

# Facilitating needs-based care of people with progressive cancer: Evaluation of a palliative care needs assessment intervention

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Thesis submitted for fulfilment of the award of:  
Doctor of Philosophy (Behavioural Science)  
The University of Newcastle

May 2010

This 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.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

The research described in this thesis was conducted within the framework of a larger program of work involving six discrete phases. A national multi-disciplinary team, including a palliative care physician, a general practitioner, nurses, two statisticians, an oncologist, a psychiatrist and behavioural scientists from our research group assisted in this work. My thesis supervisors were three members from this team.

The first two phases involved a large national qualitative study undertaken to explore perceptions of palliative care and issues surrounding referral in the Australian health care system; as well as a national survey identifying current referral patterns. In Phase 3, the *Palliative Care Needs Assessment Guidelines* were developed to provide advice and information for health professionals about the various physical and psychosocial issues affecting people with cancer and their caregivers. While I was involved in the development of the *Guidelines*, this did not form part of the work contained in this thesis.

This PhD work begins with the development and validation of the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C) (Chapter 4 and 5), which aimed to complement the *Guidelines* and assist health professionals in identifying the level and type of needs being experienced. I was responsible for drafting up each version of the NAT: PD-C with input from the multi-disciplinary advisory group; developing study protocols and materials, preparing ethics applications, recruiting participants and assisting with focus groups, liaising with clinical services, collecting and analysing data and drafting the manuscript. All authors contributed to the final manuscripts.

Study 3 (Chapter 6, 7 & 8) make up Phase 4 of the wider program. I developed the protocol with input from the multi-disciplinary team. I was responsible for implementing the protocol, supervising research staff, liaising with site investigators and overseeing data collection, analysing data (with assistance from statisticians on the advisory team) and writing up the outcomes of this work in the included chapters.

The final two phases of the program do not form part of this PhD. They involved the national dissemination of the *Guidelines* and NAT: PD-C and the generalisation of these resources to a heart failure population.

*I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included below a statement clearly outlining the extent of collaboration, with whom and under what auspices.*

Signed: \_\_\_\_\_

Date: \_\_\_\_\_



## TABLE OF CONTENTS

LIST OF FIGURES .....	VIII
LIST OF TABLES .....	IX
LIST OF ABBREVIATIONS.....	XI
SYNOPSIS .....	XII
CHAPTER 1: PALLIATIVE CARE AND CANCER.....	1
1.1 INTRODUCTION .....	2
1.2 WHAT IS PALLIATIVE CARE? .....	3
1.3 WHY IS PALLIATIVE CARE IMPORTANT? .....	6
1.3.1 <i>Changing attitudes towards death and dying</i> .....	6
1.3.2 <i>Demography: changes in population and the burden of disease</i> .....	7
1.4 BENEFITS OF PALLIATIVE CARE .....	9
1.5 CHALLENGES IN RESEARCH WITH PALLIATIVE CARE POPULATIONS.....	12
1.6 THE CURRENT RESEARCH .....	12
1.7 REFERENCES .....	14
CHAPTER 2: UTILISATION AND REFERRAL PATTERNS OF SPECIALIST PALLIATIVE CARE SERVICES: AN INTERNATIONAL PERSPECTIVE .....	19
2.1 INTRODUCTION .....	20
2.2 INTERNATIONAL COMPARISONS.....	21
2.2.1 <i>Australia</i> .....	21
2.2.2 <i>North America</i> .....	24
2.2.3 <i>Europe</i> .....	27
2.2.4 <i>Developing countries</i> .....	33
2.3 WHO USES PALLIATIVE CARE SERVICES? .....	35
2.3.1 <i>Diagnosis</i> .....	35
2.3.2 <i>Place of death</i> .....	36
2.3.3 <i>Presence of a caregiver</i> .....	37
2.3.4 <i>Marital status</i> .....	38
2.3.5 <i>Age</i> .....	38
2.3.6 <i>Geographical location</i> .....	39
2.3.7 <i>Education and socio-economic status</i> .....	39
2.3.8 <i>Ethnicity</i> .....	40
2.4 PATTERN OF REFERRAL TO PALLIATIVE CARE SERVICES.....	41
2.4.1 <i>Who refers to palliative care services?</i> .....	41
2.4.2 <i>When are people referred for specialist palliative care?</i> .....	42
2.5 REASONS FOR REFERRING TO SPECIALIST PALLIATIVE CARE SERVICES.....	45
2.5.1 <i>Physical issues</i> .....	45
2.5.2 <i>Caregiver and family issues</i> .....	45
2.5.3 <i>Psychological issues</i> .....	46
2.5.4 <i>Practical issues</i> .....	47
2.5.5 <i>Cultural and social issues</i> .....	48
2.5.6 <i>Information issues</i> .....	48
2.5.7 <i>Spiritual and existential issues</i> .....	49
2.5.8 <i>Sexuality issues</i> .....	49
2.5.9 <i>Health professional issues</i> .....	49
2.6 BARRIERS TO THE DELIVERY OF PALLIATIVE CARE .....	51
2.6.1 <i>Community perceptions as a barrier to delivery</i> .....	51

2.6.2	<i>Health professional barriers</i> .....	53
2.6.3	<i>Relationship between general and SPC providers and services</i> .....	54
2.6.4	<i>Institutional and health system</i> .....	55
2.7	SOURCE OF INFORMATION .....	56
2.8	CONCLUSION.....	57
2.9	REFERENCES .....	59
CHAPTER 3: DEVELOPMENT OF EVIDENCE-BASED RESOURCES TO FACILITATE THE APPROPRIATE ASSESSMENT OF PATIENT, CAREGIVER AND HEALTH PROFESSIONAL NEEDS.....		74
3.1	INTRODUCTION .....	75
3.2	NEEDS-BASED MODEL FOR DELIVERY OF CARE.....	75
3.3	EVIDENCE-BASED RESOURCES .....	76
3.3.1	<i>Benefits of Clinical Practice Guidelines</i> .....	76
3.3.2	<i>Barriers to the uptake of guidelines</i> .....	79
3.4	THE <i>PALLIATIVE CARE NEEDS ASSESSMENT GUIDELINES</i> .....	84
3.5	IMPROVING COMPLIANCE WITH GUIDELINES.....	85
3.5.1	<i>Passive methods</i> .....	86
3.5.2	<i>Active methods</i> .....	86
3.6	TRANSLATING RESEARCH INTO CLINICAL PRACTICE .....	88
3.7	REVIEWING THE EVIDENCE: AVAILABLE NEEDS ASSESSMENT AND SCREENING TOOLS.....	89
3.7.1	<i>Introduction</i> .....	89
3.7.2	<i>Methods</i> .....	90
3.7.3	<i>Results</i> .....	91
3.7.4	<i>Discussion</i> .....	112
3.7.5	<i>Conclusion</i> .....	115
3.8	REFERENCES .....	117
CHAPTER 4: DEVELOPMENT OF THE PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT) FOR USE BY MULTIDISCIPLINARY HEALTH PROFESSIONALS .....		127
4.1	ABSTRACT.....	130
4.2	INTRODUCTION .....	131
4.3	METHODS.....	132
4.3.1	<i>Sample and setting</i> .....	132
4.3.2	<i>Materials</i> .....	133
4.3.3	<i>Procedure</i> .....	135
4.3.4	<i>Analysis</i> .....	136
4.4	RESULTS.....	137
4.4.1	<i>Sample</i> .....	137
4.4.2	<i>Face and content validity</i> .....	138
4.4.3	<i>Inter-rater reliability</i> .....	138
4.4.4	<i>Recommended PC-NAT modifications</i> .....	142
4.5	DISCUSSION .....	142
4.5.1	<i>Limitations</i> .....	144
4.6	FUTURE DIRECTIONS .....	144
4.7	CONCLUSIONS .....	145
4.8	REFERENCES .....	146

CHAPTER 5: VALIDITY, RELIABILITY AND CLINICAL FEASIBILITY OF A NEEDS ASSESSMENT TOOL FOR PEOPLE WITH PROGRESSIVE CANCER.....	150
5.1 ABSTRACT.....	154
5.2 INTRODUCTION .....	155
5.2.1 Aim.....	156
5.3 METHODS.....	156
5.3.1 Sample.....	156
5.3.2 Materials .....	157
5.3.3 Procedure .....	158
5.3.4 Analysis .....	159
5.4 RESULTS.....	160
5.4.1 Sample.....	160
5.4.2 Inter-rater reliability .....	160
5.4.3 Concurrent validity .....	162
5.4.4 Acceptability.....	163
5.5 DISCUSSION .....	163
5.5.1 Changes to the NAT in response to validation results .....	165
5.5.2 Limitations.....	166
5.6 FUTURE DIRECTIONS.....	167
5.7 CONCLUSION.....	167
5.8 REFERENCES .....	168
CHAPTER 6: EVALUATION OF A PALLIATIVE CARE NEEDS ASSESSMENT INTERVENTION: METHODS .....	171
6.1 OBJECTIVES .....	172
6.2 STUDY DESIGN .....	172
6.3 SAMPLE .....	173
6.3.1 Participants .....	173
6.3.2 Sample size .....	174
6.4 MATERIALS.....	174
6.4.1 Interview measures (Appendix 6.1) .....	174
6.4.2 The Palliative Care Needs Assessment Guidelines and Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C).....	177
6.5 PROCEDURE.....	177
6.5.1 Recruitment sites .....	177
6.5.2 Ethics.....	179
6.5.3 Recruitment.....	179
6.5.4 Intervention .....	180
6.6 ANALYSIS.....	183
6.6.1 Potential confounders.....	185
6.6.2 Generalised Estimating Equation model.....	185
6.6.3 Service utilisation and referral patterns .....	186
6.7 REFERENCES .....	189
CHAPTER 7: IMPACT OF THE PALLIATIVE CARE NEEDS ASSESSMENT INTERVENTION ON PATIENT OUTCOMES.....	192
7.1 INTRODUCTION .....	193
7.2 KEY PERFORMANCE INDICATORS.....	193
7.2.1 Computer-assisted telephone interviews completed.....	193
7.2.2 Needs Assessment Tool: Progressive Disease - Cancer completed .....	194
7.2.3 Recruitment.....	194
7.2.4 Study sample size .....	197

7.3	PARTICIPANT CHARACTERISTICS AT BASELINE.....	197
7.3.1	<i>Type of diagnosis - baseline differences</i> .....	200
7.3.2	<i>Employment status</i> .....	201
7.3.3	<i>Geographical region</i> .....	201
7.3.4	<i>Co-morbid conditions</i> .....	203
7.4	PARTICIPANT CHARACTERISTICS IN RELATION TO RECRUITMENT SITE, NUMBER OF PRE-INTERVENTION DATA COLLECTION POINTS AND PRESENCE OF A CAREGIVER.....	205
7.4.1	<i>Recruitment site</i> .....	205
7.4.2	<i>Number of pre-intervention CATIs completed</i> .....	206
7.4.3	<i>Presence of a caregiver</i> .....	208
7.5	IMPACT OF THE INTERVENTION ON SUPPORTIVE CARE NEEDS.....	210
7.5.1	<i>Baseline prevalence of needs</i> .....	210
7.5.2	<i>Changes in needs over time</i> .....	213
7.6	IMPACT OF THE INTERVENTION ON QUALITY OF LIFE.....	220
7.6.1	<i>Baseline quality of life score</i> .....	220
7.6.2	<i>Changes in mean quality of life score over time</i> .....	220
7.7	IMPACT OF THE INTERVENTION ON DEPRESSION, ANXIETY AND DISTRESS.....	222
7.7.1	<i>Baseline prevalence of depression</i> .....	222
7.7.2	<i>Changes in prevalence of clinical depression over time</i> .....	222
7.7.3	<i>Baseline prevalence of clinical anxiety</i> .....	224
7.7.4	<i>Changes in prevalence of anxiety over time</i> .....	224
7.7.5	<i>Baseline prevalence of clinical distress</i> .....	225
7.7.6	<i>Changes in prevalence of clinical distress over time</i> .....	225
7.8	DISCUSSION .....	226
7.9	STUDY DESIGN AND LIMITATIONS.....	233
7.10	CONCLUSION.....	236
7.11	REFERENCES .....	238
CHAPTER 8: IMPACT OF THE PALLIATIVE CARE NEEDS ASSESSMENT INTERVENTION ON CLINICAL ASSESSMENT, RESPONSE AND SERVICE UTILISATION .....		244
8.1	INTRODUCTION .....	245
8.2	FEASIBILITY AND ACCEPTABILITY OF THE NAT: PD-C.....	245
8.2.1	<i>Completion rate</i> .....	245
8.2.2	<i>Length of the consultation</i> .....	246
8.2.3	<i>Consistency of NAT: PD-C ratings with patient self-reported needs</i> .....	247
8.3	ISSUES OF CONCERN RECORDED USING THE NAT: PD-C .....	248
8.4	RECORDED ACTIONS TO ADDRESS IDENTIFIED ISSUES OF CONCERN ON THE NAT: PD-CS .....	251
8.5	SELF-REPORTED SERVICE USE AND REFERRALS: CATIS .....	252
8.5.1	<i>Referrals identified in the initial CATI</i> .....	252
8.5.2	<i>Changes in numbers of self-reported referrals over time</i> .....	252
8.6	SERVICE USE AND REFERRALS: AUDIT OF MEDICAL RECORDS .....	253
8.7	DISCUSSION .....	254
8.8	STUDY DESIGN AND LIMITATIONS.....	257
8.9	CONCLUSION.....	258
8.10	REFERENCES .....	259
CHAPTER 9: BEYOND THE CONFINES OF WELL-ESTABLISHED ONCOLOGY SETTINGS.....		260
9.1	CONCLUSION.....	261
9.2	BEYOND THE CONFINES OF ONCOLOGY: OPPORTUNITIES FOR FUTURE RESEARCH 265	



9.3	IMPLICATIONS FOR POLICY AND PRACTICE.....	267
9.4	REFERENCES .....	270
APPENDICES.....		274
APPENDIX 3.1: SUMMARY OF THE <i>PALLIATIVE CARE NEEDS ASSESSMENT GUIDELINES</i>		
	275	
APPENDIX 4.1: PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT) PILOTED		
	VERSION.....	310
APPENDIX 4.2: PILOT STUDY PARTICIPANT INFORMATION LETTER .....		313
APPENDIX 4.3: PILOT STUDY PARTICIPANT CONSENT FORM .....		317
APPENDIX 4.4: PILOT STUDY PARTICIPANT DEMOGRAPHIC SURVEY.....		319
APPENDIX 4.5: SUMMARY OF PATIENT HISTORY: ANDREW DONATI .....		321
APPENDIX 4.6: SUMMARY OF PATIENT HISTORY: BARRY WHITE.....		323
APPENDIX 4.7: SUMMARY OF PATIENT HISTORY: DENISE BLACKWELL .....		325
APPENDIX 5.1: PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT) REVISED		
	VERSION.....	327
APPENDIX 5.2: PALLIATIVE CARE OUTCOMES COLLABORATION (PCOC) DATASET...		330
APPENDIX 5.3: VALIDATION STUDY HEALTH PROFESSIONAL ACCEPTABILITY SURVEY.		334
APPENDIX 5.4: VALIDATION STUDY PATIENT INFORMATION LETTER .....		338
APPENDIX 5.5: VALIDATION STUDY PATIENT CONSENT FORM.....		342
APPENDIX 5.6: VALIDATION STUDY REQUEST FOR RESULTS FORM .....		344
APPENDIX 5.7: VALIDATION STUDY HEALTH PROFESSIONAL INFORMATION LETTER....		346
APPENDIX 6.1: EVALUATION STUDY COMPUTER ASSISTED TELEPHONE INTERVIEW		
	(CATI) PATIENT QUESTIONS .....	350
APPENDIX 6.2: EVALUATION STUDY PATIENT INFORMATION LETTER .....		366
APPENDIX 6.3: EVALUATION STUDY PATIENT CONSENT FORM.....		370
APPENDIX 6.4: EVALUATION STUDY PATIENT MEDICAL RECORD AUDIT FORM .....		372
APPENDIX 7.1: SUPPORTIVE CARE NEEDS SURVEY SHORT FORM-34 (SCNS SF-34)		
	LIST OF MODERATE OR HIGH NEEDS .....	376
APPENDIX 9.2: NEEDS ASSESSMENT TOOL: PROGRESSIVE DISEASE – CANCER (NAT:		
	PD-C) FINAL VERSION.....	379

## LIST OF FIGURES

Figure 1.1:	Sequential model of palliative care.....	4
Figure 1.2:	Concurrent model of palliative care.....	4
Figure 3.1:	Barriers to health professional adherence to clinical practice guidelines in relation to behaviour change.....	80
Figure 7.1:	Summary flowchart of patient recruitment and data collection .....	196
Figure 7.2:	Percentage of participants reporting at least one moderate or high need in the physical and daily living domain of the SCNS, from six months pre- to six months post-intervention.....	214
Figure 7.3:	Percentage of participants reporting at least one moderate or high need in the psychological domain of the SCNS, from six months pre- to six months post-intervention.....	215
Figure 7.4:	Percentage of participants reporting at least one moderate or high need in the health system and information domain of the SCNS, from six months pre- to six months post-intervention.....	216
Figure 7.5:	Percentage of participants reporting at least one moderate or high need in the patient care and support domain of the SCNS, from six months pre- to six months post-intervention.....	217
Figure 7.6:	Percentage of participants reporting at least one moderate or high need in the sexuality domain of the SCNS, from six months pre- to six months post-intervention.....	218
Figure 7.7:	Percentage of participants reporting at least one moderate or high need in the spirituality domain of the NA-ACP, from six months pre- to six months post-intervention.....	219
Figure 7.8:	Mean quality of life score for study participants compared with available general population norms, from six months pre- to six months post-intervention. ....	221
Figure 7.9:	Percentage of patients with clinical levels of depression compared with Australian general population norms, from six months pre- to six months post-intervention.....	223
Figure 7.10:	Percentages of patients with clinical levels of anxiety compared with Australian general population norms, from six months pre- to six months post-intervention. ....	225
Figure 7.11:	Percentages of patients with clinical levels of distress, from six months pre- to six months post-intervention. ....	226
Figure 8.1:	Percentage of NAT: PD-Cs in which a need was recorded in the Patient Wellbeing section; and any action recorded to address that concern .....	249
Figure 8.2:	Percentages of NAT: PD-Cs in which a need was recorded in the Ability of the Caregiver to Care for the Patient section; and any action recorded to address that concern.....	250
Figure 8.3:	Percentage of NAT: PD-Cs in which a need was recorded in the Caregiver Wellbeing section; and any action recorded to address that concern.....	251
Figure 8.4:	Mean number of referrals self-reported by participants in their CATIs over the course of the study .....	253
Figure 8.5:	Mean number of health professionals seen and visits attended by participants during the 12 months prior to death, as recorded in patient medical records..	254

## LIST OF TABLES

Table 2.1:	Mean and median length of care for different palliative care settings in Australia, Canada, the USA and the UK .....	44
Table 3.1:	Search terms used singly or in combination .....	90
Table 3.2:	Coverage of domains of need in the Palliative Care Needs Assessment Guidelines by available patient needs assessment tools .....	98
Table 3.3:	Psychometric properties of needs assessment tools for patients .....	101
Table 3.4:	Coverage of domains of need in the Palliative Care Needs Assessment Guidelines by available caregiver needs assessment tools .....	110
Table 3.5:	Psychometric properties of needs assessment tools for caregivers .....	111
Table 4.1:	Demographic characteristics of participating health professionals .....	137
Table 4.2:	The Kappa (and percentage) of participants agreeing on the presence versus absence of concerns in the PC-NAT domains addressed in each consultation .....	139
Table 4.3:	The Kappa (and percentage) of participants agreeing on the three levels of concern in the PC-NAT domains addressed in each consultation .....	141
Table 5.1:	Validated scales and NAT items compared .....	160
Table 5.2:	The PABAK, Cohen's kappa and percentage of raters agreeing on the severity of the concerns in the NAT domains .....	161
Table 5.3:	The PABAK, Cohen's kappa and percentage of raters agreeing on the severity of the concerns in the NAT domains and PCPSS items.....	162
Table 5.4:	Mean scores for the RUG-ADL and AKPS according to the level of concern on the NAT daily living item. ....	163
Table 7.1:	Number of completed CATIs.....	194
Table 7.2:	Number of NAT: PD-Cs completed by different health care providers at each recruitment site.....	194
Table 7.3:	Recruitment response and consent rates for patient participants by site.....	195
Table 7.4:	Status of participants by site at study completion .....	197
Table 7.5:	Demographic profile of patient sample at baseline compared with a NSW cancer population, all Australian households and all Australians .....	199
Table 7.6:	Demographic profile of patient sample at baseline. ....	200
Table 7.7:	Employment status of study participants .....	201
Table 7.8:	Comparisons of patient demographic and baseline outcome variables according to geographical residence.....	202
Table 7.9:	Types of co-morbid conditions reported by study participants.....	203
Table 7.10:	Co-morbidity scores of study participants.....	204
Table 7.11:	Comparisons of participants' demographic and baseline outcome variables across recruitment sites .....	205
Table 7.12:	Primary cancer diagnoses of study participants across recruitment sites.....	206
Table 7.13:	Comparisons of demographic and baseline outcome variables based on number of pre-intervention CATIs completed .....	207
Table 7.14:	Comparisons of demographic and baseline outcome variables for study participants with and without caregivers.....	209
Table 7.15:	Gross household income reported by study participants with and without caregivers.....	210
Table 7.16:	Top ten items for which participants reported a moderate or high need for help in the month preceding the baseline CATI.....	210

Table 7.17:	<i>Chi square comparisons for the percentage of study participants reporting a moderate or high need in the SCNS-SF34 domains based on age, gender, presence of a caregiver and level of caregiving.....</i>	<i>211</i>
Table 7.18:	<i>Post hoc power analyses based on the observed changes in percentage of participants with at least one need in each of the domains in the SCNS-SF34 from Time 0 to Time 1.....</i>	<i>234</i>
Table 8.1:	<i>Number of NAT: PD-Cs completed by different health care providers at each recruitment site.....</i>	<i>245</i>
Table 8.2:	<i>Comparison of the length of consultations during which a NAT: PD-C was completed versus consultations in which a NAT: PD-C was not completed...247</i>	
Table 8.3:	<i>The Prevalence-Adjusted Bias-Adjusted Kappa (PABAK), Cohen's kappa and percentage agreement between the presence (or absence) of needs in the NAT: PD-C and self-reported needs identified during CATIs.....</i>	<i>248</i>
Table 8.4:	<i>Percentage of issues of concern identified on the NAT: PD-C for which an action to address that concern was recorded .....</i>	<i>252</i>

## LIST OF ABBREVIATIONS

SPCS	Specialist palliative care service
WHO	World Health Organization
PCA	Palliative Care Australia
NAT: PD-C	Needs Assessment Tool: Progressive Disease – Cancer
PC-NAT	Palliative Care Needs Assessment Tool
GP	General Practitioner
UK	United Kingdom
USA	United States of America
NHPCO	National Hospice and Palliative Care Organization (USA)
NHS	National Health Service (UK)
NCPC	National Council for Palliative Care (UK)
NHIF	National Health Insurance Fund (Hungary)
ABS	Australian Bureau of Statistics
SES	Socio-economic status
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and linguistically diverse
LLI	Life-limiting illness
PCOC	Palliative Care Outcomes Collaboration
CATI	Computer-assisted telephone interview
SAS	Statistical Analysis Software
NSAP	National Standards Assessment Program
RACGP	Royal Australian College of General Practitioners
RCNA	Royal College of Nursing Australia
ACRRM	Australian College of Rural and Remote Medicine

## SYNOPSIS

There is an expectation that palliative care will be available to all people suffering from life-limiting illnesses such as cancer. However, a disparity exists between this perception and current experiences in end-of-life care. It has been recommended that palliative care be provided according to the individual needs of the patient, caregiver and family, so that the type and level of care provided, as well as the setting in which it is delivered, are dependent on the complexity and severity of individual needs, rather than prognosis or diagnosis. This dissertation examines a strategy to facilitate this needs-based approach to the delivery of palliative care to people with advanced cancer in Australia. The overall aim of this research was to develop and examine the feasibility and efficacy of an intervention to assist in the allocation of palliative care resources according to need, within the context of the population of people with advanced cancer.

Chapter 1 describes how changes in attitudes towards death and dying, changes in demography and an increase in burden of diseases such as cancer have facilitated an increasing interest in the area of palliative care. The fundamental role that palliative care plays in caring for the dying and the benefits of this care for people with life-limiting illnesses, their caregivers and the system as a whole are outlined. Chapter 2 is a comprehensive review of the current literature describing the utilisation and referral patterns of specialist palliative care services, from an international perspective. Specifically, this chapter reviews international health system structures and funding, models of palliative care services and the personal and external factors that may influence service utilisation, in order to provide evidence for the inequitable and ill-timed delivery of care that is currently in use. In addition, the reasons for referral to specialist palliative care services, as well as the source and timing of referrals and the barriers to referral, are explored.

Chapter 3 outlines the alternative needs-based approach to the delivery of palliative care, outlining the importance and benefits of people receiving care according to the complexity and severity of their needs, independently of diagnosis or prognosis. The use of guidelines and referral pathways has been suggested as one way to determine who would benefit most from receiving palliative care; hence the Palliative Care Needs Assessment Guidelines were developed. The *Palliative Care Needs Assessment Guidelines* aim to provide advice to those caring for people with cancer and their families to ensure that they are offered the most appropriate care to meet

their specific needs. The various barriers to the uptake of guidelines are outlined, and the need for strategies to improve compliance with guidelines is acknowledged. The chapter outlines the benefits of using a needs assessment tool to improve compliance with guidelines, and this is accompanied by a review of available needs assessment tools for people with cancer and their caregivers to ascertain the suitability of these tools to complement the *Guidelines*.

The results of the review support the development of a new needs assessment tool to accompany the *Palliative Care Needs Assessment Guidelines*, and Chapters 4 and 5 outline the results of two preliminary validation studies conducted in the early stages of this PhD to assess the psychometric qualities of this new tool. Chapter 4 is a peer-reviewed published article describing the development and pilot testing of the Palliative Care Needs Assessment Tool (PC-NAT), which has since been renamed the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C). This pilot study was conducted in a simulated setting and aimed to test the PC-NAT for use by different health professionals who have contact with advanced cancer patients, in terms of its clarity, content, face validity, acceptability and inter-rater reliability. The study provides preliminary support for the psychometric properties of the tool including clarity, content validity, acceptability and inter-rater reliability. Chapter 5 describes a validation study to confirm the reliability, validity and acceptability of the NAT: PD-C in a clinical setting, in this case, a specialist palliative care service. The study offers further psychometric evidence for the NAT: PD-C and suggests that the NAT: PD-C is a highly acceptable and efficient tool that can be used by health professionals with a range of clinical expertise to identify patients' and their caregivers' levels of concern about physical and psychosocial aspects, thereby facilitating a better match of types and levels of services and resources to the types and levels of needs identified.

The need for further evaluation of the Palliative Care Needs Assessment Guidelines and NAT: PD-C to assess patients and their caregivers at multiple time points and determine the validity and responsiveness of the NAT: PD-C is acknowledged. Chapter 6 provides an outline of the methods adopted for this prospective, multi-site, multi-discipline longitudinal study. Recruitment sites and procedures, study participants and interview measures are described in this chapter, along with the proposed intervention and analyses. Chapter 7 is the first of two evaluation results chapters. This chapter describes the impact of using the Palliative Care Needs Assessment Guidelines and

NAT: PD-C on patient outcomes. The participant profile is described and any changes in the patients' unmet needs, depression, anxiety and quality of life that occurred as a result of the intervention are discussed. Chapter 8, the second evaluation results chapter, discusses the impact of the intervention on patient service use and referral patterns. Information on service utilisation was obtained from interviews, completed NAT: PD-Cs and audited medical records. This chapter also describes the suitability of the research design in terms of its strengths and weaknesses, as well as the implications of potential biases on the applicability and generalisability of the findings.

Finally, Chapter 9 examines the findings of the overall research in light of the original aims of the project. It also discusses strategies for ensuring the successful dissemination and implementation of the resources within clinical settings.



# **CHAPTER 1:**

## **PALLIATIVE CARE AND CANCER**

## 1.1 INTRODUCTION

One of the fundamental challenges of health care provision is ensuring that care is delivered in an appropriate and equitable manner. This is relevant for various areas of health care including end-of-life care, where it has been suggested that delivery is less than optimal. While specialist palliative care services (SPCSs) have an integral place in the delivery of palliative care to people with life-limiting illnesses, their caregivers and families, issues surrounding when and how palliative care should be delivered, as well as who should receive this care, are yet to be resolved.

The overall objective of this research was to develop and examine the feasibility and efficacy of an intervention to assist in the allocation of palliative care resources according to need, within the context of the population of people with advanced cancer. Specifically the aims were to:

1. Define the needs-based approach to care and outline the benefits and barriers of using Guidelines as a method for determining who would benefit from palliative care.
2. Review the suitability of tools currently available to operationalise the *Palliative Care Needs Assessment Guidelines*, by assessing the needs of people with cancer, their caregivers and the health professionals who provide their care.
3. Develop and pilot test a needs assessment tool for use with advanced cancer patients and caregivers, to prompt early intervention.
4. Assess the reliability, validity and acceptability of the needs assessment tool in a clinical setting.
5. Assess the impact of the systematic and ongoing use of the Guidelines and needs assessment tool on patient outcomes including level of need, quality of life, anxiety and depression.
6. Assess the impact of the systematic and ongoing use of the *Guidelines* and needs assessment tool on clinical assessment, response and service utilisation.
7. Provide a critical review of the research in light of the overall objectives and outline the implications that this research may have for patient care, practice and policy.

The aim of this chapter is to define palliative care and briefly outline the benefits, barriers and challenges associated with delivering palliative care within the context of the advanced cancer population.

## **1.2 WHAT IS PALLIATIVE CARE?**

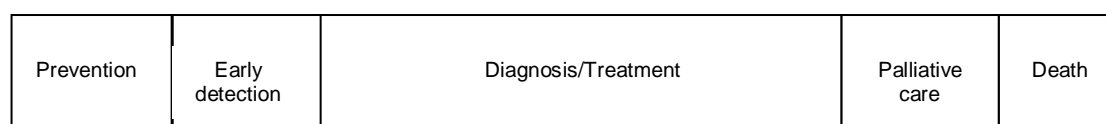
The literature suggests that palliative care has a fundamental role in care for the dying. However, the rapid development of the field has meant that there is still considerable debate about what constitutes palliative care, and this issue has been hindered further by the ongoing shift in the terminology used to describe and even define palliative care.<sup>1</sup> First used in 1974 by Balfour Mount, the phrase, “palliative care”, has often been used interchangeably with terminal care. However, it is argued that using this phrase, “terminal care”, has helped to reinforce the beliefs held by some health professionals that palliative care is only relevant for people who are in their last weeks or even days of life;<sup>2, 3</sup> hence, it has helped perpetuate the late referrals that are often made to SPCSS.<sup>4, 5</sup>

Instead, the World Health Organization (WHO) has defined palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".<sup>6</sup> Palliative care can be introduced when a person is "not amenable to cure and the symptoms require effective symptom management".<sup>7</sup> The World Health Organization has also recommended that palliative care be extended to include patients earlier in the course of the disease rather than just in the terminal phase.<sup>8</sup>

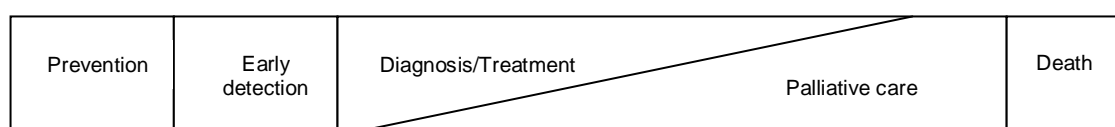
The term, “hospice”, too, has also often been used interchangeably with palliative care. However, different countries have different interpretations of these phrases. In fact, these differences in interpretation can make generalising and translating research into practice problematic.<sup>9</sup> In countries such as Australia and the United Kingdom (UK), hospice refers to a type of unit in which palliative care is provided.<sup>10</sup> In the United States of America (USA), hospice is a program of care that is provided to those with a prognosis of less than 6 months and is almost exclusively community-based care.<sup>11, 12</sup>

Alternatively, palliative care services in the USA provide care that is predominantly consultative and hospital-based.<sup>11, 12</sup> Hospice and palliative care, therefore, represent two different aspects of care with similar goals but different funding sources and eligibility criteria.<sup>13, 14</sup> The interpretation and comparison of international studies is made difficult by these differences in the interpretation of phrases used to define this type of care.<sup>9</sup> In fact, there has been a move away from the term, hospice, as it "fails to acknowledge the need for supportive care throughout the illness".<sup>3</sup> Even now, this lack of clarity in palliative care terminology causes confusion among the wider community, and even among some health professionals.<sup>1</sup>

The view that palliative care is only relevant once all life-prolonging treatments have been exhausted (Figure 1.1) is beginning to yield in practice to an alternative model in which palliative care and active therapy may be administered concurrently (Figure 1.2).<sup>15, 16</sup> According to this alternative model, the progression of the disease is often associated with fewer disease-modifying treatment alternatives, and so the "focus of care should shift toward the goals of comfort and quality of life".<sup>16</sup> Hence, treatments may still be available to health professionals as the patient moves through the illness trajectory; however, the focus is on quality of life and the comfort of the patient, caregiver and family.



*Figure 1.1: Sequential model of palliative care*



*Figure 1.2: Concurrent model of palliative care (adapted from Glare et al 2002)<sup>15</sup>*

Recently, the delivery of palliative care has been further characterised as a continuum ranging from basic to specialised palliative care.<sup>17</sup> According to Ahmedzai (2004), basic palliative care is care that can be provided by all health professionals within their normal duties, while specialised palliative care is a "higher standard of palliative care provided at the expert level by a trained multi-professional team."<sup>17</sup> This specialised care supplements the basic care offered by generalist health professionals by

accessing specific input in the form of assessment or information.<sup>7</sup> This input may range from a one-off consultation to the transfer of care from the generalist to specialist setting provided by a specialist palliative care service.<sup>7</sup> Specialist palliative care services are "multi-disciplinary health care services whose substantive work is with patients who have a life limiting illness;" and specialist palliative care professionals have recognised qualifications or training in palliative care.<sup>18</sup> Further distinction has also been made for the care provided during the last days or weeks of life, referred to as "end-of-life care", or the terminal phase of a life-limiting illness.<sup>17, 19</sup>

### **1.2.1 Palliative care population**

Palliative care can be provided to people with a life-limiting illness<sup>6</sup> or illnesses that are "reasonably expected to cause the death of the patient within a foreseeable future".<sup>18</sup> People with non-cancer diagnoses often experience a need for assistance with physical and psychosocial concerns similar to those of people with cancer, as well as similar limits to their prognosis.<sup>20, 21</sup> Palliative care has therefore been discussed as an option for people with cancer as well as for people with non-malignant diagnoses such as HIV/AIDS,<sup>22</sup> stroke,<sup>23</sup> chronic obstructive pulmonary disease<sup>24</sup> and heart failure.<sup>21</sup> Literature suggests that people with these conditions experience comparable physical and psychosocial needs to people with cancer.<sup>25</sup> This supports the assertion that there is a need for palliative care to be available to all those who need it, rather than only those suffering from a specific medical diagnosis such as cancer.<sup>26</sup> However, evidence suggests that there is a discrepancy in the use of services by these disease groups. Non-cancer patient groups often make up only a small percentage of the palliative care population; only 10.4% of patients admitted to palliative care services in Australia had a non-cancer diagnosis.<sup>27</sup> Similar trends have been found in international literature.<sup>28-30</sup>

A number of reasons for this discrepancy have been suggested. Firstly, oncology is closely allied with palliative care and has played a significant role in its development.<sup>31</sup> In fact, Clark (2007) argues that oncology has "shaped the conceptual model of palliative care, produced some of its major leaders and innovators, and provided a population with obvious potential to benefit from a new approach to the management of those with advanced disease".<sup>31</sup> The varying illness trajectories of non-malignant diseases such as heart failure and chronic lung disease appear to complicate judgements on what palliative care is needed and how and when this care is delivered.<sup>25</sup> Some have questioned the professional knowledge and experience of

specialist palliative care teams with regard to specific non-malignant illnesses.<sup>32, 33</sup> Moreover, the financial and practical impact of including non-cancer patients has been a contentious point for many, in terms of the increase in resources required to take on the increased demand, especially in those countries which rely on charitable donations.<sup>2, 20</sup>

Oncology has been closely aligned with the development of palliative care and has taken a central role in palliative care research. However, studies have shown that people with non-malignant disease have a similar need for palliative care.<sup>34, 35</sup> There is little doubt that while there is a need for further education and training in palliative care, this is not limited to non-malignant diseases.<sup>36-39</sup> Greater collaboration with specialists in non-malignant diseases is required to improve expertise of those specialist palliative care providers with limited expertise in these areas.<sup>25</sup>

The impact of extending palliative care delivery to non-malignant diseases on already limited resources is perhaps more contentious.<sup>33</sup> However, delivering care that is determined by the needs of the patient, caregiver and family, independently of individual prognosis or diagnosis, offers a potential solution to this issue.<sup>40</sup> Not everybody will require specialist palliative care services.<sup>41</sup> For some people, palliative care delivered by their generalist health professionals may be satisfactory to ensure their needs are met. This could facilitate a more appropriate allocation of limited specialist palliative care resources, thus allowing for the inclusion of people with both non-malignant and malignant diagnoses. This needs-based approach to the delivery of care provided the framework for the current research and is discussed in greater detail in Chapter 3.

## **1.3 WHY IS PALLIATIVE CARE IMPORTANT?**

### **1.3.1 Changing attitudes towards death and dying**

Early history of palliative care has been traced back to the mid-nineteenth century when Jeanne Garnier founded a hospice for the dying in Lyon, France, while in Ireland Mary Aikenhead opened St Vincent's Hospital in 1834. However, it is generally accepted that the development of the modern hospice movement and palliative care in

the English-speaking world can be traced back to the 1950s and 1960s and, in particular, to the work of Dame Cicely Saunders.<sup>2, 42</sup> Palliative care services in USA and Europe began to emerge approximately ten years later,<sup>31</sup> due to the work of a number of people including Elizabeth Kubler-Ross in the USA and Vittorio Ventafridda in Italy. Australian palliative care services began to emerge in the 1980s with Australia announcing the first Chair in Palliative Care in 1988.<sup>43</sup>

The way palliative care has developed and the increasing importance that has been placed on this care are in part a product of the changes to the way that people have viewed death and dying.<sup>44</sup> Death is reliant on the social and historical context in which it is experienced,<sup>45</sup> and the social changes to the health of the UK population in the 1960s provided a framework for a new-found focus on care of the dying.<sup>42</sup> Traditionally, death was more rapid and was associated with low life expectancy.<sup>2</sup> Later, technological advancements improved the health of the population, bringing about a reduction in death rates and an increase in life expectancy.<sup>46</sup> Accompanying these trends was the transition from deaths due to traditional causes that were often more rapid and sudden, to deaths due to long-term degenerative diseases.<sup>2</sup> Prior to these advancements, death was an integral part of the care due to the often rapid progression of disease. Now, according to James *et al* (1992), death was "removed from social view"<sup>46</sup> and was seen as something avoidable.<sup>42</sup>

Despite these technological advancements and life-sustaining treatments, however, people were still dying. Many people saw these deaths as a failure on behalf of medicine,<sup>47</sup> and it was suggested that care of the dying at this time was inadequate.<sup>42, 48</sup> In response to this, and in opposition to the culture of the day, a new approach to caring for the dying was beginning to emerge. This approach emphasised "living with dying" and the involvement of the individual in the process of dying, rather than simply relying on the authority of medical experts.<sup>2</sup> According to Clark, it was within this framework that the modern hospice movement began to emerge.<sup>2</sup>

### **1.3.2 Demography: changes in population and the burden of disease**

Aside from the changes in attitudes, evidence illustrating the increasing importance of palliative care can be seen when exploring changes in the burden of disease. The global population is expected to increase to 9 billion in the next 50 years.<sup>49</sup> Coupled with this increase in population number is the ageing nature of the population,<sup>49</sup> with

reports suggesting that the number of people aged 65 or over will increase from 7% of the world population in 2000 to over 16% by 2050.<sup>50</sup> In Australia, the population in the age range 65 and over is projected to increase by 30% by 2011.<sup>51</sup>

Due to the association between cancer risk and age, this change in demography will have a considerable impact on society's cancer burden, particularly in developing countries.<sup>49, 50, 52</sup> There are currently over 10 million new cases, 6.2 million deaths and 22.4 million persons living with cancer globally.<sup>50</sup> Currently in Australia, 1 in 2 men and 1 in 3 women will be diagnosed with cancer before the age of 85.<sup>51</sup> The burden of cancer is expected to triple in developing countries by 2050, and double in developed countries.<sup>50</sup> Within this global context, cancer deaths "will rise from 6.2 million in 2000 to nearly 10 million by 2020 and, by 2050, 16 million deaths would occur".<sup>50</sup> It is expected that these trends will exert considerable pressure on health care availability.<sup>49, 50</sup>

Determining the burden of a disease is difficult when comparing diseases that vary in prevalence, mortality and morbidity. In Australia, the burden of injury and disease has been examined in terms of "disability-adjusted life year" (DALY), or "time lost due to both fatal and non-fatal events, that is, years of life lost due to premature death coupled with years of 'healthy' life lost due to disability".<sup>53</sup> In 2003, cancer represented the highest total burden of disease and injury (DALY) in Australia at 19% and was responsible for 32% of fatal burden (years of life lost).<sup>53</sup> When broken down into age group, the contribution of cancer to total burden of disease and injury peaked at 31% in 65-74 year olds.<sup>53</sup> Moreover, more than four-fifths of the total cancer burden was due to premature mortality.<sup>53</sup>

The course of cancer is shifting from acute to chronic disease with a continuing need for long-term care.<sup>54</sup> The nature of care required by people with cancer and their families also must be taken into account to determine the burden placed on individuals and the health care system. For example, the type of care required may be different for people of different ages. In those over the age of 65, existing co-morbid conditions can complicate the diagnosis, treatment and care of cancer, placing a considerable burden not only on patients but also on the health professionals treating them.<sup>55</sup> Conversely, there has been an increase in the incidence of cancer in young people,<sup>56</sup> who experience poorer outcomes as a result of changes in treatment tolerance and cancer



biology,<sup>56</sup> and may require more complex psychosocial care due to developmental challenges.<sup>57</sup> This suggests that complexity of issues facing patients and their families requires health professionals to provide care that is coordinated and best suited to the individual's own circumstances.

## **1.4 BENEFITS OF PALLIATIVE CARE**

One publication reporting on the global burden of disease indicated that of the 56 million people who die across the world each year, 33 million (60%) would benefit from the involvement of palliative care.<sup>49</sup> In Australia, palliative care is currently involved with approximately 37.5% of the people who die each year.<sup>18</sup> In South Australia, a population-based study found that 47% of people with life-limiting illnesses were followed by specialist palliative care services.<sup>58</sup> Based on the data from this study, the authors suggested that while 70% of people with life-limiting illnesses would benefit from specialist palliative care services, 16% did not access these services.<sup>58</sup>

A number of systematic reviews have been conducted to appraise palliative care interventions and their impact on patient and caregiver outcomes. Objective outcomes are based on variables that can be recorded by various testing procedures and assessors.<sup>59, 60</sup> Symptoms or conditions are therefore perceived as a sign of disease by someone other than the person affected, such as the health professional, or through biomedical tests. Such measures may include disease activity, side-effects and survival. Subjective outcomes represent the perceptions and opinions of people affected by the disease.<sup>59, 60</sup> Because of their multidimensional nature, subjective interventions can be significantly influenced by symptom distress or cognitive abnormalities.<sup>61</sup> Subjective outcomes are measured by looking at the person's perceptions about the outcome, and may include both satisfaction and quality-of-care measures.<sup>62</sup> For example, patient and caregiver subjective outcomes may include satisfaction with care, as well as self-reported quality of life. Distinguishing between the objective and subjective outcomes is important as one may not necessarily correlate with the other.<sup>63</sup> Health system outcomes include the "promotion of quality service delivery as evidenced by the reduction of length of stay, cost per case within an acceptable range and the delivery of observable high-quality patient care".<sup>64</sup> Examples

may include readmission time, length of stay and cost to the organisation or health service.

