry (Husband).

Thus, in attending to *a life interrupted by chronic pain*, patients, despite considerable time having elapsed since any acute pathology has been identified by medical attendees, remain firmly embedded within the biomedical model of managing their illness complaints, particularly those related to pain. This requires patients to continually engage with, negotiate and in many instances endure (in their words) the health care system in order to have their needs met. This long-term engagement has had inevitable

consequences. The effect of remaining entrenched within the acute biomedical model and the associated paradigm of diagnosis and cure has translated to a lifetime spent tending to the business of being ill. While Part Two of this chapter depicted the damage resulting from applying a reductionist biomedical model to the multidimensional experience of pain, the impacts (damage) of this approach extend beyond that experienced by the patient. The impacts on patients, their loved ones and in particular the children within these families are considerable.

I had dreams for her and we had plans (husband and herself) but all that's been interrupted by this. We don't go anywhere or do anything. I haven't got the energy to give to anything, or anyone else. I'm not sure what's going to happen, who is going to look after her after we're gone. Her and my relationship is different to what it could have been if she was living on her own as a professional person, married, so our relationship is different because I am the mother, the nurse, the carer, and that's a little bit different to just being a mum, so that causes tension for us (Mother).

The impact on him (son) has been dreadful, absolutely dreadful. I blame myself, he can't read or write. I spent so much time in and out of hospital, and he missed a lot of school. He can't read or write he just fell through the system at school he got left behind. He has had to grow up so quickly. When I was sick he knew what to do for me, he knew how to call an ambulance he knew everything. He spent a lot of time in the hospital, the nurses got close to him everyone knew him and looked out for him because they're our second family. They've known him since he was a baby, and that's a big thing. I used to give myself goals (referring to staying alive) to see him go to school, then to see him into primary (school), then to finish high school, then to see him get a job, and a girlfriend and now his 21st. To see him married with a house is my next goal. He's had depression very badly, he's had five suicide attempts – he just couldn't cope with my sickness. He has a lot of anger issues. He hasn't ever had many friends; we tried to keep things as normal as possible but it just didn't happen. He has a girlfriend at the moment and things are looking brighter for him. Though she has chronic abdominal pain as well and so I guess it's good for her that he understands (during this patient interview held at the patient's home, the son's girlfriend was also in the house in bed unwell with a "bout of abdominal pain", the patient referred to this by saying "they (medical staff) are just trying to work out what is going on with her") (Patient).

As a consequence of patients' long-term engagement with the health care service and in particular at the study site, it was not surprising that many patients and their families/carers referred to the hospital, and in particular the wards they most often frequented, as their "*second homes*". Similarly, despite having recounted significant and

damming appraisal of past interactions with a number of health care professionals, there were those patients who considered some staff as their *"second family"*.

Likewise, clinicians interviewed from these ward areas referred to the study patients and their families in a similar light. Despite these same clinicians being vocal about the difficulties and tense clinical encounters that they had experienced with the patients (3/7 patients) over 10–15 years of exposure to the group, there remained a sentiment of deep concern for the patients, their families and their children. Staff frequently stated *"we've helped bring these children up in here"*, and similarly patients and their partners referred to their children having been *"watched over"* by these attending staff (mostly nurses) *"they've watched X grow up and have seen his every milestone"*.

Despite having experienced difficult encounters in the past, the empathy extended to these patients by a considerable number of clinicians was intriguing. In some instances, clinicians would talk emotively and aggressively about the difficulties and frustrations they encountered with these patients and at other times would display the deep empathy and concern they had for their situations. This was not only a product of the nursing staff members' appraisals, but appeared to be the view of those clinicians who had longer-term engagement with the cohort and who had conceded having moved on from thinking their role was intrinsically linked to facilitating or enacting a *"cure"* for these patients (nursing and consulting pain specialist staff, gastroenterologists, surgeons and GPs). I found these contradictory but complementary comments curious, particularly in light of the emotive and poignant portrayals that some of the same clinicians had offered regarding the difficulties they had had with these people.

I quite like her, and fortunately for some of these patients, they are likeable (GP).

Similar to patients' illness narratives presented earlier in this chapter, clinicians' care narratives are more illustrative when presented intact, without my imposed interpretative interruptions. I have thus attempted to make accessible to the reader, clinicians' understandings, beliefs and conceptualisations based on which they deliver care, and which I have previously noted in earlier discussions. I have elected to present a composite clinician narrative derived from a group of care givers who have

indisputably experienced the most intense and enduring relationships with the study patient participants and their families/carers. Just as patients detailed an illness odyssey characterised by accessing, negotiating and enduring the health care system, health care professionals at the centre of these odysseys have their own care narratives. These narratives also represent an odyssey of care delivery that appear to be characterised on the one hand by frustration and anger, but on the other hand to be tempered by professionalism, empathy and a genuine desire to help patients achieve their '*best lives*'.

## **6.7 Clinicians' care odysseys**

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They're draining, draining, draining it's the manipulation the emotional needs, it's just like a revolving door, you never get any sort of resolution or good outcome for these people, they manipulate they know how to get more drugs, you sort of think why bother going through the whole detox thing and cutting their doses down they just keep coming back and we have to start all over again. You're caught up in trying to keep them on the ward trying to talk them down without giving in and giving them more drugs and you might also need to be looking after someone who is critically surgically unwell. You might not give them the extra opioids, but someone else might give in tomorrow; you know as soon as you give it to them you're going to get at least 3 hours peace. It's the screaming, the begging the aggressive families, it's hard. Then they start to play staff off against one another. We just have to band together, support one another, and try to have their (patient) best interests at heart and follow the plan. But having said that we actually do form relationships with these people, quite personal relationships, you know particularly when you've been looking after them since they were 16 years old, you've seen them as young women then they have children, and they are constantly re-presenting and re-presenting you form relationships with them, it's a relationship you build up over a very long time. You can see they are happy to be here and they know they are going to be looked after here. They get quite distressed when they have to move out of here, you know this is like their second home. They have this expectation that their needs are going to be met here, they feel safe, the family have that expectation as well, and all the clinical staff, the surgeons and the pain service and anyone else involved, they all have high expectations of what we can achieve with these people. Often we haven't just got one of them on the ward; because they tend to stay here we could have two or three of them at any one time! You build up a relationship with these people. It's hard when they are your age seeing them and thinking they could be out living their lives, it's just so very sad. There is a real sadness, a real sadness because a lot of these people are so young when they start out, and then they just keep coming back, they have a hospital cupboard at home, this is their social outing and we're their social network. They tell you their dreams that they know will never happen, like the one who is

trying to adopt children and you think how on earth can she think she can manage it she can't even look after herself for 3 months at a stretch how could they possibly let her adopt a child. You know a young girl on 90 mgs of oxazepam at night to help her sleep! Or when you ask a 26 year old what she wants for her birthday and she says; 'a truck load of morphine', it's just inappropriate and sad. You get these young girls at the beginning of their journey and you just want to shake them and say 'what are you doing what is this all about?' And telling them 'don't you realise what they're doing to their lives?' They could be doing this and that. You just want to say 'I understand you have this pain, but you've got a life to live, come on get out there and get on with it'. It's so sad but you can't say that. They would count the steps to the customer complaint office. When they don't get what they want they head off to the customer complaint unit and tell them we're withholding their pain relief and then before you know it we have this whole big enquiry happening. I think we forget that these are young people; when they start they're 14, 15, 16 years old they are teenagers and they don't get their normal socialisation and their whole lives are built around being sick and being in hospital. I think we do a marvellous job with what we've got because what we've got is not designed to look after these people at all (Surgical Nurses).

## **6.8 Discussion**

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Like all clinicians involved in the clinical management of this patient cohort over many years, I was aware of the difficult developmental histories and complex psychosocial issues these participants brought to each clinical encounter. However, what became apparent during the study, and in particular through the patient interviews was that, for this patient group, their whole lives had been characterised by these challenges. What has been sobering to appreciate through their stories is the degree and extent to which these difficulties have infiltrated their lives from early/ mid-adolescence and continued well into early adulthood and beyond.

What was most striking was the recurring feature of abandonment, particularly in early childhood for many of the participants. Considering the extent to which fractured relationships with parental figures and siblings featured for all participants has been a significant outcome of this study in its attempt to better understand the phenomenon of persistent abdominal pain.

The influence of family processes and the role of psychological vulnerabilities within and considered determinant of the chronic pain experience are replete in the

contemporary pain literature. These behaviourist accounts emanate largely from the position that the “gains of illness” facilitate the ability to “restructure family relations and communication processes” (Kleinman, 1995, p.138). However, I have some sympathies with Kleinman’s (1995, p.138) assertions, that “the behaviourists’ discourses are stereotyped, overly focused on pain as the problem of the individual and dehumanising”. Consequently, this author finds a resonance with his anthropological perspective that chronic pain represents an “idiom of distress” from which “disaffirmed and disaffected” (people) grow into adolescence feeling worthless, feeling a lack of efficacy with others and being alienated from family. This, he asserts, becomes an experience of de-legitimation often reproduced in subsequent relationships, and that can represent a lifelong cycle of despair (Kleinman, 1995). He goes on to explain:

The experience of pain in a world without security (in family, job, finances, or neighbourhood) is what distinguishes chronic pain from the poor and the oppressed. When one cannot marshal resources, symbolic and instrumental, because they do not exist or one’s access to them is obstructed, the idea of control becomes untenable. The normal everyday routinization of misery, furthermore, can be experienced as bodily pain. As a result the confluence of this source of pain and bodily pathology makes it impossible for the afflicted person to determine what causes pain to worsen and what will limit it or remove it. Pain cannot be made meaningful any more than can the rest of life. The absence of control as well as legitimacy means that to survive, those patients that lack resources yet are exposed to great pressures must conduct the equivalent of a life-and-death struggle. Pain becomes the bodily component of so fundamental an experience of suffering that the local world is in effect a world of suffering. Pushed up against the limits of control and meaning making, poor and oppressed patients must take up whatever is at hand to respond to adversity that can no longer be easily assigned to either medical or nonmedical sources. Thus pain represents a kind of solution, albeit compromised, to the consequences of dwelling in a world of suffering. (Kleinman, 1995, p.140).

It was not until I reviewed my initial reflective journal entry that I appreciated how powerful were the “idioms of distress” were being portrayed by patients, and that which appeared to offer a refuge, and provide some meaning within a life of suffering.

What was not obvious to me as a clinician, but has become more evident as a researcher, were the similarities of the characteristics, dimensions and consequences of

these 'difficult' life events for all participants. The most profound feature of these early life stories is that of repeated and extensive abandonment. Abandonment by biological parent(s), adoptive parent(s), and by siblings (biological and adoptive), or as a consequence of death (for one patient), produces significant cognitive and socio-affective obstacles that need to be navigated. Why some adolescents adapt successfully, and in some situations may even be stimulated by such life events, is the product of psychological resilience. Considering the "assets and resources" necessary for achieving adolescent resilience may provide helpful insights if attempts are to be directed toward early identification and intervention for any emerging patient cohort experiencing persistent abdominal pain (Fergus & Zimmerman, 2005, p.399). Identifying the presence or more importantly the absence of these well-documented "moderating, and protective internal and external attributes" may potentially reduce the negative trajectories associated with young adults presenting regularly to GPs and EDs with persistent abdominal pain.

In addition, because of isolation from peer groups during early adolescence there were limited opportunities for patients to connect with, develop and hone social competence in the monoculture of their respective peer group(s). As a consequence of being frequently hospitalised, patient participants encountered few circumstances where interactions with peer groups would ordinarily provide opportunities to help foster self-esteem, belongingness and connectedness, all capacities referred to in the literature as elements of 'internal' resources that may mitigate against poor outcomes for adolescents at risk. In particular, in the presence of unhelpful family relationships, the potential for peer support could prove to be a 'protective' mechanism.

The excerpts chosen for inclusion illuminate the chronic illness trajectories and the consequences and implications for all the players depicted in the chronic illness scenarios.

In order to unpack the narratives to provide interpretative appreciations and explanations to inform the research agenda, it was necessary to draw on the key axioms of naturalistic enquiry as set out by Lincoln and Guba (1985). Subscribing to the

philosophical foundations of naturalistic enquiry enabled the researcher to accommodate the multiple, subjective and socially constructed realities that reside at the core of the study phenomenon, which no *a priori* theory could accommodate, thus rendering the data and their co-constructors, the reciprocity between the *knower and the known*, as the platform from which theory (explanations) is derived (Thorne, 2004; Riessman, 2008).

In essence, the illness odysseys associated with persistent abdominal pain portray the considerable consequential effects at the core of the central phenomenon;

- For patients, the disease interrupts their lives. The perpetual disruptions are a consequence of tending to the business of being ill. Being perpetually ill requires a reorientation of ones' maps and destinations in order to account for the ill body, its demands and the innate requirement for those afflicted to make meaning of their situation
- For clinicians, it represents a limitation, a challenge to their purpose and function as health care professionals and their commitments within the system that employs them. It challenges their beliefs and pushes their ethical parameters
- For carers, the odyssey represents an obligation to realign their hopes and dreams; their maps and destinations also need to be reconfigured as a consequence of having their lives and their loved ones' lives interrupted by chronic illness

## 6.9 Conclusion

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Patients with persistent abdominal pain present significant diagnostic and therapeutic challenges for health care providers. Utilising an acute care framework to manage this patient cohort is problematic. Some of the problems include: poorly coordinated interventions delivered within unidimensional models of care, professionally based siloed approaches, lack of coordinated and consistent care planning, the use of conflicting approaches and treatment paradigms, and inadequate discharge planning and community based care. On the basis of this argument, it could be claimed that the



current approach to managing patients with chronic abdominal pain is not only inefficient, but also ineffective. These treatment approaches are confusing for the patient, and lead to conflict and hostility within and between treatment teams as well as between patients, their families and the hospital staff, to escalation in patients' reports of pain, and inevitably to repeated hospital admissions.

The concerns expressed by study participants were foundational to informing any revised model of care. In the final chapter, Chapter 7 the collective endeavours of nominal group workshop participants and the resulting principles and recommendations are discussed, with particular reference to their utility for a revised model of care.

## Chapter 7 Informing a new model of care

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### 7.1 Introduction

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Previous chapters (5 and 6) have provided empirical data and interpretive descriptions, illustrating and illuminating the multidimensional impact of the phenomenon of chronic abdominal pain for all stakeholders. On the basis of the enriched understanding of context and impact derived from these earlier phases of the study, efforts were then directed toward identifying ways to improve the current and future situation(s) in relation to the management of patients presenting to acute care facilities with a history of persistent abdominal pain. This final action-oriented phase of the study involved working with health professionals, using findings from previous phases of the study to develop recommendations for change and a revised model of care. This phase focused on the third research question:

**What would need to change in order to provide a more efficient and effective model of care for current and emerging patient cohorts with persistent abdominal pain?**

From the findings discussed in previous chapters it became clear that change requires more than a restructuring of processes and the redistribution of resources. Real and sustainable models of care require critical revision of the theoretical and philosophical frameworks and cultural practices that construct and characterise care encounters. The recommendations from clinicians derived inductively in this study, together with contemporary commentary within the literature suggest that a revised treatment approach be characterised by; a whole-of-person approach, a revised way of seeing and working with patients and their problems, creation of therapeutic alliances and mollification of the paradoxical nature of encounters in a way that reduces their potential for harm. Such a model would have as its central objective the achievement of a meaningful life for chronic pain sufferers, one that would see them living at home

without the need for frequent hospitalisation. Review and discussion of these principles in relation to the study findings are presented in the following section, followed by an overview of specific characteristics of a proposed revised model of care.

Health professionals who agreed to be part in this final phase of the study brought a strong sense of professional, ethical and personal commitment. They were highly motivated to improve clinical management of this patient cohort and to identify and more effectively manage emergent patients with persistent abdominal pain.

We have two big problems here; we've got to stop new ones getting on the medical round-a-bout; and we've got to fix the ones that are already here. We're going to need two different strategies for solving these problems (Anaesthetist/Pain Consultant).

These clinicians who had vast clinical experience and exposure to the study patients brought considerable collective wisdom, across a broad range of clinical disciplines. The ability to mobilise such a diverse and experienced clinician base was the product of long-standing relationships between the researcher and participant clinician speciality groups, particularly in relation to the clinical management of the study cohort. These relationships enabled a collective and integrated clinical disciplinary sense of purpose and authority from which recommendations could be made about a revised model of care. Hence this final phase of the study engaged and mobilised clinician stakeholders in identifying a model of care that they perceived would provide better therapeutic outcomes for this and emerging patient cohorts. Involvement of clinicians in a way that engendered ownership of the project, the processes and ultimately the revised model of care, was pivotal to engaging them in the change agenda and to the success of the revised model in implementation.

No researcher crafts or disseminates findings without anticipating the needs of a particular audience, and making some assumptions about what will be relevant and convincing to that audience (Thorne et al., 2004, p.15).

The clinicians needed to be able to subsequently support, implement and most importantly adhere, in the clinical context, to the preliminary recommendations that were the catalyst for moving forward; that is, the construction of meaning around these

events was presented in a way that showed it had emerged from the interpretation of the quantitative and qualitative data sets.

The generation of the interpretive descriptive product assumes that there have been discoveries and that will be understood within complexity (Thorne et al., 2004, p 15).

In this final phase, clinicians were informed of the findings of previous phases of the study. Being aware of the patterns and themes (findings) enabled them to make sense of the complexity inherent in the management of this patient cohort and to “access their meaning in a new manner” (Thorne et al., 2004, p.15); they became catalysts for the development of meaningful elements of a revised model of care.

Hence, it was within the spirit of collective concern, professional commitment and mutual acceptance, acknowledgement and collaboration that 54 clinicians, representing 15 medical, nursing and allied health specialities dedicated their time, energies and intellect by attending one of two nominal group workshops, reported on below, that were specifically dedicated to identifying an improved solution(s) for the study and emerging patient cohorts.

## **7.2 Identifying the foundations to improvement: Lessons from the past and ideas for the future**

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In the earlier phases of the study, considerable efforts were directed toward identifying what participants considered facilitative and obstructive features within the current model of care used at the study site. During interview sessions with participants, it became apparent that individual clinicians and at times groups of clinicians had made significant attempts to improve some aspects of the management of the study patients. Considering the effects of these changes, their success or otherwise was important in informing new activities. Many past attempts to improve the situation had been met with approval by clinicians, patients and family members, whereas others were not met so enthusiastically. Many trialled strategies were difficult to maintain in isolation from the support of other clinicians, impotent because of the lack of hospital administrative support and clinical governance and redundant without the additional support of the necessary infrastructure to implement such revisions to care.

Appreciating and integrating these lessons from the past was pivotal to informing ideas for the future. Therefore, the issues identified from the retrospective chart audits along with the ideas and perceptions canvassed from interviewees were synthesised and collated for presentation to workshop attendees. These earlier findings offered a platform for the nominal group activities. Hence, an introductory presentation delivered at the beginning of the workshop activities sought to:

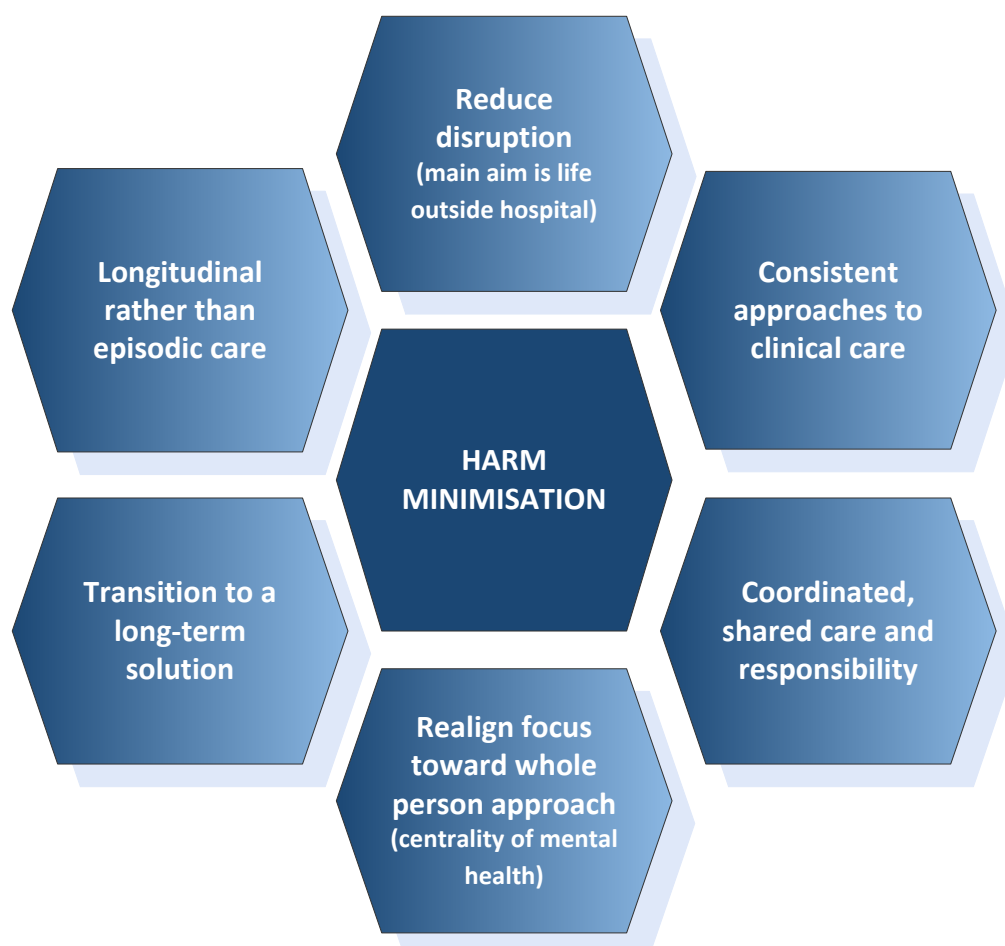
- re-orientate participants to the aims and purpose of the study
- provide feedback regarding the preliminary findings of the first three phases of the study so as to contextualise and inform the proposed workshop activities
- gain a collective agreement and consensus regarding the ‘guiding principles for managing persistent abdominal pain’, identified by clinical speciality focus group attendees (Phase Three), and
- introduce health administrators to the extent and context of the clinical issues; to demonstrate the collective clinical concern and commitment to improving the situation; to facilitate a partnership between clinicians and administrators in order to gain the necessary support and clinical governance required to implement the improvement agenda.