A meta-analysis conducted by Higginson *et al* (2003) on studies from a variety of nations, including the UK, USA, Europe, Australia, Canada and Argentina, found that the greatest benefit in pain and symptom control was found through the delivery of home care, although inpatient hospice care also showed improvement in these outcomes.<sup>65</sup> In another review, home care provided by multidisciplinary teams with a degree of training in palliative care, and inpatient hospice or palliative care, were shown to improve pain and symptom control compared with conventional care.<sup>66</sup> Mixed results were seen in a systematic review of home care, with improvements in satisfaction in 2 out of 5 studies, quality of life in 3 out of 7 studies, psychosocial outcomes in 1 out of 6 studies and lower readmission times in 4 out of 5 studies.<sup>67</sup> Hospitals that do not have a palliative care service have been found to provide inadequate care for symptom and pain relief,<sup>68</sup> and a systematic review of hospital-based palliative care teams showed small but positive effects.<sup>69</sup> A study of patients from one specialist palliative care service showed improvements in overall quality of life and reduced physical symptoms, including pain, nausea, insomnia, appetite reduction and constipation.<sup>70</sup> Another showed a reduction in pain, dyspnoea, and secretions scores.<sup>71</sup> Admission to a hospital-based palliative care service improved existential wellbeing in addition to physical and psychological symptoms.<sup>72</sup> Thus, palliative care appears to have a positive impact on the patient's pain and symptom control.

Patient and caregiver satisfaction have been shown to improve as a result of involvement in palliative care.<sup>73</sup> In Australia, both caregivers and patients rate palliative care services highly.<sup>74</sup> Improved caregiver satisfaction, along with a trend toward improvement in patient satisfaction as a result of the involvement of palliative care, were reported in a systematic review.<sup>65</sup> In particular, home care and inpatient hospice or palliative care services are associated with improved patient and caregiver satisfaction compared with conventional care.<sup>66</sup> Similarly, satisfaction with a home-based palliative care program in the USA was high when compared with the satisfaction of the usual care group.<sup>75</sup> In a systematic review of day care, patients reported high satisfaction with care.<sup>76</sup> Staff of a hospital reported high satisfaction with the palliative care services, indicating that it had a positive effect on care, that

symptoms were better managed, that the emotional needs of the patients were met and that patients understood their prognosis better.<sup>77</sup>

Accurate and timely referral to palliative care services can also have implications for the use of often limited resources, with the involvement of hospital palliative care teams reducing the time spent in hospital.<sup>66</sup> In a USA study, acute care service use was lower for the home palliative care group, as was the need for skilled nursing days and physician office visits.<sup>75</sup> Furthermore, a 45% reduction in costs was found for the home palliative care group.<sup>75</sup> Home care is suggested to be a cost-effective way of providing palliative care from the perspective of the health system,<sup>66, 78</sup> with a systematic review indicating lower readmission time for home care intervention groups.<sup>67</sup> A USA inpatient consultation service reduced mean daily costs for the institution by 33% and mean length of stay by 30%. Moreover, mean daily costs for palliative care patients were reduced by 14.5%.<sup>71</sup>

It is important to note that these institutional and health system benefits do not necessarily translate to benefits for the patient and family. The diagnosis of cancer presents a major event not only to the person diagnosed with the disease, but also to his/her family and caregivers.<sup>79-81</sup> The primary setting for the delivery of care to patients with cancer has shifted from the hospital to the home.<sup>74, 79</sup> In fact, in Australia almost 80% of primary caregivers live with the person receiving the care; 43% of all caregivers are partners, 25% are children, and 21% are parents of the person receiving the care.<sup>79</sup> Although care-giving is reported to impact significantly on the wellbeing of caregivers, their needs are frequently considered secondary to those of the patient.<sup>79, 82</sup>

A number of studies have shown that caring for a person with cancer in the home can have a deleterious impact on the wellbeing of the caregiver and family.<sup>81</sup> In fact, for those caregivers providing care at home for patients, the physical, social, financial and psychological burden of illness can often be substantial.<sup>74, 78, 83</sup> But palliative care can also have benefits for the caregiver and family. In an Australian study, specialist palliative care involvement enabled caregivers to move on with their lives after the death of the patients,<sup>84</sup> and day-to-day, hands-on caregivers who accessed specialist palliative care had fewer unmet needs than caregivers who had not accessed specialist palliative care.<sup>84</sup> Providing palliative care can offer a sense of normality within caregivers' lives, improve their ability to sustain relationships, assist simply by being available if required and, importantly, provide a sense of control.<sup>74</sup> Communication has

been shown to improve in terms of its honesty and directness after the involvement of palliative care services.<sup>74</sup>

## **1.5 CHALLENGES IN RESEARCH WITH PALLIATIVE CARE POPULATIONS**

Many authors have suggested that investigations have been hindered as a result of methodological challenges. The majority of these studies are conducted with people who have accessed specialist palliative care services, to the exclusion of those people who did not access these services. This raises questions regarding the representativeness of the sample, the characteristics of non-referred people and the generalisability of results to future patients, some of whom may share the characteristics of the non-referred population.<sup>85</sup> The difficulties experienced in recruiting study populations, including small sample sizes and attrition, the ethical considerations relating to the allocation of participants to control groups, and the process of selecting outcome variables, are just some of the issues that have been identified.<sup>73, 86-88</sup> In particular, the characteristics of the study population itself, including the patients' terminal illness, complex symptomatology, and mental and physical exhaustion, are said to be likely to hinder trial entry.<sup>89</sup> The outcomes of palliative care are not easily measured, potentially affecting the findings of the study.<sup>68</sup> For example, the nature of advanced cancer suggests that patients would not report improved quality of life as they progress towards the end of life,<sup>65</sup> and the measures used for quality of life have been found to be inadequate in some studies.<sup>90</sup> There is also a lack of evaluation studies measuring caregiver outcomes.<sup>88</sup>

## **1.6 THE CURRENT RESEARCH**

Changes in attitudes towards death and dying, changes in demography and an increase in burden of diseases such as cancer have facilitated an increasing interest in the area of palliative care. While palliative care is a relatively new medical discipline, literature suggests that it may have an important and potentially beneficial role in the care of people with cancer and their families and on health systems. However, delivery of this care has come under particular scrutiny in recent times. In Australia, this has led to the endorsement of the National Palliative Care Strategy, which emphasises the need for improvements in the quality and effectiveness of service delivery in Australian

health services.<sup>26</sup> To determine areas of inequity, the current utilisation patterns of palliative care, both in Australia and internationally, are outlined in Chapter 2. They include the various patient, health professional and health system factors that can impact on the involvement of specialist palliative care services. Chapter 3 describes the needs-based model advocated as an alternative to the current prognosis-based approach to palliative care delivery. A review of the available needs assessment and screening tools is provided, and the development of resources to facilitate appropriate needs assessment is described. Chapter 4 details the results of the pilot testing of the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C) developed for use with the *Palliative Care Needs Assessment Guidelines*<sup>91</sup> and the subsequent revisions made as a result of these findings. Chapter 5 outlines the results of a validation study which assessed the validity, reliability and clinical feasibility of the NAT: PD-C in a specialist palliative care service. Chapter 6 is a summary of the methodology for the longitudinal evaluation study, while Chapters 7 and 8 present the findings from this evaluation. Finally, Chapter 9 provides a discussion of the conclusions of the research and potential future directions.

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# **CHAPTER 2:**

## **UTILISATION AND REFERRAL PATTERNS OF SPECIALIST PALLIATIVE CARE SERVICES: AN INTERNATIONAL PERSPECTIVE**

## 2.1 INTRODUCTION

Considering ways of facilitating a more equitable and consistent approach to service delivery has been a focal point of recent literature. Chapter 1 provided an overview of palliative care and the important role this care has for people with life-limiting illnesses, their caregivers and families. This chapter provides an overview of the utilisation of specialist palliative care services (SPCS) among people with advanced cancer and their caregivers, both in Australia and internationally. The aim of this chapter is to identify whether the current service use and patterns of referral to SPCSs are appropriate and equitable; and subsequently, identify any potential areas for improvement in the delivery of palliative care.<sup>1</sup>

There is often wide variation in estimates of service numbers in countries. This may be because there are different approaches to defining services,<sup>2</sup> as well as different methods used to count services. Some have counted the service by type, while others have counted by provider organisation.<sup>3</sup> An International Observatory of End of Life Care report published in 2006 mapped the level of palliative care development in 234 countries.<sup>3</sup> It was reported that operational services existed in 87 countries,<sup>4</sup> including about 320 services in Australia, 600 services in Canada, 4000 services in the USA and 1478 services in the UK.<sup>3</sup> Approximately 15% of countries were reported to be approaching integration of palliative care into mainstream health care, while 34% had localised provision of care and 8% at least had the capacity to establish palliative care.<sup>3</sup> However, approximately 33% of countries had no known palliative care activity.<sup>3</sup>

Specialist palliative care services operate within the wider health care system, and the effectiveness of palliative care delivery depends on the system and setting in which it is implemented.<sup>5</sup> There are a variety of health care systems in operation and, subsequently, a variety of palliative care service models available.<sup>2,3</sup> Moreover, the structure and delivery of palliative care services can vary even within countries.<sup>6-9</sup> Countries differ in terms of the resources they have available to spend on palliative care.<sup>10</sup> Services are often developed according to needs of the area, may be funded in different ways, and provide varying levels of care involving various disciplines as part of their staff.<sup>11</sup> The following outlines the various health system structures and funding

mechanisms of countries approaching integration with mainstream providers, and the models of palliative care services that have developed within these frameworks to identify similarities and differences internationally.

## **2.2 INTERNATIONAL COMPARISONS**

### **2.2.1 Australia**

#### ***Health system structure***

The health care system in Australia is based on universal access.<sup>12</sup> Primary care in Australia is the first point of contact with the health system and is usually provided in the community, ambulatory settings or home.<sup>13</sup> Primary care in Australia is generally provided by general practitioners (GPs), nurses in the public health sector and home nursing services,<sup>12</sup> and allied health professionals.<sup>14</sup> Primary care professionals such as GPs act as gatekeepers to secondary care as they are the source of referral to medical specialists.<sup>14</sup> Community care has been well integrated into the system in Australia.<sup>15</sup>

#### ***Funding***

The health care system is predominately publicly funded through the government insurance program, Medicare, which refunds to patients part or all of their outpatient costs and pharmaceutical costs and a proportion of any inpatient private care.<sup>12</sup> In 2004, 51% of Australians also had private health insurance.<sup>16</sup> State and Territory governments are responsible for health services including public acute and psychiatric hospital services as well as community and public health services, while the Commonwealth government funds most medical services out of hospital and contributes to all inpatient private hospital services.<sup>17</sup> Public hospitals are jointly funded.<sup>17</sup> In terms of palliative care, there has been a shift from funding *via* grants and charitable donations toward more mainstream funding mechanisms.<sup>18</sup> Of the \$201.2 million provided under the Australian Health Care Agreements between 2003 and 2008 for palliative care, \$13.2 million (6.6%) was allocated to the Australian Government to support national initiatives,<sup>19</sup> while the remaining \$188 million (93.4%) provided funding to the states and territories for day-to-day service provision.<sup>20</sup> In addition, \$62.8 million was committed to improve the standard of palliative care in the community.<sup>19</sup> As states

and territories determine the nature and location of palliative care services delivered, the balance between service types varies from state to state.<sup>18</sup>

### ***Models of palliative care services***

Specialist palliative care services in Australia vary considerably in terms of the “disciplines represented in the teams, programs offered, and number of referrals”.<sup>6</sup> A national study investigating the provision of government-funded palliative care in Australia identified three main categories of services: inpatient, community and consultancy.<sup>9</sup>

The inpatient care setting includes acute care hospitals (in general wards and specialist palliative care wards) and hospices.<sup>9</sup> In Australia, palliative care has been integrated into mainstream services such as acute care hospitals, offering the opportunity for communication, exchange of information and sharing of the burden of care.<sup>21</sup> Accessing palliative care in acute care settings is often a result of patient preference, sudden deterioration while in hospital, or lack of family support.<sup>21, 22</sup> The majority of Australians still die in hospitals.<sup>22</sup> Of all hospitalised patients, 5% will have palliative care needs.<sup>23</sup> Alternatively, hospices “provide intensive in-patient care, day care and support, including respite care and short-term admission to stabilise symptoms or provide in-patient care when death approaches and community care is not viable”.<sup>24</sup> A 1999 report by Palliative Care Australia indicated that 30% of people registered with the palliative care services who responded to the survey died in inpatient hospice care.<sup>25</sup> The South Australian Health Omnibus Survey, a population-based survey of South Australian residents in 2006, found that 17.7% of deaths occurred in hospices.<sup>26</sup>

People with a life-limiting illness have been shown to spend approximately 90% of their last years of life in the community,<sup>7</sup> with services providing support, symptom management and counselling.<sup>27</sup> In fact, up to 10% of people are not admitted to hospital at all in the last year of life.<sup>28</sup> In Australia, the need for home care has increased as a result of earlier discharge and reduced access to acute care beds, nursing homes and hospices.<sup>29</sup> In a national study, more than half the palliative care providers surveyed offered community-based care, either solely or in combination with inpatient care.<sup>9</sup>

About one-third of respondents in an Australian nation-wide study said they provided consultancy services of one type or another. Examples included:

- medical and nurse consultants undertaking liaison roles within hospitals
- outreach programs for rural and remote areas
- specialist units and
- telephone advisory lines.<sup>9</sup>

A few respondents said they offered only consultancy services, while most offered these in combination with inpatient and community-based care.<sup>9</sup>

Day hospices are a rarely utilised form of palliative care services in Australia (in contrast to their more widespread use in the health systems of the UK).<sup>9</sup> Such contrast is probably due to differences in distance to such facilities and other community supports that may be available. This care is suitable for those who are not dying but who have diminished ability in family and societal role fulfilment.<sup>30</sup> Referral criteria are often based on the need for social interaction, psychological support, respite, monitoring, symptom control and assessment.<sup>30, 31</sup> A national study identified 10 day hospice services available in Australia, mostly in Western Australia and New South Wales.<sup>9</sup>

### ***Patient numbers***

In 1998 a National Census of 187 palliative care services was undertaken to obtain better information about palliative care services and their clients.<sup>25</sup> In a single 24-hour period, 9073 people were registered with participating services: 7027 community registrations; 1167 inpatient registrations; and 879 day or outpatient registrations.<sup>25</sup> Of these, 28% had been registered for more than 6 months, and 237 new referrals occurred during this period.<sup>25</sup> Hence, community services provided the majority of the specialist palliative care to the Australian population, followed by inpatient, outpatient and day care, independently of prognosis and diagnosis (that is, participants are not limited to having cancer and an estimated finite life expectancy).

Similar investigations have taken place at a state level. In South Australia, a population-based study found that 47% of people who had died were followed by SPCSs.<sup>6</sup> Based on the data from this study, the authors suggested that while 70% of people with life-limiting illnesses would benefit from assessment by SPCS, 16% did not access these services.<sup>6</sup> Caregivers in another South Australian population-based study

report that SPCSs provided support in 60% of deaths of terminally ill people.<sup>32</sup> In Western Australia, 68% of people who died of cancer accessed SPCS.<sup>33</sup>

## **2.2.2 North America**

### **a. United States of America**

#### ***Health system structure***

In the USA, people have free choice of their primary care physician.<sup>34</sup> In contrast to the UK and Australia, a strong primary care structure is lacking.<sup>35</sup> This has implications for the health care system, as some would argue that primary care may facilitate greater prevention measures and earlier intervention, reduce overall costs of care and reduce the total number of specialist referrals by providing a central point around which to organise care.<sup>36</sup> In fact, in comparisons between countries on various health indicators, including disability adjusted life expectancy; the USA has been shown to rate poorly, especially given absolute spending as a proportion of gross domestic product. Direct comparisons have been made between primary care systems of various countries. One study comparing the costs of five countries (including UK, USA, Australia, New Zealand and Canada) found that people from the USA had the greatest costs.<sup>37</sup> Overall, the USA primary care system was rated poorer on all patient-centred care.<sup>37</sup> The USA was also ranked 37<sup>th</sup> in the WHO (2000) ratings of health care system performance among 191 member nations and 72<sup>nd</sup> in the overall health rating.<sup>38</sup>

#### ***Funding***

While the Australian and the UK health care systems are predominantly publicly based, the USA system is predominately private on a fee-for-service basis. The federally funded Medicare program provides “health insurance for people aged over 65 years, those with end-stage renal disease, and people with certain specific disabilities”.<sup>39</sup> Part A of the system includes hospital insurance, while Part B is supplementary medical insurance for services provided in both hospital and non-hospital settings.<sup>39</sup> The state and federally funded Medicaid provides cover for those with assisted income maintenance payments, dependent children, and certain aged or disabled adults.<sup>39</sup> However, Medicaid eligibility can vary between states.<sup>39</sup> In 2006, 15.8% of people in the USA did not have health insurance.<sup>40</sup>

In the USA, a distinction is made between hospice (which is a program of care provided toward the end of life and is almost exclusively seen as community-based



care) and palliative care services (which provide care that is predominantly consultative and hospital-based).<sup>41, 42</sup> Hospice programs are well-established in the USA, while palliative care programs are a recent addition.<sup>43</sup> Funding for hospices comes from Medicare reimbursement and fundraising;<sup>44</sup> 80% of hospices are Medicare certified.<sup>44</sup> The Medicare hospice benefit was developed for people with terminal illnesses, with reimbursement on a *per diem* basis according to level of care delivered.<sup>45</sup> In the USA, the admission criteria include certification from a clinician that the patient is likely to die within 6 months and the patient's willingness to waive treatments focused on cure or prolongation of life.<sup>46</sup> This has perversely led to very late referral, with an average of 26 days between referral and death in the USA.<sup>47</sup> It is argued that Medicare funding helped shape the structure and delivery by introducing managed care, establishing minimum standards and a specific mix of services, and influencing private health insurance plans to cover hospice.<sup>45</sup> The Medicaid benefit is similar to the Medicare benefit but has higher *per diem* payments and offers services to Medicaid-qualified nursing home residents.<sup>45</sup> Medicare spending under the Medicare Hospice Benefit increased from \$445 million in 1991 to \$3.6 billion in 2001.<sup>48</sup>

### ***Models of palliative care services***

Hospice care is therefore the more established approach to the delivery of end-of-life care in the USA.<sup>46, 49</sup> In the USA, the hospice program provides care that is more nursing-based,<sup>49</sup> governed by federal and state regulations and increasingly provided to people in the last few weeks of life.<sup>43</sup> Conversely, palliative care services provide care in a consultative manner extending across the illness trajectory, most often in acute care hospitals.<sup>43</sup> Hospice is the only organised provider with team-based reimbursement,<sup>50</sup> with multidisciplinary teams providing case management.<sup>51</sup> In 2002, 41% of hospices delivered palliative care services that were not covered by the Medicare Hospice Benefit.<sup>42</sup> Of the 1200 hospice providers in a national survey, 67.6% were non-profit, 27.2% were for-profit and 5.2% were government-run.<sup>52</sup> In other countries such as Australia and the UK, hospice is a type of unit in which palliative care is provided.<sup>44</sup> These differences in terminology are problematic for generalising results in different health systems.<sup>53</sup>

### ***Patient numbers***

Since 1974, 7 million people have received care in the home, nursing home or hospital through hospice programs,<sup>42</sup> and in 2006 the United States had about 4000 hospice

programs, a third of which were hospital-based.<sup>52</sup> However, the eligibility criteria for hospice programs in the United States means that many people have missed out on this care.<sup>42</sup> There may be difficulty by some physicians in determining the 6-month prognosis.<sup>54</sup> In addition, hospice may be less likely to admit patients who have more complex or severe issues requiring expensive treatments, as a result of the limited *per diem* reimbursement provided by Medicare.<sup>55</sup> Thus, the Medicare benefit eligibility criteria may have important implications for who accesses hospice care, and when.

The National Hospice and Palliative Care Organization (NHPCO) published a report on provision of hospice in the USA in 2005. Of the 4100 services included, 93% were certified by Medicare, while 82.4% of people were covered by the Medicare Hospice Benefit.<sup>56</sup> Of the total admissions, 46% were for people with a diagnosis of cancer, 82.2% were for White/Caucasians and 80% were aged 65 or over.<sup>56</sup> Inpatient services were provided by 19.6% of units, 87.1% of which were free-standing or hospital-based and included acute and residential care.<sup>52</sup>

Approximately 36% of all deaths in the USA were under a hospice program in 2006.<sup>52</sup> Fifty-seven percent of cancer deaths occur in hospitals, 17% occur in nursing homes and 20% occur at home.<sup>57</sup> Ninety-five percent of the days that people are enrolled in a hospice program are, by definition, spent at home.<sup>58</sup> In 2002, 850,000 patients received hospice care and 2 million caregivers received bereavement services.<sup>42</sup> In 2006, the number of people receiving hospice care increased to 1.3 million people.<sup>52</sup> This increase may have been, in part, a result of legislation which made the Medicare hospice benefit more flexible in payments for hospital, home and nursing care, thus increasing the desirability of hospice enrolment, especially for patients without cancer.<sup>59</sup> Increased costs in hospital care,<sup>60</sup> along with reduced costs associated with enrolling in hospice care, may also contribute to the increase in hospice provision.<sup>61</sup>

## **b. Canada**

### ***Health system structure***

The Canada Health Act delineates five funding criteria for health care provision, and the provinces and territories are primarily responsible for the administration and delivery of these services.<sup>62</sup> There is some variation between provinces regarding services.<sup>63</sup> Primary care facilitates coordination of care and is the first point of contact in the health system for Canadians.<sup>62</sup> People are able to choose their doctors as well

as their hospitals.<sup>63</sup> Secondary care is specialised care at a hospital or community service,<sup>62</sup> and hospitals are almost exclusively public institutions.<sup>15</sup> Traditionally, hospitals have been the main setting of care.<sup>45</sup> However, a shift from institutional to community care has begun to take place in Canada.<sup>63, 64</sup>

### ***Funding***

The Canadian universal health care system is predominately publicly funded<sup>64, 65</sup> through provincial and territorial health insurance plans (Medicare).<sup>62</sup> The Federal government also shares the responsibility for funding with the provincial governments.<sup>65</sup> Physician and hospital services are funded by Medicare, while other supplementary health services are funded by public and private insurance.<sup>64</sup> Physicians are paid on a fee-for-service basis, and the Canada Health Act prohibits user fees and extra billing.<sup>63</sup>

### ***Models of palliative care services***

Information regarding the number of people accessing services is not readily available.<sup>66</sup> Palliative care was established in 1974 in Canada. There were over 600 palliative care programs in Canada in 2002.<sup>65</sup> Palliative care development and availability varies among provinces.<sup>66</sup> Unlike the USA and the UK, development of palliative care programs was initially concentrated in hospital-based services.<sup>66, 67</sup> However, reductions in resources, increased disease burden, individual preference for community care and public concern have all fuelled recent debate over the types of services being developed.<sup>66</sup> While there have been increases in long-term facilities, increases in the availability of palliative care beds in hospitals and the inclusion of multidisciplinary health professionals in palliative care teams in Canada,<sup>66</sup> in 2001 only 5% to 10% of dying Canadians received integrated interdisciplinary palliative care,<sup>68</sup> and more than half of all cancer patients died in acute care settings.<sup>69</sup>

## **2.2.3 Europe**

Health system structure and funding mechanisms also vary considerably among countries in Europe. Moreover, the differences in palliative care resources available are said to be the result of these differences in policy and funding. A report commissioned by the European Parliament, entitled *Palliative Care in the European Union*, rated countries on a global index of palliative care development.<sup>70</sup> The criteria for this index were palliative care resources and vitality, defined as the “existence of activists and

professionals who increase the likelihood of service development".<sup>70</sup> The UK was the highest ranked country and was therefore allocated a rating of 100% as the reference point. Countries with a ranking of 50% to 85% of the United Kingdom's were Ireland, Sweden, Netherlands, Poland, France, Spain, Germany, Belgium, Luxembourg, Austria, Italy, Denmark, Finland and Latvia. Lithuania, Hungary, Czech Republic, Slovenia, Cyprus, Romania, Malta, Greece, Portugal and Slovakia were between 25% and 50%.<sup>70</sup> Estonia was lowest at 8%.<sup>70</sup> A summary of the structure and funding of the health systems, as well as the models of palliative care services for every European country, is beyond the scope of this chapter. However, a brief summary of at least one country from each of the global index categories listed above are presented, in order to outline the similarities and differences of countries within these categories.

#### **a. United Kingdom**

##### ***Health system structure***

In the UK there has been an attempt to shift from the "division of care between local authority, general practitioner and hospital services to an integrated structure."<sup>71</sup> Primary care is provided by GPs on a contractual basis to the National Health Service (NHS) and by multi-professional teams in health centres,<sup>12</sup> while secondary care requires a referral from GPs and is provided by general acute NHS trusts, community hospitals, highly specialised tertiary level hospitals and private hospitals.<sup>12</sup> Each person is registered with a GP, who is the gatekeeper to NHS hospitals and specialist care.<sup>36</sup> People are able to choose with whom to register, and GPs are paid for each person they register.<sup>72</sup> However, it is argued that demand exceeds supply in the UK.<sup>72</sup> Cancer services in England are organised into 34 managed clinical Networks comprised of Specialist Cancer Centres and Cancer Units to integrate care.<sup>73</sup> Each Network includes primary, secondary and tertiary care services such as Primary Care Trusts, acute NHS Trusts and hospices.<sup>73</sup>

##### ***Funding***

The NHS is funded through taxation, and, as in Australia, health care is provided universally.<sup>12</sup> In 2001, 11.5% of the population had private health insurance.<sup>12</sup> Funding for palliative care is provided through the NHS as well as through voluntary and charitable donations.<sup>44</sup> Some independent services raise up to two-thirds of their revenue through these charitable donations.<sup>74</sup> No payment is required from patients and families to access hospice.<sup>44</sup> Of hospices available in the UK, 71% are

independent and locally managed, 6.6% are run by national cancer charities and 22% are provided by the NHS.<sup>75</sup> In 2004, total expenditure was estimated to be £398.5m *per annum* for the whole of the UK.<sup>76</sup> Of the total oncology research budget in the UK, 0.18% is allocated to palliative care research, compared with 0.9% in the USA.<sup>70</sup>

### ***Models of palliative care services***

While palliative care arose out of the charitable hospice movement in the 1950s and 1960s, the nature of early hospice development led to a variety of funding models.<sup>74</sup> Even so, independent hospices still provide 87% of all day care, 81% of all “out of hours” care, 70% of all in-patient care and 44% of all home care.<sup>75</sup> In 2005 there was a total of 882 specific palliative care services, including 63 inpatient units, 158 hospices and 305 hospital support teams.<sup>2</sup> While palliative care has traditionally been provided in an inpatient setting, it is argued that there has been a move toward improving home services.<sup>44</sup> Community services take a variety of forms and include “clinical nurse specialists in consulting/advisory capacity, extended home nursing, caregiver respite, hospice at home and crisis intervention”.<sup>74</sup> In 2005 there were 356 home care teams.<sup>2</sup> The number of day centres in the UK has risen to 237 providing 10,000 places per week.<sup>30</sup> This number far outweighs the number of day care services in other countries such as Australia, as two-thirds of day centres are funded by the independent sector.<sup>31</sup> One-third of day services are attached to inpatient units, one-third are attached to inpatient and home care teams, and one-third are free-standing or attached to home care teams only.<sup>31</sup>

Despite their association with the NHS, the development and integration of palliative care services have varied considerably among regions.<sup>77</sup> In fact, Seymour *et al* (2002), in their review of UK health improvement plans, suggest that this variation may be due in part to the perception of some authorities that palliative care is an additional program, rather than an essential program within the health care system.<sup>77</sup> For example, it is argued that palliative care may be seen as a lower priority than other areas such as acute care in hospital settings.<sup>57</sup>

### ***Patient numbers***

The United Kingdom's National Council for Palliative Care (NCPC) Minimum Data Set is the “only continuous source of data from both NHS and voluntary sector palliative care services”.<sup>78</sup> The 2005/2006 data provided information regarding use of hospice

and SPCSs in England, Northern Ireland and Wales.<sup>78</sup> Within the 163 participating inpatient services providing care in dedicated palliative care units, there were 37,753 people receiving care.<sup>78</sup> A total of 25,479 people accessed 182 day care units.<sup>78</sup> A 2000 systematic review reported that approximately 15% to 25% of UK people with cancer received inpatient hospice care,<sup>7</sup> while another found that 20% of hospital bed days are taken up by end-of-life care.<sup>4</sup> While 11% of patients in the UK die in hospices, over half die in hospitals.<sup>79</sup> Home care use in 2006 was recorded for 108,182 people, and approximately 76,509 people received care in hospital-based services.<sup>78</sup> Support teams and specialist home care nurses (e.g. McMillan nurses) provide input for 25% to 65% of people with cancer.<sup>7</sup> Finally, outpatient clinics reported care for 33,137 people.<sup>78</sup> In the UK in 2005, there were 153,491 deaths from cancer.<sup>80</sup>

#### **b. Sweden**

In Sweden, the health system is funded through taxation and covers all residents.<sup>12</sup> The first point of contact is either hospital emergency rooms or through primary care.<sup>81</sup> Hence, patients can access secondary care directly through a hospital outpatient department.<sup>12</sup> From the outset, the development of palliative care services within the health system was advocated in Sweden.<sup>81</sup> However, in contrast to Spain, Sweden emphasised home care and consultancy by multidisciplinary teams providing this care directly, given a more limited primary care system.<sup>74</sup> While there are in-patient units and hospices, they are less prominent than home care;<sup>81</sup> only 5% to 10% of the population access hospice or palliative care institutions at the end of life.<sup>82</sup>

#### **c. Netherlands**

Hospice, developed largely outside the formal health care system,<sup>74</sup> was the first model of service in the Netherlands, while most palliative care inpatient units were established in nursing homes.<sup>83</sup> Hospices vary from government-coordinated low-care hospices which care for people when home care is unavailable, to high-care inpatient hospices.<sup>84</sup> Recently there has been an increased focus on palliative care development, and health policy has dictated integration of hospice within the system with financial assistance provided.<sup>85</sup> Moreover, there has been a push for primary care professionals to deliver palliative care through the introduction of consultative teams made up of home care, oncology or hospice nurses, as well as GPs and medical specialists with extra palliative care expertise who may provide guidance and advice for other health

professionals.<sup>86, 87</sup> Thirty percent of physicians believe the provision of palliative care is inadequate in The Netherlands.<sup>88</sup>

#### **d. Spain**

Spain has a universal health system publicly funded through taxation and social security.<sup>89, 90</sup> The health care regions in Spain are overseen either by regional health authorities or by a central body.<sup>89</sup> The decentralised nature of the health system means differing involvement of regional health authorities and, subsequently, varied palliative care provision among regions.<sup>91</sup> Even so, Spain and Sweden have the highest integration of palliative care with formal health care systems in Europe.<sup>74</sup> Like Canada, Spain originally encouraged the provision of palliative care primarily in hospitals and within the health care system, rather than in hospices outside the national health system.<sup>74, 91</sup> Now, three types of service models are identified in some regions of Spain: the integrated system; hospital team; and home care team. Integral systems in acute care centres provide a range of patient needs across different levels of care. However, these are only available in a few regions.<sup>66</sup> Hospitalised care is provided in medium-stay and acute hospitals and involves consultative roles.<sup>66</sup> Home care is also available in Spain in coordination with hospital teams or health care centres.<sup>66</sup> There are few private palliative care programs in Spain.<sup>89</sup> A national study estimated that in 2000, 26% of cancer patients were covered by palliative care programs, 10% by hospital programs and 16% by home programs.<sup>92</sup> Moreover, 85% of patients in hospital palliative care units and 68% of patients in home programs had cancer.<sup>92</sup> Since the inception of the WHO Demonstration project in 1990, a range of palliative care has been implemented in the Catalan region of Spain.<sup>93</sup> In 2005, an estimated “10,500 of the 16,000 patients dying of cancer and 9,200-21,200 patients dying of other long-term chronic conditions needed palliative care”.<sup>94</sup> The authors also estimate that 75.9% of people with cancer and 25% to 56.5% of people with non-cancer diagnoses received care from specialist palliative care services; 59% of those receiving care had a cancer diagnosis.<sup>94</sup>

#### **e. Germany**

In Germany, regional differences exist in services, and there is a considerable division between outpatient and inpatient care in terms of coordination and reimbursement,<sup>95</sup> resulting in low and uneven palliative care coverage and fewer in-patient palliative care services.<sup>74</sup> There is also clear separation between inpatient units and hospices.<sup>96</sup> Most

of the in-patient palliative care units are affiliated with hospital departments, staffed by members of those departments and funded by the national health insurance system.<sup>96</sup> Inpatient hospices do not have hospital affiliation and receive less funding.<sup>96</sup> Hospices provide care in the last phase of illness, while in-patient units treat symptoms and discharge patients home or to hospice.<sup>96</sup> In 2002, legislation was passed to ensure funding would be provided through the public health system for community hospice services.<sup>97</sup>

#### **f. Italy**

Like many European countries, Italy is decentralised, with regions having autonomous decision-making and management.<sup>98</sup> Palliative care in Italy has historically lacked governmental support.<sup>74</sup> In fact, it was not until 1998 that legislation regarding palliative care introduced regulation, management and standards for palliative care, as well as structural and organisational requirements and reforms to social services.<sup>99</sup> Home care was the initial model of service in Italy,<sup>74</sup> and hospices have only just begun to emerge.<sup>100</sup> There are regional variations in service availability, with the greatest share in the northern region, followed by the central region and southern region.<sup>100</sup> A national population-based survey indicated that home care was provided more frequently in the southern regions, and northern region patients were more frequently admitted to hospitals.<sup>101</sup> In fact, almost 50% of patients in southern regions were cared for at home for the entire last 3 months of their lives.<sup>101</sup> In Italy, only 14% of people at home and 20% of those in hospital received palliative care support.<sup>101</sup>

#### **g. Hungary**

The first hospice in Hungary was founded in 1991.<sup>102</sup> The late development of palliative care in Hungary has been said to be a product of the political climate of the time, including the subsequent collapse of the Soviet regime,<sup>70</sup> and a lack of awareness and recognition both in the lay and medical communities.<sup>103</sup> Prior to the Soviet collapse, the health system was highly centralised and administered by the State.<sup>104</sup> While palliative care was established as a human right in Hungary in 1997, minimum standards were not established until 2004.<sup>103</sup> Since 2004, the majority of hospice funding has come from the National Health Insurance Fund (NHIF).<sup>70</sup> The remaining funding for hospice care comes from local governmental support, grants and a tax law which allows citizens to assign 1% of their salaries to the organisations of their choice.<sup>70</sup> Results of a national survey conducted by the Hungarian Hospice Palliative Association in 2006



indicated that 42 of the 57 hospices in Hungary were funded as “hospice services” by the NHIF.<sup>70</sup> Of the 57 operational palliative care services in Hungary, 21 were inpatient palliative care services (one free-standing unit, ten hospital units, four hospital mobile teams and six nursing home units), 34 were home care services, and two were day care services.<sup>105</sup> There were 4130 patients receiving this care, 95% of whom were cancer patients.<sup>105</sup>

#### **h. Estonia**

Estonia has the lowest ranking in the Martin-Moreno (2007) report, with only 9 home care teams providing palliative care in the country since 1997.<sup>70</sup> As with Hungary, health system reforms began following the collapse of the Soviet system.<sup>106</sup> An employer contribution health insurance scheme was introduced in 1992.<sup>106</sup> While this Central Sickness Fund provides reimbursement for home care visits, time in care is dependent on the availability of funds, rather than on patient need.<sup>70</sup> There is no national society for palliative care in Estonia, nor is there a national palliative care strategy.<sup>70</sup> Moreover, education and training of the medical profession in palliative care is limited to lectures and short courses.<sup>70</sup>

### **2.2.4 Developing countries**

The importance of providing palliative care to the developing world has been emphasised by the WHO.<sup>107</sup> Cancer is detected in advanced incurable stages in over 80% of cases in the developing world.<sup>108</sup> It is estimated that 70% of all cancer deaths occur in low- or middle-income countries.<sup>107</sup> However, only 6% of world-wide palliative care resources are found in Asia and Africa.<sup>109</sup> Similarly, in South America only 5% to 10% of people who need palliative care receive it.<sup>110</sup> For these people, 97% of provision occurs in large cities.<sup>110</sup>

The International Observatory of End of Life Care report suggested that palliative care development was closely associated with human development, as countries with high standards of living, longevity and knowledge had greater integration of palliative care and more deaths from chronic, complex conditions.<sup>3</sup> The context within which palliative care is provided is therefore an important factor in discussions surrounding delivery. There are considerable differences between countries in relation to the contribution of particular causes to disease burden,<sup>38</sup> and the focus of a particular country’s health care may be on causes that make a greater contribution.<sup>38</sup> For example, the World

Health Report 2000 shows that infectious diseases account for nearly 70% of the disease burden in Africa, compared with less than 20% in Europe.<sup>38</sup> Deaths in developed countries are often from chronic diseases, while in developing countries there are higher mortality rates from birth-related conditions, childhood diseases and acute infectious diseases, for the majority of the population.<sup>111</sup> Importantly, while chronic diseases such as cancer are increasing in developing countries, they have not replaced acute diseases.<sup>111</sup> This causes considerable strain on resources; hence, it is believed that the “rising burden of chronic diseases on developing countries has received inadequate attention.”<sup>111</sup>

It is widely recognised that in many developing countries, there is little or no integration of palliative care, a lack of allocation of public and institutional funding, little reimbursement of services,<sup>112</sup> and a lack of infrastructure administration and education.<sup>110</sup> Hence, the introduction and sustainability of services is a difficult thing to achieve.<sup>110</sup> Moreover, there may be considerable competition for limited resources, especially in those countries with poor housing and sanitation and lacking access to the most basic food and water.<sup>113</sup> As a result, questions arise as to whether providing palliative care in developing countries is justifiable, considering the majority of deaths are preventable in many developing countries.<sup>114</sup> Some argue the focus of health care should be on reducing these deaths and providing for the population’s basic needs. Others argue that improvements in both the lives *and* deaths of those in developing countries are required.<sup>114</sup> While prevention is an important public health issue, focusing all resources in this area does not provide for the needs of those with life-limiting illnesses.<sup>109</sup> Even so, the models of services that are suitable for developing countries may be different from those models that have been successfully implemented in developed countries.<sup>114, 115</sup> For example, a review of services in Africa indicated that much of the palliative care available is provided in the community; this is culturally acceptable and offers a solution to the lack of financial resources for inpatient services and the considerable HIV/AIDs population in hospitals.<sup>116</sup>

## 2.3 WHO USES PALLIATIVE CARE SERVICES?

### 2.3.1 Diagnosis

As discussed in Chapter 1, SPCSs can be used for a variety of different diagnoses. In Australia, it is estimated that 90% of people dying of cancer will need an assessment by a specialised interdisciplinary palliative care service, while 70% of people dying of cancer will benefit from ongoing contact with the team.<sup>117</sup> The Australian national census study indicated that 90% of people registered with palliative care services had cancer.<sup>25</sup> Currow *et al* (2004) study found that 61% of people with a cancer diagnosis in South Australia were followed by specialist palliative care services, while only 36% of patients with a non-cancer diagnosis were followed.<sup>6</sup> A more recent study reported that 65% of cancer and 48% of non-cancer patients accessed SPCSs in South Australia.<sup>118</sup> Similarly, people with cancer made up two-thirds of those receiving specialist palliative care in Western Australia.<sup>33</sup>

International literature supports this finding, with the UK national data set reporting that 93.9% of inpatients, 90.7% of day care patients, 86.9% of home care patients, 93.8% of hospital care patients, and 85.9% of outpatients had a cancer diagnosis.<sup>78</sup> It was estimated that 10.8% of people accessing all services had non-cancer diagnoses, including HIV/AIDS, heart disease, stroke, respiratory disease and motor neurone disease / multiple sclerosis / spinal cord injury.<sup>78</sup> Past attitudes towards the inclusion of non-cancer patients may have influenced current patient profiles in the UK. In fact, it was not until the 1990s that the inclusion of non-cancer patients was advocated by authorities in some parts of the UK.<sup>119</sup> Even so, it was believed by some at the time that including non-cancer patients could overwhelm services, that there was a lack of health professional knowledge and experience with these diseases, that it would result in the neglect of some cancer patients and finally, that voluntary funding would not keep up with the expansion of services for non-cancer patients.<sup>119</sup> The impact of HIV/AIDS admissions was also a consideration for hospices relying on charitable funding, as it was perceived by some that funding would be less likely to continue for this population.<sup>120</sup>

In a study of 143 European palliative care centres, 94% of patients had a diagnosis of cancer.<sup>121</sup> Canadian provincial studies have found that between 80% and 95% of

palliative care patients had cancer, depending on the care setting.<sup>69</sup> In contrast, only 42% of the total admissions to USA hospices in 2007 were for people with a diagnosis of cancer.<sup>122</sup> Even though the hospice eligibility criteria can make it difficult for people with non-malignant diseases to be referred to hospice due to their less predictable prognoses,<sup>123</sup> the availability of the hospice benefit for non-cancer patients means that non-cancer patients are more likely to access services in the USA compared with patients from other countries where funding is less certain, such as the UK.<sup>119</sup> Moreover, the National Hospice and Palliative Care Organization has developed referral criteria for people with non-cancer diagnoses.<sup>124</sup>

While the majority of patients utilising palliative care services appear to be people with a cancer diagnosis, service use can vary by cancer type. The Australian 1998 census compared proportion of cancer deaths (ABS, 1996) to inpatient and community registrations by diagnosis.<sup>25</sup> Breast and prostate cancers were reported to be over-represented in the Australian inpatient and community palliative care settings.<sup>25</sup> This may be because of the relatively longer 5-year survival rates for prostate and breast cancer,<sup>125</sup> with figures reflecting the very long disease trajectory. A number of Australian studies have also reported that people with haematological malignancies are less likely to have received care from designated palliative care services.<sup>1, 126</sup> Similarly, patients with haematological malignancies are less likely to have received community or domiciliary care in the UK and Europe, and consultation and follow-up in the USA.<sup>101, 127, 128</sup> This difference occurs irrespective of symptom burden.<sup>129</sup>

### **2.3.2 Place of death**

There is an overwhelming desire of many to die in the comfort of their own homes.<sup>130</sup> However, the complex and problematic needs that may be experienced, especially in the last stages of life, mean that this may not be a feasible option for everybody. In fact, inpatient care may be more suitable for those with more complex needs.<sup>131</sup> Palliative Care Australia's National Census found that 34.8% of deaths occurred at home nationwide and that South Australia had lower rates of home death compared with other states.<sup>25</sup> In the UK, 36% of people who used SPCS died in hospital, followed by 27% at home and 31% in palliative care units.<sup>78</sup> In the US, 47.1% of people accessing hospice died in private residences, 22.5% died in nursing homes and 4.6% died in residential facilities,<sup>56</sup> while in Canada 75% of people died in institutions.<sup>132</sup> Hence, the USA had higher rates of home death, followed by Australia, the UK and Canada.