During focus group interviews conducted earlier in the study, interview participants had been asked to reflect on occasions where things had gone well and when things had not gone so well during clinical encounters with study patients. It was the aggregated responses to these questions that provided what participants’ described as ‘The Guiding Principles for the Management of Persistent Abdominal Pain’ (Figure 7.1) which informed the foundations of care they believed pivotal for achieving better health outcomes for current and emergent patients with persistent abdominal pain.

### **7.2.1 The guiding principles of care**

Study participants identified six guiding principles on which care for patients should be based. The principles reflect clinicians’ concerns surrounding the actual and potential “*damage*” that can emanate as a consequence of the misuse of the acute biomedical model for patients with chronic and complex care needs. Hence, the

principles represent an orientation toward “*harm minimisation*” in these contexts. The six principles identified by clinicians were considered as the antecedents for good clinical outcomes for the study group and emergent patient cohorts (Figure 7.1).



**Figure 7.1 The Guiding Principles for the Management of Persistent Abdominal Pain**

Within the guiding principles, clinicians identified that care delivery for patients with persistent abdominal pain needs to be consistent, coordinated and integrated, with an orientation toward shared care and responsibility delivered within a whole of person approach. The model needs to promote long-term solutions and to reflect this by delivering care longitudinally rather than episodically. Finally, participants stated that the model should be focused on reducing disruption to patients’ lives and to facilitate a “*life worth living*” outside of the acute care hospital environment.

This preliminary model was presented to workshop participants for their consideration, discussion, refinement and endorsement. Subsequently, over the course

of the 2-day workshops, participants were guided by the model as they worked in multidisciplinary groups to distil elements they considered necessary for achieving the care principles. The groups were each presented with a set of critical issues (Table 7.1 & Table 7.2) for their ideas for resolution and discussion.

**Table 7.1: Principal Concerns in Managing Patients with Persistent Abdominal Pain: Day One Nominal Group Workshops.**

1. How can we ensure the exclusion of a potentially life-threatening condition through efficient and responsible assessment and diagnosis?
2. How can we best manage the issues surrounding pain management in the Emergency Department, the hospital and in the community contexts?
3. How can we ensure consideration and integration of mental health care in the context of an acute admission and beyond?
4. How can the system best function to meet the needs of this patient cohort while at the same time preventing avoidable service utilisation?

**Table 7.2: Principal Concerns in Managing Patients with Persistent Abdominal Pain: Day Two Nominal Group Workshops.**

1. How do we manage the need to individualise care while moving towards a systematic approach to this group of patients?
2. How do we transition to a changed model? Which patients, over what time frame and under what circumstances?
3. How do we move to a whole person approach? How can this be operationalised within the acute care environment and in the community?
4. How do we engage the patients and families in the change process? How can we manage resistance?
5. How do we deal with sabotage in the system?

The aim of the workshops was to gain agreement on how critical issues, identified by stakeholders could be overcome. The issues posed represented the most significant

clinical issues, which all stakeholders had identified as needing to be addressed in order to achieve improved health outcomes for the patient cohort. Addressing these issues was instrumental in achieving improvement through a revised model of care, by:

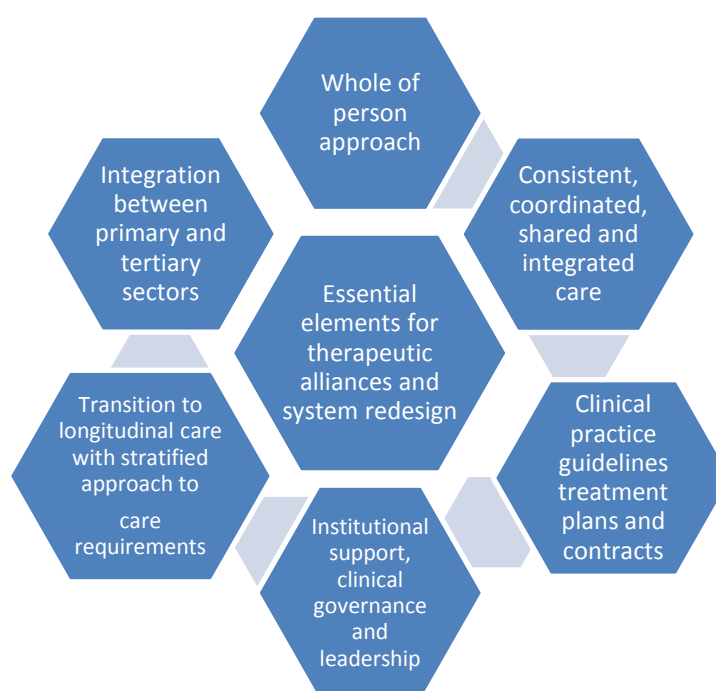
- gaining consensus around the essential elements of a revised model of care
- gaining clarity around ownership and engagement, and
- developing a provisional model of care that could be used for a pilot study.

The guiding principles and essential elements identified by study participants reflect recommendations in the contemporary literature regarding the optimal management of patients with chronic diseases (Wagner et al., 1999, 2001; Kralik et al., 2010; Kerns et al., 2011). However, the fact that clinicians recommendations were derived not only from the literature but from their own and others contextualised and collective experience appeared to produce clinician endorsement for the project and was instrumental in mobilising efforts toward distilling the essential elements to *“individualise”* the model for the study patient cohort.

The remainder of this chapter centres on consideration of the redesign of care for patients with persistent abdominal pain, within the framework of the chronic care model. Hence, this study realises its potential to inform both the contemporary literature and clinical practice. In the following discussions, I have resisted providing a descriptive account of the features within the chronic care model as these have been well documented in the literature and are widely considered fundamental to providing optimal care for patients with chronic and complex diseases (Wagner et al., 1999, 2001; Kralik et al., 2010). Issues as they relate to the essential elements of providing a whole of person approach with respect to Self-Management Approaches; Multidisciplinary Team (composition, education, preparedness and responsiveness), and Psychological Therapies such as Self-Regulatory Approaches (Biofeedback; Relaxation Training; Hypnotherapy; Mindfulness) and Behavioural Approaches (Cognitive Behavioural Therapy) and Acceptance and Commitment Therapies have been extensively discussed elsewhere. Their validity within the context of chronic pain applications has been



repeatedly demonstrated within both the pain and chronic disease literature (Gatchel et al., 2007; Kerns et al., 2011). However, reports on the clinical management of patients with persistent abdominal pain using the principles of a chronic disease framework are not in the contemporary literature. Hence, discussions below extrapolate the essence and implications of the data that informed the alternative model and treatment approaches (Figure 7.2) by highlighting the origins of the care principles and essential elements within the context of both the study findings and the relevant contemporary literature.



**Figure 7.2 The Proposed Essential Elements of Care for Patient with Persistent Abdominal Pain**

## **7.3 The essential elements of a revised model of care**

There are two central elements of an alternative approach to care for the study cohort: reorientation to more comprehensive treatment approaches, and system redesign including extending care into the community. These are presented with discussion in the remainder of 7.3 and in 7.4.

### **7.3.1 Toward a comprehensive treatment approach**

Our system [acute hospital] is geared at ruling out emergencies so the presumption is always that someone's actually got something terribly wrong until you prove that they haven't, so for these

people that means they get a lot of unnecessary X-rays, CT scans, blood tests and other investigations, especially if they get seen by junior doctors. You have to actually stop it from happening (ED Consultant).

It has long been reported that patients, particularly those with chronic and complex care needs, require an alternative model of health care delivery to that offered by the biomedical model (Wagner et al., 1999, 2001; Thorne, 2008; Coleman et al., 2009; Larsen, 2013). Many of the findings of this study highlight the deleterious outcome of pursuing a reductionist approach when managing chronic and complex health problems. Although the literature is replete with recommendations regarding the application of a broader paradigmatic approach to managing patients with chronic and complex conditions, particularly in relation to pain, an acute biological framework remains firmly entrenched within many clinical contexts.

As discussed throughout this thesis, there are many and varied influences that result in allegiance to the biomedical model. Despite these considerable social, political, educational and individual preferences and paradigmatic biases, it remains clear that patients with chronic pain, particularly in this case, require a broader framework from which their illness needs to be conceptualised and managed.

These patients have remained embedded within the acute health care arena for a number of decades. Whilst the patients themselves appear, for whatever reason, resigned to this attachment, clinicians report being challenged. Their reports echo the sentiments presented by Conway and Higgins (2011), that the biomedical model and hence the acute care system has become, in the absence of accessible alternatives a place of “*default*” for these patients’ care provisions. As such, they and their families have suffered long lasting damaging physiological and psychological sequelae.

#### **7.3.1.1 A ‘whole of person’ approach: Beyond the rhetoric**

The current model is a bad fit, in ED we treat ‘em and street ‘em [sic] (ED Nurse).

All participants recognised the limitations of the biomedical approach to managing the current patient cohort and were adamant that a broader treatment approach needed to be implemented early for those at risk of progressing from acute to persistent

abdominal pain states. Participants' allegiance to this changing paradigm was exposed through their comments. They recognised their own limited capacities and utilities for managing patients in these contexts, *"they have multiple problems and I can't fix that"*. They reported dependence on others more inclined to adopt a biopsychosocial approach to patients' management, *"you just ring the pain team or the psychologist and they'll bail you out, we just provide a name over the bed so they can weave their magic"*. In addition, they recounted circumstances where they had witnessed therapeutic gains when utilising a broader biopsychosocial treatment approach, *"the power of the team meeting, the multidisciplinary approach, the family was even involved, so the whole team was on the same page; it gave you the courage and determination to stick to the team plan, and the regular case conferences. It can really work"*.

The over reliance on the acute care model in addition to the lack of timely, accessible, consistent and coordinated biopsychosocial treatment alternatives for patients with persistent abdominal pain, remained the focus of study participants' appraisals of, as they see it, the *"mismanagement of the patients"* at the centre of this study. Although participants identified that a broader paradigm was required to optimally treat these patients, their recommendations were moderated by the reality of trying to integrate such an approach within current practice and inadequate infrastructures. In these situations, clinicians often adopt treatment strategies, directed toward minimising potential harm for patients, including maximising their chances of remaining in the community and away from acute care services.

The blanket approach is difficult, it might not be classic pain management strategy, but if I'm giving two injections of morphine a day to someone and that's keeping them out of hospital, no surgeon is doing this and that to her. And she hasn't been to a hospital or emergency department in years and she hasn't had any stupid investigations. You know, it's not perfect, but it might be functioning well as a strategy and it might be good care for that particular patient – it's a harm minimisation strategy. What's the alternative? As far as I can see, there are none (GP).

Clinicians expressed a preference to move from a reductionist appraisal of conceptualising and managing patients with persistent abdominal pain. In doing so they used interchangeable terms such as *"biopsychosocial, holistic, whole of person and integrated care"*, for what they were mostly describing as a biopsychosocial framework.

Integral to the biopsychosocial model of conceptualising chronic illness and disease is the accommodation of a whole of person perspective. Some clinician participants were more familiar and comfortable with this term and its translation into clinical practice stating, “...often their pain crises’ are precipitated by some social or inner psyche struggle and my approach is to try and help them identify the links”. Whilst others were challenged by the notion, “it’s that whole thing of if there’s an organic problem and if you can name it, that’s great, but if there isn’t what do you do then?”

Although cognisant of the need to move toward a broader framework for managing patients with persistent abdominal pain, many clinicians, undeniably socialised to operating from within their medical speciality specific silos, seemed confronted by the prospect of transferring this conceptualisation or intellectual appreciation into their clinical practice. They were challenged by: i) how to mobilise such approaches, ii) what their and other clinicians’ role(s) within the model would look like in clinical practice, iii) what would happen when the model doesn’t work (referring to patient or clinician non-compliance), and iv) who would provide the necessary authority to sanction and finance the implementation of such a model?

You can make clinics for them to attend, you can set all this stuff up for them, but they won’t show up – they’re chronic non-attenders. You can have contracts and all that stuff, and when they break the contract what do you do then? Stamp your feet? You just have to turn around and walk away when you’re angry and come back the next day and start again...//... I agree we should have a new model, but I don’t know what that is, I don’t see any great alternative, I don’t think you can do anything with these people, that’s just being realistic (Surgeon).

Despite being guarded about levels of system support, and the likelihood of the patients’ adherence to an alternative model of care, participants’ recommendations included features widely recognised as, a whole of person or holistic approach.

In articulating the realities of these situations, clinicians highlight why the status quo (biomedical model) remains the principal approach for managing the study patient cohort. That is, without the necessary infrastructure, adequate resources, and the skilled and responsive staff required to provide a reliable alternative treatment approach, things remain the same. One reason that things remain the same is because

of clinicians' judgments of the "*futility*" of attempts at trying to improve the situation for patients. Another reason revolves around clinicians' concerns about compounding patients' "*damage*" by not providing consistently reliable alternatives.

We're not completely hopeless in managing these patients; I think we have some idea. Intermittently we make it work. There are lots of wisdoms here but how do we pull all that together? How will we coordinate it and make it happen? And the challenge is getting the resources to make it happen consistently. There's only one thing worse than not offering the service and that's promising one and then not delivering. It has to be responsive, it has to have capacity and it has to be more than one or two people, otherwise it's just not sustainable (Anaesthetist/Pain Consultant).

Recommendations for a broader approach to managing patients with chronic and complex problems have led to re-engineering of health services. Engel (1977) first proposed the biopsychosocial model of understanding illness as multifactorial and multidimensional. Since then, almost three decades of research on chronic pain has culminated in the widely accepted understanding that "the bio-psychosocial model has proved to be the most widely accepted and most heuristic perspective to the understanding and treatment of chronic pain" (Gatchel et al., 2007, p.581).

As a consequence of a paradigmatic shift, considerable clinical adaptations for the provision of more appropriate management of pain have followed. There has been worldwide adoption of the concept of the specialism of pain management, which has resulted in the implementation of acute, chronic and cancer pain management services and clinics as well as dedicated pain management education and research centres. There has been considerable international political and governmental response to heeding warnings regarding the exponential impact, both economic and societal, that chronic and complex conditions and particularly unrelieved pain will have on western societies. In the face of these increased appreciations and paradigm shifts amidst generally modest resource reallocations, it would seem appropriate to consider, why these study participants describe such damaging plights.

Conway and Higgins (2011) offer some insight into the deficits in infrastructural supports and discussion in this thesis centres on the historical, political, social, personal

and professional imperatives of the biomedical manifesto. However less consideration has been given to the potential for newer ways of “seeing” beyond, what Broom (2007, p. 8.), describes as the “strait-jacket of Western bio-medical concepts and practices”. Considering the potential to see these patients’ situations and their trajectories from an alternative perspective would seem a worthy task.

#### 7.3.1.2 From biopsychosocial to mind body integration: A different way of “seeing”

Many of these people have developed some sort of psychological overlay and some type of need that we don’t understand. I don’t want to get too philosophical here but what is pain, and what is a good outcome for these patients? I don’t know what you would define as pain. Most of the time the pain is psychological. I don’t know how to deal with that (Surgeon).

Broom (1997, 2002, 2007) is sympathetic to the difficulties “biomechanistic physicians” confront in attempting to broaden conceptual understandings of illness. He comments that he himself has done so, in the process of gathering clarity of thought and expression so as to articulate his re-conceptualisations of illness, particularly medically unexplained illnesses to “suspicious biomedical peers”, he has said:

...I have struggled to relinquish deeply held assumptions rooted in a narrow biomedical scientific training, itself rooted in a wider dualistic culture. I have had to yield to the evidence of my own eyes and ears...//...I have seen so many cases of *meaningful* disease that I know the phenomenon is universal...//... *meaning-full* disease is an approach which adds another dimension and yet does not need to be in competition with biomedicine properly practiced (2007, p.9).

With this conceptual orientation, Broom offers clinicians some insight into how to think about practising holistically, that is, he offers more than just semantics and rhetoric so that such practices translate into meaningful encounters for patients. His explanation of this is eloquently depicted in the following comment:

Giving subjectivity its proper place demands a view of people that is unitary rather than divided, a view which allows both the objective and subjective aspects of our personhood to be mutually present, in the same time and space. Neither is seen to subjugate the other. Hence the phenomenon of *meaningful* disease suggests that the categories of mind, body, meaning, experience and language are interpenetrating, entangled, reciprocal and mutually sustaining. But the observer can divide them. I look at one person from one angle and I see ‘body’, I take a step sideways and ‘look’ from another angle, and I see ‘story’ (2007, p.9).

In the present study, clinicians highlighted the dilemmas they face in clinical practice when trying to reconcile patients' seemingly illogical biological presentations, explanations and subjective reports while still acknowledging their genuine, albeit, elusive, deeper needs," *it's hard to maintain two models at the same time; it's hard to disentangle them from the acute model and then plug them into a more multidisciplinary management approach*". These situations are complicated by previous diagnoses of organic chronic illness (pancreatitis, IBS), for which periodic exacerbation of symptoms would be expected. Compounding this is the patient's often "*extreme behaviours*" and their complex psychological histories of personality disorder, self-harm and suicidal tendencies. Moreover, these are histories that historically disqualify patients from enrolment in pain management cognitive behavioural programs. Demonstrating further the need to individualise chronic pain treatment approaches, particularly for patients' who might have concurrent psychiatric pathology.

While acknowledging that current treatments have been ineffective in resolving the underlying "*real*" problem and because they have an academic appreciation of the benefits that might be achieved by broadening treatment approaches, for many participant clinicians, this notion remained entrenched within the dualistic perspective of biology versus psychology. Difficulties for clinicians resided in knowing how to navigate the integrated nature of and the interrelationship between biology and psychology, "*the trick is for them (medical team) to get the psychiatrists to say they (the patient) have a psychiatric problem that would explain their presentation*". For the few clinicians that appeared comfortable beyond these dualistic conceptualisations, "*there's this brain-gut axis that we haven't begun to understand in medicine*". These clinicians appeared comfortable with or at least not challenged by, as one gastroenterologist expressed it "*always meeting them from a point of helplessness (referring to feeling helpless in these situations) and feeling powerless in the mid-zone*".

There are difficulties in appraising the patients in clinical situations where they remain "*on the medical round-a-bout for 3 or 4 years, it's very hard to move them off it*". Because these people remain attached to biological explanations, and focused on accessing biologically orientated treatments, broader treatment approach are typically delayed

until “*all else has failed*”. In the absence of being able to objectify symptoms, the problem is then perceived to reside with the patient, or more specifically, a consequence of their psychosocial limitations. This linear dichotomous appraisal supports Broom’s (2007) assertion that the biopsychosocial model is no more accommodating (integrative) than the biomedical model. This proposition is indeed reflected in the way in which treatment approaches are currently implemented, under the guise of a multidisciplinary, whole of person approach. Characteristically, because of these conceptual and paradigmatic alliances, patients in these situations are treated sequentially through the multiple dimensions: first the biological, and then the psychosocial, but rarely the two in tandem. Whatever the orientation, the therapeutic alliance between the patient and clinicians is at the centre of the encounter.

#### **7.3.1.3 Therapeutic alliances: Being heard, valued and respected**

Oh they were shocking to me in there, absolutely shocking. That’s the time I swallowed all the thumb tacks because I couldn’t get anyone to listen to me (Patient).

Essential to implementing a chronic disease approach to the management of persistent abdominal pain, is the consideration of its fundamental tenet, the patient–health care provider relationship. So much is dependent upon the effectiveness of this interaction.

Patient–health care provider relationships and encounters within the study highlighted important elements of care provisions under a revised model. While Chapter 6 makes accessible the more deleterious aspects of unproductive patient–health care provider relationships, efforts here are directed toward examining the features of more positive successful clinical encounters or relationships. Patient and health care provider relationships are central and instrumental in both facilitative and obstructive encounters that invariably influence patient outcomes. This highlights what Thorne (2006, p. 58) describes as the “pivotal moment within which damage can be done or benefit can be gained”. The quality of the patient–clinician relationship was reported by patients and their families as the most important determinant of not only how an individual clinical encounter would be perceived, but also how a hospital admission would evolve. Health care providers confirmed this by commenting:



At the very beginning (upon presentation to the ED) things can go terribly wrong and that then seems to set the scene for what staff need to cope with and manage during the hospitalisation; it just seems to lurch into a full-on crisis (Psychiatrist).

Study patients' appraisals of their relationships with clinicians were polarised, referred to as, either "good" or "bad" and intrinsically linked to whether patients felt "heard" during such encounters, thereby producing the much sought-after validation and legitimisation of their experience and symptoms, *"he took the time to actually listen to me; he even physically examined me"*. Patients reported that individual (usually) clinicians, often referred to by Christian name, were seen as a "second family", these were clinicians who had been prepared to invest time and listen to their stories; *"she listens to me; she gives me good advice; she helps me put things into perspective"*. Long-term relationships founded on "trust, respect and acceptance" seemed to be the prerequisite for achieving productive engagements with these patients, *"we just try and keep their best interests at heart and support them through difficult treatment plans"*. In contrast, if patients felt they were being dismissed, *"they just slush you off, you feel like a useless cow"*, and their symptoms not taken seriously or their presentations treated suspiciously, *"they just think I'm a drug addict"*, then clinical encounters characteristically deteriorated. The latter frequently resulted in an interaction dynamic that was tense, hostile and occasionally violent, *"one of the patient's has a very aggressive father and he has threatened physical violence on the staff"*.