In Western Australia, people who accessed community SPCSs were more likely to die in their usual places of residence.<sup>133</sup> Involvement of SPCSs were reported by three-quarters of South Australian cancer patients who died at home, 63.2% of patients who died in metropolitan hospitals, 56.5% of patients who died in private hospitals and 48.4% of patients who died in nursing homes.<sup>1</sup> A recent South Australian study found that patients with non-cancer diagnoses were less likely to die in hospice settings.<sup>118</sup> Moreover, 70% of cancer and non-cancer patients who did not use SPCSs died in hospitals.<sup>118</sup> Although the involvement of SPCSs decreased hospitalisations, there was no complementary increase in home deaths; rather, a shift to hospice deaths occurred.<sup>118</sup>

Literature suggests that preference for place of death is an important consideration for many people with cancer and their families, as it is a care indicator that is relatively easy to measure.<sup>134</sup> Even so, the usefulness of place of death as a quality of care indicator has been questioned.<sup>118, 135</sup> Currow *et al* (2008) argue that the care setting in which death occurs may not necessarily reflect the care received by that person prior to death, especially if the person's death follows a transfer to hospital in the terminal stages of the person's illness.<sup>118</sup> Moreover, the preference for place of care may not necessarily reflect the preference for place of death.<sup>135</sup>

### **2.3.3 Presence of a caregiver**

Approximately 7% to 12% of people with cancer have been reported to be living alone without a caregiver.<sup>136</sup> Patients who have no caregiver are less likely to die at home, are more likely to stay in the service longer, and have more hospital admissions.<sup>136</sup> They also require greater assistance with hygiene, more home help, and greater liaison with other health professionals.<sup>136</sup> Similar findings were reported in a review of Australian, UK and USA studies which found that patients living with someone were more likely to die at home, and that home care was less likely if carers did not live with the patient, were employed or were older.<sup>137</sup> Having a greater number of caregivers has been found to increase the likelihood of a home death.<sup>138</sup> Interestingly, home death was more likely when carers were female rather than male.<sup>137</sup> In the USA, the impact of a caregiver on access is even more pronounced, as the presence of a caregiver may be one of the criteria for admission to hospice programs.<sup>55</sup>

### 2.3.4 Marital status

Palliative care utilisation has also been found to vary with marital status. A Western Australian study found that married patients use community services more.<sup>33</sup> Patients with partners, who were married or living with someone were more likely to die at home,<sup>137</sup> and those not living alone who were married and owned their own houses were more likely to use community care in the UK.<sup>127</sup> A USA study found that people who were married were more likely to use hospice care than those who had never been married.<sup>139</sup>

### 2.3.5 Age

In the UK national minimum dataset, people over the age of 85 represented 10% of inpatients, 9% of day care users, 12% of home care users, 5% of outpatients and 14% of hospital unit users.<sup>78</sup> This age group made up 17% of all cancer deaths in the UK in 2006.<sup>140</sup> According to Palliative Care Australia, people over 75 years of age are under-represented in Australian services.<sup>25</sup> A South Australian study confirmed that patients over 80 were less likely to use palliative care.<sup>1</sup> This association between age and access has also been found in home and inpatient hospice care in other UK studies.<sup>137, 141</sup> Similar findings have also been reported in a systematic review of international studies from the UK, Canada and the USA, with older patients less likely to be referred to or use SPCs.<sup>142</sup> It has been suggested that greater inaccuracy of prognostic estimates for older patients may play a role in their lower access in some countries.<sup>143</sup> Alternatively, the needs of elderly people may be under-estimated, or elderly people may have less complex needs at the end of life.

In contrast, a recent South Australian study investigating whether there were differences in the levels of unmet need of people who did and did not access specialist palliative care (SPC) found no association between age and access to SPCs.<sup>144</sup> The authors suggest that this may be because people with both cancer and non-cancer diagnoses were included, and the age analysis focused on carer age.<sup>144</sup> However, older carer age has been significantly associated with less access to home palliative care in the UK.<sup>145</sup> Younger carers may be better at obtaining care, may need more support, or be perceived as needing more support by health professionals as a result of their life circumstances.<sup>145</sup>

### 2.3.6 Geographical location

The availability and access to palliative care varies when comparisons are made across countries. However, differences can also exist within countries. In Australia, a third of the population live in regional and remote areas.<sup>146</sup> People in rural and remote areas have been found to be at a disadvantage when it comes to accessing palliative care services, with admission rates 30% to 50% lower than in capital cities and reduced access to specialist palliative care doctors and allied health professionals.<sup>25, 147, 148</sup> However, South Australian figures suggest that there is little difference between rural and metropolitan regions. Even so, the delivery of palliative care in these areas is often provided by generalist providers such as GPs and nurses.<sup>149</sup> While this may mean the patient experiences a greater continuity of care as the GP retains the coordinating role, a study of GPs in rural NSW found that 21% of GPs thought their training in palliative care was inadequate and that if an SPCS was available to them, they would refer to it.<sup>149</sup>

Geographical location has also impacted on service use in the USA and UK. In the USA, hospice use was higher in states from the South and Southwest compared with those in the Midwest and Northeast.<sup>150</sup> Another study confirmed that the provision of hospice services varied by geographical region.<sup>48</sup> Similarly, there are some areas in the UK where demand for inpatient SPC is high, access is poor and deprivation levels are above the regional mean.<sup>151</sup> Higginson *et al* (1998) conducted a 10-year review of place of death of cancer patients in the UK, finding that the percentage of home deaths varied by region.<sup>152</sup> Other international studies from Canada,<sup>66</sup> Italy<sup>101</sup> and Spain<sup>89</sup> support the finding that availability of and access to palliative care services can vary by geographical region within countries.

### 2.3.7 Education and socio-economic status

A recent population-based study in South Australia showed that people with lower income were less likely to use SPCS.<sup>144</sup> Higher socio-economic status (SES) patients were more likely to use metropolitan hospitals and country hospitals, as well as hospices in South Australia,<sup>153</sup> while in NSW, patients with higher SES were more likely to die in dedicated palliative care institutions.<sup>154</sup> Patients of lower SES or those receiving welfare are often dependent on community services.<sup>148</sup>

In the UK, recognition of the term, “palliative care”, and awareness of the role of McMillan nurses were more prevalent among materially affluent participants.<sup>155</sup> Patients who were in the lowest social class were less likely to die in hospice; the authors suggest that patients may feel unable to ask for beds when needed, or alternatively, that they have stronger local and family networks to provide care.<sup>141</sup> In the USA financial factors, including a lack of insurance and inability to pay, have been reported to impact on people’s use of health care services, especially for ethnic minorities.<sup>156</sup> In a national study in Italy, carer education level impacted on referral to domiciliary care; people whose carer had more education were more likely to be referred to care.<sup>101</sup>

### **2.3.8 Ethnicity**

Middle class, privileged, male Anglo-Australian patients are more likely to use palliative care.<sup>157</sup> A South Australian population-based study showed that people from non-English-speaking backgrounds were less likely to want the involvement of services because their family and friends looked after them.<sup>6</sup> Patients who are Indigenous or Asian are less likely to use palliative care services.<sup>153</sup> In fact, Indigenous Australians are under-represented in 75% of palliative care services.<sup>24</sup>

In the USA, admission criteria to services are said to disadvantage the poor, rural inhabitants and those who have no regular doctor.<sup>158</sup> Eighty percent of hospice patients in the 2006 national dataset were Caucasian.<sup>52</sup> A study on use of hospice by African-Americans found that while they have a 50% higher mortality rate from cancer, less than 8% of hospice-eligible African-Americans use hospice.<sup>158</sup> Similarly, a study comparing African-Americans, Latinos and European-Americans found that the last used hospice at a higher rate than the other groups.<sup>159</sup>

The lack of access of ethnic minority groups has also been recognised in the UK<sup>7</sup> where 90% of patients were White, fewer ethnic minority groups accessed palliative care services, and even fewer accessed day care.<sup>30</sup> Awareness of the role of McMillan nurses was more prevalent among White British.<sup>155</sup> Perceived cultural beliefs may impact on referrals to palliative care services, with some GPs assuming that Black/minority families in the UK were more likely to provide palliative care for patients.<sup>160</sup> In addition, beliefs regarding the withholding of diagnosis, a lack of awareness of services available, and language difficulties were perceived to be barriers



to use.<sup>160</sup> Another study with families found that only 26% of Black Caribbean patients received community or McMillan care compared with 42% of White patients, and only 44% received adequate information compared with 56% of White patients.<sup>161</sup> The UK National Minimum data set reported that only 4.9% of patients were non-White, compared with a population rate of 7.9%.<sup>78</sup>

## **2.4 PATTERN OF REFERRAL TO PALLIATIVE CARE SERVICES**

### **2.4.1 Who refers to palliative care services?**

In Australia, the source of referral may include GPs, specialists or, in some cases, patients or their families. However, the ability of all of these sources to refer may depend on the geographical area and even the type of service being accessed. For example, in Tasmania patients, family and friends are able to make referrals to community services; however, to access a palliative care medical specialist, a referral from a doctor is required.<sup>162</sup> In NSW, patients must be referred by a GP or a medical specialist to be registered with palliative care services in many regions.<sup>162</sup> In a study of a regional centre in NSW, 49% of referrals to a palliative care outreach service were made by GPs, while the remaining referrals were made by specialists.<sup>163</sup> In the Northern Territory, referral to palliative care services can be made by patients, family members, friends, general practitioners, specialists, community health nurses or other health professionals.<sup>24</sup> In regional Queensland, 71% of referrals came from hospitals and 26% came from GPs.<sup>164</sup> The need for a medical referral to access palliative care services can cause problems for some members of the community, such as Indigenous Australians, who may have less access to the health system as a whole.<sup>24</sup>

In the UK, any health professional can refer to SPCSs; however, they must have the agreement of the GP or inpatient consultant.<sup>165</sup> In a national study, 37% of referrals were made by hospital doctors, 25% were from primary health care and 15% were from another SPCS.<sup>78</sup> In the US, while anyone can refer patients to hospice, physicians have become the primary sources of referral to hospice, with one study reporting that in 79% of cases, referrals were "often" made by the physician and rarely by the patient, family or others, such as nurses, allied health professionals and friends.<sup>166</sup> Patients referred to hospice from academic medical centres had greater medical and nursing

needs than those referred from non-academic centres.<sup>167</sup> In Italy, referrals can be made to a palliative home care team either through health professionals or informal caregivers.<sup>168</sup> In contrast to referral structures in developed countries such as Australia, the referral source in African countries is often volunteers and families within the communities.<sup>116</sup> Referrals to specialist centres are also taken from general providers who lack resources to provide palliative care.<sup>116</sup>

#### **2.4.2 When are people referred for specialist palliative care?**

Uncertainty exists for health professionals about when to refer for specialist palliative care.<sup>21, 169</sup> Traditionally, prognosis has been considered an appropriate prompt for the referral of a patient to SPCSs and hospice in the US. However, numerous studies have shown that prognostic accuracy of health professionals is often lacking, resulting in ill-timed referrals.<sup>54, 143, 170</sup> Moreover, many people equate palliative care with terminal care, often resulting in referrals that are too late for the patients and families to benefit from the range of support that can be offered by palliative care services.<sup>171, 172</sup> No Australian policy documents limit availability to palliative care by prognosis or diagnosis.

##### ***Length of inpatient admission stays***

Different indicators may be used to determine when people are referred for specialist palliative care, depending on the care setting. For example, inpatient average length of stay traditionally refers to the time a patient spends in an inpatient setting during an episode. A number of studies have reported on length of stay in inpatient services, as seen in Table 2.1 below.

##### ***Length of care***

Data on the length of care provided to people in settings other than inpatient settings is also often reported as a measure of referral timing. Length of care relates to the time a person is enrolled in a service prior to discharge or death.<sup>78</sup> For example, median survival after enrolment was 54 days in a regional NSW service, depending on diagnosis, with 9.3% of patients dying within 7 days.<sup>173</sup> Patients with community care as their first site of contact with this program had greater median survival (60 days), compared with patients whose first contact was with either a hospital (45 days) or an inpatient hospice (23 days).<sup>173</sup>

In the USA, it has been suggested that the last 6 months of life should be a trigger for referral to hospice.<sup>54</sup> However, discrepancies exist between this timeframe and existing referral practices. For example, a recent USA study reported that one-quarter of persons use hospice for one week or less, in contrast to the 12% who do so for more than 180 days.<sup>61</sup> Interestingly, survival in hospice in the USA may be affected by the prognostic accuracy of clinicians, as one of the admission criteria for hospice is the certification that the patient has a prognosis of less than 6 months.<sup>54</sup> In fact, Christakis *et al* (2000) have shown that shorter hospice survival is, in part, due to clinician prognostic inaccuracy.<sup>54</sup> In addition, the funding mechanism for hospice in the USA is said to encourage the care of those who have few needs rather than those requiring more complex care.<sup>55</sup>

Other studies report on the interval between diagnosis and referral to services, in addition to the time between referral and death. Time between diagnosis of advanced disease and palliative care consultation was 5.6 months at one USA comprehensive cancer centre, while the interval between referral and death was 1.9 months.<sup>174</sup> Intervals were shorter for patients with haematological malignancies compared with those with solid tumours, as one may expect from the disease trajectories.<sup>174</sup> In another study, the median time between admission to a medical centre and referral to the palliative care consultation team was 5 days.<sup>175</sup>

A study conducted on cancer and non-cancer patients from 21 European countries reported that expected survival time for 40% of these patients was between one and 6 months.<sup>121</sup> A study from Northern Italy found that time between diagnosis and death was greater for those accessing palliative care home teams.<sup>168</sup> In the UK, approximately 23% of patients were referred to home care and 34% of patients to hospital-based services at the time of diagnosis.<sup>78</sup> Ninety percent of people died or were discharged from hospital-based services within one month after referral.<sup>78</sup>

While length of care or time between enrolment and death may be more accurate and useful indicators of referral timing than length of inpatient stay, both length of stay for inpatient and length of care for different settings have been included where available (Table 2.1). Both mean and median length of care have been included where possible, as it has been suggested that median length of care may provide a more accurate representation of the patient's care experience than mean length of care.<sup>56</sup> However, it

is important to note that different time periods are included as some countries have rapidly evolving services, while others have more static service development.

*Table 2.1: Mean and median length of care for different palliative care settings in Australia, Canada, the USA and Europe*

Country	Author and year	Setting	Length care (days)	
			Mean	Median
AUS	Australian Government Department of Health and Ageing (2003) <sup>9</sup>	Inpatient care	12.5	-
		Home care	91	-
AUS	Palliative Care Australia <sup>25</sup>	Inpatient care	14	-
		Home care	102	-
UK	Eve (2006) <sup>78</sup>	Inpatient hospital unit	19.7	9.9
		Home care	105	97
		Hospice	13.1	12.7
UK	Higginson (2002) <sup>143</sup>	Palliative care (PC) teams (home and hospital care)	71	42
USA	National Hospice and Palliative Care Organization (2007) <sup>52</sup>	Hospice	59	20.6
		Inpatient unit	9.6	
USA	Christakis (2000) <sup>54</sup>	Outpatient hospice	-	24
USA	Farnon (1997) <sup>176</sup>	Home hospice service	34	-
CAN	Capital Health Community Care <sup>177</sup>	Inpatient unit	22.1	15
		Home care	97.6	60
		Hospice	36.4	19
CAN	Gaudette (2002) <sup>178</sup>	Hospice	10	7
		Tertiary unit	26	19
		Home care	88	34
		Chronic care	80	54
Italy	Beccarro (2007) <sup>101</sup>	Domiciliary PC team	100	46
Spain	Centeno (2000) <sup>92</sup>	PC hospital unit	18	42
		Home		

## **2.5 REASONS FOR REFERRING TO SPECIALIST PALLIATIVE CARE SERVICES**

### **2.5.1 Physical issues**

A review of studies in the UK found that pain is the most common symptom experienced by patients (11% to 84%).<sup>7</sup> Between 14% and 79% of health professionals report referring patients for specialist palliative care as a result of symptom control, and between 18% and 80% of health professionals report pain as a reason for referral.<sup>23, 30, 31, 148, 171, 174, 175, 179-182</sup> Moreover, physical symptoms in people with advanced cancer are more likely to be identified than psychosocial needs.<sup>183-185</sup> An Australian survey of cancer specialists (including oncologists, haematologists and surgeons) found that 82.5% of specialists referred to SPC for potential symptom control, 76.8% referred because the patient had a terminal illness and 65.6% referred because the person had uncontrolled physical symptoms.<sup>186</sup> Fifty-three percent of non-referring GPs said they would refer if the patient was experiencing pain and symptom control problems.<sup>187</sup> Other symptoms reported as reasons for referral to SPC include weakness, fatigue, dry mouth, anorexia, weight loss, sleep problems and dyspnoea.<sup>188</sup> Of requests made to palliative care consultation teams, 42.2% were made for assistance with physical issues.<sup>189</sup> In the UK, 60% of patients were referred to home care as a result of pain and symptom control.<sup>78</sup> Physical symptoms made up 77% of requests for palliative care consultation teams in the Netherlands.<sup>86</sup> Pain and physical symptoms were given as reasons for referral for 58% and 55% of patients respectively in a study of palliative care inpatient units in Germany.<sup>190</sup> Hence, it appears that pain and symptom control is overwhelmingly the primary reason for referral to SPC.

### **2.5.2 Caregiver and family issues**

The needs of the caregivers have also come to the forefront of palliative care in recent years, with providers recognising that the unmet needs of caregivers can have a significant impact on their ability to care for patients, and should prompt referral to SPC.<sup>29, 191, 192</sup> While caregivers have reported that care-giving can be a positive experience,<sup>193</sup> they often have a range of physical and psychosocial needs as a result of their care-giving role, which can have debilitating impacts on their own wellbeing.<sup>136, 194, 195</sup> Caring for patients with greater needs, such as those with advanced cancer, may

result in a greater burden for caregivers.<sup>196-199</sup> Caregivers may even experience more significant unmet needs than patients.<sup>200</sup> In a South Australian population-based study, 29% of caregivers reported physical support needs.<sup>32</sup> Unmet needs may vary with the level of care-giving being provided; day-to-day, hands-on caregivers in Australia who had access to SPC had fewer unmet needs than those who did not have access to SPC.<sup>32</sup> In a 2008 study, 35% of Australian specialists report the families not coping emotionally as a reason for referral.<sup>186</sup>

In a UK study, 84% of caregivers reported above-normal psychological distress.<sup>201</sup> In terms of referrals, SPCSs were identified as a source of respite for caregivers in a number of studies,<sup>30, 31, 180</sup> and up to 42% of health professionals identified this as a reason for referring to SPC.<sup>202</sup> The UK national minimum data set reported carer support as a reason for referral to home care for 9% of patients.<sup>78</sup> However, research has found that health professionals may not refer patients to SPC if their carers are coping well.<sup>187</sup>

### **2.5.3 Psychological issues**

Psychological issues are less often cited as reasons for referral to SPCSs, compared with physical issues. In fact, oncologists' ability to detect psychological co-morbidity has been found to be unsatisfactory in numerous studies,<sup>184, 203, 204</sup> as has nurses' ability to detect hospice patients' physical and psychosocial concerns.<sup>205</sup> Future need for psychosocial issues was reported as a reason for referral by 47.4% of Australian cancer specialists, while 32.7% reported the patient not coping emotionally as a reason for referral.<sup>186</sup> Moreover, only 32% reported SPCSs as having a role in addressing psychosocial issues.<sup>186</sup> It was estimated that of the 2800 cancer deaths per million in the UK, 700 cancer patients per million would suffer from acute anxiety.<sup>7</sup> Of the 6900 patients per million with progressing non-malignant disease, 1600 people per million would suffer from acute anxiety.<sup>7</sup> A review of depression in advanced cancer found that while prevalence of depression within this population is about 15%, a higher proportion experience symptoms that may affect quality of life.<sup>206</sup> In another, the prevalence of depression was even higher at 35.5%, while the prevalence of anxiety was 31.5%.<sup>207</sup>

Despite the apparent psychological concerns of the population with advanced cancer, a study of medical oncology patients found that only 33% of patients with a psychiatric disorder were referred on for a psychiatric opinion;<sup>203</sup> only 17% of anxious and 6% of

depressed patients in an Australian study were perceived as such by their medical oncologists.<sup>184</sup> Emotional distress was given as a reason for the admission leading to death for 13% of patients and the reason for intermediate admission for 14% of patients in the UK.<sup>208</sup> Approximately 32% of Australian specialists reported the patient not coping emotionally as a reason for referral.<sup>186</sup> Forty percent of patients were referred to home care for psychological reasons in a national UK study.<sup>78</sup> The importance of psychological issues is also relevant to caregivers, with earlier hospice enrolment helping to reduce the risk of major depressive disorder among caregivers during the first 6 to 8 months of bereavement.<sup>209</sup> Health professionals rate the need for education in psychosocial issues as a priority.<sup>210</sup>

#### **2.5.4 Practical issues**

Palliative care services can provide discharge and respite options, as well as increase awareness and information.<sup>171</sup> Health professionals have been found to be less likely to identify financial and work-related issues in their patients, compared with patient self-report.<sup>211</sup> End-of-life discussions and advance care planning have been advocated as an important part of end-of-life care, providing assistance in ensuring that the wishes of the patient are followed.<sup>212</sup> In fact, 33% of health professionals report end-of-life discussions as a reason for referral.<sup>188</sup> Similarly, advance care planning has been identified by 62% of health professionals, while discharge planning has been identified by 46% of health professionals as a reason for referral.<sup>175</sup>

Like many parts of the USA, three states in Australia (Victoria, South Australia and Queensland) have legislation for advance directives.<sup>213</sup> While they are also still valid in the remaining Australian states under common law, they are not enforceable and act as guides.<sup>213</sup> However, the importance of advanced directives can vary internationally. A study comparing advanced directives in Germany, USA and Japan found that 79% of USA patients had advanced directives, compared with only 18% of German patients and 9% of Japanese patients.<sup>214</sup> United States and German health professionals all had positive attitudes toward advanced directives, compared with 71% of Japanese health professionals.<sup>214</sup>

### 2.5.5 Cultural and social issues

While cultural and social needs of patients have been identified by health professionals as priorities for education,<sup>210</sup> health professionals are less likely to refer patients to SPCSs for these reasons. Both patients and caregivers have a need for both formal and informal sources of social support throughout the illness trajectory.<sup>215-218</sup> In Queensland, 7% of patients were referred to SPCSs for social reasons.<sup>164</sup> In a Swedish study, 29% of referrals to home care were for social reasons.<sup>219</sup> In the UK, 17% of doctors and 15% of nurses report psychosocial support as a reason for referral of acute hospital inpatients to specialist palliative care beds.<sup>220</sup> Social problems were a reason for referral for 14% of patients in German palliative care inpatient units<sup>190</sup> and 6% of patients in a UK study.<sup>78</sup>

Fewer studies report cultural issues as reasons for referral to SPCS, and cultural issues may be less likely to be addressed by some health professionals. Only 4% of palliative care referrals in a New Zealand study provided cultural information, while 10% provided information about social support.<sup>172</sup> Documentation on the management of these issues was limited.<sup>221</sup> However, the cultural values and traditions of the patient and family have been identified as potential barriers to the delivery of appropriate palliative care, and are thus an important consideration for health professionals.

### 2.5.6 Information issues

The information preferences of patients have been the subject of numerous studies, which suggest that the amount of information wanted by people with cancer can vary and for individuals may vary over time.<sup>222-224</sup> Health system and information needs may be affected by age, whether the cancer is diminishing, and the treatment received.<sup>225</sup> Health professionals often under-estimate the amount of information that is wanted by their patients.<sup>226</sup> Reported unmet needs in this area were second only to psychological needs among mixed cancer patients in NSW.<sup>225</sup> Fifty-nine percent of people with prostate cancer<sup>227</sup> and 21% of advanced cancer patients have reported unmet needs in this area.<sup>196</sup> Lower levels of need were found among medical oncology patients, with only 11% reporting health system and information needs.<sup>228</sup>



### **2.5.7 Spiritual and existential issues**

Despite the perceived importance of spiritual and existential issues,<sup>229-231</sup> these are often overlooked by health professionals as a prompt for referral to SPCSs.<sup>172</sup>

An Australian study found that the quality of palliative care provision with regard to spiritual support was low, and that education in the area of spiritual support was important.<sup>210</sup> Health professionals have requested consultations with palliative care providers for spiritual problems, such as the need for assistance with dealing with patients' acceptance of their illnesses and discussions about the meaning of death.<sup>189</sup> However, requests for assistance with these issues were minimal compared with requests for assistance with physical, psychological and pharmacological issues.<sup>189</sup> Only 42% of Australian specialist reported spiritual issues as an important reason for referral to SPCSs.<sup>186</sup> Of the spiritual and psychosocial problems that patients experienced, 70% were newly identified during the consultation process with Dutch palliative care teams.<sup>232</sup>

### **2.5.8 Sexuality issues**

For many people with cancer, there is an expectation that issues will be raised by their health professionals, often because they themselves are uncomfortable in doing so. These include issues concerning sexuality and relationships.<sup>233</sup> Sexuality has only recently emerged as a focus for palliative care research.<sup>234</sup> People in the earlier stages of their illness trajectories have reported that this is an important area that must be addressed by health professionals, and this attitude is echoed in palliative care patients.<sup>234</sup> In a study of people with cancer, 33% wanted more information and 31% of people with sexual dysfunction wanted more professional attention for this issue.<sup>235</sup> Younger patients (under 60 years) may be more likely to report problems with sexual dysfunction and the need for information about sexuality than older patients.<sup>235</sup> While sexuality issues may not be the most common reasons for people to be referred to palliative care, they will still be issues that people want addressed in both generalist and specialist settings.

### **2.5.9 Health professional issues**

The palliative care knowledge and skills of health professionals will differ, as will their levels of experience and numbers of patients they have contact with.<sup>236, 237</sup> While

generalist providers may have contact with people requiring palliative care, their level of contact may vary. For example, Australian GPs were reported to have contact with a median of five to six palliative care patients per year,<sup>238</sup> while another study found that 15% of GPs were caring for seven or more patients, 22% were caring for between four and six, and 63% were caring for between one and three.<sup>142</sup> Family doctors in the UK had cared for 12 palliative patients over the previous two years.<sup>239</sup> Programs such as the Gold Standards Framework in the UK have been developed to assist generalist providers such as GPs and community nurses in delivering palliative care to patients nearing the end of life.<sup>240</sup>

Differences in health professionals' involvement with specialist palliative care providers and services may be present in other disciplines. In a recent Australian study, 10% of specialists reported often disagreeing with SPCS recommendations.<sup>186</sup> When asked about their relationship with palliative care services, 70% of 895 European and American medical oncologists reported having close relationships.<sup>241</sup> However, only small percentages reported collaborating often with palliative care medical specialists (35%), psychologists (33%), inpatient hospice teams (26%), psychiatrists (15%), palliative care nurse specialists (31%) and home hospice teams (37%).<sup>241</sup> These percentages must be interpreted with caution, however, as the availability of providers varies among European countries, as illustrated in the Centeno *et al* (2007) study.<sup>2</sup> Hence, the level of involvement with these providers may not necessarily be a result of health professional willingness or interest; rather, it may be that these services were unavailable.

While some health professionals may provide the necessary care required, others may find that the level of care required is outside their area of expertise.<sup>242</sup> For example, GPs in the UK were more likely to want to hand over care to specialists if they were less involved in palliative care, had less experience or education in palliative care, and worked in smaller practices.<sup>142</sup> This lack of expertise and the need to obtain advice and information<sup>23, 172, 243</sup> have been reported as reasons for referral to SPCS. In one study, 25% of GPs reported feeling drained by caring for dying patients and 40% wanted nursing support,<sup>187</sup> while in another study 42% of health professionals thought that hospice staff could guide patients' care better.<sup>179</sup> In addition, need for assistance from allied health professionals has been reported as a reason for referral to palliative care.<sup>31</sup>

European health professionals' requests for assistance from palliative care teams have been investigated by specialty type and reason. In a Dutch study, general practitioners had the greatest number of requests for assistance (54.5%), followed by hospital nurses (16.1%), clinical physicians (10.3%), district nurses (8.7%), other health professionals (7.6%) and nursing home physicians (2.7%).<sup>189</sup> Reasons for the requests included physical problems (55.3%), organisation of care problems (20.5%), pharmacological problems (16.2%), general palliative care questions (12.6%) and psychological problems (12.2%). Assistance for daily functioning and spiritual problems were requested least.<sup>189</sup> Similarly, 66% of consultations with an Italian palliative care consultation team were requested by GPs and clinical specialists, while 22% were requested by nurses.<sup>86</sup>

## **2.6 BARRIERS TO THE DELIVERY OF PALLIATIVE CARE**

### **2.6.1 Community perceptions as a barrier to delivery**

Palliative care has been viewed in a negative way by members of the public, and has often been equated with terminal care.<sup>244</sup> Some patients may be reluctant to discuss palliative care,<sup>245</sup> while others may simply refuse to consider the assistance that these services have to offer.<sup>166</sup> In fact, confusion about the role of palliative care is present in many patients, families and especially health professionals who believe that palliative care cannot be used in conjunction with interventional therapy.<sup>246</sup> In the USA, hospice participants may be unable to receive restorative treatment while receiving palliative care symptom control.<sup>247</sup> As a result, patients may simply refuse referrals, choosing instead to pursue treatment options.<sup>50, 245</sup> Often there is a lack of information or knowledge about the services that are available and the benefit of these services,<sup>248</sup> and as a result patients are unaware that they can request the involvement of an SPCS.<sup>141, 174</sup> The attitudes of patients toward their condition may delay referral to palliative care, with patient denial, conscious fighting and optimism linked to later admission to inpatient care from home care.<sup>208</sup>

The knowledge and beliefs of family members can also impact on the involvement of SPCS. Caregivers too often lack knowledge of the services available to assist them.<sup>249</sup>

Families may be reluctant to admit the patient is dying, and this may be accompanied by a pressure to continue to find a cure.<sup>166, 182, 248</sup> The dynamics between the patient and family can also hinder the involvement of SPCSs, as inadequate coping skills may impair decision-making abilities.<sup>246</sup> Family members may also want to care for the patient themselves, due to perceived obligations and family roles.<sup>166, 248</sup>

Literature suggests that the likelihood that patients and their families will accept the assistance of palliative care may depend on their religious and cultural characteristics.<sup>24, 250, 251</sup> Consideration of particular cultural traditions is especially relevant in multi-cultural countries like Australia,<sup>250</sup> and language difficulties are a significant barrier to discussions regarding treatment and care options.<sup>250</sup> In the UK, services have been reported as being ethnocentric and lacking staff of varied and similar ethnic backgrounds to their patients.<sup>161</sup> Furthermore, in some cultures the diagnosis may be withheld from patients,<sup>160, 251</sup> while in others there are rules regarding who can discuss the condition with the health professional.<sup>24, 252, 253</sup> For example, a study conducted in Spain and Canada on the attitudes of patients and families toward disclosure found that only 20% of Spanish patients thought full disclosure was important, compared with 76% of Canadian patients.<sup>254</sup> Moreover, only 3% of Spanish family members thought full disclosure was important, compared with 71% of Canadian families.<sup>254</sup>

Cultural differences are evident between countries and can impact on development of palliative care services and what care they offer. In Spain, hospice has a negative connotation, and so palliative care developed within hospitals.<sup>255</sup> In Italy, only 15% of people could define palliative care, and 85% did not know where this care was provided.<sup>256</sup> As in Spain, in Italy disclosure of prognosis and even diagnosis is often made to the family rather than the patient.<sup>256, 257</sup>

Many ethnic groups also have different cultural meanings regarding death and illness.<sup>258</sup> For example, differing beliefs regarding place of death are present within different cultural groups, with hospital seen as the only option for some patients.<sup>24, 157, 252</sup> For other groups, care is seen as predominately the family's responsibility.<sup>258</sup> An individual approach is required as not all members of a particular cultural group will observe all traditions and values to the same degree.<sup>259, 260</sup>

## 2.6.2 Health professional barriers

A lack of awareness and knowledge of SPCSs and care options can prevent referral of patients to services.<sup>166, 179, 245, 248, 261</sup> In one study, 28% of US physicians reported that a lack of information and the restrictive eligibility requirements of the services prevented referral.<sup>179</sup> In another, physicians with greater knowledge of terminal and hospice care were more likely to discuss hospice care and refer patients to this care.<sup>262</sup> Education can improve the ability of health professionals to identify clients in need of palliative care, manage pain and other symptoms, feel more comfortable with the end-of-life care concept, communicate better, provide emotional and psychological support and respond to cultural and spiritual needs.<sup>263</sup> However, a lack of education on palliative care has been reported in Australia,<sup>147, 210, 264, 265</sup> especially in rural areas where there are often predominately generalist providers.<sup>147, 263</sup> A review of international studies confirmed health professional education to be a significant barrier to referral in the USA, UK, Sweden, Canada and Italy.<sup>236</sup> This lack of education and training is especially prevalent in developing countries.<sup>116</sup>

The personal experience and abilities of the health professionals in discussing palliative care with patients may prevent these discussions with patients.<sup>179</sup> For some health professionals, poor communication and negative previous experiences with services prevent referral.<sup>171, 243</sup> Differences in the way treatment and care are viewed by some specialties (i.e. cure *versus* palliative care) can also be a problem for referral.<sup>171</sup> There may be a lack of clarification as to the role of specialist palliative care services, in areas such as choice of appropriate time, involvement of specialist palliative care services while the patient is receiving treatment, and transfer of decision-making.<sup>21</sup> Conversely, health professionals perceived that some SPCS providers lack experience in managing particular diagnoses such as haematological malignancies, thus impacting on referral to services.<sup>171</sup>

The complexity and severity of symptoms may be difficult for a non-interdisciplinary team to deal with,<sup>180</sup> while other health professionals tend to be over-optimistic in their prognoses.<sup>171</sup> Even if a referral is made to palliative care, lack of expertise, inefficiencies and conflicting medical decisions can occur when oncologists retain the primary physician role in the transition.<sup>180</sup> For GPs, limited input and participation in palliative care, lack of financial reward and time constraints can hinder referral to these services.<sup>148</sup>

Aside from knowledge and experience with SPCS, referring specialty may impact on the timely involvement of SPCS in patients' care. In Australia, specialist referral beliefs appear to be inconsistent with referral behaviour; while 47% believe everybody with advanced cancer should be referred to an SPCS, only 25% refer more than 80% of their patients.<sup>186</sup> Referral specialty, prior experience with hospice patients and prognostic accuracy all predicted survival in USA hospice patients.<sup>266</sup> Patients referred by physicians who were accurate in their estimates of prognosis lived 24 days longer than patients whose physicians' estimates were inaccurate.<sup>266</sup> Similarly, patients whose physicians had referred at least two patients in the prior month survived 17 days longer;<sup>266</sup> patients referred by oncologists and haematologists survived 36.8 days while those referred by surgeons survived the longest (82 days).<sup>266</sup> In the UK, a study on GPs found that while most believed palliative care was part of their role, this belief was dependent on practice size.<sup>142</sup> Interestingly, one-fifth of GPs in one study did not see the patient as needing palliative care even though the hospital staff did.<sup>267</sup> In fact, GPs appeared to show greater reluctance than hospital doctors to define patients as needing palliative care.<sup>267</sup>

Some health professionals, even when possessing adequate knowledge and experience with SPCSs, may be unwilling to refer their patients.<sup>182</sup> In an Australian study, haematological staff showed a reluctance to refer, despite the majority of participants having access to palliative care.<sup>171</sup> This unwillingness may be related to the belief that palliative care will invite a loss of hope from the patient and family,<sup>179, 248</sup> or that it indicates giving up or their own failure.<sup>248</sup> Others believe that involving palliative care will result in a loss of control of their patients. This ownership of patients is a common theme in the literature.<sup>50</sup> Physician unwillingness has been reported as the main reason for lack of in-advance discussions with patient about preferred end-of-life care.<sup>182</sup> While 78% of physicians in one study believed that SPCS were under-utilised, only 15% believed that they under-referred to these services.<sup>179</sup> Others see the limited resources of SPCS being overburdened with early referrals of their patients.<sup>171</sup>

### **2.6.3 Relationship between general and SPC providers and services**

Encouraging productive relationships among specialists and primary health professionals such as GPs can be beneficial to palliative care provision.<sup>237</sup> The provision of case conferences between GPs and specialists in Australia can assist

transfer of information, improve understanding of palliative care and reduce professional isolation.<sup>268</sup> These benefits have also been reported when case conferencing takes place in rural areas among various health professional disciplines.<sup>261</sup> However, studies have shown that communication among health professionals is not always adequate. Of the GPs rating information received from hospital regarding their palliative patients in the UK, 25% received no information or received it too late and 75% rated the information as adequate.<sup>267</sup> Lack of agreement was not related to information promptness or adequacy from hospital doctors.<sup>267</sup> General practitioners report poor communication as a barrier to referral.<sup>243</sup> However, many Australian specialists reported being involved in patients' care even after referral to an SPCS.<sup>186</sup>

#### **2.6.4 Institutional and health system**

In Australia, SPCSs often have a lack of resources when compared with more established specialties.<sup>21</sup> Dying at home can often depend on the caregiver's availability, the physical condition of the patient, the environment and services available, and the desire for these services.<sup>29</sup> In some cases, there is a lack of standardised referral procedures and criteria.<sup>174</sup> In fact, many authors have identified the lack of adequate prognostic tools and staging systems as an important shortfall.<sup>148, 171, 248</sup> The need for a general practitioner or medical referral can also cause problems for ensuring that there is appropriate referral to palliative care.<sup>244</sup> There is also often a conflict between the needs of referrers for flexibility and access and the needs of services to predict demand.<sup>244</sup> This has implications for more practical resource provisions such as availability of beds and staff workloads, and there are often shortages in both.<sup>171, 248</sup> In Australia, a shortage of palliative care specialists, nurses and GPs in rural areas can result in a lack of access to palliative care.<sup>148</sup> Rosenwax *et al* (2006) argue that access to SPCSs in Australia may be affected by funding issues and lack of palliative care skills.<sup>33</sup> Australian institutions that lack designated palliative care services have been reported to have lower standards for dying patients.<sup>22</sup>

The criteria for referral used by some USA institutions often causes considerable concern to health professionals attempting to refer their patients to hospice. In the USA, financial constraints, such as payment structures and regulations, are a prominent barrier to hospice referral, as is the need for expensive palliative interventions for patients with complex needs.<sup>55, 245, 246</sup> Restricted admissions to

hospice have resulted due to the absence of a caregiver, unwillingness to forego hospitalisation, and receipt of total parenteral nutrition, radiotherapy, chemotherapy and transfusion therapy.<sup>55</sup>

However, the authors found that larger hospices were less likely to restrict admission.<sup>55</sup> Refusals by US hospices to accept referrals have occurred because of conflicting opinions about the patient's prognosis, economic reasons, the patient's unstable/unsafe home, the patient having too much active treatment, and the patient having no primary caregiver.<sup>166</sup> A recent study exploring hospice eligibility criteria in the USA found that the criteria did not help identify those patients and families with greater perceived need for hospice services, and those patients and caregivers who met the criteria did not report greater perceived need or greater caregiver burden.<sup>269</sup>

In Canada, it is argued that there is a scarcity of palliative care specialists in cancer centres and acute care.<sup>270</sup> In countries such as Spain and Italy, decentralisation of health care systems has resulted in varying degrees of service provision across regions.<sup>89, 101</sup> Health system barriers are especially relevant when addressing palliative care in developing countries. These significant barriers include the lack of availability of essential drugs and lack of training of health professionals in their use,<sup>110, 116</sup> lack of funding to develop services and an inability of patients to pay for care,<sup>110, 112</sup> inadequate infrastructure,<sup>110</sup> and a lack of policies and national associations to promote standards.<sup>110</sup>

## **2.7 SOURCE OF INFORMATION**

A literature search was performed in PubMed, CINHALL, PsycINFO and Embase databases (January 1995 – June 2009) to investigate the utilisation and access of people with cancer to specialist palliative care and hospice services. Another search was performed using already established topic searches available on the Caresearch online resource, including the Caresearch grey literature and review collection. Some articles were found through searching references of other articles, while others were found through the recommendations of the project's multidisciplinary advisory group. Systematic reviews and population-based and multi-site studies were reported in this review where they were available. It is important to note that the data obtained for this



chapter rely heavily on grey literature. This is literature that is not controlled by commercial publishers or peer review processes and includes dissertations, census and statistical data, reports of research, and technical reports from government, academic, industry and business organisations.<sup>271</sup> Palliative care is a relatively new field, and therefore indexing in databases has been found to be variable.<sup>271, 272</sup> In addition, searching grey literature can minimise publication bias.<sup>272</sup> As this chapter was concerned with the palliative care utilisation and referral patterns of people with cancer and their caregivers and families in a number of different countries, the data accrued from grey literature such as government reports also provided the most accurate and current information.

## **2.8 CONCLUSION**

The referral and utilisation of SPCSs in the various countries mentioned in this chapter appear to be inequitable and often ill-timed. Currently, people are referred to palliative care for a variety of reasons, with some health professionals referring patients irrespective of needs and others not referring at all.<sup>187</sup> In fact, it has been argued that patients are referred more by chance than by need in some cases.<sup>273</sup> In the USA, some have argued for the re-evaluation of the eligibility criteria as they do not necessarily result in access for people with greater needs.<sup>269</sup> The personal characteristics of the patient and other external factors may impact on the likelihood that SPCS will be involved in the care of some individuals. It appears that age, socio-economic status, education, marital status, geographical location and ethnicity may all affect the delivery of SPC. Similarly, illness characteristics (including diagnosis and type of cancer), the knowledge and attitudes of the patient and family, the knowledge and experiences of health professionals, and even the structure and funding of health systems, may have a bearing on the involvement of an SPCS. It is important to note, however, that while late referrals are often problematic, overly long stays caused by referrals that are too early can also cause problems, including unnecessary use of resources, adverse clinical implications and demoralisation in the patient.<sup>274</sup>

Hence, the current delivery of SPC appears to require further revision in Australia and perhaps internationally. While service provision may vary among countries, it appears that prognosis-based models have been identified as a potential hindrance to

appropriate referral. For example, the prognosis-based approach of USA hospice is said to be problematic for ensuring equitable access for people with life-limiting illnesses, and has been the subject of much debate.<sup>275</sup> However, conflicting opinions exist in the USA as to whether a needs-based approach could address the current inequality in hospice access, with the potential impact on Medicare funding a particular point of contention.<sup>275</sup>

Similarly, Palliative Care Australia has advocated for a needs-based model as a potential solution to the current inequity in Australia's palliative care delivery. For a needs-based model to be effective, Carlson (2008) argues the criteria of need must be determined, not only in terms of what constitutes need, but when assessments should take place.<sup>275</sup> PCA has suggested that the "development of well defined and transparent referral and admission protocols and procedures" would facilitate appropriate needs assessment.<sup>276</sup> It is the development of these referral protocols that is the subject of the next chapter.

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# **CHAPTER 3:**

## **DEVELOPMENT OF EVIDENCE-BASED RESOURCES TO FACILITATE THE APPROPRIATE ASSESSMENT OF PATIENT, CAREGIVER AND HEALTH PROFESSIONAL NEEDS**

### **3.1 INTRODUCTION**

The Australian and international literature outlined in the previous chapter supports the assertion that the delivery of palliative care is inequitable and often ill-timed. There is a growing recognition that a shift from the prognosis-based model currently guiding palliative care delivery, toward a more needs-based model may offer a potential solution to these delivery issues. For the purpose of this research, need is defined as “the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being”.<sup>1</sup> The aims of this chapter are to:

- define the needs-based approach to care
- outline the benefits and barriers of using Guidelines as a method for determining who would benefit from palliative care; and
- explore strategies to address these barriers and improve adherence to Guidelines.

### **3.2 NEEDS-BASED MODEL FOR DELIVERY OF CARE**

According to Palliative Care Australia (PCA), the population of people with life-limiting illnesses can be categorised into three main groups. The first sub-group is made up of patients who "do not require access to specialist care to meet their needs which are met either through their own resources or with the support of primary care providers".<sup>2</sup> In Australia, primary care providers include "general practitioners, community nurses, staff of residential aged care facilities and multipurpose centres", as well as other specialist services and staff, such as "oncologists, renal, cardiac or respiratory physicians, and staff of acute care hospitals and services".<sup>2</sup> These staff provide ongoing care, and the substantial part of their work is not in palliative care.<sup>2</sup>

The second sub-group includes patients who "may have a temporary increase in their level of need and may require access to specialist palliative care services for consultation and advice but continue to receive care from their primary care provider".<sup>2</sup> The third sub-group includes "patients with complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of care; and require highly individualised care plans developed, implemented and evaluated by knowledgeable and skilled specialist practitioners, in partnership with primary care

providers".<sup>2</sup> People may move between these groups depending on the severity and complexity of their own needs, the needs of their caregivers or families, and the needs of their health care professionals.<sup>2</sup>

The PCA model offers a way to improve the delivery of palliative care by triaging people with life-limiting illnesses, such as cancer, according to their needs. Providing care on the basis of needs offers a way to ensure that the finite palliative care resources available are provided to those people who need them most in a more equitable and transparent way,<sup>3</sup> while allowing less complex needs to be met by generalist primary care (medical, nursing, and social services). Hence, patients with minimal needs can be cared for by their primary care teams, while those with intermediate or complex needs may require the consultative or continued involvement of specialist providers.

### **3.3 EVIDENCE-BASED RESOURCES**

As Carlson (2008) suggests, implementing a needs-based model has its own challenges, including how to define need and how and when to assess need.<sup>4</sup> Having best practice standards and pathways to referral linked directly to unmet needs may assist with identifying those who require the assistance of palliative care services.<sup>5</sup>

#### **3.3.1 Benefits of Clinical Practice Guidelines**

Clinical practice guidelines are commonly defined as "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances." <sup>6</sup> Guidelines have been used in numerous medical settings, and offer a way of assisting health professionals to maintain and improve their knowledge of changes in technology and health care, including the systematic delivery of care.<sup>7</sup> It has been argued that transferring key aspects of the specialist knowledge, attitudes and skills of hospice and palliative care specialists to other health providers should be a key focus in improving end-of-life care.<sup>8</sup> The development of clinical practice guidelines has been proposed as a way to support health professionals in providing best practice care,<sup>9</sup> by improving the quality of care and reducing the inconsistencies that currently exist in the delivery of health care. <sup>9-11</sup>

### ***Improving clinical decision-making***

Part of improving the quality of the care received by patients is assisting health professionals to make correct decisions about the types and levels of care needed by patients.<sup>9</sup> For health professionals, clinical decision-making is a complicated process requiring the consideration of numerous factors, including patient preferences, complexity of the patients' conditions and resources available.<sup>12</sup> Moreover, patient preferences for involvement in decision-making and level of information often differ and are not always achieved.<sup>13-15</sup> Guidelines can serve as an aid to health professionals and patients when making clinical decisions<sup>12</sup> and can increase confidence in decision-making.<sup>13</sup> The provision of consumer versions of guidelines can further empower patients and assist their involvement in the clinical decision-making process.<sup>12</sup>

The predictable decrease in the functional abilities of most people dying of cancer and the associated worsening of their physical symptoms often results in an increased need for physical assistance.<sup>16</sup> For many people, caregivers and family members will play an important role in providing this assistance. This caring role can often be made more difficult by the lack of knowledge of the patient, caregiver or family members. In fact, patients and their families are often unaware of their own ignorance regarding the person's illness and care options, and consequently require guidance and information from health professionals to assist in making informed decisions about the patients' care.

### ***Educating health professionals***

A lack of adequate training and education in the area of palliative care has been reported in interviews, focus groups and surveys conducted with Australian multidisciplinary oncology staff, including medical and nursing staff,<sup>17</sup> general practitioners<sup>18, 19</sup> and allied health professionals.<sup>20</sup> The number of new procedures and technologies makes it difficult for health professionals to stay up-to-date and informed.<sup>21</sup> Guidelines have been reported by Australian medical practitioners, general practitioners, nurses, allied health professionals and overseas oncologists to be good educational tools,<sup>11, 22, 23</sup> and are seen as especially useful for junior trainees.<sup>11</sup>

### ***Resource allocation***

Despite the universal access of Australians to health care, there are some people who do not have access to health services. As Armstrong (2007) argues, the Australian

health system will continue to be “stretched by an ageing population, the growing burden of chronic illness, and the increasingly outmoded organisation of our health services”.<sup>24</sup> Issues such as workforce shortages, the increase in out-of-pocket costs and the roles of private and public funding have all impacted on the availability of health care.<sup>24</sup> For example, fewer people in rural and regional areas have private health insurance due to the limited private facilities available in these areas, often resulting in longer waiting times for procedures performed primarily in the private sector.<sup>24</sup> Hence, access to care is often based on ability to pay rather than need.<sup>24</sup>

Aside from the benefits to individual patients and health professionals, guidelines can play an important role within the wider context of the organisation and health system. There is a need to prioritise the resources that are available to ensure that those people who need the services the most do have access to them.<sup>9</sup> Guidelines can assist in resource utilisation<sup>12</sup> and can call attention to areas of care which require immediate focus from those involved in the provision of health care, as well as to populations who may have been previously neglected.<sup>9</sup> As such, guidelines can improve the efficiency and image of organisations and the health system as a whole.<sup>9</sup>

### ***Reduce litigation***

In some cases, patients can experience negative outcomes as a result of the care they have received. Guidelines provide a framework for health professionals to follow in provision of care, thus offering a method for potentially minimising inappropriate practice and negative outcomes of care, as well as the subsequent malpractice claims and uncertainty that may be present in litigation cases.<sup>12</sup> In fact, surgeons report that the uptake of guidelines could be facilitated by the knowledge that a successful legal defence could be produced for those who base their decisions on these guidelines and therefore conversely expose practitioners who do *not* base their practice on current evidence-based guidelines.<sup>13</sup>

### ***Improving quality of care***

One of the most cited benefits of guidelines is their potential for improving quality of care. A systematic review found that using guidelines improves the process of care as proposed by those guidelines.<sup>25</sup> Guidelines are believed to be useful in clinical settings, are viewed as a way to improve the quality of care available to patients, and are seen as helpful sources of advice to clinicians.<sup>9, 11, 23</sup> Guidelines may also assist in improving

the consistency of care being received by patients, as care can often vary according to health professional, practice setting and even location.<sup>12</sup> Importantly, the health outcomes of patients have been positively influenced by the use of clinical guidelines.<sup>25</sup> In oncology, the introduction of guidelines has led to improved treatment processes and outcomes<sup>26</sup> and changed practice patterns in the management of early breast cancer.<sup>27</sup>

Despite the wide-ranging benefits of guidelines for patients, health professionals and the health system, their use within clinical settings cannot be guaranteed.<sup>28</sup> Patient preferences and needs may influence health professionals' adherence to guidelines,<sup>29</sup> as can the health professionals' own lack of awareness, familiarity with or access to the guidelines, or lack of resources and time.<sup>11, 21, 30 31</sup> It is argued that there is a need for formal and systematic dissemination of guidelines within clinical settings to improve compliance.<sup>11</sup> Identifying the possible causes of these variations in adherence, as well as ways to rectify these issues, have become important foci for those involved in the development and implementation of guidelines.

### **3.3.2 Barriers to the uptake of guidelines**

As indicated in Figure 3.1, barriers to health professional adherence to guidelines generally fall into the three main categories of knowledge, attitudes and behaviour. Some barriers relate to health professionals themselves, and others are external to the individuals for whom they are developed.

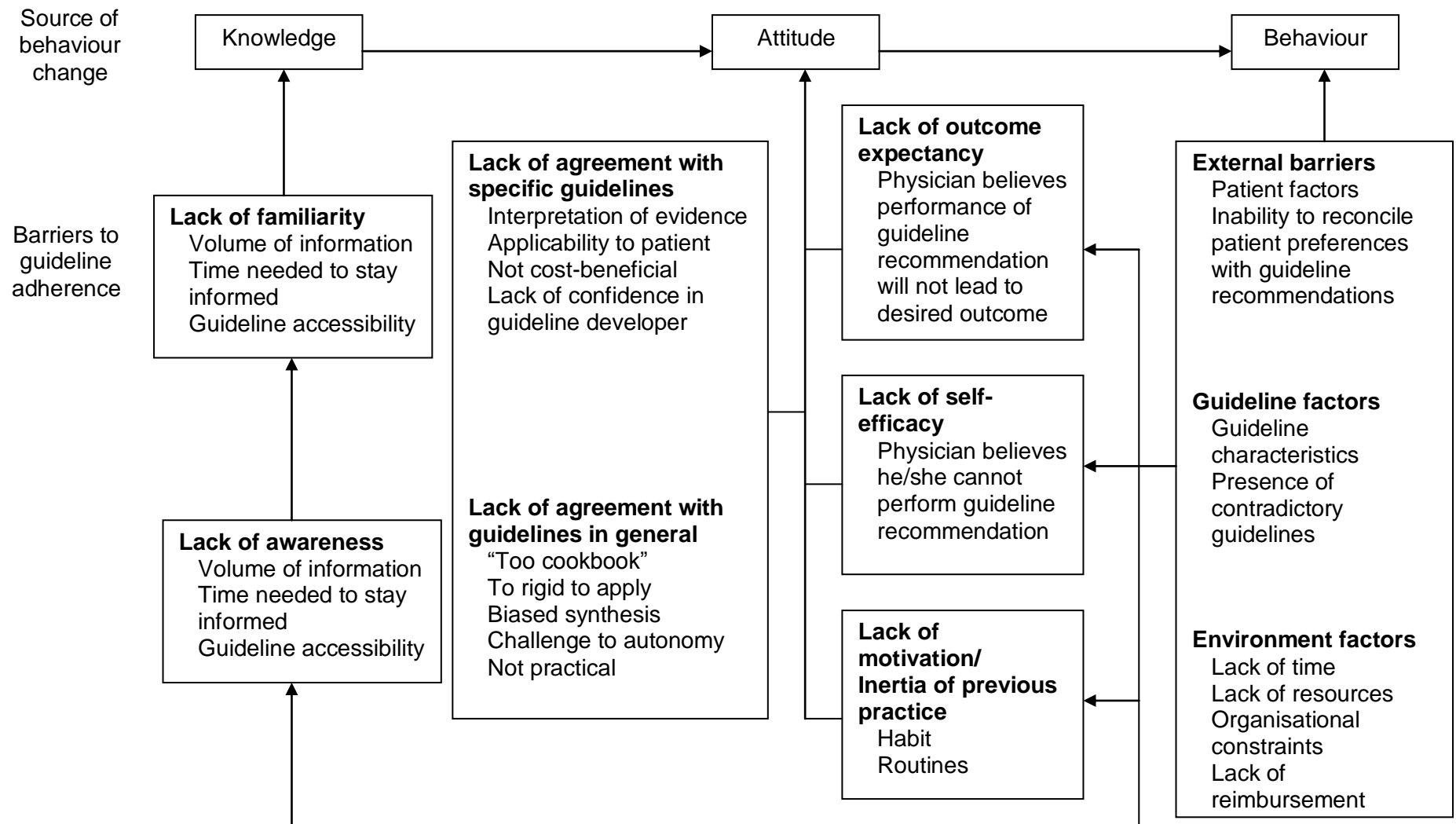


Figure 3.1: Barriers to health professional adherence to clinical practice guidelines in relation to behaviour change (reproduced with permission)<sup>31</sup>



### ***Internal barriers: health professional knowledge***

Studies have shown that adherence to clinical practice guidelines may be hindered by a number of factors related to health professionals. In order to implement guidelines in their clinical settings, health professionals must first be aware of their existence.<sup>31</sup> A review was conducted on studies between January 1966 and 1998 that described at least one barrier to adherence to clinical practice guidelines, practice parameters, clinical policies, or national consensus statements.<sup>31</sup> This review included studies that surveyed a variety of health professionals about guidelines for a variety of conditions.<sup>31</sup> A lack of awareness was addressed in 46 surveys, and this barrier was reported by between 1% to 84% of health professionals in each of the studies.<sup>31</sup> Similarly, an Australian study indicated that 45% of medical practitioners, nurses and allied health professionals were unaware of clinical practice guidelines in their own settings.<sup>11</sup> Even when health professionals are aware of guidelines, they may still choose not to adopt these practices due to a lack of access to the guidelines or lack of familiarity with the content.<sup>11, 31</sup> In 28 of the 31 surveys measuring familiarity with guidelines, at least 10% of respondents were not familiar with the content of the guidelines.<sup>31</sup>

### ***Internal barriers: health professional attitudes***

In some cases, the recommendations being made are not seen as directives,<sup>29</sup> and a lack of agreement with these recommendations can prevent health professionals from complying.<sup>11, 31</sup> This is especially true if the health professionals feel that the individual circumstances of the patient are inconsistent with the recommendations made in the guidelines.<sup>11, 12</sup> Some health professionals have reported that guidelines are too rigid and over-simplified and believe that they may reduce physician autonomy, thus challenging their authority.<sup>6</sup> Others believe that the use of guidelines can lead to an increase in litigation.<sup>6</sup> However, it has been argued that negative clinician attitudes may not be the primary barrier to the implementation of guidelines.<sup>6</sup>

Health professionals' level of experience may influence their willingness to comply with recommendations made in guidelines.<sup>29</sup> A study conducted with advanced practice nurses suggested that these nurses may have sufficient training and education to ensure best practice care, and suggest that health professionals operating at a general level may need more attention.<sup>32</sup> A Canadian study found that country of training and specialty may impact on guideline use, with participants from non-Canadian schools and radiation oncologists reporting greater compliance with guidelines.<sup>23</sup> Participants in

a study into cancer screening reported they were more likely to follow guidelines for screening early in their careers.<sup>29</sup> Meanwhile, Cabana *et al* report that in the majority of studies reviewed, at least 10% of participants reported a lack of self-efficacy as a barrier to the adherence to guidelines.<sup>31</sup> The expectation that the recommendations will actually lead to improved outcomes for the patients is also an important factor in physician compliance.<sup>31</sup> In a study looking at the impact of guidelines on the management of colorectal cancer, 44.7% of surgeons did not expect a change in practice as a result of the guidelines.<sup>33</sup>

### ***External barriers: guideline factors***

How the guidelines are developed can result in inconsistencies in the compliance of health professionals and even the guidelines' effectiveness. In some areas of research, such as palliative care, the methodological quality of studies may be compromised by issues such as patient recruitment and attrition.<sup>34</sup> Ensuring that only studies of good methodological quality are used as the basis for recommendations can result in increased compliance with guidelines and, subsequently, improved quality of care.<sup>9, 11, 29, 30</sup> It is clear that guidelines need to be both reliable and valid.<sup>12</sup> If recommendations made in guidelines are incorrect or based on studies of questionable methodological quality, they may cause considerable harm both to the patient and the health professional implementing them.<sup>12</sup>

While the guidelines require sound scientific evidence, they must also be relevant to the clinical setting for which they were intended. As Boon *et al* (2006) argue, guidelines must be specific to a population and may not be applicable from one country to another.<sup>12</sup> Moreover, the individual nature of patient situations does mean that a strict adherence to guidelines may be ineffective in some cases which may require a more flexible approach.<sup>12, 23, 31</sup> In fact, the exclusion of patients with co-morbid conditions in some clinical trials results in guidelines that may not be applicable to clinical settings where patients may have co-morbid conditions.<sup>35</sup> An Australian study investigating adherence to guidelines suggested that 85% of GPs believed guidelines were "developed by experts who don't understand general practice".<sup>22</sup> Thus, it is argued that guidelines should "complement rather than replace physician judgement".<sup>28</sup>

At a more fundamental level, the clarity of the guidelines and the language used must be considered. It has been demonstrated that ambiguous or vague guidelines are often

not followed by health professionals.<sup>30</sup> In fact, a lack of clarity in the intention of guidelines can often lead to misinterpretation and confusion for the health professional.<sup>29</sup> Complex recommendations and those that are not easily tried and discarded can result in less compliance.<sup>36</sup> An Australian study found that only 32% of surgeons read guidelines cover to cover, while 35.9% skimmed the information presented.<sup>33</sup> Health professionals report a preference for guidelines to be presented in flow charts or checklists with summaries rather than larger documents.<sup>11</sup>

### ***External barriers: patient factors***

Patient preferences and needs may influence health professionals' compliance behaviour, especially when guidelines are vague or unclear.<sup>29</sup> Patient age may impact on adherence, with one study showing lower adherence by health professionals when treating older patients.<sup>10</sup> The type of health care problem the patient has may impact on use of guidelines; health professionals treating patients with acute care issues showed greater compliance than professionals treating patients with chronic care problems.<sup>7</sup> Moreover, there is little guidance provided for older patients with multiple co-morbid illnesses.<sup>37</sup> Patient resistance and perceived lack of need for adherence by the patient have been reported as potential barriers in a systematic review.<sup>31</sup> However, Tinetti (2004) argues "it is difficult to separate inappropriate variation due to neglect or ignorance on the part of providers from appropriate variation due to the total disease burden and the preferences of patients".<sup>38</sup>

### ***External barriers: organisation and health system factors***

A lack of resources, a lack of time, conflicts with current practice, and the culture of the organisation may all impede guideline adherence.<sup>11, 21, 29, 30</sup> Compliance may also be influenced by peer attitudes,<sup>29</sup> peer support and opinion leadership.<sup>12</sup> One study reported that the compliance with guidelines regarding breast-conserving surgery was dependent on the hospital that patients attended,<sup>10</sup> while another showed that general hospitals used guidelines more than tertiary hospitals.<sup>11</sup> A lack of physician compliance may not be related to physician resistance to guidelines; rather, it may be due to institutional factors.<sup>28</sup> For example, a controlled intervention trial to improve physician compliance with a length-of-stay guideline found that although the physician agreed with the recommended discharge, health system inefficiencies prevented compliance for 14% of patients.<sup>28</sup> Guidelines may be used less if compliance affects the

organisation and staff, demands extra resources or new skills, or provokes negative reactions in patients.<sup>30</sup>

### **3.4 THE *PALLIATIVE CARE NEEDS ASSESSMENT GUIDELINES***

In 2006, the *Palliative Care Needs Assessment Guidelines*<sup>39</sup> (hereafter referred to as the *Guidelines*) were developed in an attempt to fill a gap nationally and internationally (see Appendix 3.1 for Summary version).<sup>39</sup> The *Guidelines* aim to educate and inform health professionals about the issues that affect people with advanced cancer, their families and professional carers, in order to facilitate timely referral to specialist palliative care services if required. Initially, an extensive literature review was undertaken of the needs of people with advanced cancer, caregivers and families, as well as health professionals who provide their care, and on the costs, benefits and triggers to referral to specialist palliative care services, using a large number of databases including Medline, PsycINFO, PubMed, CINAHL, Embase, Cochrane Library, Therapeutic Guidelines (eTG Complete) and Clinical Evidence. A draft of the *Guidelines* was based on the findings of this review and included information relating to patient domains, including physical, psychosocial, spiritual, cultural and other relevant issues, as well as evidence relating to the caregiver and family and to health professional domains.

An expert consensus panel consisting of 66 leaders and key stakeholders involved in the care of people with advanced cancer, consumer representatives and health advocates was convened. The panel included clinical specialists from referrer groups (including medical, radiation and surgical oncologists, haematologists, respiratory physicians, colorectal surgeons and general practitioners), key palliative care clinicians, representatives of learned colleges including the Royal Australian College of General Practitioners (RACGP) and the Australian College of Rural and Remote Medicine (ACRRM), bereavement specialists, pharmacists, Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CALD) communities, consumer advocates, and patient and carer representatives. In addition, representatives of nurses, allied health practitioners (such as psychologists, occupational therapists, social workers, and physiotherapists), health ethicists, the clergy, researchers and health economists were invited to participate. As there is significant variation between

metropolitan and rural areas and potentially between states and territories in Australia in terms of models of palliative care delivery and resourcing, the consensus panel included representatives from different states, and from rural and remote as well as urban areas.

Panel members were sent a copy of the draft *Guidelines* and asked to identify any missing triggers or aspects and to rate each proposed item of the *Guidelines* according to its importance in ensuring that the person with cancer obtains optimal specialist palliative care. The panel was then invited to attend a national consensus meeting to discuss the draft *Guidelines* further. Based on the suggestions of this expert group, amendments were again made to the *Guidelines* before a final version and summary were produced.<sup>39</sup>

The *Guidelines* provided information about people with cancer, their caregivers and families. While some health professionals may already be familiar with many of the needs of people with cancer and their families in general, there is evidence to suggest that this knowledge may not extend to all areas of need and is potentially not reflected in systematic exploration of needs not openly expressed by patients or their families; hence, education is required.<sup>17, 40, 41</sup> The *Guidelines* are intended to provide advice to those caring for people with cancer and their families, to ensure that they are offered the most appropriate care to meet their specific needs. They cover all aspects of patient, caregiver and primary health care provider characteristics that may influence the decision to provide more specialist palliative care to a particular patient or family.<sup>39</sup> For primary care providers, the *Guidelines* can establish whether needs are currently being met, or whether a specialist assessment may potentially add to the care plan.<sup>39</sup> For specialist palliative care teams working alongside primary care providers, the *Guidelines* can help to determine the complexity of ongoing needs and therefore the need for ongoing specialist team involvement.<sup>39</sup>

### **3.5 IMPROVING COMPLIANCE WITH GUIDELINES**

The wide-ranging barriers to the implementation of guidelines within clinical settings suggest that there is a need to examine the feasibility and effectiveness of introducing guidelines into each individual clinical setting, with individual health professional and

organisational factors all playing a role.<sup>6</sup> Since the processes used to disseminate and implement guidelines are as important as those used to develop them,<sup>42</sup> there is a need for formal and systematic dissemination of guidelines within clinical settings to improve compliance.<sup>11</sup> While a number of different methods have been proposed to assist in the implementation of guidelines in clinical settings, no one approach has emerged as superior to others for all circumstances.<sup>21, 43, 44</sup> The following section outlines the various approaches that have been investigated in the literature.

### **3.5.1 Passive methods**

#### ***Written materials and journal publication***

Encouraging the use of guidelines often involves the provision of written materials to health professionals informing them about the guidelines' existence. Guidelines may be published in journal articles or on websites of professional organisations, or sent out to individual health professionals in large documents.<sup>33</sup> Unfortunately, the large volume of publications and information received by health professionals can hinder their ability to incorporate all of the recommendations into practice.<sup>21</sup> In fact, only 40% of doctors in one study were aware of guidelines through journals.<sup>11</sup> A review looking at improving referral from primary to secondary care found that passive approaches are often inadequate to ensure compliance and implementation of referral guidelines into everyday practice.<sup>45</sup> Similarly, studies that used passive interventions to address barriers to appropriate care showed small, if any, effects.<sup>43, 44</sup> Thus, a more active approach or a combined approach including these written materials could be more successful.<sup>7</sup>

### **3.5.2 Active methods**

#### ***Seminars and workshops***

Local dissemination educational activities involving both primary and secondary health professionals are necessary for adherence to referral guidelines.<sup>45, 46</sup> Larger courses have shown mixed effects, while smaller, more active approaches have been more successful.<sup>7</sup> Didactic presentations are less effective in improving patient care than interactive strategies.<sup>47</sup> In an Australian study, 41% of clinicians were aware of guidelines as a result of education.<sup>11</sup> One possible barrier to this method is the availability of speakers with the necessary presentation skills and knowledge.<sup>48</sup>

### ***Audit and feedback and reminders***

Audit and feedback involves providing health professionals and organisations with a "summary of clinical performance of health care over a specified time".<sup>49</sup> While it has been shown to be moderately successful,<sup>48</sup> this success may hinge on factors such as baseline compliance,<sup>49</sup> type of feedback and format of feedback.<sup>7</sup> In fact, a large variance in effect size has been found with this method, with authors suggesting that effect size may be greater when baseline compliance is low and intensity of feedback high.<sup>49</sup> Of all the mentioned strategies, reminders have been evaluated most often as a single intervention and have been used in a variety of clinical settings with moderate success,<sup>48</sup> e.g. in patient management.<sup>7</sup> Issues regarding the extraction of information and training of staff may be of concern for some considering this option.<sup>48</sup>

### ***Educational outreach and academic detailing***

Educational outreach has improved clinical outcomes and the uptake of guidelines in the areas of prevention and prescribing.<sup>21, 44</sup> Academic detailing is a program that requires a trained individual to make one-on-one visits to the offices of health professionals to provide evidence-based information regarding professional practices.<sup>50</sup> In general practice, academic detailing has improved knowledge and understanding of evidence-based medicine<sup>51</sup> and Prostate-specific Antigen testing practices.<sup>52</sup> Similarly, physicians' use of smoking cessation strategies was enhanced by office-based academic detailing visits.<sup>53</sup> Group and individual academic detailing have both been shown to improve prescribing behaviours,<sup>54</sup> particularly for those who received individual visits.<sup>55</sup> The possible need for follow-up visits to sustain changes in behaviours has been suggested by some authors.<sup>52, 55</sup> In contrast, academic detailing did not improve cervical<sup>56, 57</sup> or colorectal screening behaviour.<sup>58</sup> The financial cost can affect the feasibility of using this method for large numbers of health professionals.<sup>48</sup>

### ***Local opinion leaders***

Both academic detailing and local opinion leaders have been used successfully by the pharmaceutical industry. The use of respected "educationally influential" members of a profession to bring about changes in the behaviours of health professionals has also been advocated.<sup>59</sup> Personal visits by peers highly ranked by surgeons have been found to be successful for implementation of guidelines with this health professional group.<sup>13</sup> While a review of this method found that it was more effective than audit and feedback and standardised lectures, and that it reduced non-compliance with appropriate

practice, effects were smaller than those associated with reminders.<sup>59</sup> The intensity of labour in addition to the reliability and validity of the process for identifying leaders have been acknowledged by some authors as potential hurdles to use of this strategy.<sup>48, 59</sup>

### **3.6 TRANSLATING RESEARCH INTO CLINICAL PRACTICE**

Evidently, the translation of research into clinical practice has been examined by many attempting to implement guidelines successfully. Academic detailing is one of the most effective methods for educating health professionals, and it was decided that this approach would be used initially to introduce the *Palliative Care Needs Assessment Guidelines*. However, there are still some who question the sustainability of changes in behaviours that result from academic detailing.<sup>52, 55</sup> Moreover, multiple interventions have shown the greatest effect in changing provider behaviour and improving compliance with guidelines.<sup>36</sup>

The *Guidelines* provide an important patient-centred approach to the delivery of care, providing information and advice to health professionals and relying on the assessment of individual need. The importance of a patient-centred approach has also been acknowledged in a review of interventions to change provider behaviour, which found that guidelines were more effective if patient-specific reminders were used to implement them.<sup>36</sup> One potential method for improving compliance with the *Guidelines*, embracing this patient-specific approach, is the use of structured checklists. In fact, checklists have been shown to improve the pre-referral management of patients, compliance with guidelines, reductions in inappropriate referrals and increases in appropriate referrals to secondary care.<sup>45</sup> It was thought that the use of an ongoing reminder system, such as a structured checklist, could supplement the initial academic detailing session and potentially sustain the change in behaviour resulting from compliance with the *Guidelines*.

Hence, it was decided that a structured checklist, in the form of a needs assessment tool, would be used to complement the *Guidelines* to provide health professionals with a method of assessing the various issues outlined in the *Guidelines* in a consistent and structured way. This review was conducted to assess the suitability of tools currently available to operationalise the *Palliative Care Needs Assessment Guidelines*, by



assessing the needs of people with cancer, their caregivers and the health professionals who provide their care.

## **3.7 REVIEWING THE EVIDENCE: AVAILABLE NEEDS ASSESSMENT AND SCREENING TOOLS**

### **3.7.1 Introduction**

Assessing the needs of people with cancer and caregivers is one of a number of strategies that have been used to evaluate morbidity.<sup>1</sup> Needs assessment not only facilitates the identification of people who have specific concerns or are dissatisfied with some aspect of their care,<sup>1</sup> but also determines the person's desire for assistance and involvement with services.<sup>1, 60-63</sup> As mentioned earlier in this chapter, Palliative Care Australia has advocated that the delivery of palliative care be determined by the severity and complexity of patient and family needs, independently of the person's diagnosis or estimated prognosis. In response, the *Palliative Care Needs Assessment Guidelines* were developed to inform health professionals about the various needs affecting people with advanced cancer, their families and professional carers, and by use of an accompanying structured tool, ultimately to facilitate a more efficient approach to the assessment and management of unmet needs.

Needs assessment tools can improve communication by providing prompts for discussions and encouraging the expression of any concerns requiring assistance.<sup>64, 65</sup> Secondly, they enable health professionals to identify the patients and caregivers with greater needs who may require targeted early interventions,<sup>1, 66-68</sup> thus allowing for the prioritisation of often limited resources.<sup>65</sup> Finally, they benefit the health services and institutions by identifying areas requiring improvement.<sup>1, 65</sup>

A number of tools have been developed and tested to assess the needs of people with cancer and their families in a variety of settings. Research shows that tools can distinguish people with high needs from those with low needs,<sup>69</sup> as well as increase the number of psychosocial problems discussed with people with cancer and the number of referrals to other health professionals.<sup>70</sup> Moreover, consultation time is not necessarily increased and may even be reduced by using checklists as they allow

health professionals to direct their focus to relevant problems.<sup>70</sup> However, it has been suggested that the potential benefits offered by needs assessment tools may not always be achieved with the tools that are in existence today due to their varied psychometric quality and content.<sup>62, 71</sup> These identified issues will be further examined below.

### 3.7.2 Methods

#### ***Searching for existing needs assessment and screening tools***

A literature search was performed in Medline, PsycINFO, Embase and CINAHL databases (January 1990 – May 2006) to investigate the development and evaluation of needs assessment and screening tools for use with people with cancer, their caregivers and/or families (see Table 3.1 for search terms). Some articles were found through searching references of other articles, while others were found through the recommendations of the project's multidisciplinary advisory group.

*Table 3.1: Search terms used singly or in combination*

<b>Disease terms</b>	<b>Subject terms</b>	<b>Checklist terms</b>
Cancer	Patient need	Tool
Oncology	Caregiver need	Instrument
Neoplasms	Family need	Measure
Palliative care	Health professional need	Questionnaire
End of life care	Needs assessment	Survey
Hospice		Checklist

#### ***Inclusion criteria***

The following inclusion criteria were used to select articles:

1. tools that assessed the needs of adult cancer patients, their caregivers and/or families and health professionals
2. tools that measured more than one domain
3. tools that could be used with people with all cancer types.

#### ***Psychometric assessment of identified tools***

During the literature search, a number of reviews on needs assessment tools for patients<sup>65, 72</sup> and caregivers,<sup>67</sup> as well as a review on instruments for assessing the patient and caregiver need for palliative care, were identified.<sup>71</sup> As the reviews identified during the literature search had a similar focus, many tools identified here are

also included in these previous studies.<sup>65, 72 67</sup> As these reviews were published in 2004, it was decided that another review would be conducted to ensure that more recently developed tools were included. On the basis of these reviews and other similar literature,<sup>73</sup> the following psychometric criteria were chosen to evaluate the tools identified:

- *Domains and items*: the domains of need as well as the type and number of items included in each of these domains
- *Population and purpose*: the intended use of the tool and the population for which it was developed
- *Question format and administration*: the response format and the method of administration
- *Content validity*: method for determining which items to include in the tool
- *Construct validity*: how the authors assessed whether the tool actually measured the construct it purported to measure
- *Internal consistency*: whether items correlated with each other in the tool
- *Inter-rater reliability*: whether different raters obtained similar scores when using the tool
- *Responsiveness*: whether the tool was able to detect change in the needs of the population it was assessing
- *Feasibility*: the time taken to complete the tool, the level of burden on the patient, caregiver/family or health professional, and the acceptability of the tool.

### 3.7.3 Results

The search methods resulted in the identification of 844 articles in Medline, PsycINFO, CINAHL, and Embase databases. Additional studies were identified through the recommendation of the advisory group and through searching other articles. Many of these identified studies investigated the need for palliative care services within communities,<sup>3, 74-76</sup> provider perspectives on palliative care provision,<sup>17</sup> or the education and information needs of patients,<sup>77</sup> their caregivers<sup>78, 79</sup> or health professionals.<sup>80-83</sup> Other studies investigated patient<sup>73, 84-86</sup> and caregiver quality of life<sup>87, 88</sup> and satisfaction with care.<sup>89, 90</sup> A number of authors have discussed the relationships among quality of life, satisfaction and needs.<sup>1, 63, 65</sup> Satisfaction measures assess the quality of care provided in terms of whether services or providers are meeting the patients' or caregivers' needs.<sup>91</sup> Even if needs are unmet, satisfaction may

still be high because of the patients' beliefs regarding the potential for these needs to be met by providers.<sup>91</sup> Quality of life measures often provide a more general picture of the patients' or caregivers' health and wellbeing.<sup>91</sup> They focus less on specific individual needs, instead assessing more general domains.<sup>91</sup> While it has been suggested that all three play a role in assessing a person's overall health situation,<sup>63</sup> only needs assessment can identify the detailed experiences of each particular individual<sup>91</sup> and the wish to receive assistance with a particular concern.<sup>1</sup> Studies which used quality of life and satisfaction assessments only were excluded from the review.

It is suggested that despite some content overlap, tools assessing the caregiver experience also fall into three main categories: caregiver quality of life; caregiver burden; and caregiver needs.<sup>67</sup> While tools assessing caregiver burden may provide insight into the impact of the care-giving role on the global wellbeing of the caregiver, they do not specifically outline whether the identified issues are important to the person or whether the issues have been satisfied.<sup>67</sup> Hence, studies with instruments assessing caregiver burden, satisfaction or quality of life were excluded.

Health professionals play an integral role in facilitating equitable and appropriate access to care.<sup>92-94</sup> Similar to the experiences of informal caregivers and family members, caring for people with cancer can have a debilitating effect on the health professionals' own wellbeing.<sup>95-98</sup> Moreover, health professionals can experience unmet need in terms of their knowledge and education and subsequently their ability to provide the necessary levels of care required by people with more complex needs.<sup>17, 82, 83, 99</sup> Despite this, needs assessment tools developed specifically for health professionals providing cancer care were difficult to locate. Tools available were focused primarily on the impact of caring for people with cancer in terms of burnout<sup>100-102</sup> and stress that may be experienced.

One hundred and twenty-six articles remained that were related to the assessment of the needs of patients with cancer, their caregivers or health professionals. Further searching of these articles for needs assessment and screening tools resulted in the identification of 33 tools. On the basis of the inclusion criteria, both patient and caregiver tools that assessed only one domain of need,<sup>103-111</sup> tools that were developed for only one type of cancer<sup>60, 112</sup> and tools developed as outcome or audit measures for palliative care services were excluded.<sup>113-115</sup> Caregiver and family tools were also

excluded if they were developed for parents of children with cancer<sup>116</sup> or were developed for a specific type of caregiver such as a husband.<sup>117</sup> Table 3.2 presents the item coverage for each of the domains of need identified as important by both PCA and WHO<sup>118</sup> for the 14 remaining patient needs assessment tools. Table 3.3 reports on their psychometric properties. Table 3.4 presents the item coverage for each of the domains of need for the three remaining caregiver and family needs assessment tools. Table 3.5 reports their psychometric properties.

### ***Patient needs assessment tools***

#### ***Populations***

The Psychosocial Needs Inventory (PNI),<sup>119, 120</sup> the Problems Checklist,<sup>121, 122</sup> the Initial Health Assessment (IHA),<sup>123</sup> the Supportive Care Needs Survey (SCNS),<sup>62</sup> the Cancer Rehabilitation Evaluation System (CARES),<sup>124</sup> the Cancer Rehabilitation Evaluation System (CARES-SF)<sup>125</sup> and the Patient Needs Assessment Tool (PNAT)<sup>126</sup> were developed for use with generic cancer patients. Other tools, such as the Sheffield Profile for Assessment and Referral to Care (SPARC),<sup>72</sup> the Problems and Needs in Palliative Care (PNPC),<sup>127</sup> the Needs Assessment for Advanced Cancer Patients (NA-ACP),<sup>128</sup> and the Needs Near the End-of-life Scale (NEST)<sup>129</sup> are used to assess patients in the later stages of their disease. The Concerns checklist has been used for the assessment of concerns of patients in the early stages of disease, as well as for those, such as palliative care patients, in the later stages of disease.<sup>130, 131</sup> While the Ongoing Needs Identification Tool (ONI)<sup>132</sup> has been used by domiciliary services as a client intake form for palliative care, it was essentially developed to screen the elderly and younger people with disabilities, as well as their caregivers, to assess the need for community and home care.<sup>133</sup>

The use of other tools was restricted to particular clinical settings. For example, the Needs Evaluation Questionnaire (NEQ)<sup>64</sup> was developed specifically for use in hospital settings, while the ONI was developed for use in primary care programs and settings, but can also be used in community services, by discharge planners and GPs.<sup>133</sup> The Cancer Rehabilitation Evaluation System Short Form (CARES-SF) was developed from the original CARES for use in clinical trials.<sup>125</sup>

### *Purpose*

Needs assessment tools have been developed to assess the outcomes of care, to monitor the care being provided, and to assess patients' current needs.<sup>113</sup> The PNI, PNPC, NA-ACP, NEQ, NEST, CARES, Concerns checklist, Problems checklist, SCNS, and PNAT were all designed for the purpose of assessing the needs or concerns of patients with cancer. Moreover, the SCNS, the CARES and the PNPC identified the need or problem as well as patient's preference for health professional attention to the identified issue. Other tools such as the SPARC and the ONI were developed as screening tools to prompt further assessment and referral to other services. Similarly, the CARES has been used as a screening tool prior to a personal interview.

### *Content*

Needs assessment tools may vary in terms of the domains of need covered.<sup>65</sup> In fact, Wen (2004) has argued for a standard set of domains to be introduced to provide consistency in needs assessment tools.<sup>65</sup> The World Health Organization and Palliative Care Australia identified a number of areas of need or domains that are commonly identified as important to palliative care,<sup>118</sup> and these domains were chosen for inclusion in the *Guidelines*. While some of the tools reviewed were found to assess a number of these domains, others did not provide a comprehensive coverage of all domains identified. Table 3.2 provides a summary of the domains of need covered by each of the patient tools and the number of items in each of these domains.

The most comprehensive tools were the PNPC, which covered all domains, followed by the PNI and SPARC. In fact, the PNI was designed so that both patients and caregivers could complete the tool. Of the nominated domains, the spiritual, information, sexuality and caregiver/family domains were the least represented by the tools reviewed. The importance of these domains to this population has been well-documented in the literature;<sup>77, 79, 134-141</sup> consequently, their absence is problematic. Some of the tools did have items about the caregiver and family but only in relation to the needs of the patient. For example, the NEQ had two items, "I need to be more reassured by my relatives" and "I need to feel more useful in my family." Other tools included items asking about needing support from family members, dealing with worries about family members' concerns, and problems in relationships with partners or children. All tools except the SPARC had items that fell into additional domains not

listed in Table 3.2, covering areas such as health professional relationships, quality of care and access to care.

### *Administration*

Mode of administration varied for the tools, and included:

- Patient- or self-administered: PNI, NA-ACP, PNPC, Problems checklist and SCNS
- Health professional administered: SPARC, IHA, ONI and PNAT
- Patient or health professional administered: NEQ, NEST, CARES, CARES-SF and Concerns checklist.

### *Content validity*

A range of strategies were used to establish items coverage, including:

- literature reviews: SPARC, PNI, PNPC, NA-ACP, NEST, CARES, Concerns checklist, IHA, Problems checklist, IHA, ONI, SCNS, PNAT
- clinical experience: SPARC, PNI, NA-ACP, NEST, CARES, Problems checklist, SCNS and PNAT
- focus groups or interviews with patients and/or families: SPARC, PNI, PNPC, NA-ACP, CARES, NEQ, NEST
- focus groups or interviews with health professionals: SPARC, NEST, PNPC and IHA
- pilot testing: SPARC, PNPC, NA-ACP, NEQ, NEST, Concerns checklist, IHA and SCNS
- Items derived from other scales: the PNPC, CARES-SF, NEST, ONI and the SCNS.

The most common strategy for determining items was literature, followed by pilot testing of tools. The PNPC and SPARC were the most comprehensive in their approach to content validity, making use of multiple strategies to determine items. Others, such as the Problems checklist, the ONI and the PNAT were developed without the input of patients, thus possibly indicating that not all domains deemed important by patients are represented.<sup>71</sup>

### *Construct validity*

A range of strategies were used to establish adequate construct validity including:

- Correlation with other well-established measures: PNAT and PNPC
- Factor analysis: NA-ACP, NEST, SCNS, CARES, Problems checklist, NEQ, Concerns checklist.

Satisfactory construct validity was shown for the majority of tools. While no construct validity information could be found for the IHA, PNI, ONI or SPARC, the authors of the SPARC reported their intentions to conduct future validation research.

### *Internal consistency*

Internal consistency was assessed using:

- Cronbach's alpha coefficient: PNPC, CARES, CARES-SF, NEST, NEQ, PNI, SCNS, NA-ACP, Concerns checklist and the Problems checklist
- Intra-class coefficient: PNAT.

Most of the tools measuring internal consistency used Cronbach's alpha. Acceptable reliability for Cronbach's alpha is a value of 0.7 or higher. The PNI had acceptable reliability for six out of seven domains, as did the NA-ACP. Similarly, the CARES-SF showed adequate reliability for all domains except the medical domain. The PNPC, CARES, Concerns checklist, Problems checklist, NEQ, NEST and SCNS also showed acceptable reliability. The reliability of the IHA, ONI and SPARC was not reported.

### *Inter-rater reliability*

Only the PNAT assessed inter-rater reliability, by assessing the agreement between expert raters on each of the subscales. The PNAT showed good reliability.

### *Test-retest reliability*

The NA-ACP measured test-retest reliability with a sub-sample of patients. The intra-class coefficient was acceptable for all domains, with 78% of items having moderate or higher agreement using kappa. Similarly, the NEQ had acceptable agreement using kappa. The CARES showed adequate test-retest reliability in a sample of 71 patients, while the CARES-SF showed acceptable reliability for 120 patients over a 10-day period.



### *Acceptability and feasibility*

Completion time was assessed for a number of tools. While the NA-ACP took an average of 76 minutes to complete, 93% of patients did not think this was too long. Twenty-six percent of users took less than 20 minutes to use the ONI form, while 40% took more than 40 minutes.<sup>132</sup> Overall, the time taken to complete the ONI ranged from 5 minutes to as long as 90 minutes.<sup>132</sup> The completion time for the PNAT was between 20 and 30 minutes, while for the SCNS it was 20 minutes. The CARES completion time ranged from 10 to 45 minutes, with an average of 20 minutes. The CARES-SF had an average of 11 minutes' completion time. Participants reported the Problems checklist as being "quick and easy".

Authors of the NA-ACP used acceptability questions, with 86% of participants reporting that the tool was acceptable.<sup>128</sup> Similarly, the NEQ was reported by participants as having good acceptability.<sup>64</sup> In an evaluation study of the use of the ONI in Queensland, the format of the ONI was found by some users to be problematic to transfer between health professionals and services.<sup>132</sup>

Other tools used completion rate and reading ease to assess feasibility. Completion rate for the IHA was 78%, while the PNI had a response rate of 40%. The NEQ had good completion rate with less than 3% of values missing. The Problems checklist had some items that had high levels of missing data. Approximately 82% of patients reported difficulty with at least one item in the CARES-SF, and 16% to 25% of the screening questions were missing. Only two items were removed from the PNPC due to their low response frequencies. The SCNS was developed for a fifth grade reading level, while the NA-ACP had a Flesch's reading ease of 76.9.

### *Responsiveness*

While the authors of the PNPC discussed the needs for further validation in terms of responsiveness, only the CARES reported on this criterion. The CARES showed statistically significant changes over time between 1 and 7 months on all scales, and between 7 and 13 months for the physical scale in a sample of breast cancer patients. The CARES-SF showed statistically significant changes over time (1, 7 and 13 months) and correlated with Functional Living Index – Cancer (FLIC)<sup>142</sup> in the breast cancer sample.