Nettleton (2006) reported comparable appraisals of a cohort of 24 patient interviewees with inexplicable clinical symptoms attending a neurology clinic in England. These patients similarly assessed encounters with health care professionals as either good or bad, based on whether they felt "dismissed" within such encounters. Nettleton's participants described being less concerned with not having a diagnosis and more concerned with being considered "genuine". The psycho-education literature suggests that the most valuable aspect of the therapeutic relationship is the clinician's capacity to, "care enough to listen" (Rigby & Alexander, 2007; Shattell et al., 2007; Wright & Jones, 2012). This resonates with this patient cohorts' longing to be, *"treated just like every other patient"*.

They just don't want to listen to you. Whose body is it anyway, theirs or mine ? They won't take my word for it. I've had one of them say I was a drug addict to my face, and they say stuff like 'back in for another hit are we?' They just won't listen to you. They think they know best. They should listen, take time out to listen to what the patient's got to say, they just diagnose you before you even tell them what's wrong, and I'm saying listen to me for God's sake. Then I get frustrated, I get anxious, I get angry, I get upset and start crying and then X (husband) gets frustrated then security gets called in. He's had people fired because they're incompetent and the whole bloody thing just goes around in this vicious cycle (Patient).

At the study site, there were a small number of clinicians (individuals as well speciality groups) that patients, carers and health care professionals recognised as being influential in achieving positive therapeutic gains for study patients.

If I didn't have X coming to the ward on a regular basis, I don't know what I'd do. I get scared of my own capabilities, my own violence, and lashing out at them (clinicians) because of the pain. But X helps me put everything into perspective and that's what I need (Patient).

These same clinicians were frequently identified as providing support for families as well as clinicians during recurrent and difficult hospital admissions.

There are a couple of very skilled and overburdened people who make a fantastic effort, but they are incredibly helpful for my patients and the staff (Staff Anaesthetist/Pain Consultant).

Good clinicians termed their roles as *"supportive"*, *"facilitative"*, and as one of *"containment"*, describing that they felt *"a bit like super-glue"* as they worked toward achieving effective therapeutic environments for clinicians, patients and family members, *"not taking the 1 minute option, but the 30-minute option (described in Chapter 6) so I can really engage with these people and where they're at and shift them to another direction (a broader treatment approach)"*. Clinicians reported often having to resort to exploiting the connections that good clinicians have with these patients in order to achieve therapeutic advances that would otherwise be difficult, for example opioid reductions or rotations. These *"good"* clinicians are aware of the therapeutic traction their roles can achieve and while some felt more comfortable with these roles, *"if I felt like I had to solve everything I wouldn't be able to do it"*, others registered difficulties, *"everyone expects a lot of us here, they (medical staff) come and go, we're here and we're left to*

*manage these difficult situations and left to manage them on our own. We don't have enough education to do this, but having said that, we do a pretty good job."*

Fundamental to these therapeutic environments was the ability of the individual or group of clinicians, for example a ward or speciality group, to operate from a position of collaboration with, rather than suspicion toward the patient. A culture of acceptance, non-judgement and respect appeared to be the foundation from which care should be delivered and this correlated with better patient outcomes. This did not mean that clinicians in these situations merely "gave into" patient demands, particularly for increased opioids, "it would be a whole lot easier to just give them what they want". On the contrary, on many occasions it was these clinicians who were responsible for implementing and supporting treatments, particularly in relation to the management of opioids, which the patients often vigorously contested.

For me I'm looking at establishing good relationships and rapport with patients and their families. If people trust you enough they will tell you a story about their life. Then sometimes why they are in horrendous pain makes perfect sense. So I'm working at this level, validating the patients' experience of their pain. It's about getting a picture of what's going on and helping them establish a plan – it helps create a flexibility that they can work with. I offer a familiar face, who knows by this stage quite a lot of the story, being able to draw on past experiences for that person. I've got a sense of who they are and what they might be able to do (Psychiatry Liaison Nurse Consultant).

It is unclear whether the therapeutic benefit that patients derive from these long-standing relationships are a product of them feeling validated in their physical complaints, or stem from a sense of feeling worthy of such encounters, or devolved from the sense of connectedness they might encounter from such long-term connections, "those nurses are like second family to me". Discussion related to the relative motivations of and benefits for these patients of being frequently hospitalised are considered under heading, 7.5.4 Minimising Disruption: A Meaningful Life. However, what is clear is the consistency within and between all patient, family and carers' responses regarding the sustained support that clinicians operating in these dimensions have offered over many years, with many acknowledging that without this support, particularly during hospitalisations they (patients') would have "fared much worse".

She has been a marvel for me over the past 17 years....she puts things into perspective for me she makes me think...she takes time to listen, she gives good advice and ideas...so I can have a better quality of life...she is positive, she motivates me...she understands where I am coming from...she's a real support....if I could put her in my pocket and take her home I would...I've never liked psychiatrists because I don't think there is anything wrong with my brain...I'm not stupid.....psychologist seems better, psychiatrists seem that you're mentally ill, psychologists are like a benefactor, a helper with your emotions....the most important thing is she doesn't judge me and she's there if I fall off the band wagon (Patient).

Commenting on their ability to achieve positive therapeutic outcomes (reduce patients' distress such that productive engagements and helpful treatments can be achieved), "good" clinicians consistently reported a number of features within their practice. Central to these practices' was a treatment orientation where they understood that *"I don't feel like I have to fix everything"*. In addition, these clinicians had a focus on supportive rather than curative care; a willingness to engage in partnerships rather than adversarial competition with patients and families; a preparedness to work with patients journeys of mutual discovery about managing particular situations; and a flexibility of practice, offering a range of treatment approaches to *"meet the patient where they're at"*. These approaches appeared to facilitate a therapeutic window within which these clinicians were able to *"engage"* and work productively with patients.

Helping them take some control, to make decisions about how do they, why do they, and what do they think is wrong and how long they think it will take before they get better...//...if you can have some flexibility in establishing a plan it gives the patient an element of control over what's happening to them. Without it I think they'd be even more difficult to manage. It's not a definite model we use; there isn't much in the way of evidence to support it – it's the eclectic stuff we use. The mindfulness, the CBT, supportive contact, the patient advocacy and facilitating, I think what we offer...I don't know how you measure it; like maybe anyone could do it or is it because of my personality that I can do it, I'm not sure. But I do believe it makes a difference and quite often in ways that people may not even recognise (Psychiatric Liaison Nurse Consultant).

#### **7.3.1.4 Reflecting on patient–provider relationships**

To complement the supportive roles "good" clinicians provide for patients at the study hospital, these same clinicians reported offering additional support or *"liaison work"* to other health care professionals involved in study patients' inpatient care. These

activities were considered by the majority of study participants to be significant, in that they helped to integrate care among and within clinical treating team(s), patients and families, and to facilitate as far as practicable the ongoing psychosocial support these patients require beyond hospitalisation and into the community. The consistent positive appraisal of the outcome of these activities from all stakeholders is that these roles help to “contain” patients during times of hospital admission and to some extent reduce and prevent behavioural escalations that might otherwise result in unnecessary hospital admission and prolonged hospital stays.

On the odd occasion I have been called to the ED and have been able to deflect an admission, often if we can come in fairly early we can settle the situation, you can get some idea of what the crisis is that’s driving the presentation and set a plan in motion early that the patient might be happy with (Nurse Consultant).

“Good clinicians” also direct efforts toward helping other clinicians contextualise patients’ presentations within a broader paradigmatic biopsychosocial orientation. Within this mandate, they attempt to respectfully challenge clinicians’ inclinations for dualistic treatment approaches and help educate about the futility of applying reductionist paradigms to the management of patients who have significant biopsychosocial issues. Hence, it is not surprising that clinicians working in this manner see their roles as educative and facilitative of treatment reforms.

Usually the referring team are asking: Is there a psychiatric component, or a psychological component to the pain? We are trying to teach the medical team that they are asking the wrong questions. So I see my most important role is to work at the systemic level to try and steer things together, so that everybody is on the same team, so that the patient, the family and all the staff can adopt a more holistic model and start to look at things in a more combined way. So that everyone can see the impact that their psychology has on their physical and the whole vicious cycle...//... working with patients so they actually believe it (Psychiatrist).

Despite the well-recognised benefits of including these clinicians in the patient cohorts’ inpatient care, a number of issues conspire against their initial, ongoing and consistent involvement. The most difficult to navigate are the historically embedded practices of delayed referrals to services such as liaison psychiatry. Such referrals are contingent upon admitting clinicians (surgeon, gastroenterologist, and gynaecologist) considering

it appropriate and necessary to invite mental health professional input. All but two of the study patient cohorts' referrals to psychological services occurred late in their illness trajectories. As such, significant inputs, such as surgery, had previously been implemented and consequential patterns of acute biomedical care orientations established, repeatedly reinforced and ultimately entrenched. The sequential rather than integrative nature of these clinical inputs, undoubtedly underpin patients' subsequent reluctance to engage in these contacts. Patients in these situations, aware they have *"failed"* the normative expectations of the biomedical model, *"I don't fit into their nice little box"*, tend to view such referrals as declarations of clinicians' suspicions of their authenticity and an indication that *"he thinks it's all in my head"*.

While patients assess the quality of their relationships with health care providers based on the degree to which clinicians are prepared to engage positively with them, clinicians report being sceptical about patients' perceptions of what constitutes a positive clinical encounter in these contexts, stating, *"what they think they want, is not necessarily what's good for them"*. In these situations, if biomedically orientated clinicians, in addition to taking the time to *"hear"* patients, are able to provide explanations for ongoing pain, *"the pain is there because the adhesions are wrapped around all my major organs"*, or even better still, can give organic diagnoses, *"pseudo-obstruction"*, and more importantly provide hope for restorative treatments, *"we could look at implanting a morphine pump"*, then such clinicians tend to procure a revered, rather than good status among patients, family members/carers.

Dear old X, I just loved him he was a gorgeous man, oh he was absolutely wonderful, he saved my life he took out my gallbladder. Every time I'd get a bout of pain after that he'd pop me back into X (hospital). He'd just nick the end of the bile duct, because apparently it's a common complication of a cholecystectomy that the end of the bile duct covers over, but mine was a bit worse than most peoples. After the nick in the bile duct, things would settle but after he did the third nick and the pain didn't go away he said that was as much as he was prepared to do. Then I went to X, he was a lovely man and he started me on the pethidine injections and that would calm it down (Patient).

Such encounters appeared to serve a number of purposes for patients. For some they provided the necessary semantics, that is, the social capital necessary to engage with subsequent clinicians from a more assertive platform, *"I know everything there is to know"*

*about my condition, more than they do and I can speak confidently about it". For others, the encounters provided long sought after biological explanations, however implausible or erroneously applied, to symptoms previously labelled as inexplicable. The accompanying explanations and semantics thus provided patients with not only the validation they required for themselves, "it was just good to know it wasn't all in my head", but also with the necessary information to contest suspicious clinicians and hence facilitate their continued navigation through the system, "when he saw the X-ray and saw the bowel obstruction he had egg on his face, but I didn't want him to come near me after that".*

However, what was characteristic of these interactions was that while these relationships remained biologically focused, patients and clinicians reported harmonious interactions. When such approaches were challenged because clinicians felt either complicit in *"reinforcing inappropriate health care behaviours"*, frustrated by the lack of progress, *"you never get anywhere with these people"*, exacerbated by the *"futility"* or overwhelmed by the complexity of the situation, tensions ensued. In contrast to the long-standing relationships good clinicians cultivate with these patients', relationships with biomedically revered clinicians appear characteristically time limited. Time limited in the sense that once these clinicians appeared to reach individual thresholds for their professional, intellectual and personal resources, relationships were typically terminated. This appears particularly the case in the earlier stages of these patients' illness trajectories and highlights patients' tendencies to have encountered numerous and fragmented care provisions during that time. While clinicians explained their withdrawal within the scope of having, *"little else to offer"*, patients interpreted such events as them being *"abandoned"* or *"slushed off"*.

In the beginning, I mostly had one doctor and he was very helpful (referring to diagnosis, treatment, pharmacological and extensive surgeries). Toward the end he said 'no more I can't do any more for you'. I think this was because the psychiatrist rang him and told him it was all in my head and that all the tests and treatment I was having were invasive and were of no use and that they shouldn't be happening and they should stop immediately. I had to in great distress go back to my doctor and beg him, beg him and say it's not in my head, it's not psychological and 'please you have to believe me'. Then he wrote a letter to all my specialists, all of them, my gynaecologists,

endocrinologist, all of them and said I was exhibiting this bizarre behaviour and that everything was psychological, it was horrendous it was pure slander. After that, we moved up here (relocated to a different LHD) and I started seeing all the specialists up here (Patient).

On the few occasions when contacts with biomedically orientated clinicians did not generate biologically focused outcomes, patients' ongoing positive appraisals appeared to reside in the clinician's ability to convey a sense of compassion, truthfulness and frankness about inexplicable symptoms and unavailable treatments, accompanied by firm but sensitive declarations that future managements ought to be directed toward symptom management rather than cure. The significance of listening to and validating the patients' physical complaints and symptomologies, rather than challenging their reality, or worse still, attributing them to an apparent psychological deficit on the part of the patient appeared to make available the therapeutic window discussed earlier. Thus patients, having felt respected and validated seemed more receptive to redirecting their pursuits of validation through biomedical diagnosis and cure to working with clinicians to manage their futures. Whether patients embraced this opportunity appeared to be related to the perceived "*authority*" and "*expertise*" of the clinician; the extensiveness of the physical examination; the ability of the clinician to instil hope for the future; and a sense of commitment they sensed in the clinician's resolve to support rather than abandon them.

He sort of said this is how it's going to be for the rest of your life. He had some powerful statements. He specialises in this group, he's studied it and studied it. He speaks at overseas conferences a lot because he has perfected this type of pain. I appreciated him being so blunt – everyone else seems to be dancing around it a bit. He also said I might wake up and one day it will be all gone. It was good seeing him because it was like this is the way it's going to be from now on. I'm not going to be able to change it. So that gave me the mindset to set the path that my life goes. I accepted it was about: let's manage the pain, let's get me to the stage where I don't have to keep coming to hospital every 2 weeks, let's keep me out of hospital (Patient).

In contrast to positive therapeutic alliances, clinician participants recognised those circumstances when clinical encounters for patients and families were problematic, electing to describe such encounters as "*unhelpful*" at best, and "*harmful*" at worst ; "*we have big challenges with the culture on the ward there; they are not very tolerant to these*



*patients. You know a vulnerable patient like X who was at the critical point of change and they come in and put knives in her back, calling her a drug addict and accusing her of being drug seeking, it's all very negative".* When clinicians operate without the foundation of trust and engagement, patient health care provider relationships become difficult.

A lot of my work comes down to just negotiating with these people, trying to get them to accept the treatment, but usually it doesn't happen because of the pain associated with eating or the rate of the enteral feeds causes too much pain, or they can't get lines in for the TPN. It's just not about providing the right diet – it's so complex, they are just always negotiating their care, negotiating and negotiating. These people are very difficult; it's like one disaster after another; it's very frustrating. It's all the negotiating, it's really quite sound advice but trying to get these people to engage, they just won't go there and the one I'm currently working with ended up in acute renal failure essentially because she wouldn't have the rate increased, they are quite rigid and difficult people (Dietician).

In these situations, therapeutic alliances are challenged and treatment impasses arise.

#### **7.3.1.5 Minimising disruption: A meaningful life**

Being in hospital for 3 months at a time must appear to them to be better than being at home, maybe that's a reflection of how bad their problems really are, that they see this as better than being at home (Gastroenterologist).

Clinicians' concerns about patients' tendencies to have their *"whole lives revolving around attending clinics and getting admitted to hospital"* were adamant that any proposed model should address, an orientation toward helping patients maintain and *"achieve some sort of life"* outside hospital. All speciality members acknowledged the entrenched nature of study patients' contact with the health service; *"this is their social outing, and we are their social network"*. While some considered the behaviour as *"opioid seeking"*, the majority saw patients' determination to have other needs met, *"hospital is home; hospital is safer than the outside world"*.

There's so much I'd like to say to them, when we get these young girls you just want to get them and shake them and say 'what are you doing to yourself, what is this all about, what has happened to you, why is your life like this, why do you need all these drugs? I want to listen to you, you poor thing how did you get here, don't you realise that you could be doing this and that, your life could be better, you've got a life to live, come on get up and get out there', but you can't say that to them,

because if you did they'd be off to the customer complaint unit. Secretly I think they're happy in this role, they don't want to get back to any other life (Surgical Nurse).

In displaying compassion for these people, whilst conceding *"frustration"* and at times *"anger"*, clinicians acknowledged the futility of caring for these patients, *"we never get anywhere; it's like a revolving door"*. Some clinicians have cared for these people over 15 years, and have come to appreciate that current treatment approaches are inadequate and misplaced in terms of meeting, either the *"conscious or subconscious"*, needs of study patients', *"it's like their needs can never be met"*. Clinicians highlighted a number of characteristics *"saboteurs"* that enable and reinforce these *"unhelpful and destructive"* circumstances.

We forget these people start young; this is their socialisation, this is their identity, we do our utmost to get these people through their acute phase, get them off all their drugs, then we throw them back out into the real world, the GP doesn't back our plan, and follow what we've established. The patients themselves feel over whelmed, their personality profile, being suicidal or whatever, then there's the family control, sometimes you feel like if you could remove the patient from the family things would be much better. It has to be said that sometimes the family like the sick role of the patient, it suits their needs, and you know they're the martyrs, whether it's the husband, mother or partner, and so we end up back at square one and we do it all over again" (Surgical Nurses).

Hence, in seeking resolutions about how to potentially improve the situations of current patients in addition to not *"repeating the same mistakes"* with emergent patients, clinicians' responses illuminated their deeper understandings of the study phenomenon. Clinicians were clear about the infrastructure, support and paradigmatic realignments required to more effectively determine, implement, organise and support a new model of care. However, the more cautious and ambivalent amongst them expressed a view that , what we conceive, even within seemingly contemporary health redesign efforts, might fall short of what is *"really required to manage the problem"*, by which they were generally referring to patients *"deeper needs"*. Clinicians' concerns were that health system efficiencies might be improved through proposed redesign efforts, but these gains might not translate into improved and meaningful patient health outcomes, particularly for those currently entrenched within the acute care system, *I don't think we can achieve anything with these people, it'd be better to put resources*

*into early intervention". Clinicians saw the recommendations of the chronic disease model and its potential to offer general improvements, without attention to the particularities of the cohorts' needs. There was a need to work with patients and others to help them identify and understand motivations and perspectives of their illness. Otherwise success in achieving patient specific improvements would most likely be modest, "it comes back to what are we trying to achieve with these people, do we keep them out of hospital just for the sake of it, what is a good outcome for these people?"*

## 7.4 Discussion

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Patients with chronic and complex care conditions and particularly patients with ill-defined or poorly explained medical symptoms have been consistently reported in the literature as describing difficult and unhelpful relationships with health care providers. Considerable attention has been directed toward highlighting the nature, significance and impact of these difficult relationships and the consequential effects on patient outcomes. Central to these reports are the problems associated with stigma, vulnerability, marginalisation and powerlessness that chronically ill patients experience (Werner & Malterud, 2003; Nettleton, 2006; Thorne, 2006; Skuladottir & Halldorsdottir, 2008; Upshur et al., 2010; Wright & Jones, 2012). These study findings support those of other reports on patients' encounters with health care professionals.

Achieving positive therapeutic relationships that translate into improved health outcomes for patients has been reported to stem from both the personal and professional attributes of the clinician (Rigby & Alexander, 2007). Within this notion are the "therapeutic use of self" and the associated elements of self-awareness, self-consciousness, self-concept, reflexivity and self-regulation, observation and efficacy as a clinician (Shattell et al., 2007; Brazier & Powell, 2008; Fox & Chesla, 2008; Wright & Jones, 2012). Much has been written in the psycho-education and chronic diseases literature regarding the patient-provider relationship and the inherent value of the clinician's use of self when attempting to engender therapeutic relationships that facilitate positive health outcomes for people (Thorne & Robinson, 1988, 1989; Wagner et al., 1999; Thorne, 2006; Kralik, 2010; Lubkin & Larsen, 2013). What has become apparent from the literature is that patients, particularly those with chronic illnesses,

value highly the connections that clinicians make with them. It is within these connections, when clinicians are able to share something of themselves that the most salient, productive and facilitative exchanges appear to emerge (Fox & Chesla, 2008).

Conspiring against the provision of what all parties understand to be a therapeutic relationship is the patient's history, the environment and the paradigmatic orientation of contemporary health care service provisions (Wileman et al., 2002; Upshur et al., 2010). As discussed in Chapters 1 and 2, and as Bortz suggests, because of its evolution and the nature of health care it has strayed from its "central commitment to well-being and become industrialized" (2011, p.5). As such, health care has become "culturally deluded" within its disease centrality. Many authors have also acknowledged the powerful influences of the industrialised, technocratic and highly specialised and consequently fragmented care that has become health care. This fragmentation of care influences and underscores patients' inflated expectations of what medicine has to offer and highlights the growing disparity between patient and provider expectations (Illich, 1975; Morris, 1993; Gabe et al., 1994; Kleinman, 1995; Golub, 1997; Lupton, 2012). It has resulted in what Thorne and Robinson (1989, p.153) refer to as, "the dehumanization of health care services" and the "erosion of health care relationships".

Fox and Chesla (2008) in a phenomenological study of the effect of the patient-provider relationship on the management of chronic illness in 25 female patients identified that developing connections with health care providers positively influenced patient outcomes. In doing this, patients achieved an increased "sense of security and trust that reduced their levels of anxiety and made them more confident and motivated to attend to the "hard work demanded of their chronic illness" (2008, p.117). Similar to this patient cohorts' tendency to utilise constructs such as "*family*" to describe the quality of connectedness they have with "*good clinicians*", Fox and Chesla's (2008) study patients also referred to their connected health care alliances being akin to having a "husband" or a "coach". This illuminates the extent to which patients from both studies perceive the benefit of physical and emotional supports they receive within these relationships.

In a paper co-authored by a mental health nurse and a patient with borderline personality disorder and a long history of self-harming (Wright & Jones, 2012), the patient's perspective of encountering a therapeutic relationships is reported. The patient had been engaged with the mental health services (20 years) in the UK for mental health treatments (including admission to a 'secure unit') from the age of 17 years. Her first experience of encountering a therapeutic relationship with a health care worker was described as "a turning point". A turning point she attributed to developing a "working relationship based on trust, mutual honesty, respect and decency" (Wright & Jones, 2012, p.31). In her descriptions of the relationship, the patient refers to the ability of the nurse to share something of herself within clinical encounters; "it wasn't anything deep, not like how she knew my history, but she was able to share something of herself with me" (ibid, p).

Thorne and Robinson (1988, 1989, 1990), provide an "insider's perspective" into the evolving nature characteristic of health care relationships among clinicians and chronically ill patients and their families. Considering the authors conceptualisations of patients experiences in encountering relationships with health care providers offers particular relevance within the context of this study. The authors describe patient-health care provider relationships traversing three discernible phases, those of "naïve trust, disenchantment and guarded alliance".

During initial encounters with health care professionals, patients and families, "naively trust" that their experiences with chronic illness would be "understood, enhanced, acknowledged and respected". Further they believe that decisions will be "collaborative and cooperative" and "mutually negotiated" (1988, p.297). When these expectations are not met, and "attitudinal misalignments" prevail, patients and families reportedly moved to a phase of "disenchantment". During this phase, patients and families, reported being frustrated, fearful and dissatisfied with their relationships with clinicians, describing care provisions during this time as "adversarial". During this phase patients and families negotiate the difficult terrain of health care services in order to gain what they require to "live well with chronic disease"; too little and they risk negative outcomes, too much and they risk reprisal and "diminished good will"

from health care professionals. Operating within these perpetually emotionally demanding situations, patients and families reportedly had emotional outbursts, described by the authors as “temper tantrums”. The “discomfort” of these situations reportedly mobilises patients and families to “reconstruct trust in health care professionals” in order to seek a more sustainable position, a phase Thorne and Robinson (1989) term as, “guarded alliance”.

Within “guarded alliance” the authors describe four relationship types that patients and families adopt in order to sustain contact with health care services. The first, “hero-worship”, is where an individual is elevated above the health care system. In these situations, ongoing contact with the system is facilitated by the supportive contact of the individual. The second, “resignation”, arises when patients and families become aware that their needs will not be met within the system and hence requisite contacts characterised by “going through the motions”. The third and that which largely characterises study patients’ orientations is one of “consumer”. Within this orientation, Thorne and Robinson (1989) describe how upon becoming aware that they do not conform to biomedical norms, patients and families, threatened by the prospect of encountering difficulties accessing care, mount considerable efforts toward becoming well versed in the “policy of the system” and the “behaviours of individuals” so that they can, “manipulate, negotiate and anticipate” situations in order to have their health care needs met. When patients move beyond the phases of hero worship, resignation and consumerism, Thorne and Robinson (1989) suggest, after having reconceptualising trust, relationships with care providers are enacted from an orientation of “guarded alliance”. Within this orientation, patients and their care givers mutually acknowledge the limitations of medicine and through “reciprocal and negotiated alliances” eventually take responsibility for their health care (Thorne, 2006, p.7s).

The guarded alliance model of health care relationships illuminates some of the behavioural manifestations characteristic of dissatisfied chronically ill patients and their families at the centre of this study. This study extends Thorne and Robinson’s (1998, 2006) conceptualisations in revealing what happens within patient–health care provider relationships when patients’ motivations are not directed toward, “living well

with chronic pain”, but remain committed to biomedical constructs of, *“this pain has got to be coming from somewhere”*. They seek biomedical treatments in attempts to have subconscious needs meet. Compounding these situations is a lack of human resources and infrastructural services to support and partner chronically ill patients in appreciating and understanding the limitations of medicine. According to Thorne and Robinson (2006) such appreciation are a requisite for patients acquiring the mutual trust and collaborative outlook to achieve a better future.

Considerable work has been published regarding treatment approaches to help patients reconceptualise unhelpful thought processes and health seeking behaviours related to pain. However, these approaches have been largely confined to the scientific orientation of cognitive psychology. Within this approach, cognitions, the mental acts of processing knowledge, are considered to be related to psychological processes within the brain, and hence influence one’s perception about personal circumstances (McLeod, 2007). Using this psychological framework, cognitive behavioural psychologists work with patients’ to identify and reconstruct unhelpful thought processes, an approach that has indisputably provided the basis of psychological inputs into contemporary management approaches including those associated with chronic pain (Gatchel et al., 2007). Perhaps what clinicians in this study recognised was that even when using well-validated evidence-based approaches there are those cases that are ‘particular’ and that in subscribing to the ‘general’, one will potentially fall short of producing meaningful outcomes.

The accounts and considerations regarding good clinicians’ abilities to engage with and affect positive outcomes for study patients’ reflect treatment approaches that account for these patients’ particularities’. This extends beyond simply being able to achieve positive therapeutic alliances within biopsychological frameworks. Describing their practices as largely *“eclectic”* in nature and not well founded in *“the scientific literature”* and thus *“not quantifiable”* these good clinicians appeared tentative in appraising their therapeutic successes arising from anything other than *“personality”* or inherent within a particular clinical discipline, *“we’re just the nurses”*. Whilst it is apparent these clinicians’ therapeutic successes are derived from being effective and

reflexive professionals, others appraising their practices concede that it is the perspective from which these clinicians engage patients that engenders successful patient and therapeutic outcomes. It seems that an orientation toward humanism is central to therapeutic advances being achieved by good clinicians. This orientation, inherent in humanistic psychology is an approach that emphasises the whole person and it is concerned with human experience and subjective perception where human behaviour is seen as connected to and reflective of a person's "inner feelings" and "self-image" (McLeod, 2007).

Within this study, patients recounted attempts at trying to achieve, as they expressed it, *"a more meaningful life"*. They mentioned tending to such things as, *"remaining employed, however part-time; that is, so I still have something left, then at least I won't fit their stereotype of a substance abuser"*; and giving themselves milestones, *"seeing him start school, go to primary school, high school, get a job, a girlfriend, get married"*. Conversely, others appeared to have lost sight of any association with wellness, such notions having evaporated behind identities of being *"very, very unwell and extremely physically and emotionally limited"*. Within patients' narratives of what represents a typical day, considerable disappointment and sadness underpinned by a loss of life's maps, destinations and associated self-identities were accompanied by a sense of helplessness and desperation about how to navigate oneself back toward a more meaningful life, *"I don't even know what being well is anymore"*. For all but three study patients (one needing to go to work, the others needing to drop children at child care and preschool), days are spent at home, inside and tending to the business of being ill, *"I'm in bed, or on the lounge, I don't move, I don't go outside I can't be bothered I think I've just got so used to being inside, I'm sick of being sick, I just want to die, I've had enough. I just feel like such a burden to everyone, and the guilt, the guilt the impact on everyone, I'm such a waste of space, and I'm not motivated. I just don't want to cope anymore"*. These accounts were supported by family members and carers, who stated, *"there is no quality of life, we don't go anywhere, and we don't do anything, it's not worth it"*, and illuminate patients' alliance with and entrenchment within an illness perspective.



For chronically ill people to return to a “wellness in the foreground” perspective (Paterson, 2001) they require insight about how their lives have become primarily focused on their illness and to resolve or accommodate the situation. Clinicians determined to provide effective help would do well to consider these points. Employing a humanistic, rather than scientific psychological (cognitive) approach, in addition to implementing system redesign efforts (the chronic disease model) would facilitate the improvements necessary for patients and families to achieve a meaningful life that is not entwined with the acute care system. Such an approach could renew health care providers’ satisfaction within these contexts, resulting in more effective collaborations and hence less hostile encounters in the event patients do require treatments for acute physiological events.

The discussion presented in this section has focused on the helpful and unhelpful nature and features of clinical encounters related to the study phenomenon. Participants identified a number of key treatment essentials, particularly in relation to the therapeutic relationship and the orientations of and therapeutic intent within which such encounters occur. Significant attention has been directed toward these features within this chapter, reflecting study participants’ main focus and concern in addition to highlighting the critical nature of attending to these fundamentals if improvements in the management of persistent abdominal pain are to be achieved.

No matter how contemporary, well-resourced, validated and evidenced a treatment model is in providing optimal care for patients such as those in this study, what remains is that patients in these situations can have a vested interest in being unwell and hospitalised, “maintaining identity as a sick person and providing evidence that the illness is real” (Paterson, 2001, p.24). Whether the roots of this behaviour are in early histories of abandonment and a lack of connectedness bears consideration; it is what Paterson refers to as the “psychological context” within which the illness is experienced. For study patients, being unwell has become an identity, an identity that is reinforced by their narratives, stories about themselves that they tell to themselves and others that perpetually define their orientation of being unwell, pained and

debilitated. Being in hospital validates this conception and highlights their orientation to an “illness in the foreground” perspective (Paterson, 2001).

## 7.5 System redesign: Consistent, coordinated, shared and integrated care

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Good management rests in compassion for the person but at the same time developing a thoughtful, streamlined minimalistic plan (Surgeon).

Attention to how care is organised and delivered required consideration in redesign efforts. The following section concentrates on the frameworks and processes identified by study participants to deliver better care to study patients. In making recommendations, clinicians identified the care processes and the patients’ illness behaviours that they believed underpin ineffective and harmful care:

You do all this work then you know she’ll just go to X hospital and the surgeon there will say ‘oh you’ve got this or that’ and they admit her then she eventually comes back to me and I’ll think to myself – no way. The discrepancies between the different teams looking after these people are difficult and it’s confusing for her (GP).

Participants recommended that care be consistent, integrated, shared and coordinated. However, the sociocultural constructions of the patient illness experience, as reported earlier in the study, highlight how situations, expectations and individuals work to reinforce these constructions and conspire against patients moving to Paterson’s (2001) “wellness in the foreground perspective”.

I’ve been hurt so many times because people use you and abuse you, I don’t get involved anymore, I used to I’d get sucked into people’s (other patients in hospital) sob stories , there’s a group of people who are in all the time, but I don’t want to get involved anymore, I’m too sick for the crap, but when you’re sick all the time you just want to know that you’re not alone, that there are others just like you, that you are normal and in today’s society and that you’re not a freak, we all just talk about our situation, about the things that happen on the ward, it helps when we get together if the nurses are being bitchy or whatever, we’re a support group for one another (Patient).

For study patients, hospitalisation provides an opportunity for social connection, a connectedness through familiarity with clinicians and other patients; it serves to relieve

the social isolation that being confined to bed and home imposes. These connections bring welcomed opportunities to feel worthwhile, however menial and misguided health care professionals interpret such events. The opportunity to harness a sense of self-worth, otherwise lost in the monotony of *"always being sick, just sick, sick, sick"*, and negated by the belief of *"feeling redundant"*, becomes a powerful motivator for patients in these situations; *"it's a rest from all the horrible things in their lives"*. Clinicians help reinforce self-worth by engaging these patients in the housekeeping activities of the ward environment, *"usually the girls (nurses) try to find a few jobs for her, defrosting the fridge and restocking equipment"*. As a result, patients feel their efforts are worthwhile, *"the nurses get really busy down there so it's good to help out"* and such situations as described by one participant provide an opportunity to have a brief encounter with *"how to live with myself"*. Further, the potential to mitigate the feelings of guilt associated with the impact the illness has on significant others, particularly children, by making sense of its existence as a means of providing support or service to others was a recurrent theme across participant patients' understandings of their circumstances. Patients pointed to these powerful reinforcers when asked if there was anything good about being in hospital:

There have been lots of opportunities for me to communicate with other people, there have been circumstances when people have been in great need and I have been there for them, and said or done something that has answered their needs. They tell me 'oh I'm so glad I meet you I wouldn't have survived without your help', they thank me for supporting them and showing them the ropes (referring to understanding the nature of the clinical environment). If I can just help one person, help them negotiate and survive the system, help them get the care they need, help them with the knowledge I've got then all the misery and horribleness of my life might be worth it, maybe that's the reason I'm in this position (Patient).

Apart from paradigmatic perspectives previously discussed, inconsistent care provided by clinicians poses one of the major challenges at the heart of the study phenomenon. When inconsistent and fragmented health care is delivered by clinicians operating within speciality silos, particularly in acute care environments, problems arise.

Generally when things go wrong it's because of isolated clinician decision making...//...she had a total colectomy for the management of opioid-induced constipation. The surgical person was responding to the patient's distress, and not playing by the team approach decided to chop her bowel out, just to shut her up. When you're an isolated clinician, it's hard. But, how to get to a point where, if a surgeon is contemplating surgery, he comes to the team and has a discussion first, that's the kind of teamwork we need (Anaesthetist/Pain Consultant).

In these situations, tensions surrounding incongruous treatment pathways underpin confusion, frustration and anger. All stakeholders recounted occasions when inconsistencies within treatment approaches not only sabotaged advances but also led to prolonged and difficult inpatient journeys, potential damage resulting from iatrogenesis and increased pain and distress for patients and families.

During the last admission my gastroenterologist was suggesting that I needed to have two tubes put in, one to aspirate and the other for feeding. Then he went on holiday and the next gastroenterologist absolutely refused to do it and said it was the wrong thing to do. Often there are two different camps and we are stuck in the middle, we didn't know what to do so we waited for the original gastro doctor to come back, and so it was another 2 weeks before decisions could be made. So that was another 2 weeks in hospital, not that I was well enough to be discharged anyway (Patient).

Clinicians suggested a lack of infrastructural and organisational support did not help them manage difficult and complex patients.

The system doesn't support us at all, it is geared to dealing with reasonable people not ones who are trying to exploit the system, so we're the ones that actually need the support to manage these patients. They go off to the patient complaints unit, but who can we get to help us? (ED Physician).

Clinicians saw these issues as instrumental in maintaining the problematic behaviours of patients and undesirable outcomes. The ability of patients to *"expertly navigate the system and exploit its weaknesses"*, particularly in relation to poor communication within and between hospital inpatient teams, and between local hospitals, particularly EDs and between primary and tertiary health care professionals, provide opportunities for patients to, *"play carers and hospitals off against one another"*, such that *"the left hand doesn't know what the right hand is doing"*. This enables patients to *"manipulate their care"* in order to achieve what it is *"they think they need"*.

You'll discharge them and then you'll see them out in the waiting room ringing an ambulance to go to X (another) hospital's ED (ED Physician).

It would seem implausible that patients have the potential to *"direct their own care"*. However, what has become apparent is that, in part, this potential has been facilitated by the inadequacies and inefficiencies within the system. Poor communication among clinicians leads to ambiguities in treatment approaches and therapeutic intents. Inadequate resources, particularly in relation to timely access to pain and psychological clinical inputs, delay appropriate care orientations and hence foster and promote a dependence on biomedical inputs. Poor communication among primary and tertiary health care providers leads to fragmented care. Lack of authoritative organisational support and clinical governance directives encourages individual/craft group siloed treatment approaches, rather than fostering multidisciplinary peer review of these complex cases. Lack of support and infrastructure for these patients in the community encourages a dependence on the acute care system and hence discourages self-management approaches. Thus, without the necessary infrastructure and supports required to manage these patients more appropriately, they will undoubtedly remain attached, by default, to the acute care system. Because their place within this system is incompatible with the purpose and function of that system, they will continue to be at risk of receiving, misguided care. Clinicians whose roles are primarily devoted to saving 'life and limb' will continue to be challenged by their sense of professional purpose in tending to these patients. These clinicians will invariably continue to resort to prioritising care for the acutely ill, and in the absence of any reliable, appropriate care alternative, continue to, at best, maintain 'the status quo' by *"containing"* patients' treatments through the deployment of *"harm minimisation"* strategies, or worse, default to the *"path of least resistance"* and give into patients sometimes misguided biomedical demands. Hence, the phenomenon will remain unabated.

Clinicians suggested that providing consistent, integrated and coordinated care for these patients was critical to achieving any improvement in their situations. They recommended integrating multidisciplinary inputs and devising individually formulated treatment plans. In describing these approaches, clinicians' responses

indicated such strategies should offer, a multimodal, multidisciplinary focus reflecting a paradigmatic orientation of holism that:

- accounts for the need to manage patients' escalations of pain
- contextualises symptom exacerbations, and ED and hospital admissions within the context and chronicity of their underlying disease
- is individually tailored toward the specific needs of the individual
- accounts for the dynamic nature of patients' underlying disease and illness progression
- is formulated and agreed upon by a multidisciplinary team, and the agreement is *"brokered between the clinician and the patient"*
- is responsive to managing the patient over the life course of their disease, with an emphasis on management
- is being supported in the community
- has attached to it the necessary organisational infrastructure and supports to provide care for patients both in the hospital and the community
- is founded on recognised and evidenced biopsychosocial treatment approaches, including the management of opioids, and
- has the necessary administrative supports and authorities to mandate care directives and adherences.

To effectively manage patients with chronic illnesses, interventions need to extend beyond adding to the "current system focused on acute care"; it requires "attention to delivery system design" (Wagener, 2002, p.59). While clinicians appreciated that redesigning the system was fundamental to achieving the improvement that patients required, they were aware that extensive redesign efforts required considerable support. It was felt that authoritative, infrastructural and financial supports would not be forthcoming from the service administrators. This led to an appraisal that redesign efforts directed toward the current cohort would be *"futile"* and that effort would better be invested in the early identification and intervention of emergent patients with chronic abdominal pain. Nevertheless, clinicians at the study site had, within the scope of their practices and jurisdictions, made attempts to improve the situation by trying,

to generate cohesive and integrated treatment approaches during acute hospital ED presentations and admissions.

### 7.5.1 Generating cohesive treatment approaches

Clinicians working closest to patients, and frustrated by inconsistent and dichotomous inpatient pathways, had already attempted to integrate and coordinate care to overcome difficulties in treatment approaches. The trial strategies involved:

- multidisciplinary case conferencing, and
- the development of individualised pain management treatment plans.

These strategies provided a reference point from which study participants could compare, contrast and appraise the utility of these strategies.

The power of the case conference has been great, she's been out of hospital for 3 months now...//...we virtually stopped all her opioids but the power to do that came out of the case conference...//...she'd really paralysed her gut from the opioids and we literally said they are killing you, so we took a strong stand with her, we took total control of the opioid thing and just said 'medically we've decided that opioids are bad for you and that they needed to be tapered and stopped', which we did. There was a lot of angst and emotional outpouring. The relatives threatened to call Today Tonight to do a story on it and it was a very draining time. We finally kind of got through it but only because of the cohesive team thing. Everyone agreed on the plan and there was no division. These people can make change but particularly at the watershed time they need a lot of resources and a lot of team processing stuff (Anaesthetist/Pain Consultant).

The acclaim that these undertakings consistently achieved, derived from clinicians' reports of a re-established sense of clinical purpose/treatment agenda and a redressing of the power imbalance they reported when patients *"negotiate"* care and *"manipulate"* health care professionals to achieve or sabotage clinical inputs. The renewed vigour for managing patients in these situations appeared to reside within clinicians' ability to share, coordinate and integrate their responsibilities for the management of these patients within a multidisciplinary framework. The agreement to adhere to the multidisciplinary treatment plan so that, *"everyone was on the same page"*, enabled clinicians to muster the necessary *"strength to be decisive about what needed to be done and to do the hard decision-making stuff"*. In addition, the team approach relieved the burden

of isolated clinicians who felt they *“carried the bulk of the responsibility”*, underpinning their positive appraisal of this approach being more broadly implemented for the ongoing management of the study patient and possibly emergent patient cohorts, *“it would be good to be PART of the team, not THE team*. Although without sanction by hospital administration or clinical governance committees, the *“power”* that clinicians conveyed regarding the revised treatment approaches was mostly described in relation to the authority inherent within a collective, cohesive multidisciplinary expert opinion, too, not only mobilise all stakeholders toward a shared goal, but if necessary, counter the criticism of dissenting clinician(s), patients’ or families.

The power and utility of the multidisciplinary case conference was repeatedly cited by clinician stakeholders as being instrumental in providing improvements in the hospital journeys for the patients and an increased sense of satisfaction for participating clinicians. Patients at the centre of these case conferences also responded positively to these proceedings, commenting that they felt clinicians were, *“all working on my behalf toward a common goal”*, providing much needed validation. Instrumental in the success of these multidisciplinary team meetings was the ability of clinicians to formulate treatment plans, including a focus on the management of opioids.

#### **7.5.1.1 Treatment plans, contracts and hospital admission criteria**

The opioid question in this group is such a vexed question. It’s such a huge issue. It is the very thing that they want, or at least think they want. When they come to the ED it becomes so much a source of their conflict with the staff, but in this group the risk of harm from opioids is significantly higher than for other groups, so the very thing they want to fix them maybe one of the key players causing their problem (Anaesthetist/Pain Consultant).