Table 3.2: Coverage of domains of need in the Palliative Care Needs Assessment Guidelines by available patient needs assessment tools

Instrument	Need Domains (number of items)									
	Physical and daily living	Psychological	Social/Cultural	Spiritual/Existential	Information	Financial/Legal	Sexuality	Caregiver/Family	Bereavement	Other
Problems and Needs in Palliative Care (PNPC) <sup>127</sup> (138 items)	✓ (31)	✓ (23)	✓ (10)	✓ (5)	✓ (9)	✓ (5)	✓ (1)	✓ (6)	N/A	✓ (48) (Quality of care issues; GP and specialist issues)
Psychosocial Needs Inventory (PNI) <sup>119</sup> (48 items)	✓ (6)	✓ (12)	✓ (7)	✓ (5)	✓ (7)	✓ (2)	✓ (2)	Caregiver version with same questions	N/A	✓ (7) (Relationship with clinician; access to care)
Sheffield Profile for Assessment and Referral to Care (SPARC) <sup>72</sup> (45 items)	✓ (26)	✓ (8)	✓ (4)	✓ (2)	✓ (3)	✓ (1)	✓ (1)		N/A	
Needs Assessment of Advanced Cancer Patients (NA-ACP) <sup>143</sup> (132 items)	✓ (41)	✓ (31)	✓ (10)	✓ (9)	✓ (12)	✓ (9)		✓ (5)	N/A	✓ (15) (Relationship with health professional; quality of care)

Instrument	Need Domains (number of items)									
	Physical and daily living	Psychological	Social/Cultural	Spiritual/Existential	Information	Financial/Legal	Sexuality	Caregiver/Family	Bereavement	Other
Cancer Rehabilitation Evaluation System (CARES) <sup>124</sup> (139 items)	✓ (44)	✓ (26)	✓ (19)		✓ (3)	✓ (9)	✓ (8)	✓ (21)	N/A	✓ (9) (Practical; relationship with health professional)
Cancer Rehabilitation Evaluation System Short Form (CARES-SF) <sup>125</sup> (59 items)	✓ (22)	✓ (10)	✓ (6)		✓ (3)	✓ (6)	✓ (4)	✓ (5)	N/A	✓ (3) (Practical; relationship with health professional)
Concerns checklist <sup>130</sup> (14 items)	✓ (5)	✓ (2)	✓ (2)	✓ (1)		✓ (1)	✓ (1)	✓ (1)	N/A	✓ (1) Other issues
Problems checklist <sup>121, 122</sup> (16 items)	✓ (4)	✓ (2)	✓ (2)	✓ (1)		✓ (2)	✓ (1)	✓ (3)	N/A	✓ (1) (Relationship with health professional)
Needs Evaluation Questionnaire (NEQ) <sup>64</sup> (23 items)	✓ (2)	✓ (6)	✓ (1)	✓ (1)	✓ (6)	✓ (2)			N/A	✓ (5) (Improved services; attention from health professional)

Instrument	Need Domains (number of items)									
	Physical and daily living	Psychological	Social/Cultural	Spiritual/Existential	Information	Financial/Legal	Sexuality	Caregiver/Family	Bereavement	Other
Needs near the end-of-life scale (NEST) <sup>129</sup> (13 items)	✓ (2)	✓ (1)	✓ (2)	✓ (3)	✓ (1)	✓ (1)			N/A	✓ (3) (Access to care; relationship with health professional)
Supportive Care Needs Survey <sup>62</sup> (59 items)	✓ (8)	✓ (22)	✓ (2)		✓ (15)	✓ (1)	✓ (3)		N/A	✓ (8) (Patient care and support)
Initial Health Assessment (IHA) <sup>123</sup> (22 items)	✓ (5)	✓ (5)	✓ (2)		✓ (1)	✓ (1)			N/A	✓ Other special needs (1); personal resources (5)
Ongoing Needs Instrument (ONI) <sup>132</sup>	✓	✓	✓			✓		✓	N/A	✓ (Caregiver assessment; health behaviours)
Patient Needs Assessment Tool (PNAT) <sup>126</sup> (16 items)	✓ (6)	✓ (5)	✓ (3)			✓ (1)			N/A	✓ (1) (Access to care)

Table 3.3: Psychometric properties of needs assessment tools for patients

Instrument	Purpose and population	Question format and administration	Validity		Reliability		Responsive	Feasibility
			Content	Construct	Internal consistency	Test-retest		
Problems and Needs in Palliative Care (PNPC) <sup>127</sup>	Comprehensive checklist for problems experienced in palliative care and need for care	Self-completed Questionnaire  2 questions for each item: - Is this a problem? (Yes/No) - Do you want attention for this item? (Yes/More, As much as now, No)	Literature Interviews with patients, caregivers and health professionals Pilot-tested Analysis of existing tool item content	Physical symptoms correlated with EORTC QLQ C30 <sup>144</sup> physical scales and COOP-WONCA <sup>145</sup> physical complaints Daily living correlated with EORTC physical functioning and COOP daily living activities. Psychological issues, role activities and financial issues correlated with corresponding EORTC and COOP domains. Social issues correlated with EORTC Social domain and COOP Social support.	Cronbach's alpha ranged from 0.67 to 0.89 for Problem aspect and from 0.73 to 0.92 for Need for care aspect			Appropriate: item response frequency (2 items removed)  Comprehensive: patient comment

Instrument	Purpose and population	Question format and administration	Validity		Reliability		Responsive	Feasibility
			Content	Construct	Internal consistency	Test-retest		
Psychosocial Needs Inventory (PNI) <sup>119</sup>	To assess the psychosocial needs of patients and caregivers	Self-completed Questionnaire  Two 5-point scales: Importance of the need; Level of satisfaction of the need	Focus groups and interviews with patients and caregivers Literature review Clinical opinion		Cronbach's alpha > 0.7 for 6 of 7 domains			Response rate: 40%
Sheffield Profile for Assessment and Referral to Care (SPARC) <sup>72</sup>	To screen cancer patients for referral or full assessment by specialist palliative care services	Self-completed  4-point scale (from 0 = Not at all to 3 = Very much)	Literature review Interviews Expert panel Pilot test					
Needs Assessment of Advanced Cancer Patients (NA-ACP) <sup>143</sup>	Assess the needs of people with advanced cancer	Self-completed Questionnaire  5-point Likert scale (No need/Not applicable, No need/Satisfied, Low need, Moderate need, High need)	Literature review Clinical opinion Focus groups with patients Pilot test	Principal component analysis	Cronbach's alpha 0.79-0.98	Sub-sample of patients completed twice over period of week Intra class coefficient 0.67-0.93 78% of items had moderate or better agreement using kappa		Flesh's reading ease: 76.9  Time taken: 76 minutes

Instrument	Purpose and population	Question format and administration	Validity		Reliability		Responsive	Feasibility
			Content	Construct	Internal consistency	Test-retest		
Cancer Rehabilitation Evaluation System <sup>124 125</sup> (CARES)	To identify the physical and psychosocial issues affecting cancer patients	Self-administered Health professional interview follow-up  5-point Likert scale (0 = Does not apply, to 4 = Applies very much)  Also asks if help with the issue is wanted (Yes/No) in clinical version	Literature Interviews with patients and caregivers Clinical opinion	Factor analysis Correlated with Symptom Checklist-90, Dyadic Adjustment Scale, Karnofsky Performance Scale	Cronbach's alpha: Physical: 0.92 Psychological: 0.94 Medical: 0.87 Sexuality: 0.88 Marital: 0.92	Correlations (n=71) ranged from r=0.84 to r=0.95	Statistically significant changes over time between 1 and 7 months on all scales, and between 7 and 13 months for physical scale only in breast cancer patients	Time taken: 20 minutes (range 10-45 minutes)  Easy to use
Cancer Rehabilitation Evaluation System Short Form <sup>125</sup> (CARES-SF)	To identify the physical and psychosocial issues affecting cancer patients	Self-administered Health professional interview  5-point Likert scale (0 = Does not apply to 4 = Applies very much)  Also asks if help with the issue is wanted (Yes/No) in clinical version	From original CARES by experts	Correlated with CARES, FLIC, Dyadic Adjustment Scale, Karnofsky Performance Scale	Cronbach's alpha: Physical: 0.83 Psychological: 0.85 Medical: 0.67 Sexuality: 0.73 Marital: 0.72	Time 1 and Time 2 were 10 days apart  Correlations with CARES (n=120) ranged from r=0.69 to r=0.92.  81-86% agreement	Statistically significant changes over time (1, 7 and 13 months) and correlated with FLIC in breast cancer sample	Time taken: 11 minutes  82% reported difficulty with at least one item  16-25% of screening question responses missing

Instrument	Purpose and population	Question format and administration	Validity		Reliability		Responsive	Feasibility
			Content	Construct	Internal consistency	Test-retest		
Concerns checklist <sup>120, 130, 146</sup>	To identify the main concerns of people with cancer over the previous weeks  Used for people in early stage and people accessing palliative care	Self-completed Health professional completed (interview format)  5-point Likert scale (1 = Not worried to 5 = Extremely worried)	Literature review Pilot test Patient review	Factor analysis	Cronbach's alpha			
Problems checklist <sup>121, 122</sup>	To assess the prevalence and severity of psychosocial problems experienced by cancer patients	Self-completed Questionnaire  Five response options (0 = No difficulty to 3 = Severe difficulty; a category, "Does not apply to me" was added)	Literature Clinical opinion	Factor analysis	Cronbach's alpha ranged from 0.70 to 0.82			Easy to administer  Completion rate: high level of missing data for some items



Instrument	Purpose and population	Question format and administration	Validity		Reliability		Responsive	Feasibility
			Content	Construct	Internal consistency	Test-retest		
Needs Evaluation Questionnaire (NEQ) <sup>64</sup>	To identify the needs of people with cancer who are hospitalised	Self-completed Questionnaire  Yes/No response scale	Semi-structured interviews with patients Pilot test	Confirmatory factor analysis (factors confirmed only in part)	Cronbach's alpha values ranged from 0.69 to 0.81	Cohen's kappa ranged from moderate (4 items) to almost perfect (19 items). 2 low-scoring items were removed from final version		Time taken: median of 5 minutes  Completion rate: low missing values for questions (< 3%)
Needs near the end-of-life scale (NEST) <sup>129, 147</sup>	To identify the subjective experiences and overall care of people at the end of life	Self-completed or completed by health professional Interview format  Scale from 0 = None to 10 = A great deal	Literature review Focus groups and interviews with patients, caregivers and health professionals Pilot test Clinical opinion Items from other scales	Exploratory factor analysis	Cronbach's alpha baseline values ranged from 0.63 to 0.85; follow-up values ranged from 0.64 to 0.89			

Instrument	Purpose and population	Question format and administration	Validity		Reliability		Responsive	Feasibility
			Content	Construct	Internal consistency	Test-retest		
Initial Health Assessment (IHA) <sup>123</sup>	Identify the patient's medical history, supportive care needs and personal resources available to meet needs	Checklist Completed by health professional	Literature review Pilot test Patient survey Focus groups with health professionals					Completion rate: 78%
Ongoing Needs Instrument (ONI) <sup>132</sup>	A screening tool to prompt timely and appropriate service delivery, referral and/or further assessment based on identified needs	Completed by health professional  Core ONI (all answer) and Optional ONI (depending on priority rating obtained)	Literature review					Time taken: 26% took less than 20 minutes; 40% took more than 40 minutes
Supportive Care Needs Survey <sup>62</sup>	To assess the generic needs of cancer patients over the previous month	Self-completed Questionnaire  5-point Likert scale (No need/Not applicable, No need/Satisfied, Low need, Moderate need, High need)	Based on CPNQ Interviews Pilot study Clinical opinion	Factor analysis	Cronbach's alpha ranged from 0.87 to 0.97			Time taken: 20 minutes  Reading ease: 5 <sup>th</sup> grade level

Instrument	Purpose and population	Question format and administration	Validity		Reliability		Responsive	Feasibility
			Content	Construct	Internal consistency	Test-retest		
Patient Needs Assessment Tool (PNAT) <sup>126</sup>	To screen people with cancer for potential physical and psychosocial concerns	Completed by health professional Structured interview	Literature review Clinical opinion	Physical domain correlated with KPSS Psychological domain correlated with Global Adjustment to Illness Scale (GAIS) <sup>148</sup> , Memorial Pain Assessment Scale <sup>149</sup> , Beck Depression Inventory <sup>150</sup> and Brief Symptom Inventory <sup>151</sup> Social domain correlated with Interpersonal Support Evaluation List <sup>152</sup>	Intra-class coefficients ranged from 0.85 to 0.94	Concordance coefficient ranged from 0.73 to 0.87  Spearman ranged from 0.59 to 0.98 (average 0.85)		Time taken: 20-30 minutes  Low training level

### ***Caregivers' needs assessment tools***

It is important to make a distinction between caregiver and family needs assessment tools within the context of this review. Caregiver tools are aimed at the person who provides care to the person with cancer. While this may in fact be a family member, it may also be a non-family member. Moreover, while family members will certainly be affected in some way as a result of a cancer diagnosis, they may experience different unmet needs from the caregiver. For example, the caregiver providing day-to-day care may experience considerable physical and emotional hardship as a result of tasks directly related to the care-giving role. There are a limited number of tools that assess caregiver or family needs, and both have been included in this review.

#### ***Populations***

While there are a number of other tools that have been developed for caregivers of different patient populations, relatively few have been developed specifically for caregivers of people with cancer or advanced cancer. The Problems and Needs in Palliative Care questionnaire - caregiver form (PNPC-c)<sup>153</sup> is one tool that has been developed for caregivers of people with advanced cancer. The Home Caregiver Needs Survey (HCNS)<sup>154</sup> was initially tested in caregivers of people with cancer but has been used in a variety of caregiver populations. In contrast, the Family Inventory of Needs (FIN)<sup>155</sup> was developed for use with any family member, whether a caregiver or not.

#### ***Purpose***

Few tools have been developed to assess the needs of the caregiver.<sup>67</sup> A review of caregiver assessment tools identified a number of tools assessing caregiver burden and quality of life but these were excluded from this review.<sup>67</sup> Of the tools that were included, the PNPC-c has been advocated as a comprehensive and systematic method for assessing caregiver needs.<sup>153</sup> The HCNS and the FIN, on the other hand, were designed to assess whether identified needs are considered important and whether assistance is required to meet these needs.

#### ***Content***

Similar to patient tools, caregiver tools lack comprehensiveness with regard to the issues prevalent in the advanced cancer population. The HCNS and PNPC-c covered the majority of the domains, with the exception of sexuality and bereavement needs. In

fact, bereavement has been an area of the care-giving experience that has been relatively ignored in the development of caregiver and family needs assessment tools.<sup>67</sup> The FIN largely addressed the information needs of families, but also has additional items in other domains. Table 3.4 provides a summary of the domains covered by these tools and the number of items in each domain.

#### *Administration*

All caregiver tools identified in this review are self-administered. Like cancer patients, caregivers may also find that longer instruments are burdensome, depending on their own health and wellbeing and extent of care they are required to provide. For example, completing the HCNS may be problematic for caregivers who spend a greater amount of time in the care-giving role, as they may have less time to complete the tool.

#### *Content validity*

The HCNS used needs statements taken from caregivers in previous studies, as well as clinical opinion. The PNPC-c developed items on the basis of clinical opinion, while items in the FIN were developed from interviews with patients and caregivers. Overall, methods for determining content validity were less extensive than for patient needs assessment tools.

#### *Construct validity*

Construct validity was determined for the HCNS by correlating with the Karnofsky Performance Status Scale (KPSS)<sup>156</sup>, and for the FIN by correlating with the FAMCARE<sup>90</sup>. The validity of the PNPC-c was unavailable as the data were unpublished.

#### *Internal consistency*

Cronbach's alpha was used to determine the internal consistency of the FIN and the HCNS. However, information about internal consistency was again unavailable for the PNPC-c. Both the HCNS and FIN indicated good internal consistency with values greater than 0.70.

#### *Responsiveness*

Changes in the needs of the sample were identified over a period of 4 months when using the HCNS.<sup>154</sup> However, information about the responsiveness of the FIN and PNPC-c was unavailable.

**Table 3.4:** Coverage of domains of need in the Palliative Care Needs Assessment Guidelines by available caregiver needs assessment tools

Instrument	Need Domains (number of items)									
	Physical and daily living	Psychological	Social/Cultural	Spiritual/Existential	Information	Financial/Legal	Sexuality	Caregiver/Family	Bereavement	Other
Home Caregiver Needs Survey (HCNS) <sup>154</sup> (90 items)	✓ (12)	✓ (30)	✓ (6)	✓ (6)	✓ (14)	✓ ( )		✓ ( )		✓ (16) (Relationship with health professional)
Family Needs Inventory (FIN) <sup>155</sup> (20 items)	✓ (1)	✓ (3)		✓ (1)	✓ (15)					✓ (1) (Help with patient's care)
Problems and Needs in Palliative Care questionnaire - caregiver form (PNPC-c) <sup>153</sup> (67 items)	✓ (8)	✓ (7)	✓ (4)	✓ (4)	✓ (7)	✓ (5)		✓ (5)		✓ (27) (Autonomy; care delivery)

Table 3.5: Psychometric properties of needs assessment tools for caregivers

Instrument	Purpose and population	Question format and administration	Validity		Reliability		Responsive	Feasibility
			Content	Construct	Internal consistency	Test-retest		
Home Caregiver Needs Survey (HCNS) <sup>154</sup>	To assess the importance and satisfaction of caregiver psychosocial needs	Self-completed Questionnaire  Two 7-point scales: Importance of the need; Level of satisfaction of the need	Needs statements from previous studies Clinical opinion	Correlated with patient activity measured by the PSS  Factor analysis	Overall Cronbach's alpha was 0.93 Dimensions ranged from 0.85 to 0.97			Time taken: 30 minutes  Reading level: 5 <sup>th</sup> grade
Family Needs Inventory (FIN) <sup>155</sup>	To measure needs of family and extent to which needs are met	Family completes 10-point scale for importance (Not at all important to Very important)  Dichotomous fulfilment of identified needs (Met/Unmet)	Expert panel	FAMCARE scale  Predictive modelling	Cronbach's alpha 0.83			
Problems and Needs in Palliative Care questionnaire – caregiver form (PNPC-c) <sup>153</sup>	Checklist to assess comprehensive problems experienced by caregivers and need for care	Self-administered Options for whether problem exists (Yes, Somewhat, No)  Options for whether care is needed (Yes, More, As much as now, No)	Interviews with patients and caregivers	Checklist to assess comprehensive problems experienced by caregivers and need for care				

### ***Health professional needs assessment tools***

Assessment tools such as the Maslach Burnout Inventory<sup>100</sup> have been used to assess the levels of burnout or stress experienced by health professionals providing cancer care, as these can impact on whether health professionals need assistance in managing care. However, a need for assistance may also result from issues such as a lack of practical or financial resources or a lack of knowledge or education. No tools identified in this review were able to encompass all of these potential issues.

### **3.7.4 Discussion**

There has been an increasing trend toward developing and implementing guidelines to bring about behaviour change and subsequently improve the quality of care provided by health care professionals.<sup>6, 7, 9-11</sup> However, the success of these resources depends on the levels of compliance of health professionals at which they are aimed. Numerous individual patient<sup>29, 31</sup> and health professional<sup>6, 11, 29, 31</sup> barriers may prevent the uptake of guidelines, as can organisational barriers.<sup>11, 21, 29, 30</sup> Identifying ways to improve the uptake of guidelines has thus become a primary concern, and research has advocated a number of different approaches, one of which is the use of structured checklists or tools.<sup>45</sup> While the Cochrane review reporting on studies examining the dissemination of referral guidelines with structured referral checklists did not refer specifically to needs assessment tools, these checklists served a similar purpose to that of the proposed needs assessment tool. These health professional checklists were to be completed at the time of referral prompting the physician about important elements of pre-referral investigation and management. Similarly, the NAT: PD-C is a health professional completed tool that aims to serve as an aide memoire prompting the assessment and management of physical and psychosocial aspects of the needs of the patient and caregiver.

A review identified 17 needs assessment and screening tools in the literature for assessing the needs of patients with cancer and their caregivers across the illness trajectory. Needs assessment tools varied in terms of the populations for which they were developed and subsequently utilised. Many tools have been developed for use with patients with cancer across the illness trajectory,<sup>72</sup> while other tools are used to assess patients in the later stages of their diseases. Furthermore, some tools were limited in terms of the clinical settings to which they could be applied.<sup>72</sup> Assessing the



patient's, caregiver's or family's current needs was the main purpose of many of the tools.<sup>113</sup> Few tools were developed for screening purposes.

The importance of identifying the needs of caregivers and families of people with cancer has also resulted in a number of tools being developed specifically for this population.<sup>67</sup> Two of the 17 tools identified in the review assessed the needs of the caregiver, while another assessed the needs of family members, irrespective of whether they were caregivers of patients with cancer. Assessing the needs of health professionals who provide cancer care has been investigated in terms of their knowledge and education requirements and their levels of burnout or stress. However, these tools did not include all potential areas of need in one measure.

Providing a comprehensive assessment of the areas of need for patients with cancer and their families is an important consideration for tool developers.<sup>71</sup> For some of the tools, coverage of the domains identified as important by PCA and WHO was satisfactory. However, as suggested in a similar review, other tools did not provide a comprehensive coverage of all domains.<sup>71</sup> Like patient tools, caregiver tools also lack comprehensiveness with regard to the issues prevalent in this population.

Most tools that were reviewed were developed for self-administering by patients or caregivers. Advantages of the self-administered questionnaires include increased accuracy, reduced financial costs and reduced time required for interviews.<sup>65</sup> Because of their high-volume workloads, health professionals often report that time is a factor affecting the accurate and timely identification of needs.<sup>70</sup> For example, services which have clients with stable, low needs and are run by volunteers may encounter capacity issues when attempting to undertake the ONI at initial intake and review.<sup>132</sup> However, in populations with advanced disease, patients may have difficulty completing tools themselves due to the complexity and gravity of their symptoms.<sup>113</sup> Moreover, they may misinterpret items in even the simple tools.<sup>157</sup> Even when tools are self-administered by the patient or caregiver, they may be problematic for health professionals when they are required to interpret the scores.<sup>122</sup>

An alternative to the self-administered questionnaire is the tool completed by health professionals.<sup>126</sup> Similarly, health professionals can administer tools to screen patients for the need for further assessment. It has been argued that using caregivers or health

professionals to assess needs may affect the accuracy of data about the severity and complexity of needs.<sup>113</sup> The ability of any health professional to use the tools must be a consideration for developers, as some tools cannot be used by health professionals from a wide range of disciplines.<sup>126</sup> For example, while it is advocated that clinicians and non-clinicians can use the ONI, it is recommended that training be undertaken.<sup>132</sup> There is a lack of consensus as to which mode of administration is most suitable in different populations and settings.<sup>65</sup>

While some tools were excluded due to their lack of coverage of all necessary domains, other available tools did show excellent coverage. However, the psychometric properties of these tools were insufficient. For example, the SPARC and PNPC lacked any information regarding their validity, feasibility or responsiveness. Similarly, the PNI lacked validation and test-retest reliability information, as well as any information on the time taken to complete the tool. Other tools which covered the majority of domains had similar psychometric shortcomings.

Determining whether tools can adequately assess changes in the needs of people with cancer and their caregivers is imperative for systematically meeting the needs of these populations.<sup>65</sup> The lack of evidence to support the responsiveness of tools already developed and in use within clinical settings was reported by a number of authors, and the findings of this review are in agreement.<sup>65, 72</sup> There is a definite need for further validation in terms of responsiveness.<sup>72</sup> In addition, the acceptability and feasibility of the tools were often only measured by the time taken to complete the tool. Tools of greater length, such as the NA-ACP and PNPC, may be especially problematic for people with advanced cancer who are experiencing more severe and complex issues. Conversely, the time taken to complete health professional administered tools must be taken into account, as many health professionals have limited time during consultations.<sup>71 72</sup>

The few tools that have been developed to assess the needs of the caregiver were reviewed and found to be inadequate due to their length and methods for testing psychometric properties.<sup>67</sup> While needs assessment tools have the potential to identify people who have a need for assistance with particular issues and prompt referral to services for further assessment, there is no caregiver tool currently available that can perform this role.<sup>67</sup> As Deekin (2003) argues, there is a "need for a screening tool that

meets the dual tests of psychometric robustness and ease of administration" to assess the needs of caregivers.<sup>67</sup>

It has been suggested that there is a need for further work in testing the tools currently available in this area.<sup>72</sup> While continued testing of available tools was considered as an alternative to developing a new assessment tool, in this study it was decided that a new tool would be more appropriate. For tools that did cover the necessary domains outlined in the *Guidelines* (i.e. the PNI and the PNPC), further testing of psychometric properties such as responsiveness would have been difficult as the envisaged purpose of the tool was to provide a quick and easy measure that could be implemented at multiple time points to identify changes in need readily, and prompt further assessment if required. This would have been difficult to achieve with the PNI and PNPC due to the length and subsequent burden on patients completing the tool multiple times. Similarly, further psychometric work with other tools reviewed would have been difficult as many lacked items in all of the domains deemed important and would have needed additional items included and re-testing of already established psychometric properties.

Most importantly, however, there were no tools that included items assessing patients, their caregivers and the health professionals providing their care. The literature reviewed in the *Guidelines* illustrated that any one of these people could have unmet needs which could, in turn, impact on the needs experienced by the others. Concurrent assessment at multiple time points of patients, caregivers and health professionals is therefore paramount to ensuring that all needs are being met and that the most appropriate course of action with regard to care is being taken.

### **3.7.5 Conclusion**

Patients and caregiver needs assessment tools vary considerably in their coverage and psychometric properties. Tools that are comprehensive in terms of the domains of need assessed are often inadequate in terms of psychometric robustness. In fact, other reviews of needs assessment tools have indicated that the tools that are in existence are poor in terms of their psychometric quality, including their acceptability, clinical useability, validity and reliability.<sup>65, 71, 72</sup> Overall, this review confirmed these findings with limitations in relation to psychometric properties, clinical feasibility and acceptability of both patient and caregiver tools. In terms of health professional needs assessment tools, previous work in this area was limited. There were no identified tools

that assessed health professionals' need for assistance with managing care *per se*; rather, tools focused on the education and information needs and degree of burnout that these people may experience when providing day-to-day cancer care.

The detrimental impact of a cancer diagnosis on the patient and the caregiver has been well-documented in the literature. Caregivers of patients with more severe physical symptoms and with more rapidly advancing diseases have been found to experience more emotional distress.<sup>158-160</sup> Hence, assessing the needs of both people with cancer and their caregivers is imperative to ensure that both are receiving the care they need. Moreover, the ability of the health professional to provide appropriate care can have a significant impact on the outcomes for the patient and caregiver. Prompting health professionals to assess their own abilities in this area should be considered. Assessing caregiver and patient needs simultaneously could provide an important step in ensuring that both parties receive the assistance they need at the time they need it.

While a review of needs assessment tools in cancer care found two whose purpose was to identify patient PC needs and guide PC referral,<sup>72</sup> there were no national or international screening tools that assessed caregivers' and professional carers' needs, in conjunction with patients' needs, to prompt needs-based delivery of palliative care.<sup>161</sup> As a result, it was decided that a new tool would be developed to assist in the accurate and timely identification of patients', caregivers' and health professionals' needs. The development and pilot testing of this new tool, the Palliative Care Needs Assessment Tool (PC-NAT) is described in the next chapter.

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# **CHAPTER 4:**

## **DEVELOPMENT OF THE PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT) FOR USE BY MULTIDISCIPLINARY HEALTH PROFESSIONALS**

## **Development of the Palliative Care Needs Assessment Tool (PC-NAT) for use by multidisciplinary health professionals**

### **Running title: Development of a Palliative Care Needs Assessment Tool (PC-NAT)**

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### **Acknowledgements**

This project was undertaken by The Cancer Council New South Wales' Centre for Health Research & Psycho-oncology (CHeRP), with research funding from the Australian Government Department of Health and Ageing and the Cancer Council NSW, PhD scholarship support from the University of Newcastle and infrastructure support from the Hunter Medical Research Institute. The views expressed are not necessarily those of The Cancer Council. The authors would like to acknowledge the staff of the Pam McLean Cancer Communication Centre, The University of Sydney and Royal North Shore Hospital, Sydney for their assistance with development and filming of the three standardised scenarios viewed by participants.

The study was approved by the University of Newcastle Human Research Ethics Committee, Princess Alexandra Hospital and Health District Services Human Research Ethics Committee, Tasmania Social Sciences Human Research Ethics Committee and the Hunter New England Area Health Service Human Research Ethics Committee.

### **Author's contributions**

AG and DC developed the study concept and aims and sought funding for the project. AW and AG developed the protocol and all of the other authors assisted in further development of the protocol. AW and AG were responsible for drafting the manuscript. AW and AG implemented the protocol and collected the data; and AW, CL and AG were involved in the data analyses. All authors contributed to the final manuscript.

## 4.1 ABSTRACT

**Background.** Needs assessment strategies can facilitate prioritisation of resources.

**Aim.** To develop a needs assessment tool for use with advanced cancer patients and caregivers, to prompt early intervention.

**Methods.** A convenience sample of 103 health professionals viewed three videotaped consultations involving a simulated patient, his/her caregiver and a health professional, completed the Palliative Care Needs Assessment Tool (PC-NAT) and provided feedback on clarity, content and acceptability of the PC-NAT.

**Results.** Face and content validity, acceptability and feasibility of the PC-NAT were confirmed. Kappa scores indicated adequate inter-rater reliability for the majority of domains; the patient spirituality domain and the caregiver physical and family and relationship domains had low reliability.

**Conclusions.** The PC-NAT can be used by health professionals with a range of clinical expertise to identify individuals' needs, thereby enabling early intervention. Further psychometric testing and an evaluation to assess the impact of the systematic use of the PC-NAT on quality of life, unmet needs and service utilisation of patients and caregivers are underway.

**Keywords:**

Cancer

Palliative care

Needs assessment

Patient

Caregiver

*Citation:* Waller A, Girgis A, Currow D, Lecathelinais C. Development and pilot testing of the Palliative Care Needs Assessment Tool (PC-NAT) for use by multi-disciplinary health professionals. *Palliative Medicine* 2008;22(8):956-964.

## 4.2 INTRODUCTION

Australia's cancer incidence is projected to increase by 31% from 2001 to 2011,<sup>1</sup> placing a considerable burden on individuals, communities and the health-care system.<sup>2</sup> Provisions for health services for people with cancer and their families must be made,<sup>2</sup> particularly for the delivery of palliative care (PC), given that one in two people with solid tumours will have their life shortened by their cancer.<sup>3</sup>

The Australian health care system is based on universal access with primarily public funding.<sup>4</sup> Primary care is largely the first point of contact for patients,<sup>5</sup> with general practitioner (GP) referrals required for access to most specialist palliative care services (SPCSs).<sup>6</sup> The needs of advanced cancer patients may not be adequately met by later provision of PC,<sup>7-9</sup> with recommendations for PC to include patients earlier in the disease course.<sup>10</sup> However, negative attitudes and misconceptions regarding PC can often impede the involvement of services,<sup>11-16</sup> as can the practical and financial resources available within the organisation and health system.<sup>14, 16-18</sup> Accordingly, Palliative Care Australia has identified access and referral to PC as a research priority.<sup>19</sup>

It is argued that PC provision should not be on the basis of time, but on the basis of identifiable physical and psychosocial needs of the patient, family and health professionals;<sup>8</sup> and is considered appropriate at any time when needs are not being adequately addressed. Complexity and severity of needs may vary across the illness trajectory<sup>20</sup> and with the level of care giving.<sup>21</sup> Hence, not everybody with a life limiting illness (LLI) will require SPCSs, nor will everybody with unmet needs seek or accept SPCSs.<sup>22</sup> Whilst the benefits of PC for patients and caregivers are well documented,<sup>23, 24</sup> research suggests a level of mismatch between access to SPCSs and level of need. Estimates suggest that whilst 30% of Australians with a LLI would not gain additional benefit from the involvement of SPCSs,<sup>3</sup> 16% of those who might indeed have gained additional benefit did not utilise this care.<sup>3</sup>

Providing needs-based care offers a strategy for allocating finite PC resources to those most in need;<sup>3</sup> and guidelines and referral pathways may identify those most likely to

benefit from PC services.<sup>25</sup> No national or international guidelines or screening tools currently exist to concurrently assess patient, caregiver and professional carer's needs to prompt needs based referrals to PC services.<sup>26</sup> Hence, the *Palliative Care Needs Assessment Guidelines*<sup>27</sup> (hereafter referred to as the *Guidelines*) were developed in 2006, based on published evidence and a national consensus process, to inform needs based PC. These *Guidelines* provide a comprehensive review of the physical and psychosocial issues that may impact upon advanced cancer patients (currently representing approximately 90% of the SPCS caseload in Australia<sup>28</sup>) and their caregivers, families and health professionals. Cancer is one of the most frequently encountered examples of predictable death in clinical practice; and there is considerable empirical evidence regarding beneficial PC interventions.<sup>23, 24, 29-32</sup>

Despite reported benefits, guidelines are not consistently adhered to.<sup>33</sup> Structured checklists and tools can improve compliance with guidelines and appropriateness of referrals to secondary care;<sup>34</sup> and, with appropriate instruction, facilitate communication, increase detection of issues and tailor interventions, leading to a better match between referrals and identified needs.<sup>35, 36</sup> However, available tools are of limited psychometric quality, including acceptability, clinical useability, validity and reliability.<sup>22, 36, 37</sup>

This paper reports on the development and pilot testing of the Palliative Care Needs Assessment Tool (PC-NAT), developed to complement the *Guidelines*.<sup>27</sup> The pilot study objective was to test the PC-NAT for use by different health professionals who have contact with advanced cancer patients, in terms of its clarity, content and face validity, acceptability, and inter-rater reliability.

## **4.3 METHODS**

### **4.3.1 Sample and setting**

A convenience sample of health professionals was selected on the basis of having the most contact with advanced cancer patients and their caregivers and generating a high proportion of referrals to PC services in Australia. Participants were drawn from a Division of General Practice, a Radiation Oncology Department, two Medical Oncology

Departments, a Haematology Department and seven community nursing agencies from three of the eight states and territories in Australia.

### **4.3.2 Materials**

#### ***The PC-NAT***

An extensive literature review of the needs of patients with advanced cancer, caregivers and families as well as health professionals who provide their care was conducted. An Expert Consensus Panel of 66 leaders and key stakeholders in palliative care, consumer representatives and health advocates who were invited to a National Consensus Meeting were asked to comment on the literature review and the draft guidelines which were developed using this review. The panel members were also asked to identify the most important guidelines in each chapter. This process informed the development of a draft PC-NAT which incorporated each of the domains of patient and caregiver need identified in the literature. The National Consensus Meeting attendees were asked to review the draft PC-NAT and amendments were made in response to their advice, prior to pilot testing commencing.

The one-page PC-NAT (Appendix 4.1) includes:

1. Section 1 - three items to fast-track a review by a SPCS: absence of a caregiver; a patient or caregiver request for SPCS referral; and the health professional's need for assistance in managing care.
2. Section 2 – seven items to assess the patient's wellbeing, including physical, changes in functional status, psychological, information, spiritual/existential, health beliefs/cultural/social and financial/legal domains.
3. Section 3 – five items to assess the ability of the caregiver/family to care for the patient, including physical, changes in functional status, psychological, information and family and relationship domains.
4. Section 4 – two items to assess the caregiver's wellbeing, including physical and psychological issues and bereavement grief.
5. Section 5 – one item to assess whether the health professional thought the patient needed assessment by a SPCS.

For Sections 1 and 5, response options were “Yes” or “No”. The items in Sections 2-4 were assessed according to the level of concern ("none", "some", "significant") they were causing. Prompt questions for each item were included on the back page,

providing standard language for health professionals to employ when using the tool; for example “Is the patient having difficulty with toileting, showering, bathing, or food preparation?” for the changes in functional status domain. Given the expected differences in capacity as well as access to relevant health professionals to assist in the provision of required care, the PC-NAT has no specific scoring system. Rather, the unmet needs identified are intended to act as a prompt for the health professional completing it either to address identified concerns directly (either personally or through other members of their team) or to make a referral to another health professional or to a SPCS to assist the patient or family, as warranted by the types and levels of needs identified.

According to Ahmedzai (2004), basic palliative care can be provided by all health professionals within their normal duties; while specialised palliative care is “provided at the expert level by a trained multi-professional team.”<sup>38</sup> The PC-NAT was designed for ongoing use in both generalist and specialist care settings. Rather than simply determining who would benefit from a referral to a SPCS, the PC-NAT assists health professionals in matching the types and levels of need with the most appropriate person or service to address that need. Specifically, generalist providers can use the PC-NAT to determine which needs may be met in their own setting and which needs may be more complex and better managed by qualified specialists. If a patient is referred, specialists can continue to use the PC-NAT to determine when complex needs have been met. Essentially, the PC-NAT is intended to provide a pathway for people to become involved in specialist care should their needs require it, but also allows for those people who no longer require assistance from these services to be followed up for care by their primary health team.

### ***Standardised health professional-patient-caregiver consultations***

Simulated patients have been increasingly used to examine health professionals’ interaction with and assessment of patients and their caregivers in a controlled environment.<sup>39-41</sup> As a new instrument in early stages of development, using simulated patients to test the PC-NAT minimised potential harm and burden to a vulnerable population and allowed for variations in age, cancer type and issues to be presented to participants.

A DVD of three 10-minute consultations was produced by the research team in collaboration with a specialist Cancer Communication Centre. Scenarios included background information about a simulated patient and caregiver and an illness narrative from diagnosis until the presentation of advanced cancer, with consultations including:

- a) An oncologist consulting with a 25 year-old male patient with lymphoma and his mother; with some concerns in the physical, psychological and spiritual domains in Section 2, as well as significant concerns in the family and relationship domain and some concerns in the physical and psychological domains in Section 3.
- b) A GP consulting with a 65 year-old male patient with colon cancer and his wife; with significant concerns in the psychological and financial domains in Section 2 and the information and family and relationship domain in Section 3, as well as some concerns in the physical domain in Section 2.
- c) A nurse consulting with a 34 year-old female patient with breast cancer and her husband; with some concerns in the physical, changes in functional status domains in Section 2 and the family and relationship domain in Section 3 and significant concerns in the financial domain and caregiver wellbeing domain in Section 4.

Patient and caregiver roles were played by professional actors with extensive experience and training in medical role plays and the three consultations were filmed with a practising nurse, GP and oncologist.

### **4.3.3 Procedure**

Participants were sent a Summary of the *Guidelines* (Appendix 3.1) and the piloted version of the Palliative Care Needs Assessment Tool (PC-NAT) (Appendix 4.1) to read before attending 1.5-hour group sessions, hosted at their respective institutions. Participants were also sent a pilot study participant Information Letter (Appendix 4.2), a pilot study participant Consent Form (Appendix 4.3) and a pilot study participant demographic survey (Appendix 4.4). At the group sessions, following a brief overview of the project, for each of the consultations, participants read the summary of the patient's personal history and disease progression (Appendices 4.5, 4.6 and 4.7), watched the 10-minute consultation on DVD and completed the PC-NAT, and then provided qualitative feedback following the completion of the three PC-NATs. Each discussion group was video-taped and discussions transcribed *verbatim* by the

researcher. General practitioners were awarded a total of 4 Continuing Medical Education points from The Royal Australian College of General Practitioners.

#### **4.3.4 Analysis**

Participant data was grouped according to the specialty groups of general practitioners, medical specialists, nurses and allied health professionals; each completed a total of three PC-NATs. The data were analysed using SAS Version 8 (SAS Institute Inc., NC, USA). Due to the nature of the sample, where there were multiple raters for only three consultations, it was not possible to produce an accurate measure of agreement using a conventional statistical method (such as Fleiss' kappa statistic). Instead, within each specialty group, pairs of every possible unique combination of raters were created. For example, each GP was paired with every other GP. For each consultation, each pair was assigned a score of 1 if they agreed and a score of 0 if they did not agree on the rating. The total proportion agreement was also calculated. Initially, ratings were dichotomised into “none” versus “some/significant”; to determine whether participants agreed on the presence or absence of a concern using the PC-NAT. Then, reliability was reassessed with the three levels of concern as separate categories to determine whether participants agreed on the severity of the concern (i.e. “none” versus “some” versus “significant”).

To determine how different the agreement was from chance, a kappa statistic was computed [ $K=(P-P_e)/(1-P_e)$ ], where P was the percentage agreement and  $P_e$  was the agreement expected by chance. Agreement ranging from 0.2-0.4 was considered fair, 0.4-0.6 was moderate, 0.6-0.8 was substantial and 0.8-1 was almost perfect.<sup>42</sup> As each consultation addressed different issues, ratings were compared on each consultation separately.

A thematic analysis of the group discussion data was performed to obtain participant feedback about the acceptability and clarity of the PC-NAT domains and format; and suggested strategies for improving the PC-NAT.



## 4.4 RESULTS

### 4.4.1 Sample

Participants (n=103) included 18 general practitioners, 25 specialists (4 medical, 13 radiation oncologists, 1 PC physician, 7 haematologists); 39 community, PC, radiation oncology and haematology nurses; and 21 allied health professionals (4 social workers, 2 occupational therapists, 3 dietitians, 9 radiation therapists, 2 speech therapists and a pastoral care worker).

*Table 4.1: Demographic characteristics of participating health professionals*

Characteristics	Sample (n=98)*	
	Number	%
Age (yrs)		
18-30	11	11
31-40	24	25
41-50	38	39
51-60	21	21
61+	4	4
Gender		
Male	30	31
Female	66	69
Undergraduate training		
Australia	85	87
Other	13	13
Postgraduate training in PC		
Yes	11	12
No	86	88
Experience (yrs) in PC		
1-10	39	40
11-20	23	24
21-30	20	20
31+	16	16
Current practice setting		
Regional	33	34
Metropolitan	56	57
Rural	4	4
Other	5	5

\*Demographic data missing on 5 participants from the total sample (n=103)

#### **4.4.2 Face and content validity**

During the development of the *Guidelines*<sup>27</sup> and PC-NAT, a national consensus meeting was held, providing preliminary support of the PC-NAT's face and content validity. This was confirmed by study participants, who felt comfortable and capable using the PC-NAT and agreed the tool was acceptable and comprehensive, covering all potential areas of need. Importantly, participants reported that the inclusion of caregiver and family sections was very helpful. Feasibility was also confirmed, with participants taking 5-10 minutes per consultation to complete the PC-NAT, with familiarity with the PC-NAT reducing completion time. The simple language and inclusion of prompt questions were reported to assist the PC-NAT's clarity.

#### **4.4.3 Inter-rater reliability**

The Kappa statistic was used to determine whether participants responded in the same way to each domain as other members of their own specialty group.<sup>43</sup> Kappa values for each domains addressed in the consultation are presented in Tables 2 and 3 according to specialty group, with proportion exact values presented in brackets. Kappa values for the dichotomised ratings of levels of concern are presented in Table 4.2; and kappa values for the categorised ratings of levels of concern are presented in Table 4.3.

In consultation 1, dichotomised kappa values ranged from 0-1.00. In consultation 2, kappa values ranged from 0.01-1.00. Caregiver wellbeing issues (Section 4) were not addressed in either consultation 1 or 2, so were not rated. In consultation 3, kappa values ranged from 0.10-0.70.

Table 4.2: The Kappa (and percentage) of participants agreeing on the presence versus absence of concerns in the PC-NAT domains addressed in each consultation

PC-NAT Domains	GPs	Oncologists	Nurses	Allied Health
<b>CONSULTATION 1</b>				
<b><i>Patient wellbeing</i></b>				
Physical	1.00 (100)	1.00 (100)	0.80 (89.88)	1.00 (100)
Psychological	0.58 (79.08)	1.00 (100)	0.80 (89.88)	0.81 (90.48)
Spiritual	0.06 (47.06)	0.09 (54.67)	0.00 (49.93)	0.01 (50.48)
<b><i>Ability of caregiver/family to care for the patient</i></b>				
Physical	1.00 (100)	1.00 (100)	0.80 (89.88)	1.00 (100)
Psychological	1.00 (100)	1.00 (100)	0.80 (89.88)	1.00 (100)
Family & rel'ps	0.78 (88.89)	0.55 (77.33)	0.80 (89.88)	0.63 (81.43)
<b><i>Referral to SPCS</i></b>	0.58 (79.08)	0.84 (92.00)	0.52 (76.11)	0.64 (81.90)
<b>CONSULTATION 2</b>				
<b><i>Patient wellbeing</i></b>				
Physical	0.78 (88.89)	0.58 (78.77)	0.80 (89.76)	0.44 (72.11)
Psychological	0.78 (88.89)	0.70 (85.23)	0.89 (94.74)	0.61 (80.53)
Financial	0.78 (88.89)	0.70 (85.23)	0.80 (89.76)	0.80 (90.00)
<b><i>Ability of caregiver/family to care for the patient</i></b>				
Physical	0.58 (79.08)	0.58 (78.77)	1.00 (100)	0.61 (80.53)
Psychological	1.00 (100)	1.00 (100)	1.00 (100)	1.00 (100)
Information	1.00 (100)	1.00 (100)	1.00 (100)	1.00 (100)
Family & rel'ps	0.58 (88.89)	0.55 (77.33)	0.80 (89.88)	0.63 (81.43)
<b><i>Referral to SPCS</i></b>	0.01 (49.67)	0.35 (67.69)	0.70 (85.06)	0.62 (81.05)
<b>CONSULTATION 3</b>				
<b><i>Patient wellbeing</i></b>				
Physical	1.00 (100)	1.00 (100)	1.00 (100)	1.00 (100)
Changes in functional status	1.00 (100)	1.00 (100)	1.00 (100)	1.00 (100)
Financial	0.78 (88.89)	0.85 (92.31)	0.90 (94.87)	0.80 (90.00)
<b><i>Ability of caregiver/family to care for the patient</i></b>				
Physical	0.78 (88.89)	0.85 (92.31)	1.00 (100)	0.62 (90.00)
Family & rel'ps	0.10 (54.90)	0.70 (85.23)	0.47 (73.28)	0.12 (55.79)
<b><i>Caregiver wellbeing</i></b>				
Physical and Psychosocial	0.58 (79.08)	0.85 (92.31)	0.62 (81.11)	0.29 (64.74)
<b><i>Referral to SPCS</i></b>	0.58 (79.08)	1.00 (100)	0.71 (85.43)	0.46 (73.16)

NB: Percentage agreement and kappa statistics are based on all possible combinations of unique pairs.