The development of a pain management treatment plan enabled more effective communication within and between hospital-based treatment teams, and between inpatient and outpatient service providers. These communications provide a predetermined treatment plan for the management of a patient’s persistent abdominal pain complaint in addition to making recommendations in relation to treatment regimes in the event of an acute exacerbation of the patient’s pain. Included in these plans are biological thresholds, clinical indicators that ED clinicians and GPs can



consider in context, when contemplating whether a particular presentation requires investigations and admission to an acute care facility. However, while largely recognised as a welcome inclusion in the patients' treatments, clinicians made frequent references to such plans being, *"buried under volumes and volumes of notes"* or *"being out-dated"* and that updates were not conveyed to other stakeholders in a timely fashion particularly between hospital staff and GPs, *"it takes me 2 weeks to get a letter saying what's been happening, and by then she's already been banging on the door saying Dr, X said I could have this or that"*.

Management plans, in the nature of a clinical contract should be established with these patients and by agreement with the principal clinical players. The contract should outline the things we will do and the things which we will not do and should address issues such as the use of blood tests, the use of X-rays, analgesia, thresholds for hospital admission, IV fluids, feeding, etc. (Surgeon).

Generally, clinicians were supportive of the introduction of treatment plans documenting biological thresholds for hospital admission and implementing opioid management approaches; however, there were some dissenting voices. These opposition were not related to the intent to improve a patient's situation, but rather were reflective of these clinicians' appreciations that, for this cohort, such imposed *"hurdles"* might be counterproductive in that *"some people will do anything to get in here"*.

It comes back to what are we trying to achieve with these people, if you're trying to just build a brick wall around the hospital and make it impossible for them to get into the place, you might just create problems (Surgeon).

While all clinicians agreed that having biological thresholds, beyond which clinicians should consider admitting patients to an acute care facility, and hence in this way contextualise patients' acute presentation profiles, many clinicians cautioned, *"It's not that easy"*. They rationalised that these patients do present unwell and that preventing them from accessing the acute care system was both inappropriate and unrealistic since *"the reality is this is how they present"*, and justifying that *"just because they are unusual, doesn't mean they can't be unusual and sick"*. These mostly senior clinicians stated that, for this patient cohort, hospital presentation and subsequent admissions can be seen as a *"circuit breaker"*, not only a circuit breaker to *"relieve them from the horrible things in their*

*lives*”, but more importantly to prevent the likelihood of them perpetually pursuing clinicians, mostly junior or unfamiliar clinicians, who might implement potentially *“extreme, unnecessary or unhelpful treatment”*. To safeguard against these situations, it was recommended that only *“senior clinicians”* should be deployed to manage these patients because of their authority within the system and their ability to navigate and mobilise it on behalf of the patient, and also because of their ability to be comfortable in the *“middle ground”* and not be *“sucked into doing anything other than supporting them with managing their pain”*. Clinicians advocating this approach, while being supportive of the generalised notion of implementing treatment plans, contracts and thresholds, were cautious about such approaches aggravating the situation and hence escalating patients’ behaviours.

If you’re just focusing on pushing them away, you’ll just create problems, like X who uses her babies to get in, I’m not joking, it’s another way of getting into the place. That’s the latest trick, and they know all the symptoms and all the presentation profiles they need to get admitted, and if you confront them it becomes a big long protracted thing and then they just dig their heels in. You don’t know what you’re trying to achieve, so you just try and minimise the damage (Surgeon).

#### **7.5.1.2 Opioids in non-malignant pain**

The use of opioid therapy in chronic non-malignant pain is a controversial subject. Issues related to long-term efficacy and adverse events (Chou et al., 2003) such as iatrogenic addiction produce significant ethical dilemmas for clinicians confronted with patients with severe and debilitating pain (Sullivan & Ferrell, 2005; Fields, 2011). Balancing the potential therapeutic benefit against adverse outcomes in these contexts presents clinicians with considerable ethical, professional and personal challenges. This is particularly heightened for chronic abdominal pain cases, where the potential for long-term opioid treatment further compounds the patients’ underlying problems (Drossman, 2004, 2008; Sperber & Drossman, 2011; Hauser et al., 2012). Nowhere are these dilemmas more evident than in the acute care environment. When a patient’s subjective reports of pain appear to escalate exponentially and their demand for ever-increasing opioids confront time-poor, ill-equipped acute care clinicians, results in an ‘insidious ramping up’ of opioid doses that paradoxically compounds problems with

intestinal motility, constipation, visceral hyperalgesia, or other underlying biological problems (Quinlan & Carter, 2012).

These issues have been extensively covered in the literature. International, national and state regulatory and professional bodies have invested considerable resources to develop: i) clinical practice guidelines, ii) consensus statements, iii) patient selection criteria, iv) opioid patient-provider contracts, and v) conditions of withdrawal from treatment to help guide and regulate opioid administration within clinical contexts, particularly in relation to the long-term administration of opioids in non-malignant pain conditions (Denisco et al., 2008; American Pain Society, 2009; Chou et al., 2009). Similarly, clinicians and researchers have contributed to the literature with case studies and expert opinion regarding the efficacy of the treatment modality (Ballantyne & Mao, 2003; Noble et al., 2008), opioid withdrawal and rotation regimes (Baron & McDonald, 2006; Wiedemer et al., 2007; Hawkins et al., 2008), and the relative efficacy of opioids for specific chronic pain conditions, including functional abdominal pain (Drossman, 2004, 2008; Sperber & Drossman, 2011). Within this literature, guidance is beginning to emerge; to help clinicians screen patients for the potential administration of long-term opioids; to determine the propensity of patients with certain psychological correlates to progress to “pain opioid downhill spiral”, whereby their condition is made worse in the presence of opioid administration; and to outline management related to the introduction, maintenance, rotation and withdrawal of this contentious treatment approach. These new understandings are now available to help guide the production of opioid treatment pathways and underpin treatment plans for this study cohort. These contemporary findings should inform the revised model of care. This would require a comprehensive review of the literature and a consensus on guidelines that could be introduced at the study site.

Implementing care approaches consistently rather than intermittently, would undoubtedly improve the lot of patients, families and health care providers. Delivering care that is pre-emptive and proactive rather than reactive and episodic could be instrumental in reducing crisis situations. To achieve this requires having care teams

that are “prepared, in that they have the necessary expertise, information, time and resources to effectively manage” (Wagner, 2002, p.59) these patients.

Having a system that is responsive to the patient’s needs is an anecdote to things escalating out of control (GP).

### **7.5.1.3 Identifying the care team**

I think we need a standard approach. The patients need to come in with the same people all the time otherwise it just perpetrates the problem. The person needs to be supported by a multidisciplinary team with liaison between surgeon and pain teams and ED, the goals of hospitalisation need to be clearly defined very early and a contract needs to be brokered between the team and the patient saying this is what we are able to achieve and when it’s done, we’re done (Gastroenterologist).

While all stakeholders had positively appraised multidisciplinary inputs, including the utility of the team approach, and identified the individual traits of productive therapeutic relationships and treatment orientations, discussions regarding how best and who best to include in a “*dedicated team*” were less definitive.

In general, participant clinicians advocated for a dedicated team, one that reflected the skills and expertise required to effectively manage patients’ individual clinical problems. In acknowledging that “*every speciality has these refractory types of patients*”, clinicians highlighted the potential utility of a dedicated team to work across speciality domains. Thus, they recognised that a small “*core team*” that responded to patients’ pain management and psychosocial needs could potentially integrate with adjunctive team members whose speciality expertise might be required in relation to a broad range of potential physiological scenarios. For example, in the case of functional abdominal pain, the team might be comprised of a pain specialist, a psychiatrist/psychologist/and a psychiatry liaison nurse consultant, with the addition of a gastroenterologist and surgeon when/if required. Expanding the concept, if a patient’s underlying physiological problem was determined to be gynaecological, the gastroenterologist would be substituted for a gynaecologist. Similarly, if there were concerns about substance abuse, expertise from drug and alcohol services should be sought. However, clinicians remained resolute that in the advent of introducing such

teams, there was a need to be responsive, *“patients have to trust that someone will get back to them if they are struggling”*. Teams should not simply duplicate other services, but rather integrate them in a more rational and pre-emptive manner.

## 7.6 Discussion

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What clinicians seemed to be suggesting was a more contemporary approach to the management of chronic illness, an approach more consistent with interdisciplinary rather than multidisciplinary team management. Interdisciplinary team management reflects an approach that has a “team working together to identify and analyse problems, plan action, interventions and monitor results of the team’s efforts that are directed toward patient and care giver outcomes” (Lubkin & Larsen, 2013, p.264). Within this approach, lines of communication between team members are “highly visible, while disciplinary boundaries are connected” (Lubkin & Larsen, 2013, p.264). This approach is in contrast to the more traditional approach of multidisciplinary care where, although representatives from different disciplines share a common goal, clinicians “typically work independently to propose and implement patient interventions” (Lubkin & Larsen, 2013, p.264). Some authors suggest that despite multidisciplinary teams’ attempts at providing a comprehensive treatment approach, that in reality any such attempt remains essentially a “series of evaluations that lead to a diagnosis by exclusion and hence implies a hierarchy of diagnostic importance, with psychiatry often the last speciality to evaluate the patient, reinforcing the belief that pain is truly mysterious and just a figment of your imagination” (Clark & Cox, 2002, p.73). Further, Clark and Cox state that, “Cartesian dualism still survives”, as patients’ pain and symptoms are usually regarded from one of the two camps as being either “organic” or “functional”. Hence, the shared, integrated and collaborative formulation of treatment plans, responsibilities and accountabilities characteristic of interdisciplinary management offers what clinicians stated was a preferred outcome for them personally, that is, *“to be PART of the team not THE team”*. Clark and Cox contest dualism by suggesting that the approach “emphasises that all diagnoses are real and when a specific diagnosis cannot be made a cause has simply not been discovered” (2002, p.74).

There is something in the mind gut interaction that we don't fully understand as yet (Gastroenterologist).

The preferred orientation toward a more collaborative and integrated treatment approach was best described by a participant gastroenterologist when he suggested *"When care is medically centred it is paternalistic; When care is patient centred it is chaos; When care is problem centred it is coordinated and integrated."*

Clinicians were unanimous in their recommendations that a central figure was required to coordinate activities on behalf of the team and to facilitate communications between the tertiary and primary health care sectors.

There are actually generations of these hard-core patients coming through now. So if you're just focusing on pushing them away sometimes you might just create problems (Surgeon).

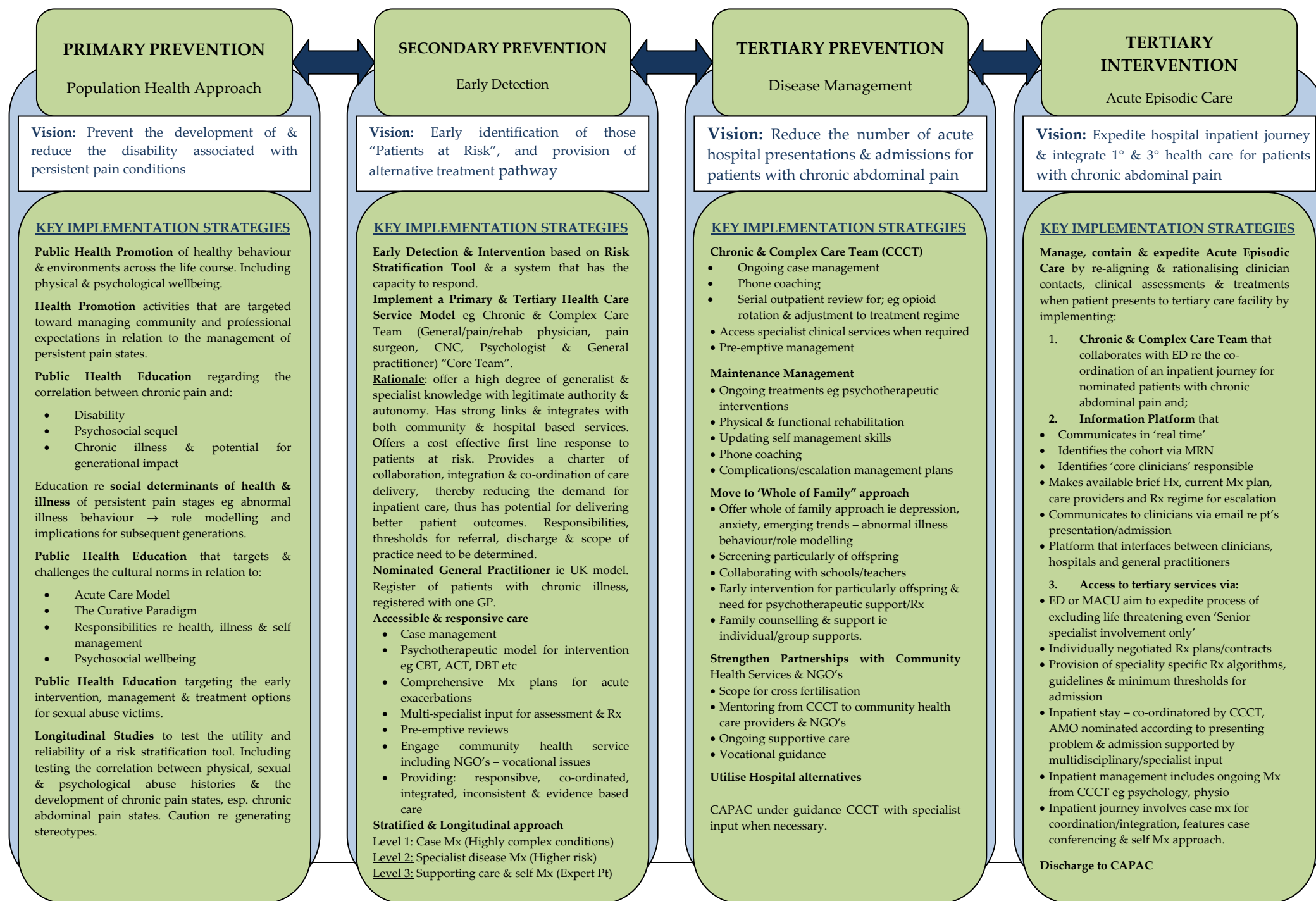
Enabling care provision and support for patients in the community and providing longitudinal rather than episodic management to patients was deemed necessary.

We need better resources and wider community involvement for this group. They obviously need full time support of some description and if they had this support they might lessen their presentations and decrease their LOS and there might be less of an incentive to come into hospital if their needs are being met in the community (Surgeon).

Participants recommended that a revised model for the management of persistent abdominal pain at the study site facility should encompass self-management and patient-centred care approaches: a, *"need to come to some sort of symbiosis with the patient and build a streamlined approach to their management that is contracted between the physician and the patient"*. However, consideration by participants included questions and issues such as: What do such care models look like? How does one implement and monitor them? What resources are required? How does the approach account for resistance or sabotage (patients or clinicians) and what is the evidence associated with the model and its ability to effect improved health outcomes? Hence, beyond the familiar rhetoric what was needed was a structured and informed approach that would identify and instruct how best to implement the principles of self-management and patient-centred care associated with improved health outcomes. This would require health service investment.

While the intent of the entire study, and in particular the fourth phase, was restricted to achieving consensus on the essential elements of the model and agreement on a treatment approach that included patient-centred and self-management principles, it became evident that clinicians were guarded about implementing these approaches without attention being given to the details and provisions, as discussed above. Clinicians were not only concerned about this because they valued evidence-based practice, but also because they did not want to perpetrate harm or cause confusion for patients and families as a result of ill-conceived and poorly resourced alternatives being offered and then subsequently withdrawn. The clinicians' care directives, even within redesign efforts, remained orientated toward "*harm minimisation*" strategies.

Whilst recommendations from the nominal group workshops were principally directed towards improving the hospital management of patients, it was recognised that efforts directed toward managing acute episodic exacerbations was part of a broader treatment approach necessary to achieve and sustain improved patient health outcomes. In acknowledging this, Figure 7.3 represents a diagrammatic presentation of how care for patients with persistent abdominal pain might be better conceived, delivered and stratified. The approach reflects the dynamic and longitudinal nature and characteristics inherent within chronic illness. Study participants have made some preliminary recommendations directed toward primary, secondary and tertiary preventative strategies with a focus on tertiary (acute episodic care) management.



**Table 7.3: A Longitudinal Approach to Managing Persistent Abdominal Pain**



Stakeholders' narratives confirmed the pre-eminence of the biomedical model for addressing societal ills. This needs to be challenged to enable a paradigm transformation from cure to management, particularly for refractory pain conditions. The importance of challenging these entrenched beliefs and assumptions about the role, purpose and limitations of medicine and health care professionals is paramount if optimal health care is to be delivered to meet the challenges of predicted escalations in chronic disease. Continuing to subscribe to a biomedical model to address a biopsychosocial phenomenon will not only sabotage the potential for patients to achieve optimal health outcomes, but will continue to perpetrate harm, not only for the patient, but also for the families of such patients, as demonstrated in this study.

Recommendations posed within a framework of primary prevention, include a population health approach. These primary prevention approaches are largely directed toward ensuring community expectations in relation to the management of a chronic pain complaint(s) are congruent with what health care providers, given current understandings, knowledge and evidence are able to offer. One recommendation was the early identification of patients at risk of progressing to persistent abdominal pain. Clinicians highlighted the importance of this work in preventing subsequent generational impacts of the disease through early detection, and timely access to more appropriate, comprehensive, accessible and responsive treatment pathways. Priority needs to be given to development of a risk stratification tool that could be used to screen and detect patients at risk of progressing toward persistent abdominal pain. A collation of study patients' shared features and characteristics (some of which have previously been validated in the literature to have correlation with high health care utilisation, pain and disability) provide a useful point of reference from which subsequent work to test their predictive validity for identifying 'at risk' patients can progress.

Throughout this study, stakeholder narratives have highlighted views and observations consistent with the literature; that is, that the sociological constructs related to pain remain firmly entrenched within the curative paradigm of the biomedical model. Societal expectations and belief in the ability of science and

medicine to provide explanations for and treatment of pain such that all associated suffering and disability can be ameliorated are powerfully reinforced by the technocratic influences that pervade contemporary health care. However, it has become evident that transforming these dualistic forces is necessary if advances are to be made for patients suffering from chronic illnesses that medicine and science cannot cure. Accepted notions of multidisciplinary work need to be contested and replaced with interdisciplinary approaches that allows for the unification of psyche and soma, whereby “the meanings generated by the mind and the mechanisms generated by the body” are considered within the broader sociopolitical context within which they occur (Broom, 1997, 2002, 2007; Clark & Cox, 2002). While Broom says that “somatic metaphor” should be considered, Clark and Cox (2002) offer a perspective approach that offers a systematic interdisciplinary approach that can accommodate the comprehensive integrative formulation of an individual treatment plan – a plan that considers the diverse perspectives from which the patients’ suffering, distress and disability arise. Clark and Cox (2002) suggest that within this framework, treatment plans that address the following four perspectives should be considered:

- i. **The patient’s life stories:** “Life stories are what people want”. Within this dimension, the authors encourage clinicians to help patients excavate their life narratives to consider meaningful connections between past events and present circumstances. This aids the re-interpretation of ‘distress provoking’ events and helps patients move toward answering the question ‘what good does life hold for me?’
- ii. **The patient’s dimensions:** “Dimensions are what people are”. Within this dimension, the authors encourage clinicians to identify patient’s personal features and traits that predispose them to strengths and vulnerabilities, and help assist patients to restore “stability” by focusing on strengths and avoiding provoking vulnerabilities.
- iii. **The patient’s behaviours:** “Behaviours are what people do”. Within this perspective patients are helped to identify problematic behaviours and their underlying design and purpose. Treatments within this perspective are directed toward assisting patients to take responsibility for their own choices and recognise the consequences.
- iv. **The patient’s diseases:** “Diseases are what people have”. Within this perspective, clinicians are encouraged to consider the causal relationship of disease and its impact on abnormal structure or function, and if not explicable then considering the diagnosis “not

yet discovered". This would help overcome the stigma associated with patients having 'false' conditions and would allow progress to be made toward optimising functional restorative approaches within a preventative (by selecting treatment that will minimise damage and subsequent damage), or a palliative orientation.

Approaching concepts of care using Clark and Cox's (2002) 'perspectives', allows patients with refractory chronic pain to be acknowledged as having a "legitimate problem with understandable suffering". The conceptual framework considers that the "patient is struggling through important life events, but also that he is a person composed of vulnerabilities and strengths, having made many choices and afflicted by disease" (Clark & Cox, 2002, p.83).

## **7.7 Recommendations on an alternative approach**

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Based on the platform of treatment re-orientation, interdisciplinary efforts that are organised and directed toward providing patients with multimodal, multiperspective treatment approaches, provide the foundation of management recommendations within each of the domains of secondary prevention, disease management, and acute episodic management (see Figure 7.3). Stratifying the "dose-response" of these interdisciplinary multiperspective inputs reflects and acknowledges that patients' needs change over time given the dynamic nature of the illness trajectory.

The proposed model is based on strategies of containment through early identification of emerging cohorts, by pre-emptive approaches to de-escalating acute exacerbations of chronic underlying conditions, and by minimising harm associated with managing multidimensional phenomenon with biological solutions. The model seeks to mitigate fear of missed diagnosis of a potentially life-threatening pathology, through the provision of shared care, responsibility and accountability. It acknowledges the multidimensional perspectives of the phenomenon of persistent abdominal pain and thus adopts a biopsychosocially driven model that validates patients' needs, acknowledges clinician capacity and relative expertise, and makes the system accountable for the support and governance required to manage the difficulties and complexities within these patient encounters.

The model seeks to encourage clinicians to respond longitudinally rather than episodically to patient needs, to allow family involvement and to include the integration of care provision between primary and tertiary service providers. Care is aimed at delivering organised, coordinated, integrated and individualised approaches to treatments aimed at restoring and maintaining a life outside hospital.

## **7.8 Strengths, limitations and reflections**

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The strengths of the study reside in the provision of a composite profile of patients who repeatedly present to a tertiary referral hospital with unresolved persistent abdominal pain, including information about the patterns and extent of health care utilisation, and the impact on all major stakeholders. The study findings shed light on the phenomenon, and informed efforts to improve the situation. The analysis of reports on the frequent and lengthy hospitalisations provided an opportunity to interrogate the impact of the presentations and the underlying symptoms from multiple view points and dimensions. During the course of the study, particularly during the nominal group workshops, clinicians from multiple clinical specialities and administrators collaborated on the development of a 'Draft Model of Care for the Management of Patients with Persistent Abdominal Pain' in acute care settings. The iterative process fostered a sense of responsibility and ownership. These are critical components that will later underpin the likelihood of pivotal clinicians' engaging and complying with a new model of care related to the study and emerging patient groups.

The commitment, enthusiasm and honesty of all clinicians were evident. This illustrates the positive attributes that can be harvested from interdisciplinary collaboration in research that is closely linked with practical aspects of delivering health care to patients, particularly within large organisations such as hospitals that tend to operate within delineated speciality silos. Conducting research into health service practices and outcomes in a way that sheds light on the context can strengthen the likelihood of outcomes being translated into contemporary health care practices by enabling interdisciplinary communications, understandings and collaborations that in turn facilitate improved outcomes for people.

‘Stand-alone’ positivist or phenomenological research approaches had the potential to overlook critical data about phenomenon that would aid the development of a new model of care that was responsive to **all** the needs of all stakeholders, particularly patients. A mixed methods approach respected the ontological and epistemological foundations, which reflected the clinical and administrative imperatives that govern contemporary health care service provision. Clinicians engaged with the research, acknowledging the extent of the challenges whilst being committed to improving the situation.

Positive feedback from individual clinicians about benefits they perceived deriving from participating in the study cannot be overlooked. When embarking on the study I had assumed that clinicians and in particular senior medical officers might be reluctant to engage in or would be sceptical about the validity of participating in a study that drew heavily on qualitative methods. These assumptions were negated, with all focus group interviews and nominal group workshops being attended by a large number of clinicians making considerable efforts to reschedule clinical commitments, and in one case flying interstate to attend the nominal group workshops.

Patient participants expressed gratitude for the research as a *“chance to be heard”*. Considerable input from patients to the revised model of care indicated their sense that it would be helpful to them and their families. Originally, while this was a contentious issue among some clinicians concerned about the patient groups’ propensity to sabotage such activities in order to fulfil individual agendas, the patients’ inputs remained critical. It was considered by the researcher that managing subsequent patient engagement and compliance with the relevant governance and institutional support would emerge within the new model and be inherent in structuring an approach to transitioning patients from the current to the proposed revised model of care. Similar to the clinician responses patients took the time to write and send cards of appreciation and to continue to provide written information they believed relevant to the study, way beyond their individual interview sessions.

Although anecdotal and not solely a consequence of the conduct of this study many clinicians have subsequently reported a perceived *“improvement”* in the overall situation surrounding the management of the patient group. While not true for all encounters, clinicians have made the effort to note that they feel patients are *“more contained”*, and *“not presenting as often or staying as long”*. Further, pivotal clinician stakeholders have since reported a *“small shift”* in the clinical approach to the patient group, with a gradual departure from the biomedical paradigm and movement toward a multimodal and multidisciplinary approach, earlier during inpatient admissions.

Patients have also reported an improvement in their inpatient journeys, mostly related to perceived attitudes toward them following involvement in the study. Although this was pleasing, it can only be seen as a consequence of ‘turning the spotlight on’ the phenomenon and challenging previously held beliefs, assumptions and behaviours. Any effort by clinicians and patients to change was independent of the study. The dialogue among all stakeholders may have provided a catalyst for consideration and been instrumental in clinicians/patients choosing to modify their behaviours. Although not an intentional aim of the study, such outcomes, whether positive or negative, cannot be dismissed. However, the expectation that *“improvements”* will be sustained in the absence of such critical foundations as clinical governance and infrastructure to support the proposed revised model of care is not well founded. However pleasing that more amicable therapeutic encounters are, significant and long-lasting improvements extend beyond those related to communication.

Carers who engaged in focus groups also recounted a benefit from attending the sessions, as confirmed by their request for an additional session. Through supportive contact with others in similar situations, benefits ensued. *“X [family member] is still talking about how good it was”*. Thus having family-centred therapies included in the revised model of care, particularly for children of patients with persistent abdominal pain, was important.

Given the multiple dimensions and perspectives of the stakeholders, limitations exist in the extent and depth of data that can be managed by a researcher working

independently. The intent of the study was to excavate a composite cohort profile of the following items that exist as a consequence caring for and supporting a patient with persistent abdominal pain:

- the extent and pattern of health care utilisation, frequency of ED presentations frequency of admissions, the wards most utilised for care
- the types of health care service provision sought and delivered
- the types of diagnoses recorded, and the investigations and treatments delivered
- the financial cost associated with inpatient care
- the barriers to efficient and effective care for patients
- the unhelpful encounters with the health care system that sabotage good clinical outcomes ; and finally
- the impact on carers, family members and health care providers

The sample size, while facilitating an “in depth” approach to appreciating the phenomenon, needs to be tested for transferability of results to other similar patient groups. This is particularly relevant to implementation of the “proposed model of care” as limited funding may be directed by administrators toward other competing service needs.

The financial implications presented in this study were associated with the **direct costs** incurred by the hospital as quantified by the DRG-9 as a consequence of caring for the study patient group over a 3 year period. There are a number of inherent limitations in these costing appraisals:

- i. There is a lack of sensitivity and specificity associated with using a broad diagnosis-related group (DRG). The patient study group are ‘outliers’ in this regard, both in terms of possessing a discreet DRG code that accurately reflects their presentations and because they fall under the “average costing pathways/DRG” from which associated costs are calculated. This inevitably leads to underreporting of the true cost associated for each patient admission, and thus cost estimates are conservative at best.

- ii. The direct costs do not reflect the **total** cost to the health care system, given the repeated and extensive contacts with health care providers in and outside of acute care facilities for this patient group. In addition, there is a social impact because of lost productivity, and because pensions and support benefits are needed for patients as well as carers. Further, the emerging generation of these patients are now also beginning to rely on government funding, mostly in relation to unemployment benefits, but also in terms of their own emerging high health care utilisation patterns.

#### 7.8.1.1 Implications for clinical practice

The fundamental tenet of conducting this study was to make recommendations, based on consensus agreements regarding improved approaches to the clinical management of patients with persistent abdominal pain. While study participants have highlighted the shortcomings of current clinical approaches, particularly within acute care hospital settings, they have also made recommendations regarding the guiding principles and essential elements for an alternative model. However, implications regarding the proposed model require further consideration and refinement. These are:

- Identifying and appointing the 'core team'. While general consensus (clinician and patient participants) was reached regarding the need to appoint and introduce a 'core team' of health care professionals responsible for the coordination and monitoring of patients with persistent abdominal pain, mobilising the necessary resources to implement this recommendation will be difficult. Discussion with hospital administration and departmental heads is required to seek financial support to, in the first instance, trial the utility of such a team in improving outcomes for patients with persistent abdominal pain
- Further discussion with key clinicians regarding their input into and support of the proposed 'core team' is required. Similarly patients and family members will need to be consulted and agree to proposed changes to care process and therapeutic intents
- Speciality specific working parties need to be established to review the current literature regarding specific elements of treatments directed toward patients



with persistent abdominal pain and to develop consensus or 'expert opinion' clinical practice guidelines for the management of the multiple dimensions inherent within the phenomenon. These working parties need to be established for each of the respective speciality domains implicit in the phenomenon that is; psychology/psychiatry, to consider and develop psychological and behavioural treatment approaches; surgery, to revise and refine biomedical clinical treatment approaches, inclusive of documenting clinical parameters and thresholds and treatment pathways during maintenance and escalation phases of the illness trajectory; pain management, to consider treatment pathways and provision of longitudinal care to patients and support for health care providers and general practitioners, in order to integrate and share care responsibilities

- Clinical care plans need to be created for individual patients that accounts for their specific needs. The care plan needs to be generated from an interdisciplinary platform and include physical and functional targets to assess efficacy and outcomes of revised treatment approaches. The plans need to accommodate physical, social, functional and psychological dimensions reflecting a biopsychosocial orientation to treatment approaches. Pre-emptive and regular patient reviews would be a requisite of patients' ongoing engagement with the health care service provider and the professionals it employs
- A nominated member of the 'core team' will assume a case manager role for the patient on behalf of the team. Within this role the health care professional will be responsible for managing pre-emptive reviews and clinical inputs for the patient and regularly updating other 'core team' members regarding progress and alterations to treatment approaches
- Care contracts need to be formulated by the 'core team' in consultation with patients and their general practitioners. The care plan needs to be explicit about the nature and extent of clinical inputs that patients will receive in the advent of an acute episodic event requiring hospitalisation. The contracts need to be regularly reviewed and endorsed by the LHD clinical governance unit. Hospital administration, supported by the clinical governance unit will provide the

necessary authority to sanction care contracts and manage patients and clinicians who breach recommendations within the care contracts

- Communication systems need to be refined to accommodate the immediate identification of the patient cohort upon presentation to a hospital ED. When presenting to a hospital ED a patient profile that 'flags' the patients as a chronic pain patient, identifies the care team responsible for inpatient hospital management and provides an individualised treatment protocol will be made available. This information needs to be interfaced through the LHD IT network and therefore accessible to all staff within and between the LHD.

#### **7.8.1.2 Implications for education**

The study presented within this thesis has illuminated how ideological and paradigmatic orientations effect conceptual appreciations of health and illness and in turn influence behaviours regarding seeking and delivering health care. The consequence of the biomedical model and the reductionist approach to managing illness needs to be redressed if attempts to manage illness, particularly chronic illness are to be improved. Fundamental to encouraging this paradigmatic shift of all clinicians, not just those insulated within specialty specific domains such as pain management, is education. To this end efforts need to be directed toward the following items,

- Undergraduate health care professional programs are needed that will help equip future clinicians with the necessary knowledge and ontological orientation where they can conceive and hence direct biomedical inputs for chronic pain patients from a holistic and integrative perspective.
- Similarly, societal expectations regarding the medicine and the 'cure mantra' need to be challenged by providing informative, accurate and honest public health education regarding current understandings, approaches and limitations of medicine in the management of pain, particularly refractory chronic pain conditions.
- Undergraduate and postgraduate programs need to account for the predicted rise in chronic illnesses and as such equip health care professionals with the

necessary skill to provide care that is directed toward health promotion, self-management and behavioural modification. These educative reforms will help mobilise and embed these patient-centred approaches to chronic disease management into the culture and practices of the health care system.

- Strategies to improve information for patients regarding their illness and expected trajectories are required. These should provide education and support mechanisms to assist patients in transitioning to a whole of life approach to integrating productive relationships with health care providers and self-efficacy.

### **7.8.1.3 Implications for research**

While the intent of this study focused on scoping, identifying and highlighting issues concerning persistent abdominal pain, the study has subsequently illuminated the countless research potentials within the phenomenon. Given that pain is now widely accepted as occurring on a continuum, from acute through to chronic, efforts directed toward the early identification and management of patients at risk of suffering from persistent abdominal pain represent arguably the most pressing agenda needing attention. To this end:

- Work needs to be directed toward, in the first instance identifying correlates (behavioural, psychological and biological) that have predictive value in identifying patients at risk of progressing to abdominal pain chronicity. Testing correlates across populations for validity and reliability would be the precursor to being able to work toward developing a risk stratification assessment tool that primary care or front line clinicians could potentially use to identify those at risk of progressing toward persistent abdominal pain and redirecting treatments toward broader biopsychosocial approaches, including referral to a multidisciplinary pain service
- Whilst significant efforts, particularly within the last decade have been directed toward providing epidemiological and economic data for the general chronic pain population, more focused attention is required to better appreciate some of the more specific and poorly defined populations with chronic pain. One such

group is the persistent and debilitating abdominal pain group. Greater attention is needed to identify the prevalence and impact of this phenomenon in order to redress its seemingly disproportionate cost to individuals, health care service providers and society at large

- Work is also required to refine a DRG that adequately represents the phenomenon of persistent abdominal pain, its symptom, characteristics and treatment pathways. This work would consequently highlight the need to redirect funding associated with the illness from acute to chronic modelling methodologies
- Continuing to monitor the current patient cohorts' progress and clinical outcomes over the next 20 years would provide significant insight into the trajectory of the illness over a life course. In addition to amassing longitudinal data for the study cohort, the generational impact of chronic pain illnesses, such as persistent abdominal pain could be better understood by enrolling children of the cohort into a parallel longitudinal study. This information would provide valuable contributions to the literature and potentially guide treatment approaches that expand to include a 'whole of family approach' for families affected by chronic and debilitating pain
- A pilot study of the revised model of care is the most pressing project to undertake. Within the pilot phase, seeking 'proof of principle' around elements of the proposed model and the utility of its recommendations is necessary. Following these efforts, extending investigations toward a multicentre trial that was focused on comparing the proposed model to that of a CBT approach and/or current practice approaches would contribute considerably to contemporary practice knowledge.

## 7.9 Concluding statement

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It is my contention that:

*Pain is simultaneously physically, emotionally and phenomenologically embodied. It is influenced by culture, experience, psychology and personality and thus one's perception of the reality of living with pain is the construction of these influences and domains. When patients experiencing chronic debilitating symptoms related to unresolved pain associated with socio-psycho-pathophysiology present to acute care settings, optimal care can be achieved through adherence to principles of care that represent a paradigm consistent with a contemporary bio-psycho-social model. Optimal care for this patient cohort needs to be individualised, contextualised and different from that enshrined within the acute bio-medical model.*

Patients with persistent abdominal pain present significant diagnostic and therapeutic challenges for health care providers. Using an acute care framework to manage this patient cohort is problematic. Some of the problems include, poorly coordinated interventions delivered within unidimensional models of care, professionally based siloed approaches, lack of coordinated and consistent care planning, the use of conflicting approaches and treatment paradigms, and inadequate discharge planning and community-based care. On the basis of these challenges, it was claimed that the current approach to managing patients with chronic abdominal pain was not only inefficient, but also ineffective for all concerned. These treatment approaches were confusing for the patient, led to conflict and hostility within and between treatment teams as well as between patients, their families and the hospital staff. They prompted escalations in patients' reports of pain, and inevitably led to repeated hospital admissions.

Clinicians and patients reported on the perceived shortcomings of the model of care used for patients with persistent abdominal pain within the acute care environment at the study site. They also made significant suggestions for an alternative model of care. Clinicians' have provided ideas in relation to the critical issues of concern, the guiding principles and essential elements of a revised model of care have been formulated and a draft model of care has been proposed: This is not solely focused on acute care

management, but is targeted toward 'a life course approach'. The approach includes the management of acute episodic events and hence has implications for both primary and tertiary health care clinicians and service providers.

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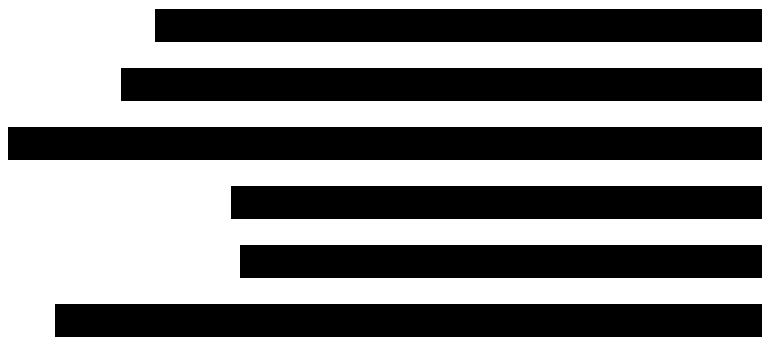
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## APPENDICES

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### APPENDIX 1 Chart audit

Version 1: 29 June 2006



Form for data to be extracted from patients' records for the research project:

**"Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting"**

Code number: .....

<i>Emergency Presentation:</i>	<i>Dept</i>	
Emergency Presentation	Dept	Date:  Time:  Accompanied by:

Referred by	Self/ General Practitioner/Consultant (specify).....				
Emergency Dept notified of referral:	Yes/No				
Clinical features of Presentation/Admission:  DRG Code:					
Diagnostic Investigations:	<b>Type:</b>	<b>Date:</b>	<b>Time Rx:</b>	<b>Time attended</b>	
Discharged from Emergency Dept:	Yes/No	Date:	Time:		
Clinical Follow-up post discharge from Emergency Dept:	Yes/No Details:				
Clinical/Organisational Issues arising in Emergency Dept:					

<b>Hospital Admission:</b>	Date:		Time:		
Admitting Diagnosis:					
Admitting Team:					
Transit Time in A&E→ Ward					
Ward Admitted:					
<b>Diagnostic Investigations:</b> (including pathology and radiological studies):	<b>Type</b>	<b>Date/Time RX</b>	<b>Date/Time Attended</b>	<b>Outcome</b>	<b>Comments (ie. Δ Rx Regime)</b>
	1)				
	2)				
	3)				
	4)				
	5)				
	6)				
	7)				
	8)				

	9)				
	10)				
	Others:				
<b>Procedural Interventions:</b> (including pain related procedures)	<b>Type</b>	<b>Date/Time RX</b>	<b>Date/Time Attended</b>	<b>Outcome</b>	<b>Comments (ie. <math>\Delta</math> Rx Regime)</b>
	1)				
	2)				
	3)				
	4)				
	5)				
	6)				
	7)				

	8)				
	9)				
	10)				
Others:					
<b>Surgical Interventions:</b>	<b>Type</b>	<b>Date/Time RX</b>	<b>Date/Time Attended</b>	<b>Outcome</b>	<b>Comments (ie. Δ Rx Regieme)</b>
	1)				
	2)				
	3)				
	4)				
	5)				

	6)				
	7)				
	8)				
	9)				
	10)				
Others:					
<b>Clinical features</b> during admission:	Physiological:  Functional:  Psychosocial:				

<b>Clinical Consulted Admission:</b>	<b>Services During</b>	<b>Who:</b>	<b>Date/time ref:</b>	<b>Why:</b>	<b>Date/time seen:</b>	<b>Outcome</b>	<b>Frequency visits:</b>	<b>Comment</b>



	<p>General Comments:</p>						
<p><b>Medication utilisation:</b></p> <p>Opioids</p>	<p><i>On Admission:</i> <span style="float: right;"><i>Dose:</i></span></p> <p>Type: 1)</p> <p style="padding-left: 100px;">2)</p> <p>Prescribing Physician:</p> <p><i>During Admission:</i> <span style="float: right;"><i>Average Daily dose:</i></span></p> <p>Type: 1)</p> <p style="padding-left: 100px;">2)</p>						

	<p>3)</p> <p>4)</p> <p><i>On Discharge:</i></p> <p>Type: 1)</p> <p>2)</p> <p>3)</p> <p><i>Average Daily Dose:</i></p>
Anti-neuropathic Agents:	<p><i>On Admission:</i></p> <p>Type: 1)</p> <p>2)</p> <p>Prescribing Physician:</p> <p><i>During Admission:</i></p> <p>Type: 1)</p> <p><i>Dose:</i></p> <p><i>Average Daily dose:</i></p>

	<p>2)</p> <p><i>During Admission:</i> <i>Average Daily dose:</i></p> <p>Type: 1)</p> <p>2)</p> <p><i>On Discharge:</i> <i>Average Daily Dose:</i></p> <p>Type: 1)</p> <p>2)</p> <p>3)</p>
Other Pharmacological agents:	<p><i>On Admission:</i> <i>Dose:</i></p> <p>Type: 1)</p> <p>2)</p>

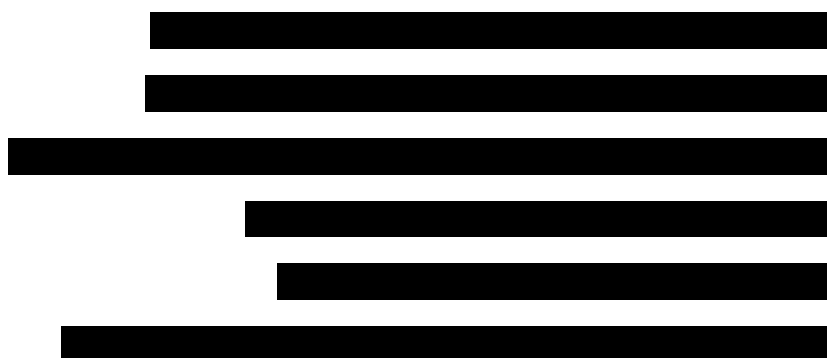
	<p>3)</p> <p>Prescribing Physician:</p> <p><i>During Admission:</i> <i>Average Daily dose:</i></p> <p>Type: 1)</p> <p>2)</p> <p>3)</p> <p><i>During Admission:</i> <i>Average Daily dose:</i></p> <p>Type: 1)</p> <p>2)</p> <p><i>On Discharge:</i> <i>Average Daily Dose:</i></p> <p>Type: 1)</p> <p>2)</p> <p>3)</p>
<b>Clinical/Organisational Issues</b> arising during	

<p>admissions: (ie Δ of Rx plans, case conferences, who's involved→outcomes, need for extra staffing—\$)</p>	
<p><b><i>Discharge Planning:</i></b></p> <p>Discharge Summary attended:</p>	<p>Yes/No</p> <p>Have all issues been addressed: Yes/No</p> <p>If No, What information has been omitted:</p>
<p>Follow up appointments:</p>	<p>Yes/No</p> <p>With all relevant parties yes/no</p> <p>If No, Who has been omitted:</p>

<p>Subsequent treatment plans:</p>	<p>Has the patient been provided with relevant information about the ongoing management of their conditions/medications on discharge? Yes/No</p> <p>Who has provided this information:</p> <p>Has the general practitioner been provided with the relevant information about the ongoing management of the patients' condition/medications? Yes/No</p> <p>By Whom:</p> <p>Is it comprehensive?</p>
<p>Other Comments:</p>	

## APPENDIX 2 Information statement (patients)

Version 1: 29 June 2006



### Information statement for the research project:

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Patients)**

You are invited to take part in the research project identified above, which is being conducted by Ms **Gena Lantry**, Project Manager in Persistent Pain, in collaboration with Dr XXX and Ms XXX from the XXX Pain Service, and Dr XXX, an independent Research Associate.