Kappa values were also obtained for each of the consultations, with level of concern analysed as three separate categories (Table 4.3). Kappas ranged from 0.02-1.00 in Consultation 1, 0.07-0.92 in Consultation 2; and 0.02-0.83 in Consultation 3. The lowest reliability was found for the patient spirituality domain in Consultation 1, the caregiver physical domain in Consultation 2 and the family and relationships domain in Consultation 3.

Table 4.3: The Kappa (and percentage) of participants agreeing on the three levels of concern in the PC-NAT domains addressed in each consultation

PC-NAT Domains	GPs	Oncologists	Nurses	Allied Health
<b>CONSULTATION 1</b>				
<b><i>Patient wellbeing</i></b>				
Physical	0.21 (47.06)	0.32 (54.67)	0.16 (43.72)	0.26 (50.48)
Psychological	0.22 (47.71)	0.37 (58.00)	0.38 (58.57)	0.26 (50.48)
Spiritual	0.07 (37.91)	0.02 (34.67)	0.09 (27.26)	0.09 (39.05)
<b><i>Ability of caregiver/family to care for the patient</i></b>				
Physical	0.45 (63.40)	0.43 (62.00)	0.58 (72.06)	1 (100)
Psychological	0.83 (88.89)	1 (100)	0.78 (85.02)	1 (100)
Family & rel'ps	0.42 (61.44)	0.3 (53.33)	0.52 (68.29)	0.48 (65.24)
<b><i>Referral to SPCS</i></b>	0.58 (79.08)	1.00 (100)	0.71 (85.43)	0.46 (73.16)
<b>CONSULTATION 2</b>				
<b><i>Patient wellbeing</i></b>				
Physical	0.25 (49.67)	0.21 (47.38)	0.37 (57.89)	0.34 (56.32)
Psychological	0.15 (43.14)	0.34 (56.00)	0.43 (61.74)	0.14 (42.63)
Financial	0.13 (41.83)	0.13 (42.15)	0.29 (52.77)	0.14 (42.63)
<b><i>Ability of caregiver/family to care for the patient</i></b>				
Physical	0.10 (39.87)	0.13 (41.85)	0.23 (48.79)	0.07 (37.89)
Psychological	0.36 (57.52)	0.59 (72.92)	0.78 (85.06)	0.41 (60.53)
Information	0.83 (88.89)	0.68 (78.77)	0.92 (94.74)	0.85 (90.00)
Family & rel'ps	0.29 (52.94)	0.78 (85.23)	0.59 (72.69)	0.38 (58.42)
<b><i>Referral to SPCS</i></b>	0.14 (49.67)	0.32 (67.69)	0.70 (85.06)	0.62 (81.05)
<b>CONSULTATION 3</b>				
<b><i>Patient wellbeing</i></b>				
Physical	0.83 (88.89)	0.52 (67.69)	0.55 (69.77)	0.49 (66.32)
Changes in functional status	0.56 (70.59)	0.39 (59.08)	0.26 (50.34)	0.34 (55.79)
Financial	0.13 (41.83)	0.19 (46.15)	0.32 (54.39)	0.23 (48.95)
<b><i>Ability of caregiver/family to care for the patient</i></b>				
Physical	0.19 (45.75)	0.22 (48.00)	0.23 (48.99)	0.08 (38.95)
Family & rel'ps	0.03 (35.29)	0.13 (42.15)	0.06 (37.38)	0.02 (32.11)
<b><i>Caregiver wellbeing</i></b>				
Physical and Psychosocial	0.41 (60.78)	0.30 (53.54)	0.11 (40.62)	0.09 (39.47)
<b><i>Referral to SPCS</i></b>	0.57 (79.08)	1.00 (100)	0.70 (85.43)	0.44 (73.16)

NB: Percentage agreement and kappa statistics are based on all possible combinations of unique pairs.

#### **4.4.4 Recommended PC-NAT modifications**

Improvements recommended by participants included the addition of a referral section, including the priority of assessment, to whom the referral is made and client knowledge of the referral, with a strong perception that the information regarding areas and levels of needs noted on the PC-NAT would be extremely helpful to the health professional receiving the referral. Section 5, which asked whether the health professional thought the patient required a referral to SPCS, was deemed superfluous in light of information provided in other sections. Inclusion of a space for comments at the end of each section was deemed important for specific notes regarding the issues identified. The response category "Some need" was expanded to include "Potential for" as it was suggested that while the person may not be experiencing a need now, this need may develop at a later date, thus assisting in monitoring potential problem areas.

### **4.5 DISCUSSION**

Assessments should function as a prompt for communication between health professionals, caregivers and patients, identify specific issues and provide health professionals with information regarding planning of care and resource allocation.<sup>22</sup> Moreover, assessments should be responsive to changes in the types and level of needs experienced by the patient or caregiver across the complete trajectory of illness where change is certain to occur;<sup>37, 44</sup> and be easy to complete and understand by health professionals from any discipline.<sup>22, 45</sup> The PC-NAT was developed for implementation at multiple time points so changes in needs are identified readily. Our preliminary assessments confirm the tool's potential as a consistent approach that can be implemented by any members of the care team, promoting continuity of care between generalist and specialist providers.

The PC-NAT exhibits good face and content validity and includes domains that are comprehensive and, importantly, were developed with input from patients, caregivers and health professionals. Time and workload are often cited as barriers for health professionals, limiting the feasibility of some available tools.<sup>37</sup> In contrast, the one page PC-NAT requires minimal completion time, with prompts on the back page providing a

structured approach to guide assessment. It can serve as an *aide memoire* for domains that should be covered for any person at this stage of their illness.

The dichotomised kappa values indicated excellent reliability for many domains, suggesting that participants were able to identify the presence or absence of patient and caregiver issues. Compared to these, the categorised kappa values for the three categories of concern were lower, indicating that participants had some difficulty in determining the severity of the issue in the standardised format in which these consultations were presented. Hence, whilst the PC-NAT showed adequate reliability for many of the domains, low reliability was observed particularly for the areas where further questioning of the patient and partner/caregiver may have increased reliability.

The patient spirituality domain had low reliability in both dichotomised and categorised analyses. This finding is consistent with the verbal feedback received during group discussions, which suggested that spiritual issues are difficult to discuss. Literature suggests that spirituality is often not addressed by health professionals,<sup>46-49</sup> despite its importance to patients<sup>50-52</sup> and a majority of patients reporting that they want their physicians to ask about spirituality.<sup>53</sup>

The family and relationship domain had low reliability in the categorised analyses for one consultation and good reliability in the other two consultations. Reliability improved in all three consultations when level of concern was dichotomised. This improvement, along with the difference in reliability between consultations, suggests that the ability to clarify this issue in a real life setting may have improved participants' ability to determine the severity of the issue. Similar trends were found for the patient physical and psychological domains.

Inclusion of both patient and caregiver/family issues in the PC-NAT is an important and novel approach to needs assessment tools in this population. Informal carers account for over 50% of cancer patients' care throughout their illness;<sup>54</sup> and the presence of a caregiver can impact on care setting and the level of support patients require.<sup>55, 56</sup> However, the caregiver physical domain, assessing the caregiver's distress over the patient's physical issues, had low levels of agreement in two of the three consultations. While caregivers experience a range of needs as a result of their care giving role,<sup>29, 56-58</sup> these are often seen as secondary to those of the patient.<sup>56, 59</sup> Moreover, caregivers

are often reluctant to disclose their needs to health professionals;<sup>60</sup> or even to the patient.<sup>61</sup> As with the patient domains, reliability was higher for one consultation and also increased substantially in the dichotomised analysis which considered only the presence or absence, rather than level of concern.

#### **4.5.1 Limitations**

The use of simulated consultations may have contributed to the low reliability of some domains. Participants had no prior knowledge of the patients or caregivers and were given only a brief patient history. There was also no opportunity for participants to clarify issues presented or to make enquiries to facilitate a more informed judgement of the issues. While health professionals may differ in their assessment of patient needs,<sup>62</sup> the opportunity to clarify certain areas in the PC-NAT with the patient or caregiver would have facilitated more accurate completion of the tool. The differences between the dichotomised kappa and categorised kappa values clearly demonstrate the importance of this issue.

Participants did not receive any training prior to the pilot test. While some have found minimal impact of training on reliability,<sup>62</sup> participants suggested that gaining familiarity with the tool would increase accuracy in the future. Domains with low reliability have therefore been retained on the basis of participant feedback, because of their importance in addressing holistic needs. In addition to the modifications recommended in the group discussions, the PC-NAT was further improved with the addition of tick boxes for each item to indicate the action taken by the health professional ("directly managed", "managed by another care team member", "referral required") to address identified needs. The amended version is currently the subject of further testing.

### **4.6 FUTURE DIRECTIONS**

There has been little research on the effect of needs assessments on the utilisation of services and quality of care as well as their feasibility in PC settings.<sup>22</sup> As a result, further evaluation of the *Guidelines* and PC-NAT in a real life setting is currently underway. In the prospective, multi-site, multi-discipline study, the introduction of these resources will be the intervention and outcomes will be compared pre- and post-intervention. This longitudinal study will allow the researchers to assess patients and



their caregivers at multiple time points and determine the validity and responsiveness of the PC-NAT, an important consideration for accurate identification of needs.<sup>36, 37, 44</sup> Ultimately, it will determine whether the PC-NAT facilitates a more appropriate match of needs with service access.

## **4.7 CONCLUSIONS**

The PC-NAT is a short, easy to use tool which is completed by the health professional, thereby reducing burden on patients and caregivers. However, training and education of health professionals regarding the interpretation of the domains and rating system of the PC-NAT and an improved knowledge of background information in the *Guidelines* may assist in improving the reliability of the PC-NAT. By incorporating these resources as part of the care of patients at an early stage of their advancing disease, health professionals can identify those with greater needs who may require targeted early interventions, thus reducing burden and improving quality of life.

### ***Potential conflicts of interest***

There are no known conflicts of interest for any of the authors.

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# **CHAPTER 5:**

## **VALIDITY, RELIABILITY AND CLINICAL FEASIBILITY OF A NEEDS ASSESSMENT TOOL FOR PEOPLE WITH PROGRESSIVE CANCER**

## **Validity, reliability and clinical feasibility of a Needs Assessment Tool for people with progressive cancer**

**Running title: Validation of a Needs Assessment Tool for progressive cancer**

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*Citation: Waller A, Girgis A, Scott W, Foot L, Lecathelinais C, Sibbritt D, et al. Validity, reliability and clinical feasibility of a Needs Assessment Tool for use in people with progressive cancer. Psycho-oncology (in press).*

**Author's contributions**

AG and DC developed the study concept and aims and sought funding for the project. AW and AG developed the protocol and all of the other authors assisted in further development of the protocol. AW and AG were responsible for drafting the manuscript. AW and AG implemented the protocol and WS and LF collected the data; and AW, CL and AG were involved in the data analyses. All authors contributed to the final manuscript.

This is the pre-peer reviewed version of the following article: Waller, A., Girgis, A., Lecathelinais, C., Scott, W., Foot, L., Sibbritt, D. and Currow, D. (2010), Validity, reliability and clinical feasibility of a Needs Assessment Tool for people with progressive cancer. *Psycho-Oncology*, 19: 726–733, which has been published in final form at <http://dx.doi.org/10.1002/pon.1624>



### ***Acknowledgements***

This project was undertaken by The Cancer Council New South Wales' Centre for Health Research & Psycho-oncology (CHeRP), with research funding from the Australian Government Department of Health and Ageing and the Cancer Council NSW, PhD scholarship support from the National Health and Medical Research Council (NHMRC) and infrastructure support from the Hunter Medical Research Institute. The views expressed are not necessarily those of The Cancer Council. The authors would like to acknowledge the staff of the Sir Charles Gairdner Hospital Palliative Care Service, Western Australia, for their assistance with this study.

The study was approved by the University of Newcastle Human Research Ethics Committee, the Hunter New England Area Health Service Human Research Ethics Committee and the Sir Charles Gairdner Hospital Human Research Ethics Committee.

## 5.1 ABSTRACT

**Background:** Needs assessment is a valuable approach for determining the way health and social services allocate resources to people with cancer and their caregivers.

**Aim:** To assess the reliability, validity and acceptability of a Needs Assessment Tool (NAT) in a palliative care clinical setting.

**Methods:** Psychometric properties of the NAT were initially explored in a pilot study involving filmed simulated advanced cancer patient and caregiver consultations. Further testing was undertaken in a clinical setting to determine the inter-rater reliability, validity and feasibility of the NAT.

**Results:** The results of the pilot study suggested good reliability and acceptability in a simulated setting. Further testing indicated that the patient daily living item was positively correlated with the Resource Utilization Groups - Activities of Daily Living (RUG-ADL) ( $r=0.74$ ) and negatively correlated with the Australian Karnofsky Performance Scale (AKPS) ( $r=-0.84$ ). Prevalence and bias adjusted kappa (PABAK) values also indicated adequate agreement between Palliative Care Problem Severity Score items and the patient physical item (0.48); psychological item (0.45); and caregiver wellbeing item (0.42).

**Conclusions:** Needs assessment not only facilitates the identification of people who have specific concerns or are dissatisfied with some aspect of their care, but also determines the person's desire for assistance and involvement with services. The NAT is a highly acceptable and efficient tool that can be used by health professionals with a range of clinical expertise to identify individuals' needs, thereby enabling a better match of interventions of specialist services more closely linked to needs.

**Keywords:**

Cancer

Palliative care

Needs assessment

Patient

Caregiver

## 5.2 INTRODUCTION

Understanding the individual experiences and needs of people with cancer and their caregivers is essential to providing care that is explicitly and individually tailored. Articulated benefits of needs assessment include its potential for identifying issues that are not being addressed, and determining whether patients perceive these issues as problems for which they require further assistance and, if so, the level of assistance they require.<sup>1-3</sup> A needs-based approach to the delivery of cancer care has become an important focus, to ensure people receive care according to the complexity and severity of their needs, independently of diagnosis or prognosis.<sup>4</sup> However, as Carslon (2008) suggests, implementing care based on the assessment of needs has its own challenges, including how to define need and how and when to assess need.<sup>5</sup> Therefore, the accurate assessment of these experiences and needs within the clinical setting continues to be a challenge.

Capturing information pertaining to a person's needs in an accurate and efficient manner has led to the development of a variety of needs assessment tools. Using a structured tool can prompt the discussion of issues among patients, families and health professionals,<sup>6, 7</sup> while providing a strategy for triaging people according to the degree of burden they experience as a result of their perceived unmet needs.<sup>2, 8-10</sup> Tools can also assist institutions in prioritising resources and identifying areas that require improvement.<sup>7, 8</sup> Unfortunately, many of the existing needs assessment tools have psychometric problems, including inadequate reliability, validity and responsiveness.<sup>7,9,11</sup>

The Needs Assessment Tool (NAT)<sup>12</sup> in palliative care was developed to help determine the type of care required by people with advanced cancer and their caregivers, based on the assessment of the complexity and severity of their physical and psychosocial needs. Used in both generalist and specialist settings to support the recommendations in the *Palliative Care Needs Assessment Guidelines*,<sup>13</sup> the NAT can assist in matching the types and levels of need experienced by people with the most appropriate personnel or services to address those needs.<sup>12</sup> The NAT was initially

developed and pilot tested with a sample of multidisciplinary health professionals; the results of this study have been published elsewhere.<sup>12</sup> Findings suggested that the NAT was easy to administer, covered all areas of needs pertinent to patients with advanced cancer and their caregivers, and was able to differentiate between the different levels of need that may be present.<sup>12</sup>

The pilot study confirmed the NAT's potential for assisting any member of the care team to identify patient and caregiver needs.<sup>12</sup> However, it has been suggested that few needs assessment tools in cancer have been tested within clinical settings.<sup>11, 14</sup> Since the NAT was designed for use in clinical practice, this follow-up study was undertaken to test its usefulness in a clinical setting of a hospital-based specialist palliative care service (SPCS).

### **5.2.1 Aim**

The aim of this study was to assess the reliability, validity and acceptability of the NAT in a palliative care clinical setting.

## **5.3 METHODS**

### **5.3.1 Sample**

Participants included people with advanced cancer referred to the Sir Charles Gairdner Hospital Palliative Care Service, Western Australia.

To be eligible to participate, patients:

1. had a current diagnosis of advanced cancer, i.e. no longer amenable to cure, with either locally extensive, regional spread or metastatic disease, or a haematological malignancy where there is relapse, or resistant or refractory disease
2. were sufficiently fluent in the English language to provide informed consent
3. were over 18 years of age.

### 5.3.2 Materials

#### ***Needs Assessment Tool (NAT) (Appendix 5.1)***

The NAT was revised on the basis of recommendations made by the participants in the pilot study;<sup>12</sup> and included four sections:

1. Section 1 included three items to fast-track a review by a SPCS: the presence of a caregiver if needed, a request for a referral by the patient or caregiver, and the health professional's need for assistance in managing care;
2. Section 2 assessed the patient's wellbeing, and included physical, daily living, psychological, information, spiritual/existential, cultural and social, financial and legal domains;
3. Section 3 assessed the ability of the caregiver/family to care for the patient, and included physical, daily living, psychological, information, financial and legal and family and relationship domains;
4. Section 4 assessed the caregiver's wellbeing, including physical, psychological and bereavement issues.

For Section 1, response options were “Yes” or “No”. Items in Sections 2-4 were assessed according to the level of concern (“none”, “some/potential for”, “significant”) they were causing. Prompt questions for each item were included on the back page, to facilitate consistency in how issues were addressed. Each item had a set of tick boxes to indicate the action taken (“directly managed”, “managed by another care team member”, “referral required”) to address any identified needs. Finally, should a referral be required, a section detailing the type of referral made (e.g. to SPCS, social worker, general practitioner, medical oncologist), the urgency of the referral (“urgent”, “semi-urgent”, “non-urgent”) and client knowledge of the referral was included. (A copy of the Guidelines<sup>13</sup> and NAT can be found at: <http://www.newcastle.edu.au/research-centre/cherp/professional-resources>).

#### ***Australian Karnofsky Performance Scale (Appendix 5.2)***

The AKPS is a modified version of the original scale (KPS) that can be used in palliative care settings.<sup>15</sup> The AKPS is a health professional completed scale that assesses functional status of patients, ranging from 0 (death) to 100 (normal functioning without evidence of disease).<sup>15</sup> The original scale has been extensively tested and has acceptable reliability and validity.<sup>16, 17</sup> The AKPS was found to perform

better than the original scale (KPS) in an Australia study in a population seen by a SPCS.<sup>15</sup>

### ***Resource Utilisation Groups – Activities of Daily Living (Appendix 5.2)***

The RUG-ADL is a 4-item health professional completed scale measuring four activities of daily living including eating, sleeping, bed mobility and transfers.<sup>18</sup> Scores for the transfers, sleeping and bed mobility items range from 1 (independent/limited supervision) to 5 (two or more persons physical assist). Scores for the eating item range from 1 (independent/limited supervision) to 3 (extensive assistance/total dependence/tube feed). Higher scores indicate lower functional ability.<sup>19</sup> A total score was used in the analyses (range 4-18).

### ***Palliative Care Problem Severity Scale (Appendix 5.2)***

The PCPSS has four items to profile pain, other physical symptoms, family and psycho-spiritual problems. Scores range from 0 (absent) to 3 (severe). Higher scores indicate more intense difficulties.<sup>20</sup>

### ***Health professional acceptability survey (Appendix 5.3)***

Staff members of the service who completed at least one NAT were asked to complete a 6-item acceptability survey at the end of the study. This survey was designed specifically for this study and included items relating to the acceptability of the NAT in terms of the time taken to complete the tool, content, difficulty and usefulness.

## **5.3.3 Procedure**

Patients participating in the validation study were given a validation study patient information letter (Appendix 5.4), a validation study patient consent form (Appendix 5.5) and a validation study request for results form (Appendix 5.6). Health professionals participating in the validation study were given a validation study health professional information letter (Appendix 5.7) and a validation study request for results form (Appendix 5.6).

A staff member from the palliative care service completed the one-page NAT for each participant during his/her consultation if an outpatient, or during his/her stay if an inpatient. A second staff member completed a second copy of the NAT for the same participant on the same day without discussing the patient or comparing responses.

This provided a measure of inter-rater reliability. The AKPS, RUG-ADL and PCPSS were collected by one of these staff members as part of standard practice on the same day as the NAT to provide a measure of concurrent validity. At the conclusion of the study, staff members who completed the NAT were asked to complete the acceptability survey (Appendix 5.3).

### **5.3.4 Analysis**

The data were analysed using SAS Version 9 (SAS Institute Inc, NC, USA, 2007). To assess inter-rater reliability, Cohen's kappa<sup>21</sup> and the prevalence- and bias-adjusted kappa (PABAK) statistic<sup>22</sup> were used to determine the level of agreement between the two raters for each item in the NAT. As both prevalence and bias impact on the magnitude of the kappa statistic, the PABAK represents an adjustment to Cohen's kappa to take into account these influences.<sup>22</sup>

The reliability of the NAT was assessed with the three levels of concern as separate categories to determine whether participants agreed on the severity of the concern (ie "none" versus "some" versus "significant"). Agreement ranging from 0.2-0.4 was considered fair, 0.4-0.6 was moderate, 0.6-0.8 was substantial and 0.8-1 was almost perfect.<sup>21</sup>

To assess validity, comparisons were made between the NAT items and PCPSS items. Validity was assessed using the three levels of concern in the NAT; and for each of the PCPSS items, the four response options were categorised into three options ("none" versus "mild/moderate" versus "severe"). The PABAK and Cohen's kappa were used to assess the agreement between the NAT and PCPSS items (see Table 1). The Pearson's correlation coefficient was used to assess the relationship between the NAT daily living item and both the total RUG-ADL score and the AKPS. Analysis of Variance (ANOVA) was used to determine any significant differences in the mean scores of the RUG-ADL and AKPS according to the level of concern recorded in the NAT item.

*Table 5.1: Validated scales and NAT items compared*

<b>Validated scales</b>	<b>NAT items</b>
PCPSS - pain	Is the patient experiencing unresolved physical symptoms?
PCPSS - other symptoms	
Total RUG-ADL AKPS	Does the patient need help with daily living activities?
PCPSS - psychological/spiritual	Are the patient's psychological symptoms interfering with wellbeing or relationships?
PCPSS - carer/family	Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?

## 5.4 RESULTS

### 5.4.1 Sample

A total of 50 people with advanced cancer participated in the study. The consent rate was 96%. Of those patients who participated, 55% were male and the average age was 67 years (SD=14.32; median 70 years; range 32-88 years). Eleven staff members from the palliative care service completed at least one NAT during the course of the study. These included seven nurses, two palliative care consultants and two registrars.

### 5.4.2 Inter-rater reliability

The PABAK statistic<sup>22</sup> was used to determine whether staff members responded in the same way to each item in the NAT. The PABAK values are presented in Table 5.2, along with Cohen's kappa and the proportion exact values (% agreement).



Table 5.2: The PABAK, Cohen's kappa and percentage of raters agreeing on the severity of the concerns in the NAT domains

NAT item	N	Severity of concern		
		PABAK	Cohen's kappa	% agreed
<b>Patient wellbeing</b>				
Does the patient have concerns about spiritual or existential issues?	48	0.76	0.04	88
Does the patient have financial or legal concerns that are causing distress or require assistance?	49	0.60	0.38	73
Does the patient need help with daily living activities?	50	0.58	0.59	72
From the health delivery point of view, are there health beliefs, or cultural or social factors involving the patient or family that are making care more complex?	50	0.52	0.13	68
Are the patient's psychological symptoms interfering with wellbeing or relationships?	48	0.51	0.34	67
Is the patient experiencing unresolved physical symptoms?	50	0.31	0.27	54
Does the patient have an unmet need for information?	48	0.28	0.02	52
<b>Ability of caregiver/family to care for the patient</b>				
Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?	44	0.54	0.31	77
Is the family currently experiencing problems that are interfering with their functioning or interpersonal relationships, or is there a history of such problems?	42	0.57	0.10	71
Does the caregiver or family have unmet needs for information?	44	0.52	0.31	68
Is the caregiver or family having difficulty coping?	45	0.51	0.43	67
Is the caregiver or family having difficulty providing physical care?	45	0.40	0.17	60
Is the caregiver or family distressed about the patient's physical symptoms?	44	0.22	0.17	48
<b>Caregiver wellbeing</b>				
Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?	41	0.39	0.02	59
Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?	40	0.37	0.13	58

### 5.4.3 Concurrent validity

Validity was assessed by comparing the ratings on items from the NAT to ratings on a number of items from the other measures. The PABAK was used to determine whether staff members responded in the same way to items in the NAT and the PCPSS that assessed similar areas of concern. The PABAK values are presented in Table 5.3, along with Cohen's kappa and the proportion exact values (% agreement).

*Table 5.3: The PABAK, Cohen's kappa and percentage of raters agreeing on the severity of the concerns in the NAT domains and PCPSS items*

NAT item	PCPSS item	N	Severity of concern		
			PABAK	Cohen's kappa	% agreed
Is the patient experiencing unresolved physical symptoms?	PCPSS Pain	48	0.48	0.42	65
Are the patient's psychological symptoms interfering with wellbeing or relationships?	PCPSS Psychological	48	0.45	0.34	63
Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?	PCPSS Family	41	0.42	0.47	61
Is the patient experiencing unresolved physical symptoms?	PCPSS Other symptoms	47	0.24	0.25	49

The NAT patient daily living item was negatively strongly correlated with the AKPS score  $r(45) = -0.84$ ,  $p < 0.001$  and positively correlated with the RUG-ADL total score  $r(47) = 0.74$ ,  $p < 0.001$ . Table 5.4 presents the mean scores for both the RUG-ADL and AKPS, according to the level of concern on the NAT daily living item. For example, of the 22 participants who had no daily living needs recorded on the NAT, the mean score for the RUG-ADL was 4.18, the lowest possible score. However, the RUG-ADL mean score was significantly greater for those participants who had some (mean = 7.59) or significant (mean = 9.80) daily living needs identified on the NAT ( $F(2, 46)=10.15$ ,  $p<0.001$ ). The AKPS was significantly lower for participants with greater needs identified on the NAT ( $F(2, 44)=16.62$ ,  $p<0.001$ ).

*Table 5.4: Mean scores for the RUG-ADL and AKPS according to the level of concern on the NAT daily living item.*

NAT level of concern	RUG-ADL			AKPS		
	N	Mean	SD	N	mean	SD
None	22	4.18	0.85	21	72.86	11.02
Some	22	7.59	4.10	21	55.71	11.64
Significant	5	9.80	4.38	5	42	21.68
p-value		0.0002			0.0001	

#### 5.4.4 Acceptability

Of the 11 staff members who completed at least one NAT during the study, six staff members returned the acceptability survey. The NAT was largely considered to be a comprehensive, useful and feasible measure. However three of the health professionals were worried about the time taken to discuss the issues and concerns that were raised as a result of using the tool. It was thought by one staff member that the NAT may be more useful in generalist settings such as general practice or oncology clinics. Three staff members also reported that some caregivers may not accompany the patient to appointments and in those instances completing the sections on caregiver needs is difficult. This is reflected in the number of NATs that had missing data for these sections.

## 5.5 DISCUSSION

Given its already established inter-rater reliability, acceptability and face and content validity,<sup>12</sup> this study further supports the NAT as an efficient approach to assessment and management of unmet patient and caregiver needs. Initial psychometric testing of the NAT<sup>12</sup> found low reliability for some domains, likely influenced by health professionals having limited prior knowledge of the patients and caregivers and being unable to clarify the severity of issues.<sup>12</sup> This study addresses this concern by quantifying health professionals' ability to gauge the severity of an issue when they are able to clarify issues personally. Raters' agreement on the severity of issues ranging from fair to substantial on all NAT items, with PABAK values of at least moderate agreement on two-thirds of the items. Hence, the inter-rater reliability of the NAT in a clinical setting was confirmed.

Comparison of the NAT items against standardised scales assessing similar issues also confirmed the concurrent validity of the NAT within a clinical setting. The agreement between the PCPSS physical item and the NAT patient physical item, the PCPSS psychological item and the NAT patient psychological item; and the agreement between the PCPSS family item and the NAT caregiver wellbeing item was good. Validity of the NAT was again confirmed with significant correlations between the NAT daily living item and both the RUG-ADL and AKPS.

The Palliative Care Outcomes Collaboration (PCOC) is an “Australian initiative that allows SPCSs to collect nationally agreed-upon measures to better understand quality, safety, and outcomes of palliative care”.<sup>19</sup> Information about the palliative care service, the person receiving care and their clinical characteristics is collected.<sup>19</sup> The AKPS, RUG-ADL and PCPSS are part of the PCOC dataset collected on every person referred to participating SPCSs with each clinical encounter; and have been shown to be both reliable and valid.<sup>15, 18, 23, 24</sup>

The AKPS has been validated in both community and inpatient palliative care settings.<sup>15</sup> The PCPSS has been used previously in a case mix classification dataset for sub-acute and non-acute care in Australia (AN-SNAP classification).<sup>25</sup> The RUG-ADL, a component of the RUG-III system predominately used in nursing homes, is also a component of the AN-SNAP classification.<sup>25</sup> While there are some criticisms regarding inadequacies in dealing with mental illness such as dementia, the RUG-ADL has shown adequate inter-rater reliability, feasibility and good predictive validity in terms of determining resource use.<sup>23, 24</sup> The validation of the NAT with these measures is a highly important finding. Given the brevity of the NAT items, the tool offers a highly efficient and acceptable option for use in clinical settings, where time and resources are often limited.

Some NAT items showed lower reliability than others. Inter-rater reliability was lowest (fair) for the item assessing caregiver distress about the patient’s physical symptoms in Section 3. Caregiver reluctance to discuss these issues in great detail may have contributed to the results, since previous research has found that caregivers prefer to concentrate on the issues of the patient during consultations.<sup>26, 27</sup> Furthermore, caregivers’ distress over patients’ physical symptoms may have been captured in the patient physical item of the tool instead of the caregiver section.

Inter-rater reliability was also lower (fair) for the patient physical concerns item. This is a surprising finding given research indicating that health professionals are more likely to identify physical needs compared to psychosocial needs.<sup>28-31</sup> However, this item encompassed potential physical symptoms including fatigue, pain, dyspnoea, loss of appetite, nausea, constipation, diarrhoea, drowsiness and sleep problems. It is possible that some health professionals considered a number of these symptoms in making their assessment; while others focussed predominately on pain, the most prevalent physical symptom reported by patients with advanced cancer.<sup>32-39</sup> Given the importance of accurate assessment of physical concerns, the results suggest a need for greater specificity in this item.

Similarly, only half the raters agreed on the information needs of participants. The amount of information wanted by people with cancer varies.<sup>40-42</sup> Moreover, there are a number of different topics for which information may be required.<sup>43</sup> People may want information about their cancer, prognosis or treatment options, but they also may want coping or financial/legal information or information about available medical and health services.<sup>43</sup> Raters may not have dealt with all of these potential areas for information need in a consistent way.

In terms of concurrent validity, the lowest agreement (fair) was found for the PCPSS (other symptoms) item and the NAT physical item. Importantly, the NAT has only one item that addresses patient physical issues while physical issues are addressed in two separate items in the PCPSS. In fact, the agreement between the PCPSS (pain) item and the NAT patient physical item was moderate, again reiterating the primacy of pain in the symptom assessment of many clinicians. The physical needs identified using the NAT may have largely related to pain rather than other physical symptoms. Again, raters may have been less consistent in their discussions about physical symptoms other than pain, therefore resulting in lower agreement for the PCPSS (other symptoms) item.

### **5.5.1 Changes to the NAT in response to validation results**

As a result of the lower reliability of some items and the issues raised by health professionals completing the tool, a number of changes were made to the NAT. The

most frequently encountered physical symptoms in people with advanced cancer were added to the physical item description on the front page. The information item was changed so that it asked whether the patient required information about particular issues including cancer specific information, prognosis, treatment options, coping information, social information, financial/legal information and information about medical and health service assistance.<sup>43</sup> A tick box was added to the two caregiver sections to indicate whether the patient or caregiver had provided the information so that health professionals can obtain information about the caregiver from the patient if the caregiver is not in attendance, while still acknowledging that the information did not come directly from the caregiver themselves. Finally, the name of the tool was changed to Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C).

### **5.5.2 Limitations**

Some staff members had concerns about the time taken to discuss the issues raised as a result of using the NAT. In response to this a recommendation will be made in the dissemination phase for the most significant of these issues to be addressed first, and then those that are less severe at a later date if time is an issue during appointments. Importantly, the NAT can assist the health professional by ensuring that they are aware of all these areas which may be a concern to patients and caregivers, and allow them to prioritise these issues. This complaint may highlight for the health professional current inadequate assessments.

While the inter-rater reliability for each of the NAT items was assessed, not all NAT items were examined for concurrent validity. Ensuring the validity of all the NAT items would have required the completion of a large number of validated measures assessing different areas of concern. Even if such “gold standard” measures were available for each of these comparisons, completing all these measures in a clinical setting would have been potentially difficult, given the population and the setting.

The feasibility and acceptability of the NAT will need to be examined further in generalist settings. It was even suggested by some of the palliative care staff that the NAT may be more relevant for use in generalist settings; despite noted concerns about the issues raised by the tool that had not been raised in the clinical consultation. It is important that a tool like the NAT is readily available to prompt the discussion of issues

that are not always discussed by all health professionals, irrespective of whether they are generalists or specialists.

## **5.6 FUTURE DIRECTIONS**

The NAT offers a potential solution for prioritising limited resources to meet increasing demand as well as improving coordination of care and communication among multidisciplinary providers. Ensuring that these resources are available to any health professionals providing care for people with advanced cancer is therefore necessary. Since the processes used to disseminate and implement newly developed resources are as important as those used to develop them,<sup>44</sup> there is a need for formal and systematic dissemination of resources within clinical settings to improve compliance.<sup>45</sup> Hence, developing and implementing a process for disseminating the NAT, both nationally and internationally, will be undertaken.

## **5.7 CONCLUSION**

Overall, a high level of reliability and validity was found for the NAT in the clinical practice setting, suggesting that it may be a highly efficient resource for identifying patient and caregiver concerns during consultations. In fact, using the NAT can assist health professionals to address these concerns in a timely and appropriate manner either themselves or through referrals to other care team members or specialist providers; thus offering a potential solution to the limited resources available in some health services, improving coordination of care and communication between patients, caregivers and health professionals.

### ***Potential conflicts of interest***

There are no known conflicts of interest for any of the authors.

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# **CHAPTER 6:**

## **EVALUATION OF A PALLIATIVE CARE NEEDS ASSESSMENT INTERVENTION: METHODS**

## 6.1 OBJECTIVES

Based on the findings of the pilot study and validation study outlined in Chapter 4 and 5, the need for further testing of the *Guidelines* and Needs Assessment Tool:

Progressive Disease – Cancer (NAT: PD-C) to assess patients and their caregivers at multiple time points and determine the validity and responsiveness of the NAT: PD-C was acknowledged as the next step. The aim of this chapter is to describe the methods used in a prospective, multi-site, multi-discipline longitudinal study to assess the systematic and ongoing use of the *Guidelines* and NAT: PD-C on patient outcomes (including unmet needs, quality of life, depression and anxiety); as well as clinical assessment response and service utilisation.

## 6.2 STUDY DESIGN

Randomised control trials (RCTs) are considered gold standard in research to evaluate any intervention.<sup>1</sup> However, they are argued to be less applicable in advanced cancer and, more specifically, palliative care research as they often pose a number of methodological challenges.<sup>2</sup> Similar issues have been discussed by other authors in the area.<sup>1,3</sup> In fact, a systematic review of RCTs in palliative care research in 1997 reported only 11 studies, all of which possessed problems with recruitment, homogeneity, selection of outcome variables and patient attrition.<sup>2</sup> However, a recent study quantifying available palliative care literature reported that there has been a significant increase in clinical trials research in palliative care.<sup>4</sup> Other issues argued to impede research in palliative care include gate-keeping, changes in clinical situations, and limited survival times.<sup>5</sup> Some authors have even suggested that RCTs may be inappropriate as some patients and their families may be unwilling to participate in non-intervention arms of studies;<sup>5</sup> however, this is not unique to palliative care research. Using a design which randomises regions would not have been feasible due to the differences in palliative care service availability in the different areas. Moreover, the referral of people to services is dependent on the service, and there is considerable heterogeneity in the design of services and availability of resources.

Instead, an interrupted time series design was used for the study. The interrupted time series design is a quasi-experimental design<sup>6</sup> in which data are collected at multiple time points, both before and after an intervention is introduced.<sup>7</sup> By collecting data before and after the intervention, researchers can determine whether the intervention has an effect significantly greater than the underlying secular trend.<sup>7, 8</sup> One advantage of this design is that it allows both the short-term and long-term effects of the intervention to be examined.<sup>6</sup> Moreover, it is a relatively simple method that can be used in smaller populations.<sup>6</sup>

## **6.3 SAMPLE**

### **6.3.1 Participants**

#### ***Patients***

To be eligible to participate, patients had to fulfil the following criteria:

1. have a current diagnosis of advanced cancer, defined as cancer that is no longer amenable to cure, with either locally extensive, regional spread or metastatic disease, or haematological malignancy where there is relapse, or resistant or refractory disease. This can be either a new diagnosis or progression of a previous diagnosis
2. be sufficiently fluent in the English language to complete the Computer Assisted Telephone Interviews (CATIs), as determined by the research nurse and clinic staff
3. be over 18 years of age.

#### ***Caregivers***

Caregivers of all consenting patients were also invited to participate in the study. For the purpose of this study, a caregiver was defined as the primary carer or the family member who provided, or may provide when needed, the most help to the patient, as nominated by the patient. Caregivers aged less than 18 years were not excluded from the study on the basis of age, as children can take on the caregiver role for parents or other relatives in some cases.

### 6.3.2 Sample size

The main outcome of interest in this study was each patient's level of unmet needs as measured by the Supportive Care Needs Survey - Short Form (SCNS-SF34). The percentage of people reporting at least one moderate or high need in each of the domains in the SCNS was calculated pre- and post-intervention. A systematic review of unmet supportive care needs in people with cancer reported that a number of studies have used a classification of moderate or high need to assess the prevalence of needs in people with cancer.<sup>9-13</sup> Many of these studies have reported prevalence for individual items (range 9% to 41%) rather than the prevalence of people with at least one need in each domain.<sup>10-13</sup> A recent study reported that the percentage of people with cancer identified as having at least one moderate or high need for help using the SCNS-SF34 ranged from 15% (sexuality domain) to 53% (psychological domain).<sup>14</sup>

Assuming a maximum prevalence of 50% (worst case scenario) at pre-intervention for all domains, it was calculated that using a 5% significance level and having a minimum of 407 patients would give the study 80% power to detect a reduction in prevalence of 10% in each of the SCNS-SF34 domains post-intervention. However, this estimation of expected change in prevalence could not be supported by any previous literature, as few studies have looked at changes in needs over time or changes in the prevalence of needs resulting from an intervention.<sup>9</sup>

## 6.4 MATERIALS

Patient participants completed bi-monthly computer-assisted telephone interviews (CATIs) over a period of 18 months. It was estimated that each interview took approximately 40 minutes. Similarly, caregiver participants completed bi-monthly computer-assisted telephone interviews over a period of 18 months. However, caregiver data will not be presented in this dissertation.

### 6.4.1 Interview measures (Appendix 6.1)

#### *Demographics*

Eleven demographic questions were included in the baseline interview. These questions included patients' age, gender, marital status, level of education, type of health insurance, gross income, employment during the 12 months prior to diagnosis

(Employed, Unemployed/retired, On leave, Household duties), current employment (Employed, Unemployed/retired, On leave, Household duties), type of diagnosis and time since initial diagnosis.

### ***Co-morbidities***

Co-morbid conditions were derived from the Charlson index, initially developed and validated with breast cancer patients.<sup>15</sup> The original index has also been validated with other populations, including people with lung cancer,<sup>16</sup> people with diabetes,<sup>17</sup> and hospitalised older people.<sup>18</sup> Similar to the Prostate Cancer Outcomes Study,<sup>19</sup> this study used an index which included 12 items corresponding to 12 different conditions. The items included were cerebrovascular disease, inflammatory bowel disease, liver disease, gastric ulcers, arthritis, diabetes, depression, hypertension, chest pain, heart attack, heart failure and chronic lung disease. For each condition, patients were asked to state whether they had ever been told they had the condition. If so, they were asked to state whether it had ever limited their activities, and how severely it had limited these activities. Patients were asked to nominate by means of an open-ended question any other major conditions not included in the index.

### ***Quality of Life***

The two global questions from the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) instrument were used.<sup>20</sup> This measure has been validated extensively in a variety of populations, including people with heterogeneous cancer diagnoses<sup>20-23</sup> and palliative care patients.<sup>24</sup> These questions use a 7-point Likert scale where patients identified their overall health and overall quality of life during the week preceding the interview. The scores for the two items were added together and averaged, and then scaled out of 100, with a higher score indicating a greater quality of life.<sup>25</sup>

### ***Supportive Care Needs Survey - Short Form 34 (SCNS-SF34)***

The Supportive Care Needs Survey - Short Form (SCNS-SF34)<sup>14, 26</sup> has been validated with a heterogeneous population of people with cancer<sup>14, 27</sup> and has been used with people with advanced cancer.<sup>10</sup> Each of the 34 items is mapped to five different domains: physical and daily living; psychological; patient care and support; health system and information; and sexuality. The physical and daily living domain assesses needs related to coping with physical symptoms, side-effects of treatment and

performing usual tasks and activities.<sup>26</sup> The psychological domain assesses needs related to emotions and coping.<sup>26</sup> The patient care and support domain assesses needs related to health care providers showing sensitivity to physical and emotional needs, privacy and choice.<sup>26</sup> The health system and information domain assesses needs related to the treatment centre and information about the disease, diagnosis, treatment and follow-up.<sup>26</sup> Finally, the sexuality domain of the SCNS-SF34 assesses needs related to sexuality.<sup>26</sup>

People with cancer are asked to identify the level of concern in the last month for each of the items. The five response options include:

- *No need: not applicable* - this indicates that the item was not a problem for the patient as a result of having cancer.
- *No need: satisfied* - this suggests that the patient did need help with this, but his/her need for help was satisfied at the time.
- *Some need: low need for help* - this suggests that this item caused little concern or discomfort and the patient had little need for additional help.
- *Some need: moderate need for help* - this suggests that the item caused some concern or discomfort and the patient had some need for additional help.
- *Some need: high need for help* - this suggests that the item caused a lot of concern or discomfort and the patient had a strong need for additional help.<sup>26</sup>

### ***Additional need questions***

Included in the interview were six spiritual items and four additional items from the Needs Assessment for Advanced Cancer Patients (NA-ACP) which is a 132-item instrument assessing the needs of people with advanced incurable cancer.<sup>28</sup> The NA-ACP has been found to be a reliable, valid and acceptable instrument, and the spiritual domain of the NA-ACP has excellent internal consistency and test-retest reliability.<sup>28</sup> This instrument uses the same response options as the SCNS-SF34. People with cancer were asked an open-ended question regarding any other issues they were experiencing that were not included in the previous need questions.

### ***Hospital Anxiety and Depression Scale (HADS)***

The 14-item Hospital Anxiety and Depression Scale (HADS)<sup>29</sup> is a self-screening instrument used to detect anxiety and depression. The HADS has been used in a number of studies with people with cancer,<sup>30, 31</sup> and has been validated in various



countries with a variety of medical populations including people with cancer.<sup>32</sup> Of the 14 items, seven assess anxiety and seven assess depression. A score out of 21 is obtained for each subscale, classifying people as normal (score 0-7), borderline (score 8-10) or clinically anxious or depressed (score 11-21).<sup>29</sup> In addition to a separate anxiety and depression sub-scale score, a total HADS score (with a maximum of 42) may be used to measure overall level of distress in people with cancer. Scores of 15 or more have been used in a number of studies of people with cancer to indicate clinically significant distress.<sup>33-35</sup>

### ***Health service use***

Patients were also asked to report on their use of health care providers, support services, and complementary and alternative medicines, using three items. Patients were asked to identify which health care providers they had been referred to in the last month, and whether they had followed up on that referral. If patients had not followed up on the referrals, they were asked to relate any reasons for this. They were also asked to indicate which (if any) support services, and complementary and alternative medicines they had used.

## **6.4.2 The *Palliative Care Needs Assessment Guidelines* and Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C)**

The materials used for the intervention included the *Palliative Care Needs Assessment Guidelines* and Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C). These materials have been described in Chapters 3, 4 and 5.

## **6.5 PROCEDURE**

### **6.5.1 Recruitment sites**

#### ***Newcastle Mater Misericordiae Hospital***

The Newcastle Mater Misericordiae Hospital is a 187-bed facility servicing the Hunter and New England areas in NSW. It is one of the teaching hospitals for the University of Newcastle and is the Hunter region's major centre for oncology services, including cancer outreach services, screening, radiotherapy, pathology, chemotherapy, bone marrow transplants, surgery, stoma care, medical oncology, radiation oncology,

palliative care and allied health. It also has specialist breast, head and neck, leukaemia, lung and melanoma/skin teams. Patients were recruited from the outpatient clinics of the Medical Oncology and Haematology departments.

### ***Cancer Therapy Centre – Liverpool Hospital***

Liverpool Hospital is a large tertiary referral hospital and major trauma centre in South Western Sydney Area Health Service, NSW, and is one of the teaching hospitals for the University of New South Wales. Within the hospital, the Cancer Therapy Centre provides full cancer services, including chemotherapy, lymphoedema and stoma care, surgery, medical oncology, radiation oncology, palliative care and allied health services. It also provides specialist bone, breast, cervical, colorectal, gynaecological, haematology, head and neck, leukaemia, lung, melanoma/skin, ovarian, stomach and oesophageal, prostate, testicular, upper gastro-intestinal tract, and urology teams. Patients for this study were recruited from the radiation oncology outpatient clinics.

### ***Cancer Care Centre - St George Hospital***

St George Hospital is a large accredited principal teaching hospital of the University of New South Wales and designated major trauma service in South Eastern Sydney and Illawarra Area Health Service, NSW. The purpose-built Cancer Care Centre provides cancer genetics and screening, cancer outreach services, chemotherapy, lymphoedema, surgery, medical oncology, radiation oncology, palliative care and allied health services. It also provides specialist breast, cervical, colorectal, gynaecological, haematology, head and neck, lung, ovarian, prostate, testicular and urology teams. Patients were recruited from medical oncology and haematology outpatient clinics.

### ***John Hunter Hospital***

John Hunter Hospital is the principal referral centre, teaching hospital and community hospital for Newcastle, Lake Macquarie and the Hunter Region. It is the only trauma centre in NSW outside Sydney and has the busiest emergency department in the state. The Hunter Centre for Gynaecological Cancer provides urology, gastrointestinal, lymphoedema, surgery and allied health services, and has specialist cervical, gynaecological and ovarian teams. Participants were recruited from the gynaecological oncology outpatient clinic only.

### ***Private clinics***

A small number of participants were also recruited from two private gynaecological oncologists in Newcastle.

## **6.5.2 Ethics**

The study was approved by the following Human Research Ethics Committees:

- University of Newcastle Human Research Ethics Committee
- Hunter New England Area Health Service Human Research Ethics Committee
- Sydney South West Area Health Service Human Research Ethics Committee
- South Eastern Sydney and Illawarra Area Health Service Human Research Ethics Committee.

## **6.5.3 Recruitment**

Three research nurses (RN) were employed for the purpose of identifying and recruiting eligible patients from the outpatient clinic at each of the major cancer centres (Newcastle Mater Misericordiae, Liverpool and St George Hospitals). The CHeRP research team was responsible for the recruitment of patients at the private clinics and at John Hunter Hospital. Each week the research nurse at each site identified eligible people with cancer from the clinic lists for that week. A note was then placed in the medical record of each eligible person to notify his/her clinician of the patient's eligibility for the study. Clinicians or clinic nurses made the initial approach to the person with cancer during the consultation, thus allowing the clinician or clinic nurse to screen out people who were ineligible due to not being emotionally or cognitively capable of participating. Clinicians asked the person with cancer if they would be willing to speak to the research nurse about the study. The research nurse then provided those people who agreed to see her with a verbal explanation of the study and information packs containing an information letter (Appendix 6.2), consent form (Appendix 6.3) and request for results form (Appendix 5.6). The person with cancer was given time and privacy to read the information. Consent could be given immediately, or the information could be taken home and returned to the research nurse or CHeRP research team by post.

The person with cancer was also asked by the research nurse to nominate a caregiver. If the caregiver was present at the clinic at the time of recruitment, the research nurse

provided the caregiver with an information pack, also containing an information letter, consent form and request for results form. If the caregiver was not present, however, the caregiver information was given to the person with cancer who was asked to pass it on to the caregiver. Caregivers who agreed to participate were able to return the consent form to the research team by post. If the person with cancer did not have a caregiver at the time of recruitment, he or she was later asked during the telephone interviews to nominate a caregiver in case circumstances had changed.

Upon receipt of the consent form, paper copies of the interview questions (Appendix 6.1) were mailed to the person with cancer and to the caregiver. The interviewers then contacted participants to arrange times to complete baseline interviews by telephone. Patient participants completed bi-monthly interviews over the course of the study from the time of their recruitment, or until the patient's death or withdrawal. Caregiver participants also completed bi-monthly interviews over the course of the study. If a person with cancer died during that time, the caregiver stopped the bi-monthly interviews and completed a bereavement interview approximately six months after the person's death. Both the person with cancer and the caregiver were able to continue participation if the other withdrew from the study.

#### **6.5.4 Intervention**

Between five and nine months after the beginning of recruitment (depending on recruitment site) the intervention was introduced. It is suggested that for interrupted time series, at least two pre- and two post-intervention data points be available for analysis.<sup>6</sup> In this study, recruitment was staggered at the sites. To ensure that participants had sufficient data points available for analysis, the intervention was also staggered. Hence, for those sites at which recruitment started earlier, the intervention was started earlier.

A systematic review of interventions to change provider behaviour found that guidelines were more effective if active educational interventions and patient-specific reminders were used to disseminate them.<sup>36</sup> The use of workshops and seminars were considered to assist in educating and training clinicians in the use of the *Guidelines* and NAT: PD-C. However, research suggests that educational approaches using self-directed learning vary in effectiveness as health professionals have differences in motivation to attend, change and self-assess.<sup>37</sup> Alternatively, academic detailing

sessions are often more time-efficient than workshops and seminars as they are brief, focused and delivered in the health professionals' own environments,<sup>38</sup> and health professionals have expressed preference for this method along with audit and feedback.<sup>38</sup> For the purpose of the evaluation study, it was decided that an academic detailing approach would be used to inform health professionals about the importance of the *Guidelines* and NAT: PD-C, as well as provide initial training in the use of these resources.

Academic detailing involves training with a limited set of objectives, delivered by expert trainers to individuals in their own environments at their own convenience.<sup>39</sup> As outlined in Chapter 3, academic detailing is a program that requires a trained individual to visit the offices of health professionals, on a one-on-one basis, to provide evidence-based information regarding professional practices.<sup>40</sup> Group and individual academic detailing have both been shown to change health professional behaviours,<sup>41</sup> particularly for those who received individual visits.<sup>42</sup> In this study, both individual and group sessions were used, depending on the availability of health professionals and their perceived degree of involvement. For example, individual sessions were preferred for oncologists and haematologists as well as palliative care service staff. For clinic nurses and allied health staff, group sessions were more widely used. In each session the *Guidelines* and NAT: PD-C were introduced to the health professionals. A number of key issues and potential barriers were identified by the project advisory group prior to these sessions, and these were also discussed within the sessions.

Key academic detailing messages included the following:

1. Referral to palliative care should be on the basis of identifiable physical, psychological, social or spiritual needs of the patient, family or health professional.
2. The *Palliative Care Needs Assessment Guidelines* and NAT: PD-C can improve the physical and psychosocial wellbeing of people with cancer and caregivers by informing health professionals of needs which may otherwise go unnoticed and by improving their ability to assess and respond to these identified needs.
3. The NAT: PD-C can be implemented by any health professional in any care setting, and should be used at multiple time points (approximately monthly) so that changes in needs are identified quickly and easily.

4. The NAT: PD-C differentiates between patients who have:
  - no problems and need no further services
  - minor problems (i.e. low need), which may be met by their primary health professionals or their own support networks
  - medium to high needs, potentially requiring referral for full assessment by specialist services.
5. The NAT: PD-C provides a pathway for referrals to SPCS, as well as a pathway for discharge from SPCS to generalist care once needs are met.

Potential barriers to the uptake of the NAT: PD-C and delivery of palliative care were identified from literature outlined in Chapter 2. These barriers included:

- financial issues (remuneration)
- lack of time
- limited caseload of palliative care patients
- lack of palliative care education and training
- confusion regarding the health professionals' role in transition of patients to palliative care and subsequent care
- lack of communication between patients and health professionals
- lack of communication between specialists and generalist providers.

### **Completing NAT: PD-Cs**

Once the training had been completed at a particular site, the research nurse identified the appointment dates of each patient participant. Prior to each appointment, the research nurse placed a copy of the NAT: PD-C in the medical record of the patient. The research nurse emailed clinicians at the beginning of each week to inform them about which patients had NAT: PD-Cs due that week. At two of the cancer centres, clinicians completed the NAT: PD-C during their consultations with the patients. At the third centre a clinic nurse completed the NAT: PD-C with the patients prior to the consultations. If any needs were identified, the clinician was notified by the clinic nurse, and was given a copy of the NAT: PD-C to discuss with the patient and devise what action would be taken.

Staff members of SPCSs and allied health professionals were asked to complete the NAT: PD-C for each of the patients referred to them at initial assessment and monthly thereafter. General practitioners were sent letters requesting that they complete the

NAT: PD-C at the patients' next appointments. For each NAT: PD-C that was completed on the patient and returned to the research team, the GP was reimbursed \$30 to cover any difference in Medicare payment between a Level B consultation (10-minute consultation) and a Level C consultation (20-minute consultation).

The NAT: PD-C was provided in triplicate. One copy stayed in the medical record of the patient for future reference for the clinician. One copy was collected by the research nurse and returned to CHERP for data entry. The third copy could be used by the clinician as a referral form, if required. This meant that the health professional or service to which the patient was referred had a copy of the completed NAT: PD-C and the concerns identified by the clinician. A NAT: PD-C was completed at every appointment for each patient. However, if the patient had more frequent appointments, the NAT: PD-C was completed approximately monthly.

## **6.6 ANALYSIS**

To examine the effect of the intervention, it was important to conduct analyses that compared the information collected from the CATIs completed immediately prior to the introduction of the intervention to those completed immediately following the introduction of the intervention. Patients were recruited over a 9-month period but patients were exposed to the intervention at different points in the disease process. Therefore, the number of CATIs completed by participants varied depending on how long they had been participating in the study. Some participants had completed as many as five CATIs before the intervention was introduced at their sites, while others had completed as few as two CATIs prior to the intervention being introduced. In addition, each health professional received training at a different time. Hence, an "intervention date" was identified for each individual participant. The date of the patient's first appointment following their own clinician's training acted as their intervention date. The last CATI preceding the intervention date was their last pre-intervention CATI (Time 0), and all CATIs preceding became pre-intervention CATIs. The first CATI that was completed after the intervention date became the first post-intervention CATI (Time 1), and all CATIs completed after this were regarded as post-intervention CATIs.

Descriptive statistics of patient characteristics at baseline and summary measures of their levels of need, anxiety, depression and quality of life at each time point were presented as means and 95% confidence intervals for continuous variables, and as proportions and 95% confidence where the data were categorical. The patients' baseline interview scores for each of these outcomes were examined to determine whether scores varied according to age, gender, presence of a caregiver and level of care-giving provided to them. Statistical significance was assessed using chi square tests for categorical variables and t-tests for continuous outcomes ( $\alpha = 0.05$ ). While some sample characteristics of the caregiver sample are presented in the results chapter, results of the analyses conducted on the outcomes of caregivers are not reported in this dissertation.

For each of the domains in the patient SCNS, having a need was defined as having a "moderate to high" level of need. Therefore, the 5-point Likert scales for each item in that domain were dichotomised into two categories: "No/low need" ("No need/Not applicable", "No need/Satisfied" and "Low need"); and "Mod/high need" ("Moderate need" or "High need"), as described in the manual.<sup>26</sup> Similarly, the anxiety and depression subscales of the HADS were dichotomised into "Normal/Borderline depression" (score of 0-10) and "Clinical depression" (score of 11+). As suggested by Jacobsen (2008), "by evaluating psychosocial interventions with patients experiencing moderate to severe symptoms, future research is likely to yield findings of greater relevance to clinical practice".<sup>43</sup> Quality of life scores remained a continuous variable.

Prior to the main outcome analyses, chi square tests and t-tests were used to compare patients according to the sites from which they were recruited to determine comparability across sites in terms of age, gender, education, marital status, private insurance, co-morbidities, time since diagnosis, type of cancer, anxiety, depression and quality of life. While multiple comparisons were made, the purpose of these comparisons was exploratory and did not set out to confirm that all hypotheses were true simultaneously. Hence, no further statistical adjustments to the significance level ( $p < 0.05$ ) were made. Chi square tests and t-tests were also used to compare patients who completed only one pre-intervention CATI with those who completed more than one pre-intervention CATI, to determine any differences in the same demographic characteristics used in the site comparisons. Finally, chi square tests and t-tests were also used to compare patients who had identified caregivers with those who had no



caregivers, to determine any differences in terms of the same demographic characteristics as the site comparisons.

### **6.6.1 Potential confounders**

Age, gender, time since diagnosis, co-morbidity score and presence of a caregiver were all included as potential confounding variables for patient participants. Age and gender have been shown to be associated with patient perceived unmet needs,<sup>13</sup> anxiety,<sup>44</sup> depression<sup>45</sup> and quality of life.<sup>46</sup> While people with cancer may suffer from other co-morbid conditions, these conditions are often only addressed in the cancer population in terms of exclusion criteria in clinical trials.<sup>47</sup> It is argued that co-morbidities can have an impact on cancer care throughout the cancer trajectory.<sup>47</sup> For the purpose of this study, “presence of a caregiver” denoted patients who had participating caregivers, as well as patients who indicated they had caregivers in any of their CATIs (irrespective of whether their caregivers consented to participate).

### **6.6.2 Generalised Estimating Equation model**

For each patient, level of need, anxiety, depression and quality of life were measured repeatedly over the study. For this reason, a Generalised Estimating Equation (GEE) model was used to analyse the data. This type of modelling is a “multivariate statistical technique that analyses the contribution of one variable to another in a longitudinal design”.<sup>48</sup> Liang and Zeger (1986) proposed the GEE approach to handle correlated responses obtained in longitudinal studies.<sup>49</sup> Other statistical approaches require that the “data should have no missing data at any time points and equal observations for all units across time points are necessary.”<sup>49</sup> However, GEE allow patients to be compared even when they have different numbers of observations, in this case, the numbers of CATIs completed. This is particularly useful in longitudinal studies with people with high likelihood of attrition due to mortality.<sup>48</sup> In this study the GEE model fit time as a factor and also analysed the number of CATIs completed as an interaction variable. The GEE analyses were run for both continuous and categorical outcome variables, adjusting for the potential confounders listed above, to ascertain whether the intervention had any impact on patient outcomes. While analyses were conducted for caregiver participants, these findings are not reported in this dissertation.

### 6.6.3 Service utilisation and referral patterns

#### ***Feasibility and acceptability of the NAT: PD-C***

##### *Completion rate*

The uptake of the NAT: PD-C was also examined within the outpatient clinic setting by comparing the number of NAT: PD-Cs that were due for completion for each patient during the study (depending on the regularity of their appointments) with the number of NAT: PD-Cs that were actually completed.

##### *Consistency of NAT: PD-C ratings with patient self-reported needs*

Data from patient interviews and NAT: PD-Cs completed within a week of each other were compared to determine whether patients and health professionals reported the types of needs being experienced by patients in a similar way. The levels of concern recorded in the patient physical, psychological, information and spiritual domains in the NAT: PD-C were compared with the levels of need reported by patients in the physical symptom and daily living, psychological, and health system and information domains of the SCNS, as well as the spirituality domain of the NA-ACP. Consistency was assessed by dichotomising the levels of concern for each domain in the NAT: PD-C (“None” versus “Some/Significant”), while for each of the SCNS and NA-ACP domains, the response options were dichotomised (“No need” versus “At least one need”) to determine whether patients and health professionals agreed on the presence or absence of a concern. Cohen’s kappa<sup>50</sup> and the prevalence- and bias-adjusted kappa (PABAK) statistic<sup>51</sup> were used to assess the consistency between the domains. Only people for whom a NAT: PD-C was completed within one week of an interview (n=67) were included in the analysis. Agreement ranging from 0.2 to 0.4 was considered fair, from 0.4 to 0.6 moderate, from 0.6 to 0.8 substantial and from 0.8 to 1 almost perfect.<sup>50</sup>

##### *Length of consultation*

A sub-sample of Newcastle Mater Misericordiae patients participating in the evaluation study was approached for consent for a number of their consultations to be audio-taped by the research team. Clinicians were also asked for consent for the audio-taping of consultations. Each patient had at least two consultations audio-taped, unless they died or withdrew from the main study. The research nurse attended the clinic for each consenting participant, started the tape at the beginning of the consultation and then left the consultation room. The research nurse remained in the clinic waiting area to stop the tape when the consultation ended (ie when the patient left the room). In cases

when the research nurse was unable to be present at the scheduled consultation, reminder notes were placed in the files of participating patients to prompt clinicians to tape the consultations. All tapes were collected by the research nurse for transcription by members of the research team. Copies of the tapes of their own consultations were provided to patients upon request. Consultation times were presented as means and medians.

### ***Issues of concern and actions to address identified concerns recorded using the NAT: PD-C***

The date of completion of each NAT: PD-C, the levels of need recorded on each NAT: PD-C, and the actions taken to meet identified unmet needs (including referrals to health professionals and/or services) were identified. From the total possible number of items of need from the completed NAT: PD-Cs, the proportion of items rated as being of “Some/Potential” or “Significant” levels of concern, and the proportion of these items with proposed actions to meet the identified needs, were determined.

### ***Service use and referrals: CATIs***

Patients were asked in each of their interviews which health professionals or services they had been referred to in the month preceding the interview and which of these referrals had been taken up. Patients who did not see the health professionals even after they were referred were also asked the reasons. Patients were also asked about the support services and the complementary or alternative medicine services they had used in the previous month. Using self-report CATI information, the mean numbers of health professionals to whom referrals were suggested at each time point pre- and post-intervention were determined. Any change in the number of health professionals seen over time was assessed using GEE. This analysis included only the participants reporting a referral to at least one health professional in their interviews.

### ***Service use and referrals: audit of medical records***

Each patient’s medical record was audited to determine the dates of referral to health professional/services and the dates on which the patient was seen by these health professional/services (Appendix 6.4). The information retrieval covered the period from the date of patient consent to participate in the study until the end of the study or the patient’s death. The mean numbers of health professionals seen by patients in the 12

months prior to their deaths and the mean numbers of consultations with all health professionals prior to their deaths are presented.

The results of the analyses are reported in Chapters 7 and 8.

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# **CHAPTER 7:**

## **IMPACT OF THE PALLIATIVE CARE NEEDS ASSESSMENT INTERVENTION ON PATIENT OUTCOMES**



## **7.1 INTRODUCTION**

The previous chapter summarised the methods of a study to evaluate the *Palliative Care Needs Assessment Guidelines* and Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C). The aims of the study were two-fold: to assess the impact of the systematic and ongoing use of the *Guidelines* and NAT: PD-C on patient outcomes, including level of need, quality of life, anxiety and depression, and to assess their impact on service use and referral patterns. The results from this study will therefore be reported in two separate chapters. This aim of this chapter is to profile the participant sample and report on the the results of the impact of the intervention on patient outcomes, including unmet needs, quality of life, anxiety and depression. Chapter 8 will report on the impact of the intervention on clinical assessment, response and service utilisation.

## **7.2 KEY PERFORMANCE INDICATORS**

### **7.2.1 Computer-assisted telephone interviews completed**

A total of 219 patients consented to participate, and during the course of the study a total of 915 patient computer-assisted telephone interviews (CATIs) were completed (mean = 4.16; SD = 2.69). As recruitment was progressive over a period of approximately 15 months, participants recruited in the early stages completed a greater numbers of CATI interviews, as detailed in Table 7.1.

Table 7.1: Number of completed CATIs

Number of CATIs completed	Number of patients
0	24
1	22
2	17
3	34
4	27
5	18
6	19
7	30
8	17
9	11
<b>Total CATIs completed</b>	<b>915</b>

## 7.2.2 Needs Assessment Tool: Progressive Disease - Cancer completed

In addition to the extensive number of CATIs completed, information was collected about the participants' levels of need and service use, using the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C). A total of 342 NAT: PD-Cs were completed for 120 patients across all study sites (Table 7.2). There was a significant association between number of NAT: PD-Cs completed in each clinical setting and recruitment site, with 75% of NAT: PD-Cs completed at the Newcastle Mater Misericordiae site ( $\chi^2=27.94$   $df=6$   $p<0.001$ ).

Table 7.2: Number of NAT: PD-Cs completed by different health care providers at each recruitment site

Site	Number of NAT: PD-Cs completed				p-value
	Clinic n (%)	GP n (%)	SPCS n (%)	Total n	
Newcastle Mater	188 (73)	45 (17)	25 (10)	258	<0.001
St George	19 (51)	5 (14)	13 (35)	37	
Private clinics	10 (100)	0	0	10	
Liverpool	20 (54)	7 (19)	10 (27)	37	
<b>Total</b>	<b>237(69)</b>	<b>57 (17)</b>	<b>48 (14)</b>	<b>342</b>	

## 7.2.3 Recruitment

Table 7.3 reports on the recruitment numbers for each of the sites for patient participants. The response rate was calculated by dividing the number of eligible participants (identified through weekly clinic lists) by the number of participants who consented to the study. The consent rates were calculated by dividing the number of

participants who discussed the study with the research nurse (RN) by the number of people who consented. These recruitment rates are also illustrated in Figure 7.1. A significant association between recruitment site and recruitment rate was found ( $\chi^2=45.25$   $df=12$   $p<0.001$ ); the Liverpool site had a greater recruitment rate but over a much lower sample size.

*Table 7.3: Recruitment response and consent rates for patient participants by site*

	<b>Newcastle Mater (n)</b>	<b>Liverpool (n)</b>	<b>St George (n)</b>	<b>Private clinics &amp; JHH (n)</b>	<b>Total (n)</b>
Eligible	428	71	96	18	613
Approached by clinician	422	68	94	18	602
Discussed with RN	252	61	82	16	411
Consented	117	56	35	11	219
Response rate (%)	27%	79%	36%	61%	36%
Consent rate (%)	46%	92%	43%	69%	53%

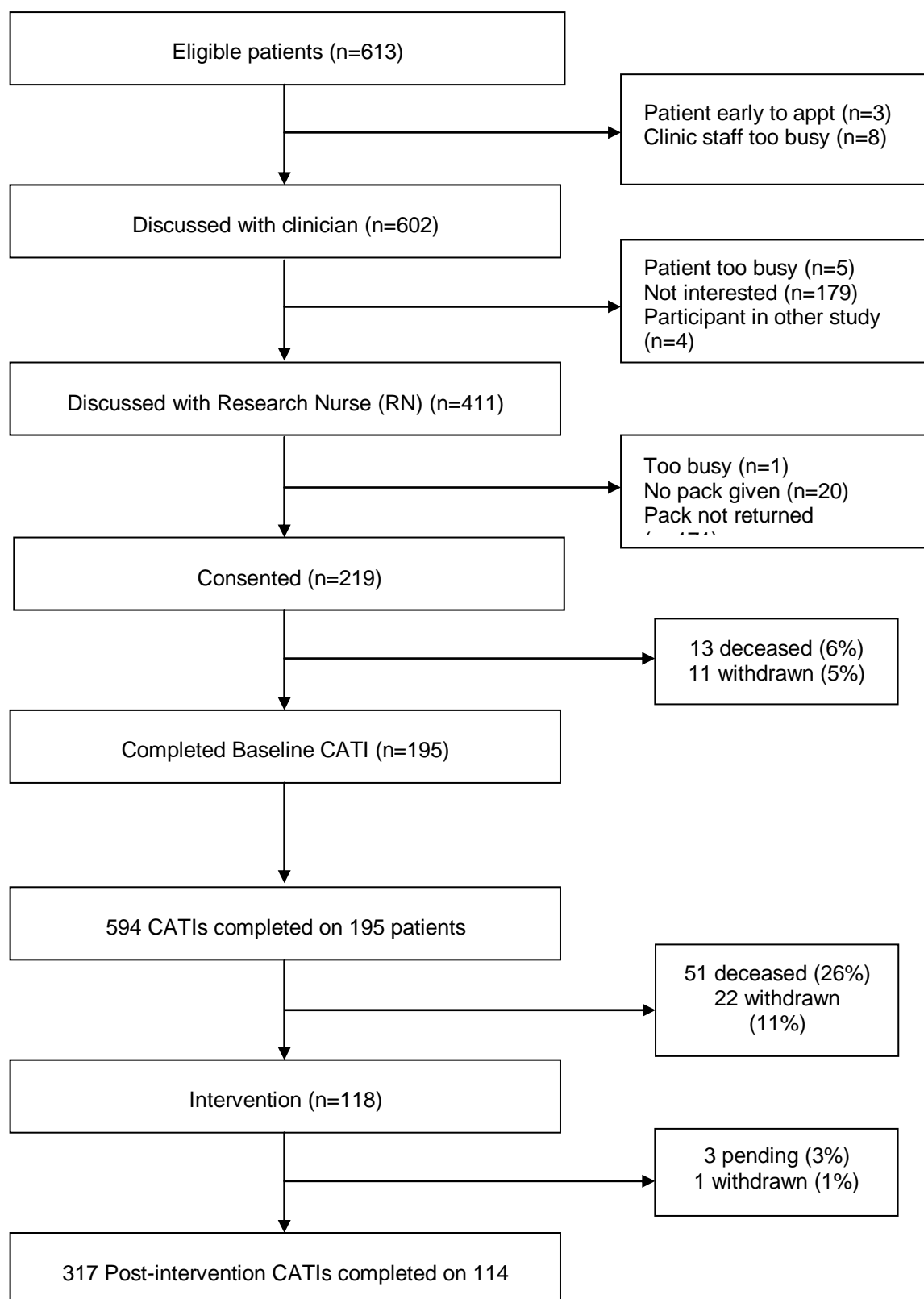


Figure 7.1: Summary flowchart of patient recruitment and data collection

## 7.2.4 Study sample size

A total of 219 participants consented to participate in the study. At the end of data collection 100 participants (46%) were still actively involved in the study (see Table 7.4). Of the 119 patients who were no longer actively involved in the study, 77 (65%) were deceased and 42 (35%) had withdrawn. The majority of these withdrawals occurred because the patients had declining health (n=17), they could not be contacted (n=11), they were no longer interested (n=5), they were refused by a third party (n=2) or dropped out themselves (n=3), they were too busy (n=2) or for other reasons (n=2).

Table 7.4: Status of participants by site at study completion

Site	Patient participants							
	Active		Withdrawn		Deceased		Total	
	N	%	N	%	N	%	N	%
Newcastle Mater Misericordiae	60	51	19	16	38	32	117	100
Liverpool	23	41	17	30	16	29	56	100
St George	12	34	4	11	19	54	35	100
Private clinics and John Hunter Hospital	5	45	2	18	4	36	11	100
<b>Total</b>	<b>100</b>	<b>46</b>	<b>42</b>	<b>19</b>	<b>77</b>	<b>35</b>	<b>219</b>	<b>100</b>

The status of participants was examined to determine whether recruitment sites had different rates of people who were active, withdrawn or deceased during the study period. No statistically significant association was found between recruitment site and status of patient participants ( $\chi^2=11.98$   $df=6$   $p=0.06$ ).

## 7.3 PARTICIPANT CHARACTERISTICS AT BASELINE

As the patient sample was recruited from a number of clinical settings in metropolitan and regional NSW, the demographic profile of study participants was compared with a NSW cancer population, as detailed in Table 7.5.<sup>1</sup> The two groups were comparable with respect to gender ( $\chi^2=1.11$   $df=1$   $p=0.29$ ) but differed in the age profile ( $\chi^2=19.86$   $df=5$   $p<0.01$ ). Where significant chi square comparisons were found, z-tests were used to determine the levels of the demographic or outcome variables at which the

differences occurred. It was found that, compared with the NSW cancer population, those aged 65 to 74 years were over-represented in the study sample ( $z=2.02$ ,  $p<0.05$ ) and those aged 75 years and over were under-represented ( $z=-2.44$ ,  $p<0.05$ ). A significant association was also found with respect to cancer type ( $\chi^2=103.8$   $df=7$   $p<0.001$ ). People with lymphoid and haematopoietic diagnoses were over-represented in the study sample ( $z=6.74$ ,  $p<0.01$ ), as were females with breast ( $z=2.51$ ,  $p<0.05$ ) and female genital cancers ( $z=6.34$ ,  $p<0.001$ ). Males with prostate cancer were under-represented ( $z=-2.37$ ,  $p<0.05$ ), as were people with diagnoses not represented in the eight diagnosis categories reported ( $z=-6.70$ ,  $p<0.001$ ).

Chi square comparison between the study sample and Australian census data found a significant association with respect to marital status ( $\chi^2=200652.26$   $df=4$   $p<0.001$ ). A greater percentage of the study sample were married ( $z=4.80$ ,  $p<0.001$ ) or widowed ( $z=5.52$ ,  $p<0.001$ ), while a lower percentage had single ( $z=-8.86$ ,  $p<0.001$ ) or *de facto* marital status ( $z=18.75$ ,  $p<0.001$ ). Finally, a significant association was found in terms of gross income ( $\chi^2=215.61$   $df=4$   $p<0.001$ ). A greater percentage of the study participants had incomes of less than \$300 a week ( $z=6.38$ ,  $p<0.001$ ) and incomes of between \$300 and \$499 per week ( $z=11.47$ ,  $p<0.001$ ), while a lower percentage had incomes of more than \$1000 a week when compared with all Australian households<sup>2</sup> ( $z=-11.93$ ,  $p<0.001$ ).

Table 7.5: Demographic profile of patient sample at baseline compared with a NSW cancer population, all Australian households and all Australians

Characteristics	Patient sample	Reference population	p-value
	%	%	
	n=198		
<b>Age (Mean = 66.1, SD=10.7; range 31-89 years) <sup>a</sup></b>			
0-34 years	1.0	3.4	<0.01
35-44 years	2.0	5.0	
45-54 years	12.1	11.6	
55-64 years	24.8	22.2	
65-74 years	36.4	25.9	
75+ years	23.7	31.8	
<b>Gender <sup>a</sup></b>			
Male	53.0	56.8	0.29
Female	47.0	43.2	
<b>Marital status <sup>c</sup></b>			
Married	66.7	49.6	<0.001
Widowed	15.2	5.9	
Separated or divorced	13.6	11.3	
Never married or single	3.5	33.2	
<i>De facto</i> or living with a partner	1.0	-	
<b>Gross income <sup>b</sup></b>			
Less than \$300 per week	25.6	11.2	<0.001
\$300-\$499 per week	39.3	12.3	
\$500-\$799 per week	17.3	15.3	
\$800-\$1000 per week	8.4	9.3	
More than \$1000 per week	9.4	51.9	
<b>Diagnosis <sup>a</sup></b>			
Digestive	22.2	18.5	<0.001
Lymphoid, haematopoietic	20.2	7.5	
Breast	17.7	11.9	
Prostate	11.1	17.5	
Female genital	7.6	1.7	
Urinary	7.1	4.7	
Lung	6.6	8.9	
other	7.6	29.3	

<sup>a</sup> compared with sample (n=35,159) from *Cancer in NSW Incidence and Mortality 2006*<sup>1</sup>

<sup>b</sup> compared with all Australian households (n=7,926,200) from *Household Income and Income Distribution, Australia, 2005-06*<sup>2</sup>

<sup>c</sup> compared with all Australians (n=19,855,288) from *Census of Population and Housing, 2006*.<sup>3</sup>

The demographic characteristics of study participants for which there was no comparative data reported are detailed in Table 7.6. For three-quarters of study participants, the highest level of education was secondary school, or certificate or diploma. Half of the participants had no private health insurance, and 73% of participants' initial diagnoses of cancer were more than 1 year prior to the CATI.

*Table 7.6: Demographic profile of patient sample at baseline.*

Characteristics	Patient sample
	% n=198
<b>Education</b>	
Primary school	8.6
Secondary school	54.0
Certificate or diploma	27.8
University degree	9.6
<b>Health insurance</b>	
No, Medicare only	52.8
Hospital cover only	10.7
Ancillary or extras cover only	2.0
Hospital and ancillary or extras	34.5
<b>Initial cancer diagnoses</b>	
Within last month	0.5
1-12 months ago	26.3
>1-5 years ago	34.7
>5-10 years ago	21.7
More than 10 years ago	16.8

### 7.3.1 Type of diagnosis - baseline differences

The five most common diagnoses of study participants were digestive, lymphoid/haematopoietic, breast, prostate and female genital cancers (see Table 7.5). In this study, the digestive category included people with colon, rectal, oesophageal, pancreatic and stomach cancers. The lymphoid/haematopoietic category included people with leukaemia, lymphomas and myelomas. Female genital category included people with ovarian and uterine cancer. The urinary category included people with renal and bladder cancers. Finally, the "other" category included people with all remaining cancers in the sample (in this study, melanoma, skin, brain, merkel cell, bone, thyroid and mouth cancers).



Comparisons were undertaken to determine whether there was any association between cancer diagnosis and a number of baseline outcome variables. Quality of life did not differ by diagnosis ( $F(7, 189)=1.33, p=0.24$ ). There was no association between the percentage of people with identified needs physical and daily living, ( $\chi^2=3.89 df=7 p=0.79$ ), psychological ( $\chi^2=10.89 df=7 p=0.14$ ), health system and information ( $\chi^2=13.45 df=7 p=0.06$ ), patient care and support ( $\chi^2=9.19 df=7 p=0.24$ ), sexuality ( $\chi^2=5.78 df=7 p=0.57$ ) or spirituality needs ( $\chi^2=12.35 df=7 p=0.09$ ) and cancer diagnosis. There was no association between clinical depression ( $\chi^2=3.98 df=7 p=0.78$ ), anxiety ( $\chi^2=3.57 df=7 p=0.83$ ) or distress ( $\chi^2=2.51 df=7 p=0.93$ ) and diagnosis at baseline.

### 7.3.2 Employment status

Study participants' employment status 12 months prior to diagnosis was compared with their employment status at the time of their baseline interviews (see Table 7.7). There was a significant association between employment status and time ( $\chi^2=35.52 df=4 p<0.001$ ). A greater percentage of participants were employed in the 12 months prior to their diagnosis compared with at the time of their initial interview ( $z=10.34, p<0.001$ ), while a higher percentage were unemployed, retired or on disability pensions at the time of their initial interviews ( $z=-7.79, p<0.001$ ).

Table 7.7: Employment status of study participants

Employment status	12 months prior to diagnosis	At time of interview	p-value
	n (%)	n (%)	
Employed	66 (33.4)	21 (10.6)	<0.001
On leave	1 (0.5)	4 (2.0)	
Unemployed/retired	107 (54.0)	153 (77.3)	
Household duties	16 (8.08)	17 (8.6)	
Other	8 (4.0)	3 (1.5)	

### 7.3.3 Geographical region

Using the Accessibility/Remoteness Index of Australia (ARIA) classification<sup>4</sup>, 76% of study participants resided in major cities, 19% in inner regional areas and 5% in outer regional areas. Due to the small number of people from outer regional areas, the sub-groups were dichotomised into participants from major cities (n=144) and participants

from both inner and outer regional areas (n=48) before being compared at their initial interviews. Comparisons were undertaken to determine whether there were any differences between people from different geographical regions on a number of demographic and outcome variables (see Table 7.8). The only significant association was found between depression and geographical region ( $\chi^2=5.62$   $df=1$   $p<0.05$ ). Specifically, a greater percentage of people from major cities were classified as normal (77.5%) compared with people from regional areas (22.5%) ( $z=6.86$ ,  $p<0.001$ ).

*Table 7.8: Comparisons of patient demographic and baseline outcome variables according to geographical residence*

Variable	N	Major cities	Regional	p-value
Age				0.52
Young (under 65 years)	56	80.0	20.0	
Old (65 years and over)	142	74.6	25.4	
Gender				0.91
Male	103	75.7	24.3	
Female	92	75.0	25.0	
Marital status				0.11
Partner	132	72.0	28.0	
No partner	63	82.5	17.5	
Education				0.44
Primary	17	88.2	11.8	
Secondary	105	71.4	28.6	
Certificate/diploma	54	77.8	22.2	
University	19	79.0	21.0	
Gross income				0.43
Less than \$300 per week	48	83.3	16.7	
\$300-\$499 per week	75	73.3	26.7	
\$500-\$799 per week	32	68.7	31.3	
\$800-\$1000 per week	16	81.2	18.8	
More than \$1000 per week	17	64.7	35.3	
Co-morbidity score				0.16
None	51	64.7	35.3	
1	32	84.9	15.1	
2	33	75.0	25.0	
3 or more	80	78.8	21.2	
Time since diagnosis				0.62
Mean (months)	194	70.1	63.4	
Type of diagnosis				0.99
Lung	13	76.9	23.1	
Breast	34	76.5	23.5	
Prostate	22	72.7	27.3	
Digestive	43	76.7	23.3	
Lymphoid	40	72.5	27.5	
Female genital	15	73.3	26.7	
Urinary	14	78.6	21.4	
Other	14	78.6	21.4	

Variable	N	Major cities	Regional	p-value
Depression				<0.05
Normal/borderline (Hospital & Anxiety Depression Scale (HADS) score 0-10)	173	77.5	22.5	
Clinical (HADS score 11+)	19	52.6	47.4	
Anxiety				0.07
Normal/borderline (HADS score 0-10)	179	76.5	23.5	
Clinical (HADS score 11+)	13	53.9	46.1	
Distress				0.68
Normal/borderline (HADS score 0-14)	152	75.7	24.3	
Clinical (HADS score 15+)	40	72.5	27.5	
Quality of life				0.24
European Organization for Research and Treatment of Cancer QLQ C30 (EORTC QLQ C30)				
Mean score	194	60.9	64.9	

### 7.3.4 Co-morbid conditions

The most common co-morbidity reported by study participants was high blood pressure, followed by arthritis, depression, respiratory illness and diabetes, as indicated in Table 7.9. Based on the Charlson index,<sup>5</sup> scores on the 12 items corresponding to 12 different conditions were also obtained, with 26% of study participants reporting no co-morbidities, as indicated in Table 7.10.

Table 7.9: Types of co-morbid conditions reported by study participants

Co-Morbidity	Number of patients	Percent of patients
High blood pressure	85	42.9
Arthritis	74	37.4
Depression	49	24.8
Respiratory	48	24.2
Diabetes	27	13.6
Ischemic heart disease	27	13.6
Liver disease	13	6.6
Inflammatory bowel disease	12	6.1
Cerebrovascular accident	9	4.6
Heart failure	7	3.5
Rectal ulcers	6	3.0

Table 7.10: Co-morbidity scores of study participants

Co-morbidity score (maximum co-morbidity score 20)	Number of patients	Percent of patients
0	52	26.2
1	33	16.7
2	32	16.2
3	33	16.7
4	22	11.0
5	12	6.1
6	11	5.6
7	3	1.5

A number of comparisons were undertaken to determine whether co-morbidity score had any effect on reported level of need, clinical depression, anxiety, distress or quality of life. The co-morbidity score was analysed by organising scores into categories of 0, 1, 2 and 3+, as previously analysed by Hoffman *et al* in the Prostate Cancer Outcomes Study.<sup>6, 7</sup> In terms of quality of life, participants with co-morbidity scores of 3 or more had lower quality of life compared with those with co-morbidity scores of zero (mean 58.3 *versus* 66.7,  $F(2, 193)=2.81$ ,  $p<0.05$ ). The percentage of people with at least one need in the physical and daily living domain also varied according to co-morbidity score ( $\chi^2=8.10$   $df=3$   $p<0.05$ ); those with higher co-morbidity scores were more likely to have at least one physical and daily living need. However, there were no differences in the psychological ( $\chi^2=6.65$   $df=3$   $p=0.08$ ), health system and information ( $\chi^2=0.51$   $df=3$   $p=0.92$ ), patient care and support ( $\chi^2=1.51$   $df=3$   $p=0.68$ ), sexuality ( $\chi^2=1.57$   $df=3$   $p=0.67$ ) or spirituality ( $\chi^2=0.25$   $df=3$   $p=0.97$ ) domains, based on co-morbidity scores. Co-morbidity scores were also not associated with levels of clinical depression ( $\chi^2=3.76$   $df=3$   $p=0.29$ ), anxiety ( $\chi^2=3.17$   $df=3$   $p=0.37$ ) or distress ( $\chi^2=4.13$   $df=3$   $p=0.25$ ).

## 7.4 PARTICIPANT CHARACTERISTICS IN RELATION TO RECRUITMENT SITE, NUMBER OF PRE-INTERVENTION DATA COLLECTION POINTS AND PRESENCE OF A CAREGIVER

### 7.4.1 Recruitment site

Prior to the main analyses, comparisons were made based on recruitment site to determine comparability across these sites in a number of demographic characteristics and outcomes at baseline (see Table 7.11). Comparisons were made between the three main recruitment sites: Newcastle Mater Misericordiae Hospital, Liverpool Hospital and St George Hospital. Liverpool Hospital participants (n=40) reported significantly lower quality of life scores, compared with Newcastle Mater Misericordiae participants (n=115) (mean score 54.2 *versus* 64.4,  $F(2, 184)=3.63$ ,  $p<0.05$ ). Recruitment site was also associated with type of diagnosis ( $\chi^2=46.09$   $df=14$   $p<0.001$ ; Table 7.12).

*Table 7.11: Comparisons of participants' demographic and baseline outcome variables across recruitment sites*

Variable	N	Liverpool	Newcastle	St George	p-value
Age					0.42
Young (under 65 years)	29	22	13.9	12.5	
Old (65 years and over)	159	78	86.1	87.5	
Gender					0.99
Male	105	56.1	55.7	56.3	
Female	83	43.9	44.3	43.7	
Marital status					0.30
Partner	128	63.4	72.2	59.4	
No partner	60	36.6	27.8	40.6	
Education					0.37
Primary	15	14.6	6.1	6.2	
Secondary	101	51.2	57.4	43.8	
Certificate/diploma	54	29.3	27.0	34.4	
University	18	4.9	9.5	15.6	
Gross income					0.06
Less than \$300 per week	46	40.5	18.6	32.3	
\$300-\$499 per week	70	35.1	43.4	25.8	
\$500-\$799 per week	31	10.8	20.3	12.9	
\$800-\$1000 per week	16	5.4	7.1	19.3	
More than \$1000 per week	18	8.1	10.6	9.7	
Co-morbidity score					0.39
None	53	30.9	27.8	25.0	
1	32	26.2	13.0	18.8	
2	29	11.9	14.8	21.9	
3 or more	75	31.0	44.4	34.4	

Variable	N	Liverpool	Newcastle	St George	p-value
Time since diagnosis					0.17
Mean (months)	189	47.7	75.3	64.9	
Type of diagnosis					<0.001
Lung	13	17.1	2.6	9.4	
Breast	35	19.5	19.1	15.6	
Prostate	22	17.1	12.2	3.1	
Digestive	44	12.2	23.5	37.5	
Lymphoid	40	2.4	31.3	9.4	
Female genital	6	2.4	3.5	3.1	
Urinary	14	9.8	5.2	12.5	
Other	14	19.5	2.6	9.4	
Depression					0.36
Normal (HADS score 0-10)	167	87.2	92.2	84.4	
Clinical (HADS score 11+)	19	12.8	7.8	15.6	
Anxiety					0.64
Normal (HADS score 0-10)	173	92.3	92.2	96.9	
Clinical (HADS score 11+)	13	7.7	7.8	3.1	
Distress					0.71
Normal (HADS score 0-14)	147	74.4	83.5	84.4	
Clinical (HADS score 15+)	39	25.6	16.5	15.6	
Quality of life					<0.001
Mean score	189	54.2	64.4	61.5	

Table 7.12: Primary cancer diagnoses of study participants across recruitment sites

Cancer diagnosis	n (%) of participants at each recruitment site		
	Newcastle Mater Hospital (n=115)	Liverpool Hospital (n=41)	St George Hospital (n=32)
Lymphoid haematopoietic	36 (31)	1 (2)	3 (9)
Digestive	27 (23)	5 (12)	12 (38)
Breast	22 (19)	8 (20)	5 (16)
Male urogenital	17 (15)	13 (32)	4 (13)
Female urogenital	5 (4)	1 (2)	2 (6)
Lung	3 (3)	7 (17)	3 (9)
Other	3 (3)	8 (20)	3 (9)

#### 7.4.2 Number of pre-intervention CATIs completed

Comparisons were also made between participants who completed only one pre-intervention CATI (n=28) and those participants who completed more than one pre-intervention CATI (n=167) to determine if there were any differences in demographic characteristics (Table 7.13). Participants who had more than one pre-intervention CATI had a greater mean time since diagnosis (months) compared with those with only one pre-intervention CATI (mean 59.9 *versus* 20.7;  $t(192)=-2.15$ ,  $p<0.05$ ). There were no other significant differences between the two groups.