### Why is the research being done?

Patients with persistent abdominal pain who require frequent admissions to hospital because of acute flare-ups of pain and related symptoms have special needs that our current health services may not be organised to meet in the most effective and efficient way. We are trying to identify ways in which we can better provide health care to such patients. To do that, we need to look at the issues from everyone’s point of view – the patients; their family or friends who are involved in their care; doctors and nurses in the emergency department, hospital wards and the pain clinic, and allied health staff such as physiotherapists, social workers or others who might be called in from time to time.

We hope that this study will help us to develop better organised services to patients and their families, from referral or presentation in the Emergency Department, throughout the hospital stay, and after discharge.

### **Who can participate in this research?**

We are seeking *men and women, over 18 years of age, with persistent abdominal pain and related symptoms* of at least three years duration and who have had at least six admissions to the XXX XXX Hospital in the past 12 months.

Your specialist at the XXX XXX Hospital has agreed to mention this study to patients who are in the position we have outlined above, and to give or mail you the written information about our research. Your specialist will not be told which patients decide to take part in the study and will not be given any information that patients provide during the study that could identify individual patients.

(As mentioned above, we will also include family members, doctors, nurses and other hospital staff in the study, so that they can also give us information on what is happening now and how things could be changed for the better. Staff will not be asked to make comments about any individual patient.)

### **What choice do I have?**

Participation in this study is *entirely your choice*. Only people who give informed consent can take part in the study. Whether you decide to take part will not disadvantage you in any way, or affect the care you or your family members may be receiving from the XXX XXX Hospital or other health services.

If you decide to participate, you will be *free to withdraw from the project at any time* without having to give a reason, by letting the researchers know of your decision. If you decide to withdraw, you may also choose to tell us not to use any information we have collected from your interview, questionnaires or hospital records, and we will respect your decision.

### **What would I be asked to do?**

If you agree to participate, we will ask you to do four things:

(1) To *take part in an interview* with Gena Lantry, who is a registered nurse with experience in pain management and has done other research with patients and nurses. This interview will take about one to one and a half hours, and could take place at the



XXX XXX Hospital, or in your home, or another private place that might be suitable, within the next two weeks or so. The sort of topics Gena would like to ask you about include:

Your life before you developed persistent pain

Your experiences of investigations that led to the diagnosis of persistent abdominal pain

The impact pain has had on your life and relationships

More recent experiences of hospitalisation

Going to the Emergency Department

Being admitted to a ward

Experience of various assessments, consultations with different staff, and care received

Helpful and unhelpful aspects of care and interactions with staff

The impact of hospitalisation on you and those close to you

What you think works well, does not work well, or needs to change to improve the overall care of patients with persistent abdominal pain.

(2) To *complete a set of questionnaires* that can tell us about your general level of health, your mood and feelings, and your pain and how you are coping with it. In most cases you will be asked to tick or circle an answer rather than having to write your own words. We would send you the questionnaires before the interview so that you could complete them in your own time and then either post them or bring them with you to the interview with Gena Lantry. It takes about one and a half hours to answer all the questions but you can choose whether to do it all at once or one or two at a time.

(3) To give us permission to *review your medical records* at the XXX XXX Hospital so that we can extract information about your previous admissions, the tests and investigations you had, what treatments were recommended or given, and any follow-up arrangements that might have been made.

(4) Finally, if you agree to participate, we would also like to *talk with someone from your family* or another special person who has been involved in helping you to manage your health and daily activities. You can decide who that person is. We will ask you to tell them about the project and to pass on the information we have prepared for them, so that they can decide if they want to take part.

### **What are the benefits and risks of participating?**

You and your family member or friend may find it helpful to share your experience with a researcher who is interested in what you have been going through and how you feel about it, but we cannot promise that this will be so in your case. Our aim is to improve the quality of care for patients such as you and we hope that you and other patients will experience the improvements in the future.

There are no physical risks to the patients or family members who choose to take part in this study. Participation will not negatively affect the care or services you may be receiving from the XXX XXX Hospital or other health services. You may find yourself reflecting on past or ongoing experiences that make you sad, frustrated, or angry and you may want to share these emotions. Such reactions may be a normal part of coping with challenging experiences, but if necessary, Gena Lantry can advise you about the most appropriate services you can contact to help you with any problems or concerns you have.

### **How will my privacy be protected?**

Interviews will be audio recorded, and later transcribed by a research assistant. We will ensure that any names or other identifying information is removed from the tapes and transcripts. You will be given the opportunity to *review the tape-recording or the written transcript* of the interview and to edit or delete any portion of the tape/script that you do not want us to use in our research. You may also add additional information or clarification by telling Gena Lantry who will note your comments.

Once transcripts have been validated, audio-tapes of interviews will be destroyed.

Only Gena Lantry will have access to information that could identify you. Identifying information will not be provided to other members of the research team. Because we want to keep clinical care and research separate, Dr XXX and Ms XXX who work in the XXX Integrated Pain Service and are also members of the research team, will not have access to the tape recordings of your interviews or any other information that might identify you. All data will be stored in a secure place at the XXX XXX Hospital and all electronic files will be password protected and kept for the required period of five years.

### **What will happen to the information I provide?**

Transcribed text will be analysed to identify key issues and themes. Any quoted material that we publish as a result of this project will be presented in a way that does not identify individual patients, family members or staff. Reports of this research will be presented at professional conferences and published in scientific and professional journals.

If you would like to receive a brief report of the findings of this study (available in early 2007), please contact Gena Lantry and she will send you a copy.

### **What do I need to do to participate?**

*If you have questions* or would like more information about this study please contact Gena Lantry on Tel: 0422 989 667 (The voice mail on this number is password protected. If the phone is unattended when you call, please leave a message and contact details so that Gena can return your call.)

*If you would like to participate*, please complete the enclosed consent form and return it in the envelope provided, phone Gena Lantry on 0422 989667, or email her on [gena.lantry@hnehealth.nsw.gov.au](mailto:gena.lantry@hnehealth.nsw.gov.au). It would be appreciated if you could respond within the next week. Gena will then contact you to arrange a mutually convenient time for the interview.

Thank you for considering this invitation.

Yours sincerely,

Gena Lantry

(on behalf of the research team)

*This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter Hew England Health (ref. no. xxxxx). Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Professional Officer (Research Ethic), Hunter New England Human Research Ethics Committee, Hunter Hew England Health, Locked Bag 1, New Lambton, NSW 2305, Tel: (02) 4921 4950, Email: [Nicole.Gerrand@hnehealth.nsw.gov.au](mailto:Nicole.Gerrand@hnehealth.nsw.gov.au).*

Contact details for other research team members:

<b>Dr XXX</b>	<b>Ms XXX</b>	<b>Dr XXX</b>
Medical Director	Operations Manager	Research Associate
XXX XXX Pain Service	XXX XXX Pain Service	

### APPENDIX 3 Consent form (patients)

Version 1: 29 June 2006

[REDACTED]

#### Consent Form for participants in the research project:

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Patients)**

I, (please print name) \_\_\_\_\_ have been invited to participate in the above named study to be conducted by Ms Gena Lantry and her research team.

I understand the study will be carried out as described in the information statement, a copy of which I have read and retained.

I understand that my participation is voluntary and that whether or not I decide to participate my decision will not affect my current health care or have any other repercussions.

I also understand that I do not have to answer all questions raised during the interview and that I can withdraw from the study at any time without having to give any reasons.

I understand that all information I provide will be treated in confidence by the researchers.

I understand that I will be given an opportunity to review the audiotaped interview and to edit or delete any statement I have contributed which I do not wish to have included in the research data.

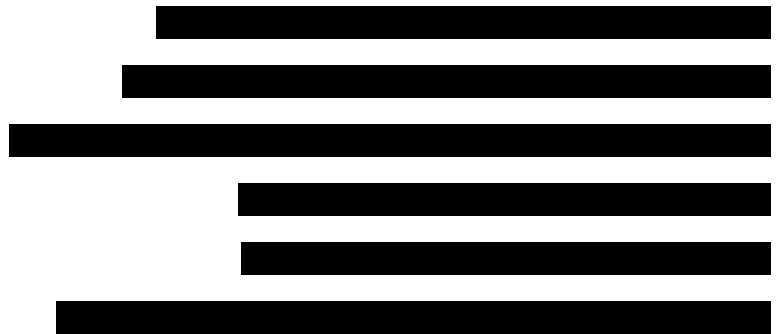
I have had all questions answered to my satisfaction.

I agree to take part in the study.

Participant's Signature ..... Date .....

## APPENDIX 4 Interview schedule (patients)

Version 1: 29 June 2006



**Interview schedule for the research project:**

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Individual Patients)**

*A low-key, conversational approach will be adopted in all interviews in order to encourage participants to share their experiences and views in their own words and in a way that they find comfortable. The questions and issues to be explored are listed below. The order and format of questions and prompts may vary slightly between interviews to allow for spontaneity and conversational style to be maintained.*

Greetings and introductions (clarify nature of interview and participant’s rights)

You and your life before you developed persistent pain

Your experiences of investigations that led to the diagnosis of persistent abdominal pain

The impact pain has had on your life and relationships

More recent experiences of hospitalisation

Factors contributing to decision to contact family/GP/hospital

(What, if anything, might have been helpful at this stage in avoiding going to hospital?)

Going to the Emergency Department (time, people, questions, investigations, communication with staff – what/who was helpful/frustrating/challenging?)

Being admitted to a ward (time, people, questions, investigations, communication with staff – what/who was helpful/frustrating/challenging?)

Experience of various assessments, consultations with different staff, and interventions and care received (what were your / your family's expectations and needs and how well were they met?)

Helpful and unhelpful aspects of care and interactions with staff (How coordinated is the care? Is all communication from different staff clear and congruent?)

The impact of hospitalisation on you and those close to you

Present situation (pain levels, coping, plans and aspirations)

What you think works well, does not work well, or needs to change to improve the overall care of patients with persistent abdominal pain.

*A brief summary of the issues covered will be provided by the interviewer at the end of the interview. Participants will be thanked for their time and contribution, and asked if they would like to have anything edited or removed from the tape recording of the interview.*



## APPENDIX 5 Information statement (family/significant other)

Version 1: 29 June 2006

[REDACTED]

### Information statement for the research project:

#### **“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Family/Significant Other)**

You are invited to take part in the research project identified above, which is being conducted by Ms **Gena Lantry**, Project Manager in Persistent Pain, in collaboration with Dr XXX and Ms XXX from the XXX XXX Pain Service, and Dr XXX, an independent Research Associate.

#### **Why is the research being done?**

Patients with persistent abdominal pain who require frequent admissions to hospital because of acute flare-ups of pain and related symptoms have special needs that our current health services may not be organised to meet in the most effective and efficient way. We are trying to identify ways in which we can better provide health care to such patients. To do that, we need to look at the issues from everyone’s point of view – the patients; their family or friends who are involved in their care; doctors and nurses in the emergency department, hospital wards and the pain clinic, and allied health staff such as physiotherapists, social workers or others who might be called in from time to time.

We hope that this study will help us to develop better organised services to patients and their families, from referral or presentation in the Emergency Department, throughout the hospital stay, and after discharge.

### **Who can participate in this research?**

We are seeking men and women, over 18 years of age, with persistent abdominal pain and related symptoms of at least three years duration and who have had at least six admissions to the XXX XXX Hospital in the past 12 months.

We are also seeking *family members or those close to a person with pain* as described above, who either live with that person or are closely involved in their care and day to day activities. As researchers we do not have your name or any other information about you at this time. We have asked people with persistent abdominal pain who have agreed to be in the study to pass on information about the study to a family member or another close person of their choice. It is now up to you to decide whether you would like to take part and to contact us.

(As mentioned above, we will also include patients, doctors, nurses and other hospital staff in the study, so that they can also give us information on what is happening now and how things could be changed for the better. Staff will not be asked to make comments about any individual patient or family member.)

### **What choice do I have?**

Participation in this study is *entirely your choice*. Only people who give informed consent can take part in the study. Whether you decide to take part will not disadvantage you in any way, or affect the care your family member/friend may be receiving from the XXX XXX Hospital or other health services.

If you decide to participate, you will be *free to withdraw from the project at any time* without having to give a reason, by letting the researchers know of your decision. If you decide to withdraw, you may also choose to tell us not to use any information we have collected from you and we will respect your decision.

### **What would I be asked to do?**

If you agree to participate, we will ask you to do two things:

(1) To *take part in a group discussion* with Gena Lantry and XXX and up to seven other family members or friends of patients with persistent pain. (This is sometimes called a *focus group*.) Gena is a registered nurse with experience in pain management and has done this type of research before. XXX is an experienced nurse and researcher. This group discussion will take about one to one and a half hours, and could take place at the XXX XXX Hospital, or another private place that is suitable to members of the group, within the next two to four weeks. The sort of topics we would like to discuss with the group include:

Your introduction to being with and helping someone with chronic pain

The impact of pain on the person and those close to them

The impact of interactions with all aspects of the health care system (on the patient and on you)

Your observations of the more recent hospitalisations (as they affected the patient and you)

Going to the Emergency Department

Being admitted to a ward

Experience of various assessments, consultations with different staff, and care received

Helpful and unhelpful aspects of care and interactions with staff

The impact of hospitalisation on the patient, on you, and on other family members

What you think works well, does not work well, or needs to change to improve the overall care of patients with persistent abdominal pain and their families/significant others.

(2) To *complete a brief questionnaire* providing information about your age, relationship to the person with pain, occupation, your own health, and how you contribute to the care of the person in pain. This will take only a couple of minutes and will be done at the time of the group discussion.

### **What are the benefits and risks of participating?**

You and your family member or friend may find it helpful to share your experience with a researcher who is interested in what you have been going through and how you feel about it, but we cannot promise that this will be so in your case. Our aim is to improve the quality of care for patients with chronic pain and their families and we hope that they will experience these improvements in the future.

There are no physical risks to the patients or family members who choose to take part in this study. You may find yourself reflecting on past or ongoing experiences that make you sad, frustrated, or angry and you may want to share these emotions. Such reactions may be a normal part of coping with challenging experiences, but if necessary, Gena Lantry and XXX can advise you about the most appropriate services you can contact to help you with any problems or concerns you have.

### **How will my privacy be protected?**

Group discussions will be audio recorded, and later transcribed by a research assistant. We will ensure that any names or other identifying information is removed from the tapes and transcripts. You will be given the opportunity to *review the tape-recording or the written transcript* of the group discussion and to edit or delete any portion of your contribution that you do not want us to use in our research. You may also add additional information or clarification by telling Gena Lantry who will note your comments.

We will ask all members of the discussion group to keep all information confidential, and not to share it with anyone outside the group. However, because of the group situation, we cannot guarantee complete confidentiality of information provided if someone within the group breaks their promise. For this reason, we will ask you not to use actual names of patients, doctors, nurses or other staff, and not to share highly sensitive information, or information that may have legal implications.

Once transcripts have been validated, audio-tapes of group discussions will be destroyed.

Only Gena Lantry will have access to your consent form and questionnaire. Identifying information will not be provided to other members of the research team. Because we want to keep clinical care and research separate, Dr XXX and Ms XXX who work in the XXX XXX Pain Service and are also members of the research team, will not have access to the tape recordings of group discussions or any other information that might identify you. All data will be stored in a secure place at the XXX XXX Hospital and all electronic files will be password protected and kept for the required period of five years.

### **What will happen to the information I provide?**

Transcribed text will be analysed to identify key issues and themes. Any quoted material that we publish as a result of this project will be presented in a way that does

not identify individual patients, family members or staff. Reports of this research will be presented at professional conferences and published in scientific and professional journals.

If you would like to receive a brief report of the findings of this study (available in early 2007), please contact Gena Lantry and she will send you a copy.

**What do I need to do to participate?**

*If you have questions* or would like more information about this study please contact Gena Lantry on Tel: 0422 989 667 (The voice mail on this number is password protected. If the phone is unattended when you call, please leave a message and contact details so that Gena can return your call.)

*If you would like to participate*, please complete the enclosed consent form and return it in the envelope provided, phone Gena Lantry on 0422 989667, or email her on [gena.lantry@hnehealth.nsw.gov.au](mailto:gena.lantry@hnehealth.nsw.gov.au). It would be appreciated if you could respond within the next week. Gena will then contact you to arrange a mutually convenient venue and time for the group discussion.

Thank you for considering this invitation.

Yours sincerely,

Gena Lantry

(on behalf of the research team)

*This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health (ref. no. xxxxx). Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Professional Officer (Research Ethic), Hunter New England Human Research Ethics Committee, Hunter New England Health, Locked Bag 1, New Lambton, NSW 2305, Tel: (02) 4921 4950, Email: [Nicole.Gerrand@hnehealth.nsw.gov.au](mailto:Nicole.Gerrand@hnehealth.nsw.gov.au).*

Contact details for other research team members:

<p><b>Dr XXX</b></p> <p>Medical Director</p> <p>XXX XXX Pain Service</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p>	<p><b>Ms XXX</b></p> <p>Operations Manager</p> <p>XXX XXX Pain Service</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p>	<p><b>Dr XXX</b></p> <p>Research Associate</p> <p>C/o Ms Gena Lantry</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p> <p>[REDACTED]</p>
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## APPENDIX 6 Consent form (family/significant other)

Version 1: 29 June 2006

[REDACTED]

### Consent Form for participants in the research project:

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Family/Significant Other)**

I, (please print name) \_\_\_\_\_ have been invited to participate in the above named study to be conducted by Ms Gena Lantry and her research team.

I understand the study will be carried out as described in the information statement, a copy of which I have read and retained.

I understand that my participation is voluntary and that whether or not I decide to participate my decision will not have any negative consequences.

I also understand that I do not have to answer all questions raised during the group discussion and that I can withdraw from the study at any time without having to give any reasons.

I understand that all information I provide will be treated in confidence by the researchers.

I understand that I will be given an opportunity to review the audiotaped discussion and to edit or delete any statement I have contributed which I do not wish to have included in the research data.

I have had all questions answered to my satisfaction.

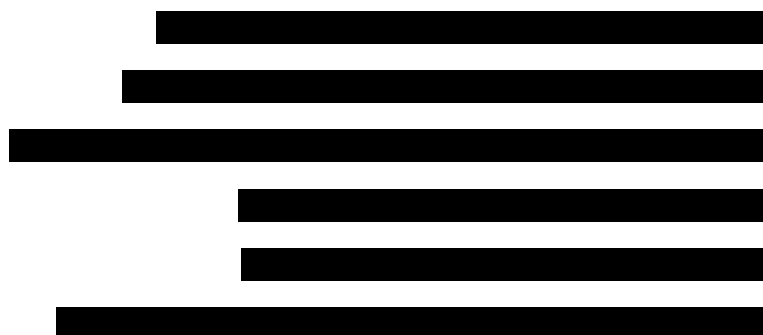
I agree to take part in the study.

Participant's Signature ..... Date .....



## APPENDIX 7 Topics for focus group (family/significant other)

Version 1: 29 June 2006



**Focus group discussion topics for the research project:**

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Family/Significant Other)**

*A low-key, conversational approach will be adopted in all focus groups in order to encourage participants to share their experiences and views in their own words and in a way that they find comfortable. The questions and issues to be explored are listed below. The order and format of questions and prompts may vary slightly between interviews to allow for spontaneity and conversational style to be maintained.*

Greetings and introductions (clarify nature of focus groups, basic rules of consideration for all participants, importance of confidentiality, and participant’s rights)

Your introduction to being with and helping someone with chronic pain

The impact of pain on the person, you, and others in the family

The impact of interactions with all aspects of the health care system over time – GPs, Emergency Department, doctors, nurses, pain specialists, and others (on the patient and on you)

Your observations of the more recent hospitalisations (as they affected the patient and you)

Going to the Emergency Department

Admission to a ward

Experience of various assessments, consultations with different staff, and care received

Helpful and unhelpful aspects of care and interactions with staff (How coordinated is the care? Is all communication from different staff clear and congruent?)

What role do you play / are expected by others to play during this time

The impact of hospitalisation on the patient, on you, and on other family members

Present situation (how well are things going? Plans/aspirations for the future)

What you think works well, does not work well, or needs to change to improve the overall care of patients with persistent abdominal pain and their families/significant others.

*A brief summary of the issues covered will be provided by the group facilitator at the end of the session. Participants will be thanked for their time and contribution, and asked if they would like to have anything edited or removed from the tape recording.*

## APPENDIX 8A Request for assistance with recruitment (patients)

Version 2: 4<sup>th</sup> August 2006

[REDACTED]

**Request for assistance with recruitment for the research project:**

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

Dear Doctor .....

You might already be aware that I am currently heading a research project that seeks to evaluate the effectiveness and efficiency of the current approach to management of patients with persistent abdominal pain with repeat admissions to the XXX XXX Hospital. For ethical reasons I cannot make a direct approach to potential participants, so I am seeking your assistance to pass on the information about the study to patients who meet the following inclusion criteria:

**Adult** male or female (18 years or older);

Has been **diagnosed with persistent abdominal pain** of at least three years’ duration;

Has been **admitted to the XXX XXX Hospital** at least six times in the past 12 months;

Is able to communicate in English.

If a patient in your care meets the above criteria, I would be grateful if you would pass on or mail the enclosed "Patient Information Package" to that person. The decision to take part is entirely up to the patient so I would ask that you do not follow up or check what decision the person makes.

Please contact me if you need further information. Your help is very much appreciated.

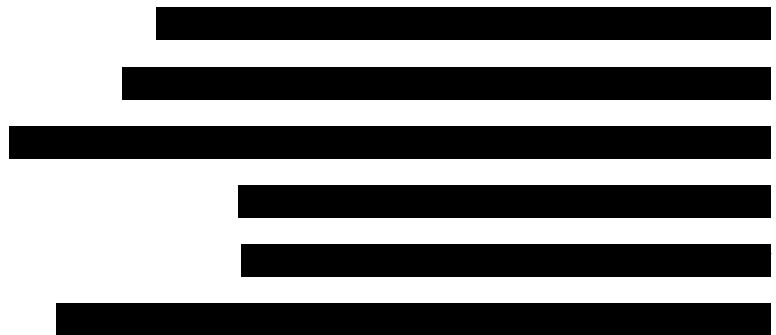
Gena Lantry

(on behalf of the research team)

*This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health (ref. no.06/07/26/5.07). Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Professional Officer (Research Ethic), Hunter New England Human Research Ethics Committee, Hunter New England Health, Locked Bag 1, New Lambton, NSW 2305, Tel: (02) 4921 4950, Email: [Nicole.Gerrand@hnehealth.nsw.gov.au](mailto:Nicole.Gerrand@hnehealth.nsw.gov.au).*

## APPENDIX 8B Request for assistance with recruitment (health professionals)

Version 1: 29 June 2006



**Request for assistance with recruitment for the research project:**

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

Dear .....

You might already be aware that I am currently heading a research project that seeks to evaluate the effectiveness and efficiency of the current approach to management of patients with persistent abdominal pain with repeat admissions to the XXX XXX Hospital. For ethical reasons I cannot make a direct approach to potential participants, so I am seeking your assistance to pass on the information about the study to staff within your area who meet the following inclusion criteria:

**Emergency Department: Medical Residents, Registrars, Registered Nurses** (working full or part time; with at least 6 months work experience at the XXX XXX Hospital)

**Ward G1: Registered Nurses** (working full or part time in G1 Ward; with at least 6 months work experience at the XXX XXX Hospital)

**Medical and Surgical Registrars and Residents** (working full or part time in any clinical area; with at least 6 months work experience at the XXX XXX Hospital)

**Pain Management Registrars** (working full or part time; with at least 6 months work experience at the XXX XXX Hospital; currently attached to the XXX XXX Pain Service)

**Clinical Nurse Specialists and Consultants** (working full or part time; with at least 6 months work experience at the XXX XXX Hospital; currently attached to the XXX XXX Pain Service)

**Allied Health staff** (Physiotherapists, occupational therapists, dieticians, social workers, psychologists and psychiatric liaison nurse consultant (working full or part time; with at least six months experience at the XXX XXX Hospital and who are currently attached either to XXX or Ward G1)

Please pass on or mail appropriate Information Packages only to those categories of people indicated with a tick (and not to those crossed out).

Please contact me if you need further information. Your help is very much appreciated.

Gena Lantry

(on behalf of the research team)

*This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health (ref. no. xxxxx). Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Professional Officer (Research Ethic), Hunter New England Human Research Ethics Committee, Hunter New England Health, Locked Bag 1, New Lambton, NSW 2305, Tel: (02) 4921 4950, Email: [Nicole.Gerrand@hnehealth.nsw.gov.au](mailto:Nicole.Gerrand@hnehealth.nsw.gov.au).*

## APPENDIX 9 Information statement (health professionals)

Version 1: 29 June 2006

[REDACTED]

### Information statement for the research project:

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Health Professionals)**

You are invited to take part in the research project identified above, which is being conducted by Ms **Gena Lantry**, Project Manager in Persistent Pain, in collaboration with Dr XXX and Ms XXX from the XXX XXX Pain Service, and Dr XXX, an independent Research Associate.

### Why is the research being done?

Patients with persistent abdominal pain who present in the Emergency Department and are admitted to acute care hospitals at frequent intervals because of acute flare-ups of pain and related symptoms have special needs that our current health services may not be organised to meet in the most effective and efficient way. As a result, a significant burden is placed on limited hospital resources, health professionals, patients and families.

We are trying to identify ways in which we can better provide health care to such patients. To do that, we need to look at the issues from everyone’s point of view – the patients; their family or friends who are involved in their care; medical and surgical consultants, residents, nurses, pain specialists, and allied health staff who contribute to patient care.

We hope that this study will help us to develop better organised services to patients and their families, from referral or presentation in the Emergency Department, throughout the hospital stay, and after discharge.

### **Who can participate in this research?**

We are seeking to involve different categories of health professionals in a series of focus groups, as follows:

**General Practitioners** from Newcastle and Lake Macquarie area with recent experience of ongoing medical care of patients with chronic pain (not necessarily patients who agree to participate in this study)

**Emergency Department: Medical Residents, Registrars, Registered Nurses** (working full or part time; with at least 6 months work experience at the XXX XXX Hospital)

**Ward G1: Registered Nurses** (working full or part time in G1 Ward; with at least 6 months work experience at the XXX XXX Hospital)

**Medical and Surgical Registrars and Residents** (working full or part time in any clinical area; with at least 6 months work experience at the XXX XXX Hospital)

**Pain Management Registrars** (working full or part time; with at least 6 months work experience at the XXX XXX Hospital; currently attached to the XXX XXX Pain Service)

**Clinical Nurse Specialists and Consultants** (working full or part time; with at least 6 months work experience at the XXX XXX Hospital; currently attached to the XXX XXX Pain Service)

**Allied Health staff** (Physiotherapists, occupational therapists, dieticians, social workers, psychologists and psychiatric liaison nurse consultant (working full or part time; with at least six months experience at the XXX XXX Hospital and who are currently attached either to XXX or Ward G1)

(As mentioned above, we will also interview patients and nominated family members or significant others to gain a clearer understanding of their perspective on the hospital services provided to patients with persistent abdominal pain and how things could be changed for the better.)

### **What choice do I have?**

Participation in this study is *entirely your choice*. Only people who give informed consent can take part in the study. Whether you decide to take part will not affect your employment or other contacts with XXX Health or disadvantage you in any other way.

If you decide to participate, you will be *free to withdraw from the project at any time* without having to give a reason, by letting the researchers know of your decision. If you decide to withdraw, you may also choose to withdraw your research data.



### What would I be asked to do?

If you agree to participate, we will ask you to do two things:

(1) To *take part in a focus group* with Gena Lantry and XXX and up to seven fellow health professionals. Gena is a registered nurse with experience in pain management and has done this type of research before. Irena is an experienced nurse and researcher. Focus groups have been organised to reflect common professional backgrounds or areas of work. Focus groups will take about one hour, and will take place at the XXX XXX Hospital, unless the group finds it more convenient to meet in a different location. It is important that all members of a focus group are present at the start and stay for the whole discussion. The sort of topics we would like to raise with each focus group include:

The extent of your experience with patients with chronic pain and history of frequent hospital admissions

Your views of how the hospital services currently cater for this patient population (with specific reference to your area of clinical practice)

Your views on what you have to offer such patients

Your views on what other health professionals have to offer such patients

Any gaps or overlaps in the care/services you have observed

The impact such patients have on you, your colleagues, other patients, and the hospital services

What you think works well, does not work well, or needs to change to improve the overall care of patients with persistent abdominal pain and their families/significant others.

(2) To *complete a brief questionnaire* providing information about your age, educational and professional qualifications, current level and area of practice and involvement in the care of patients with persistent abdominal pain. This will take only a few minutes and will be done at the start of the focus group.

### What are the benefits and risks of participating?

There are no specific benefits to individual participants beyond possible satisfaction of contributing to improvements in the health services.

There are no physical risks to anyone who chooses to take part in this study. You may find yourself reflecting on past or ongoing experiences that make you disappointed, frustrated, or angry and you may want to share these emotions. We would ask,

however, that all participants show consideration for others in the group, listen to others' views, and direct their comments to the whole group rather than an individual.

### **How will my privacy be protected?**

Group discussions will be audio recorded, and later transcribed by a research assistant. We will ensure that any names or other identifying information is removed from the tapes and transcripts. You will be given the opportunity to *review the tape-recording or the written transcript* of the focus group and to edit or delete any portion of your contribution that you do not want us to use in our research. You may also add additional information or clarification by telling Gena Lantry who will note your comments.

We will ask all members of the discussion group to keep all information confidential, and not to share it with anyone outside the group. However, because of the group situation, we cannot guarantee complete confidentiality of information provided if someone within the group breaks their promise. For this reason, we will ask you not to use actual names of patients, family members or colleagues, and not to share highly sensitive information, or information that may have legal implications.

Once transcripts have been validated, audio-tapes of focus groups will be destroyed.

Only Gena Lantry will have access to your consent form and questionnaire. Identifying information will not be provided to other members of the research team. Because we want to keep clinical care, professional relationships and research separate, Dr XXX and Ms XXX from the XXX XXX Pain Service who are also members of the research team, will not have access to the tape recordings of focus groups or any other information that might identify you. All data will be stored in a secure place at the XXX XXX Hospital and all electronic files will be password protected and kept for the required period of five years.

### **What will happen to the information I provide?**

Transcribed text will be analysed to identify key issues and themes. Any quoted material that we publish as a result of this project will be presented in a way that does not identify individual patients, family members or health professionals. Reports of this research will be presented at professional conferences and published in scientific and professional journals.

We intend to report initial findings in a series of forums at the XXX XXX Hospital. If you would like to receive a brief written report of the findings of this study (available in early 2007), please contact Gena Lantry and she will send you a copy.

**What do I need to do to participate?**

*If you have questions* or would like more information about this study please contact Gena Lantry on Tel: 0422 989 667 (The voice mail on this number is password protected. If the phone is unattended when you call, please leave a message and contact details so that Gena can return your call.)

*If you would like to participate*, please complete the enclosed consent form and return it in the envelope provided, phone Gena Lantry on 0422 989667, or email her on [gena.lantry@hnehealth.nsw.gov.au](mailto:gena.lantry@hnehealth.nsw.gov.au). It would be appreciated if you could respond within the next week. Gena will then contact you to arrange a mutually convenient venue and time for the relevant focus group.

Thank you for considering this invitation.

Yours sincerely,

Gena Lantry

(on behalf of the research team)

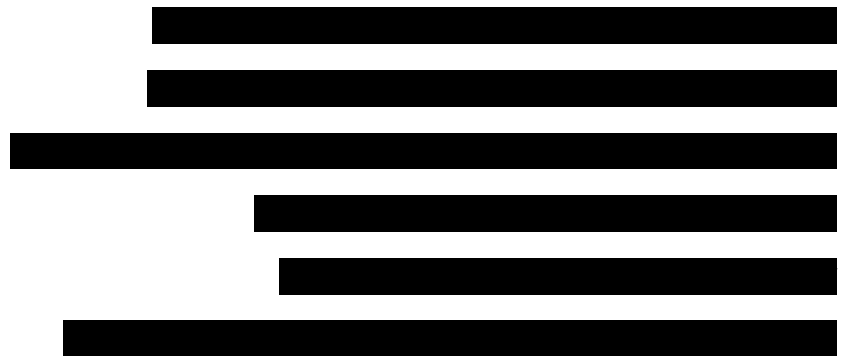
*This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter Hew England Health (ref. no. xxxxx). Should you have any concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Professional Officer (Research Ethic), Hunter New England Human Research Ethics Committee, Hunter Hew England Health, Locked Bag 1, New Lambton, NSW 2305, Tel: (02) 4921 4950, Email: [Nicole.Gerrand@hnehealth.nsw.gov.au](mailto:Nicole.Gerrand@hnehealth.nsw.gov.au).*

Contact details for other research team members:

<div>Dr XXX</div> <div>Medical Director</div> <div></div> <div></div> <div></div> <div></div> <div></div> <div></div>	<div>Ms XXX</div> <div>Operations Manager</div> <div></div> <div></div> <div></div> <div></div> <div></div> <div></div>	<div>Dr XXX</div> <div>Research Associate</div> <div>C/o Ms Gena Lantry</div> <div></div> <div></div> <div></div> <div></div> <div></div>
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## APPENDIX 10 Consent form (health professionals)

Version 1: 29 June 2006



### Consent Form for participants in the research project:

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Health Professionals)**

I, (please print name) \_\_\_\_\_ have been invited to participate in the above named study to be conducted by Ms Gena Lantry and her research team.

I understand the study will be carried out as described in the information statement, a copy of which I have read and retained.

I understand that my participation is voluntary and that whether or not I decide to participate my decision will not have any negative consequences.

I also understand that I do not have to answer all questions raised during the focus group and that I can withdraw from the study at any time without having to give any reasons.

I understand that all information I provide will be treated in confidence by the researchers.

I understand that I will be given an opportunity to review the audiotaped discussion and to edit or delete any statement I have contributed which I do not wish to have included in the research data.

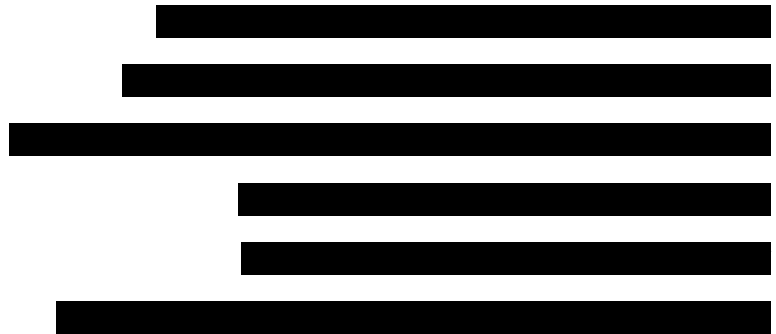
I have had all questions answered to my satisfaction.

I agree to take part in the study.

Participant's Signature ..... Date .....

## APPENDIX 11 Topics for focus group (health professionals)

Version 1: 29 June 2006



**Focus group discussion topics for the research project:**

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Health Professionals)**

*A low-key, conversational approach will be adopted in all focus groups in order to encourage participants to share their experiences and views in their own words and in a way that they find comfortable. The questions and issues to be explored are listed below. The order and format of questions and prompts may vary slightly between interviews to allow for spontaneity and conversational style to be maintained.*

Greetings and introductions (clarify nature of focus groups, basic rules of consideration for all participants, importance of confidentiality, and participant’s rights)

The extent of your experience with patients with chronic pain and history of frequent hospital admissions

Your views of how the hospital services currently cater for this patient population (with specific reference to your area of clinical practice)

Your views on what you have to offer such patients

Your views on what other health professionals have to offer such patients

Any gaps or overlaps in the care/services

The impact such patients have on you, your colleagues, other patients, and the hospital services

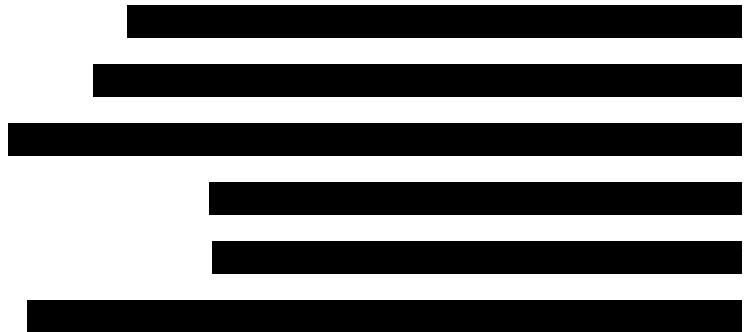
What you think works well, does not work well, or needs to change to improve the overall care of patients with persistent abdominal pain and their families/significant others.

*A brief summary of the issues covered will be provided by the group facilitator at the end of the session. Participants will be thanked for their time and contribution, and asked if they would like to have anything edited or removed from the tape recording.*



## APPENDIX 12 Demographic questionnaire (health professionals)

Version 1: 29 June 2006



### Demographic Questionnaire for the research project:

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

**(Health Professionals)**

*Please note that you do not need to include your name on this questionnaire. Please circle or tick appropriate response, and answer questions asked.*

1. **Gender:** Female ☐ Male ☐

2. **Age:** 20 – 29 ☐ 30 – 39 ☐ 40 – 49 ☐ 50 and above ☐

3. **Undergraduate qualifications:**

.....  
.....

Year(s) awarded: .....

4. **Postgraduate/professional qualifications:**

a).....Year awarded: .....

b).....Year awarded: .....

c).....Year awarded: .....

d).....Year awarded: .....

5. **Current profession/occupation:** .....

6. **Current Clinical Position:** .....

7. **Current Clinical Speciality** (area of practice): .....

8. **Years in Clinical Speciality** (current area of practice): .....

9. **How many patients** with persistent abdominal pain have you had to care for

In the last 4 weeks: .....

In the last 12 months: .....

10. On average, **how much time** do you spend with a patient with persistent abdominal pain, as compared to other patients?

Less than with other patients ☐

About the same amount of time ☐

About 25% more time ☐

About 50% more tome ☐

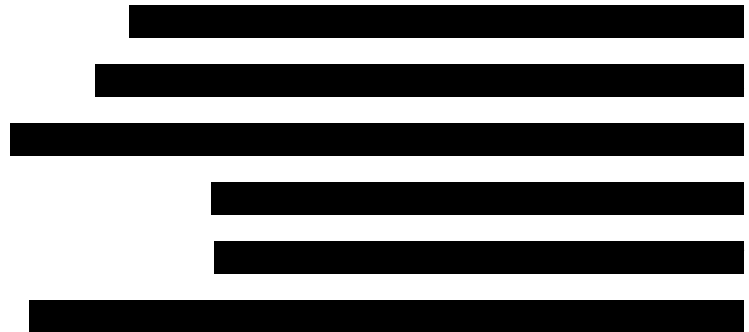
About 75% more time ☐

Twice as much or more time ☐

*Thank you for taking the time to complete this questionnaire.*

## APPENDIX 13 Demographic questionnaire (family/significant other)

Version 1: 29 June 2006



### Demographic Questionnaire for the research project:

#### “Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”

#### (Family/Significant Other)

*Please note that you do not need to include your name on this questionnaire. Please circle or tick appropriate response, and answer questions asked.*

1. **Gender:** Female ☐ Male ☐
2. **Age:** 18 – 29 ☐ 30 – 39 ☐ 40 – 49 ☐ 50 and above ☐
3. **Education:**  
Completed high school education: Yes ☐ No ☐  
Completed trade/occupational training: Yes ☐ No ☐

Completed university degree: Yes ☐ No ☐

**4. Current employment:**

Working: Full time ☐ Part time ☐ Casual ☐

Looking for paid employment: ☐

Self employed: Full time ☐ Part time ☐ Casual ☐

On government pension (aged/sickness or disability/carer): ☐

Self funded retiree: ☐

**5. Relationship to the person with pain:**

Husband/wife/partner ☐

Parent ☐

Daughter/Son ☐

Other relative ☐ (specify) .....

Friend ☐

**6. Care you give to the person in pain (please tick all that apply to you):**

Physical care (moving, showering/bathing, dressing...) ☐

Housekeeping tasks (shopping, cleaning, cooking, ironing...) ☐

Transport (to medical appointments, shopping, social outings...) ☐

Social and emotional support ☐

Other (please specify)

.....

7. **Your general health:** Excellent ☐ Good ☐ Poor ☐

Do you have any of the following? (please tick all that apply to you)

Diabetes ☐

High blood pressure ☐

Heart problems ☐

Arthritis or other muscle or joint problems ☐

Chronic pain ☐

Other (please specify)

.....

8. Any other comments?

.....

.....

.....

.....

.....

*Thank you for taking the time to complete this questionnaire.*

## APPENDIX 14 Transcriber (typist) confidentiality agreement

Version 1: 29 June 2006

[REDACTED]

### TRANSCRIBER CONFIDENTIALITY AGREEMENT

for the research project

**“Persistent Abdominal Pain: Defining a New Model of Care in the Acute Care Setting”**

*I have been contracted to undertake transcription of tape-recorded research interviews for the above named study conducted by Ms Gena Lantry and her research team. In undertaking this work, I accept the following conditions:*

I understand that the material I have been contracted to transcribe contains confidential information and I will discuss it only with the principal researcher (Gena Lantry).

I will ensure that no other person has access at any time to the audio-tapes, computer files, or typed transcripts in my possession.

I will ensure that all documents are password protected.

On completion of transcription, I will ensure that all original documents and copies are returned to the researcher (Gena Lantry), including audio-tapes, computer discs, and paper copies of transcripts.

Once all documents have been returned to the researcher (Gena Lantry), I will delete from the computer hard drive and any other devices any documents that relate to this research.

Typist's full name (please print).....

Signature: .....

Date: .....