*Table 7.13: Comparisons of demographic and baseline outcome variables based on number of pre-intervention CATIs completed*

Variable	N	1 pre-intervention CATI	> 1 pre-intervention CATI	p-value
Age				0.18
Young (under 65 years)	32	25.0	15.0	
Old (65 years and over)	163	75.0	85.0	
Gender				0.66
Male	104	57.1	52.7	
Female	91	42.9	47.3	
Marital status				0.39
Partner	132	60.7	68.9	
No partner	63	39.3	31.1	
Education				0.99
Primary	16	7.1	8.4	
Secondary	105	53.6	53.9	
Certificate/diploma	55	28.6	28.1	
University	19	10.7	9.6	
Gross income				0.16
Less than \$300 per week	47	40.8	22.4	
\$300-\$499 per week	75	37.0	40.4	
\$500-\$799 per week	32	11.1	18.0	
\$800-\$1000 per week	16	0	9.9	
More than \$1000 per week	18	11.1	9.3	
Co-morbidity score				0.61
None	52	25.0	26.9	
1	33	25.0	15.6	
2	32	17.9	16.2	
3 or more	78	32.1	41.3	
Time since diagnosis				<0.001
Mean (months)	194	20.7	59.9	
Type of diagnosis				0.08
Lung	13	10.7	6.0	
Breast	35	17.9	17.9	
Prostate	22	14.3	10.8	
Digestive	43	32.1	20.3	
Lymphoid	40	3.6	23.4	
Female genital	15	0	9.0	
Urinary	14	7.1	7.2	
Other	13	14.3	5.4	
Depression				0.52
Normal (HADS score 0-10)	174	85.7	89.8	
Clinical (HADS score 11+)	21	14.3	10.2	
Anxiety				0.42
Normal (HADS score 0-10)	181	96.4	92.2	
Clinical (HADS score 11+)	14	3.6	7.8	
Distress				0.33
Normal (HADS score 0-14)	153	71.4	79.6	
Clinical (HADS score 15+)	42	28.6	20.4	
Quality of life				0.77
Mean score	194	51.9	59.3	

### 7.4.3 Presence of a caregiver

Of consenting participants, 85% indicated that they had a caregiver (n=186).

Comparisons were made between patients who identified caregivers and those who reported having no caregiver at any time during the study period, to determine whether there were any differences in demographic and outcome variables (Table 7.14).

Patients with partners were more likely to also have caregivers ( $\chi^2=17.32$   $df=1$   $p<0.001$ ). There was also a significant association between presence of a caregiver and gross income ( $\chi^2=20.64$   $df=4$   $p<0.001$ ); a greater percentage of people with caregivers had gross incomes of between \$300 and \$499 per week ( $z=5.18$ ,  $p<.0001$ ). Table 7.15 details the gross household incomes reported by study participants with and without caregivers.



*Table 7.14: Comparisons of demographic and baseline outcome variables for study participants with and without caregivers*

<b>Variable</b>	<b>N</b>	<b>No caregiver</b>	<b>Caregiver</b>	<b>p-value</b>
Age				0.93
Young (under 65 years)	77	40	39.3	
Old (65 years and over)	118	60	61.7	
Gender				0.92
Male	104	52.7	53.6	
Female	91	47.3	46.4	
Marital status				<0.001
Partner	132	45.4	76.4	
No partner	63	54.6	33.6	
Education				0.66
Primary	16	10.9	7.1	
Secondary	105	47.3	56.4	
Certificate/diploma	55	30.9	27.1	
University	19	10.9	9.3	
Gross income				<0.001
Less than \$300 per week	47	41.8	18.0	
\$300-\$499 per week	75	21.8	22.4	
\$500-\$799 per week	32	25.4	13.5	
\$800-\$1000 per week	16	5.5	9.8	
More than \$1000 per week	18	5.5	11.3	
Co-morbidity score				0.10
None	52	25.4	27.2	
1	33	16.4	17.1	
2	32	7.3	20.0	
3 or more	78	50.9	35.7	
Time since diagnosis				0.80
Mean (months)	194	65.6	69.0	
Type of diagnosis				0.98
Lung	13	7.3	6.5	
Breast	35	20.0	17.1	
Prostate	22	10.9	11.4	
Digestive	43	25.4	20.8	
Lymphoid	13	16.4	22.1	
Female genital	40	7.3	7.9	
Urinary	15	7.3	7.1	
Other	14	5.4	7.1	
Depression				0.63
Normal (HADS score 0-10)	174	90.9	88.6	
Clinical (HADS score 11+)	21	9.1	11.4	
Anxiety				0.97
Normal (HADS score 0-10)	181	92.7	92.9	
Clinical (HADS score 11+)	14	7.3	7.1	
Distress				0.74
Normal (HADS score 0-14)	153	80.0	77.9	
Clinical (HADS score 15+)	42	20.0	22.1	
Quality of life				0.96
Mean score	194	62.0	62.2	

*Table 7.15: Gross household income reported by study participants with and without caregivers*

Gross household income	n (%) of participants	
	Caregiver	No caregiver
Less than \$300 per week	24 (18)	23 (42)
\$300-\$499 per week	63 (47)	12 (22)
\$500-\$799 per week	18 (14)	14 (26)
\$800-\$1000 per week	13 (10)	3 (5)
More than \$1000 per week	15 (11)	3 (5)

## 7.5 IMPACT OF THE INTERVENTION ON SUPPORTIVE CARE NEEDS

During each interview, patients were asked to indicate their levels of need for each item on the Supportive Care Needs Survey Short Form (SCNS-SF34).<sup>8,9</sup>

### 7.5.1 Baseline prevalence of needs

Table 7.16 presents data from the baseline CATI. Approximately one-third of the sample reported moderate or high need for help with "Not being able to do the things you used to do", with the highest levels of need overall in the physical and daily living, and psychological domains (see Appendix 7.1 for full list). At baseline, 37% of the sample did not report having any moderate or high needs in any of the domains.

*Table 7.16: Top ten items for which participants reported a moderate or high need for help in the month preceding the baseline CATI*

SCNS items	% with moderate /high need	Domain
Not being able to do the things you used to do	33.0	Daily living
Concerns about the worries of those close to you	27.9	Psychological
Lack of energy/tiredness	26.2	Daily living
Work around the home	23.0	Daily living
Uncertainty about the future	21.4	Psychological
Pain	20.9	Daily living
Worry that results of treatment are beyond your control	19.4	Psychological
Fears about the cancer spreading	18.8	Psychological
Feeling unwell a lot of the time	17.3	Daily living
Anxiety	15.3	Psychological

Analyses were conducted to determine whether the presence of a caregiver, the level of caregiving provided and the participant's gender and age had an impact on whether they reported a moderate or high need in any of the domains of the SCNS-SF34 (see Table 7.17). A significant association was found between age and the percentage of people reporting a moderate or high need in the psychological, health system and information, patient care and support and spirituality domains; with a lower percentage of older people reporting needs in each domain. A significant association was found between gender and the percentage of people reporting a moderate or high need in the physical and daily living and spirituality domains; with a greater percentage of females reporting needs. Finally, a greater percentage of patients with caregivers who provided day-to-day care reported a moderate or high physical symptom and daily living need. No other significant associations were found.

*Table 7 17: Chi square comparisons for the percentage of study participants reporting a moderate or high need in the SCNS-SF34 domains based on age, gender, presence of a caregiver and level of caregiving.*

SCNS-SF34 domains	% reporting a moderate or high need	Chi square	df	p-value
<b>Psychological</b>				
Age				
Young (under 65 years) (n=56)	59	11.79	1	<0.01
Old (65 years and over) (n=142)	32			
Gender				
Male (n=105)	34	2.94	1	0.09
Female (n=93)	46			
Presence of a caregiver				
Caregiver (n=142)	42	0.71	1	0.40
No caregiver (n=57)	35			
Level of care-giving				
Day to day (n=66)	44	0.08	1	0.78
Less frequent than day to day (n=27)	41			
<b>Physical and daily living</b>				
Age				
Young (under 65 years) (n=56)	55	2.21	1	0.14
Old (65 years and over) (n=142)	44			
Gender				
Male (n=105)	40	4.36	1	<0.05
Female (n=93)	55			
Presence of a caregiver				
Caregiver (n=142)	49	0.69	1	0.41
No caregiver (n=57)	42			
Level of care-giving				
Day to day (n=66)	53	5.68	1	<0.05
Less frequent than day to day (n=27)	26			

**Health system and information**

Age				
Young (under 65 years) (n=56)	45	9.57	1	<0.01
Old (65 years and over) (n=142)	23			
Gender				
Male (n=105)	26	1.03	1	0.31
Female (n=93)	32			
Presence of a caregiver				
Caregiver (n=142)	32	3.41	1	0.06
No caregiver (n=57)	19			
Level of care-giving				
Day to day (n=66)	29	0.006	1	0.94
Less frequent than day to day (n=27)	30			

**Patient care and support**

Age				
Young (under 65 years) (n=56)	29	9.87	1	<0.01
Old (65 years and over) (n=142)	11			
Gender				
Male (n=105)	13	0.91	1	0.34
Female (n=93)	18			
Presence of a caregiver				
Caregiver (n=142)	12	0.66	1	0.42
No caregiver (n=57)	17			
Level of care-giving				
Day to day (n=66)	14	0.11	1	0.74
Less frequent than day to day (n=27)	11			

**Sexuality**

Age				
Young (under 65 years) (n=56)	16	1.95	1	0.16
Old (65 years and over) (n=142)	9			
Gender				
Male (n=105)	11	0.02	1	0.88
Female (n=93)	11			
Presence of a caregiver				
Caregiver (n=142)	14	0.72	1	0.40
No caregiver (n=57)	10			
Level of care-giving				
Day to day (n=66)	15	1.02	1	0.31
Less frequent than day to day (n=27)	7			

**Spirituality**

Age				
Young (under 65 years) (n=56)	25	9.64	1	<0.001
Old (65 years and over) (n=142)	8			
Gender				
Male (n=105)	9	4.07	1	<0.05
Female (n=93)	18			
Presence of a caregiver				
Caregiver (n=142)	9	1.30	1	0.25
No caregiver (n=57)	15			
Level of care-giving				
Day to day (n=66)	12	1.55	1	0.21
Less frequent than day to day (n=27)	4			

\*Level of care-giving comparisons include only those patients who indicated they had caregivers (n=93)

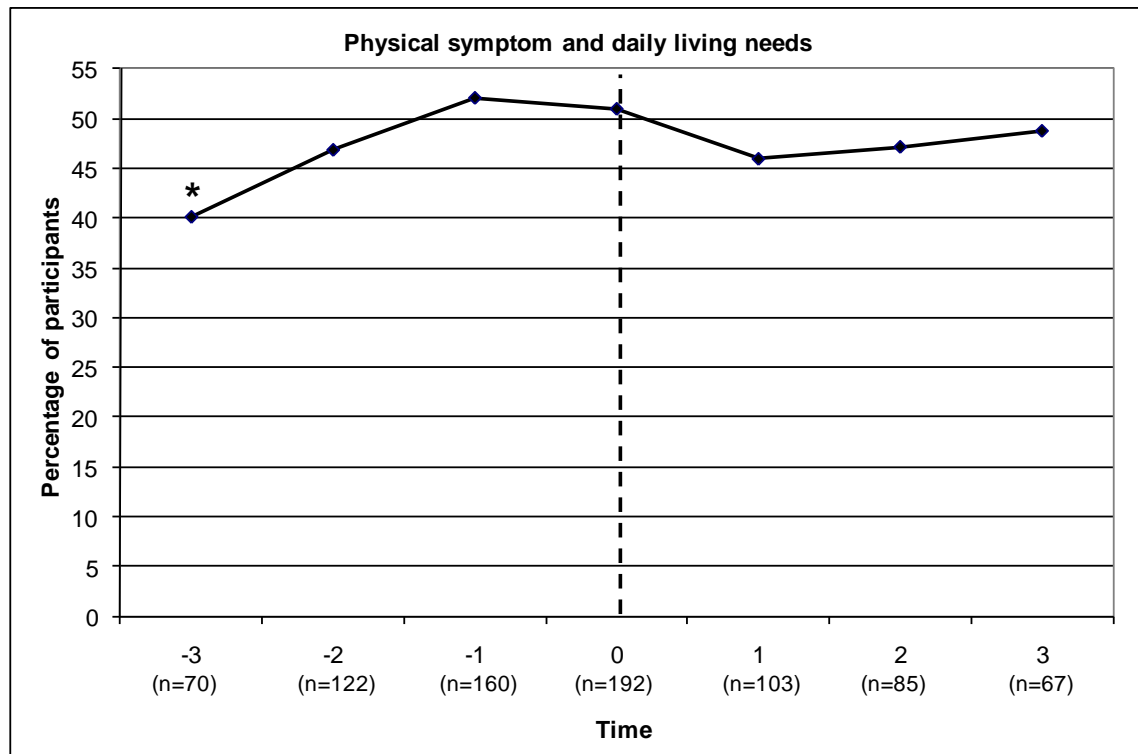
### 7.5.2 Changes in needs over time

Each participant was allocated an individual intervention date, which was the date of his/her first appointment after his/her clinician had received training in the use of the *Guidelines* and NAT: PD-C. Based on this date, every CATI completed was allocated to either a pre-intervention or post-intervention time point. The last CATI completed prior to the intervention date was Time 0. Any CATI prior to this was allocated to pre-intervention time points (T-3, T-2 and T-1 are approximately 6, 4, and 2 months pre-intervention), while any CATIs after this date were post-intervention CATIs (T1, T2 and T3 are approximately 2, 4 and 6 months post-intervention).

In Figures 7.2 to 7.7, presenting the changes over time in the percentage of patients reporting moderate or high needs in each domain, the dotted vertical lines represent the time at which the intervention was introduced (T0). Significant differences between each of the pre- and post-intervention time points and the intervention time point (T0) were determined using General Estimating Equations (GEE). Those time points that were statistically significantly different from T0 are denoted by \* ( $p < 0.05$ ) or \*\* ( $p < 0.01$ ). Analyses were adjusted for confounders, including age, gender, time since diagnosis, co-morbidity score and presence of a caregiver. The data presented included active, deceased and withdrawn patients in the analysis.

### ***Physical symptom and daily living needs***

As indicated in Figure 7.2, the percentage of participants reporting moderate or high daily living needs increased significantly six months prior to the intervention. The percentage of participants reporting at least one moderate or high need was as high as 52% prior to the intervention and decreased by almost 5% immediately following the intervention, though these changes were not statistically significant.



*Figure 7.2: Percentage of participants reporting at least one moderate or high need in the physical and daily living domain of the SCNS, from six months pre- to six months post-intervention.<sup>a</sup>*

<sup>a</sup> (\*p<0.05; \*\* p<0.01)

### **Psychological needs**

As indicated in Figure 7.3, almost half of participants reported having at least one moderate or high psychological need prior to the introduction of the intervention. While there were no statistically significant changes in the percentage of psychological needs following the introduction of the intervention, the prevalence of needs did decrease almost 13% over the study period. The largest decrease occurred just prior to the intervention commencing.

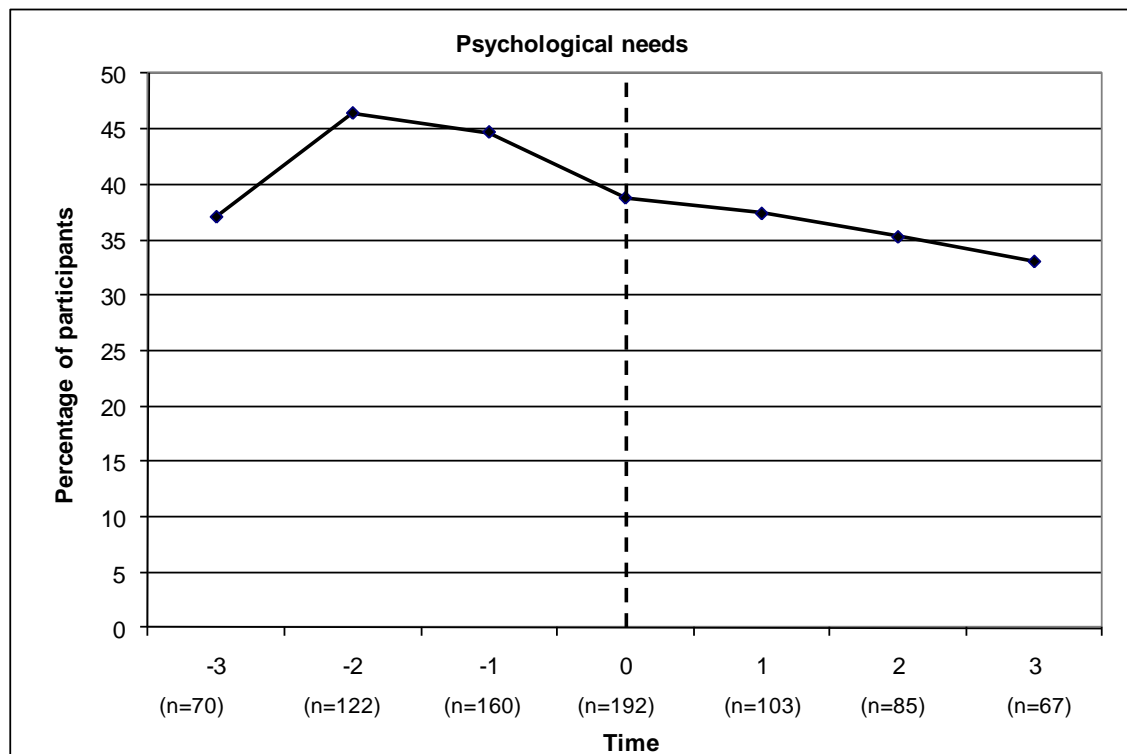


Figure 7.3: *Percentage of participants reporting at least one moderate or high need in the psychological domain of the SCNS, from six months pre- to six months post-intervention.<sup>b</sup>*

<sup>b</sup> (\*p<0.05; \*\* p<0.01)

### Health system and information needs

Figure 7.4 presents the changes in the percentage of patients who reported at least one moderate or high health system and information need from pre- to post-intervention. The percentage of patients with moderate or high needs remained highest prior to the intervention, with a statistically significant reduction in participants reporting moderate or high needs in this domain at 2, 4 and 6 months following the intervention (13% decrease from T0 to T3).

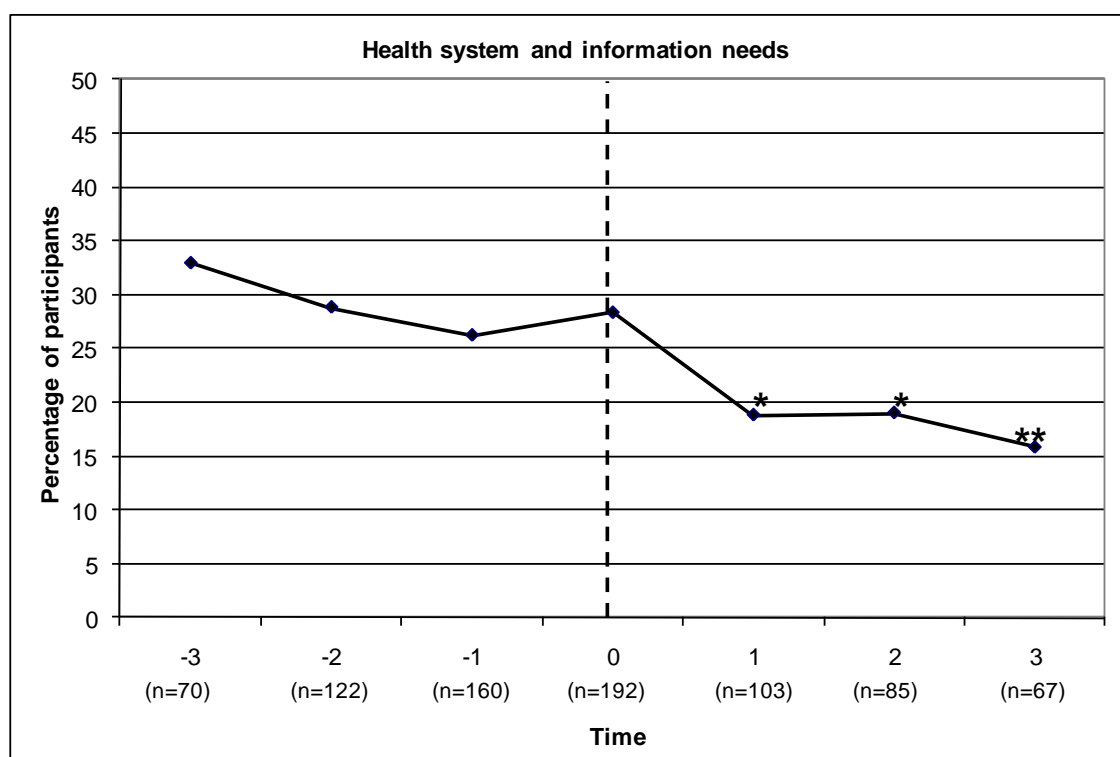


Figure 7.4: Percentage of participants reporting at least one moderate or high need in the health system and information domain of the SCNS, from six months pre- to six months post-intervention.<sup>c</sup>

<sup>c</sup> (\*p<0.05; \*\* p<0.01)



### ***Patient care and support needs***

Few participants in the sample had moderate or high patient care and support needs. Even so, the results shown in Figure 7.5 indicate a progressive decrease over the study period in the percentage of the participants with moderate or high needs. Significantly fewer people reported moderate or high needs at T3, ie 6 months following the intervention, compared with T0.

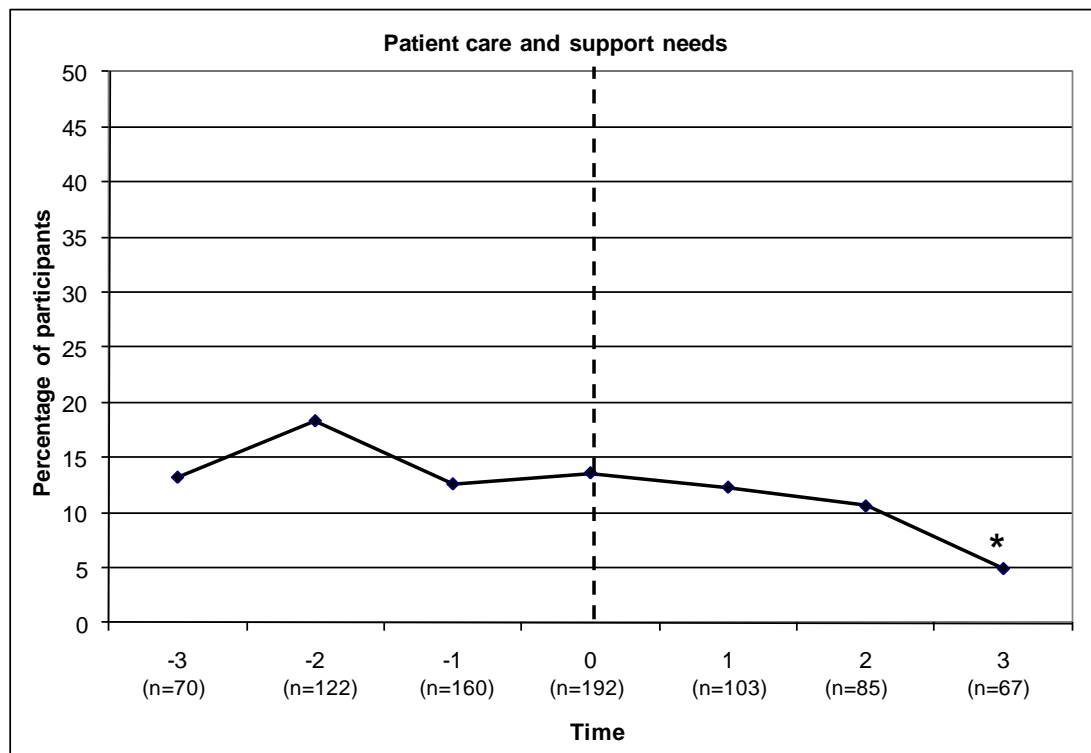


Figure 7.5: *Percentage of participants reporting at least one moderate or high need in the patient care and support domain of the SCNS, from six months pre- to six months post-intervention.<sup>d</sup>*

<sup>d</sup> (\*p<0.05; \*\* p<0.01)

### Sexuality needs

From Figure 7.6, it is evident that the percentage of people with sexuality needs began to decrease significantly during the pre-intervention period and levelled off in the post-intervention period.

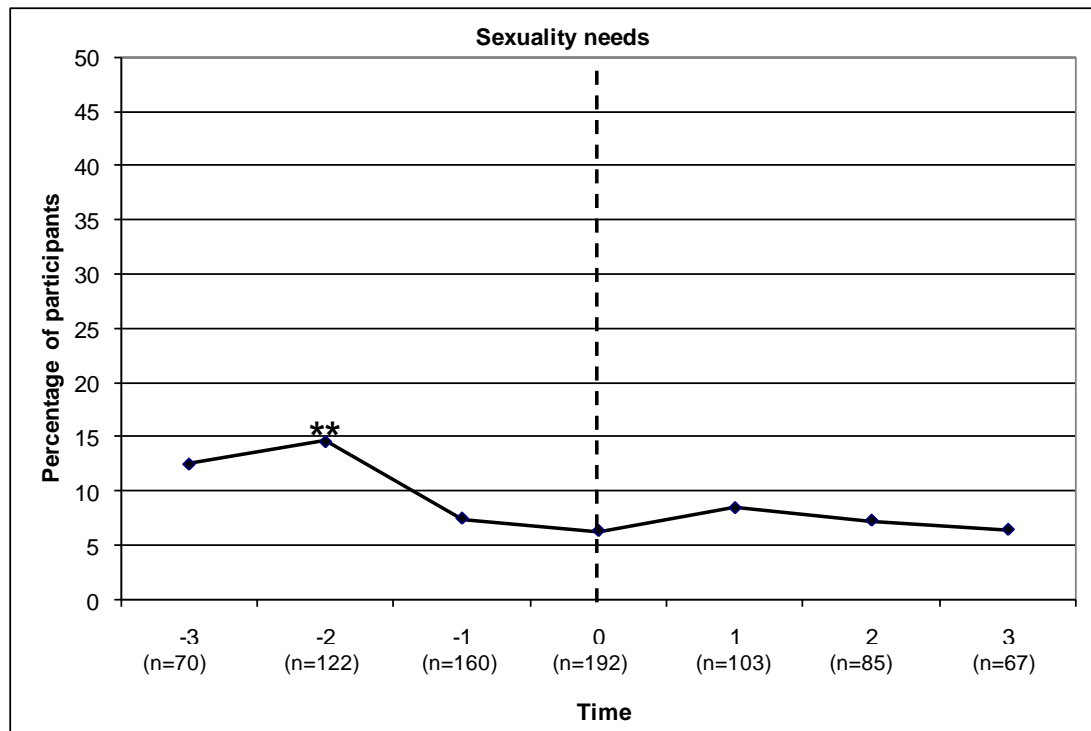
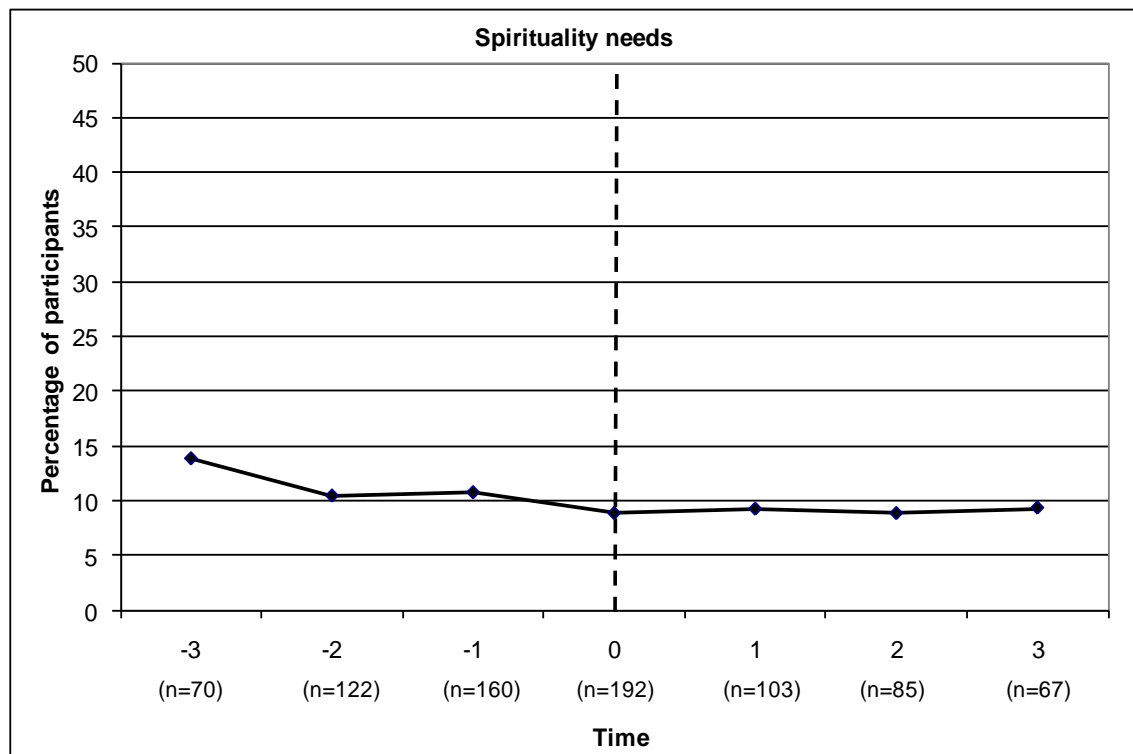


Figure 7.6: Percentage of participants reporting at least one moderate or high need in the sexuality domain of the SCNS, from six months pre- to six months post-intervention.<sup>e</sup>

<sup>e</sup> (\*p<0.05; \*\* p<0.01)

### **Spirituality needs**

The spirituality domain from the Needs Assessment for Advanced Cancer Patients (NA-ACP)<sup>10</sup> was included in the study in addition to the five SCNS domains, given its potential relevance to this population. The percentage of the study participants who reported moderate or high spirituality needs was lower than for any other needs domain, and remained relatively low over the study period (Figure 7.7).



*Figure 7.7: Percentage of participants reporting at least one moderate or high need in the spirituality domain of the NA-ACP, from six months pre- to six months post-intervention.<sup>†</sup>*

<sup>†</sup> (\*p<0.05; \*\* p<0.01)

## 7.6 IMPACT OF THE INTERVENTION ON QUALITY OF LIFE

During each CATI, participants' quality of life was assessed using the two items from the European Organization for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ C30) instrument.<sup>11</sup> The scores for the two items were added together and averaged and then scaled out of 100, with a higher score indicating a greater quality of life.<sup>12</sup>

### 7.6.1 Baseline quality of life score

The mean quality of life score of the participant sample at baseline was 61.8 (SD=20.6), while the mean quality of life score for available general population reference data was 71.2 (SD=22.4).<sup>13</sup> There was a statistically significant difference in the mean quality of life score between the participant sample and the general population of 9.40 (95% CI = 6.22 to 12.58); the participant sample had a lower quality of life. Consistent with previous research,<sup>14</sup> participant quality of life score did not differ by age ( $t(195) = -0.38, p=0.70$ ) or gender ( $t(195) = 0.53, p=0.60$ ) of participants. Moreover, quality of life score was not associated with the presence or absence of a caregiver ( $t(195) = -0.23, p=0.82$ ) or with the level of care-giving provided by the caregiver ( $t(91) = -1.01, p=0.32$ ).

### 7.6.2 Changes in mean quality of life score over time

Figure 7.8 presents the changes in the mean quality of life score of participants from pre- to post-intervention, and compared these with available general population norms.<sup>13</sup> For the participants, quality of life was significantly higher at T-3, i.e. six months prior to the intervention, compared with T0. However, no significant changes were found following the introduction of the intervention, with mean scores remaining relatively stable across this period.

When comparing the study sample with the general population,<sup>13</sup> the participant sample had significantly lower mean quality of life score at T-3 (mean difference 6.70; 95% CI = 1.45 to 11.95); T-2 (mean difference 9.90; 95% CI = 5.92 to 13.88); T-1

(mean difference 10; 95% CI = 6.53 to 13.47); T0 (mean difference 13.20; 95% CI = 10.03 to 16.37); T1 (mean difference 13.70; 95% CI = 9.37 to 18.03); T2 (mean difference 14.70; 95% CI = 9.94 to 19.46); and T3 (mean difference 6.70; 95% CI = 8.33 to 19.07). However, quality of life scores were higher than scores for published studies of palliative care patients (range of reported quality of life score of 31 to 44<sup>15, 16</sup>).

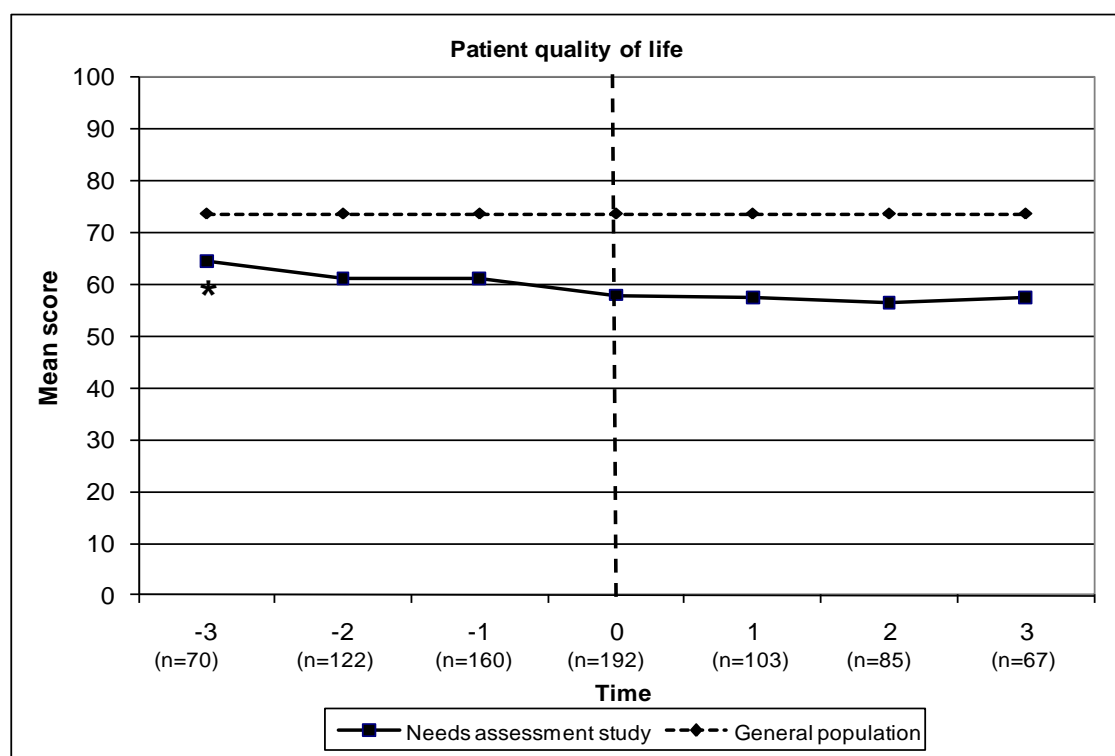


Figure 7.8: Mean quality of life score for study participants compared with available general population norms, from six months pre- to six months post-intervention.<sup>9</sup>

<sup>9</sup> (\*p<0.05; \*\* p<0.01)

## **7.7 IMPACT OF THE INTERVENTION ON DEPRESSION, ANXIETY AND DISTRESS**

During each interview, participants' levels of anxiety, depression and distress were determined from their scores on the Hospital Anxiety and Depression Scale (HADS).<sup>17</sup>

### **7.7.1 Baseline prevalence of depression**

From their baseline CATIs, 11% of participants were classified as clinically depressed (score of 11+), compared with the reported levels in 2007 in the general Australian population of 6.2%.<sup>18</sup> The difference between the proportions was 5% (95% CI = 1% to 10%). Hence, a significantly greater percentage of the participant sample was classified as clinically depressed compared with the available general population norms.

Comparisons were undertaken to determine the association between clinical depression and the presence of a caregiver, the level of care-giving provided and the participant's gender. These revealed no significant associations with the presence or absence of a caregiver (irrespective of whether the caregiver was involved in the study) ( $\chi^2=0.22$   $df=1$   $p=0.64$ ), the level of care-giving provided by the caregiver ( $\chi^2=1.24$   $df=1$   $p=0.27$ ), participant gender ( $\chi^2=0.008$   $df=1$   $p=0.93$ ) or participant age ( $\chi^2=2.50$   $df=1$   $p=0.11$ ).

### **7.7.2 Changes in prevalence of clinical depression over time**

Figure 7.9 presents the changes in the percentages of participants with clinical levels of depression (i.e. HADS depression score of 11+) from pre- to post-intervention. The GEE analysis was adjusted for confounders, including age, gender, presence of a caregiver, time since diagnosis and co-morbidities.

While the percentage of patients in the sample who were clinically depressed increased significantly in the pre-intervention period, the variations in levels of depression at post-intervention compared with pre-intervention were not statistically significant. The percentage of depressed patients decreased immediately following T0, but began increasing after T1 and at T3 returned to a level higher than that of T0. The

highest prevalence of clinical depression (score of 11+) in this patient sample was 13.8%, at T3.

When the study sample was compared with the general population,<sup>18</sup> the sample had a significantly lower percentage of clinically depressed people at T-3 (difference between the proportions 8%; 95% CI = 2% to 18%); T-1 (difference between the proportions 4%; 95% CI = 0% to 9%); T0 (difference between the proportions 8%; 95% CI = 3% to 13%); and T3 (difference between the proportions 7%; 95% CI = 1% to 17%). However, there were no significant differences in the proportions of people classified as clinically depressed at T-2 (difference between the proportions 2%; 95% CI = -2% to 8%); T1 (difference between the proportions 4%; 95% CI = -1% to 11%); or T2 (difference between the proportions 5%; 95% CI = -1% to 13%).

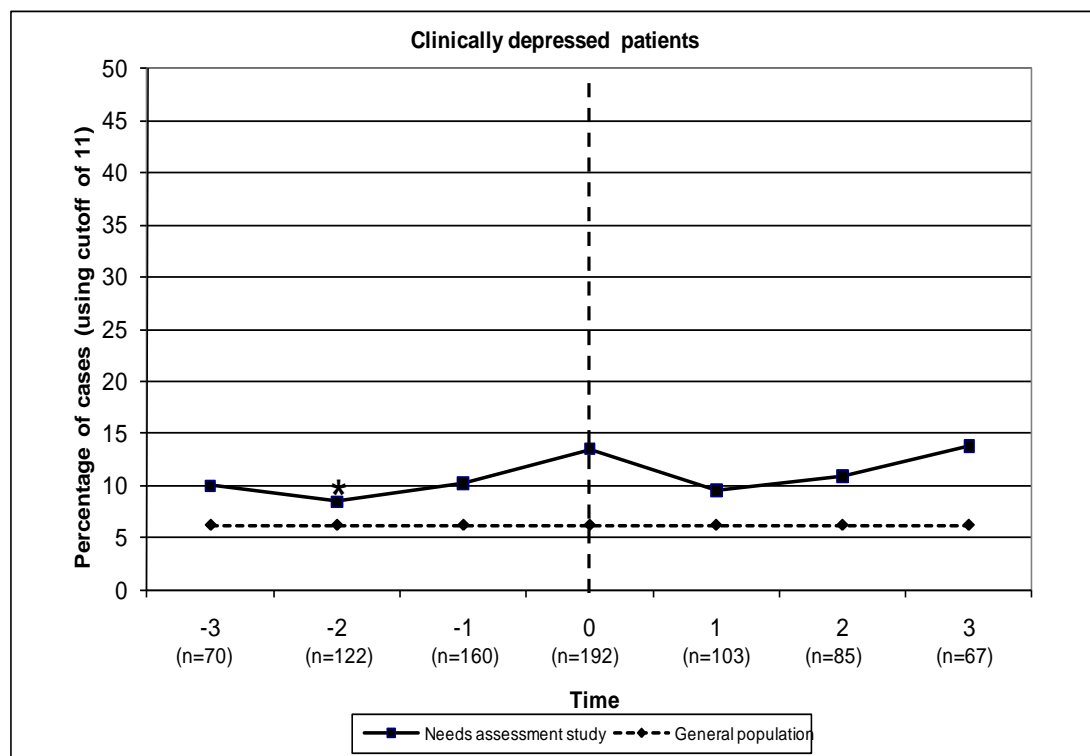


Figure 7.9: Percentage of patients with clinical levels of depression compared with Australian general population norms, from six months pre- to six months post-intervention.<sup>h</sup>

<sup>h</sup> (\*p<0.05; \*\* p<0.01)

### 7.7.3 Baseline prevalence of clinical anxiety

Of study participants, 7% were classified as clinically anxious (using a HADS anxiety score of 11+) compared with 14.4% of the general Australian population.<sup>18</sup> A significantly lower percentage of the participant sample was classified as clinically anxious compared with the available general population norms (7%; 95% CI = -10% to -3%).<sup>18</sup> In line with published literature,<sup>18, 19</sup> a greater percentage of female participants were clinically anxious compared with male participants (11% *versus* 4%,  $\chi^2=3.72$   $df=1$   $p<.0.05$ ). There was no association between participants' anxiety and age ( $\chi^2=1.60$   $df=1$   $p=0.21$ ), presence of a caregiver ( $\chi^2=0.001$   $df=1$   $p=0.97$ ) or the level of care-giving provided by their caregivers ( $\chi^2=2.23$   $df=1$   $p=0.14$ ).

### 7.7.4 Changes in prevalence of anxiety over time

Figure 7.10 presents the changes in the percentage of patients in the sample with clinical levels of anxiety (i.e. HADS anxiety score of 11+), from pre- to post-intervention. The GEE analysis was adjusted for confounders, including age, gender, presence of a caregiver, time since diagnosis and co-morbidities. The percentage of clinically anxious patients in the sample did not significantly change following the intervention.

When comparing the study sample with the general population,<sup>18</sup> the sample had a significantly lower percentage of clinically anxious people at T-1 (difference between the proportions 7%; 95% CI = -11% to -3%) and T0 (difference between the proportions 5%; 95% CI = -9% to -1%). However, there were no significant differences in the percentage of people classified as clinically anxious at T-3 (difference between the proportions 5%; 95% CI = -10% to 3%); T-2 (difference between the proportions 6%; 95% CI = -10% to 0%); T1 (difference between the proportions 5%; 95% CI = -10% to 1%); T2 (difference between the proportions 1%; 95% CI = -7% to 7%); or T3 (difference between the proportions 6%; 95% CI = -11% to 2%).



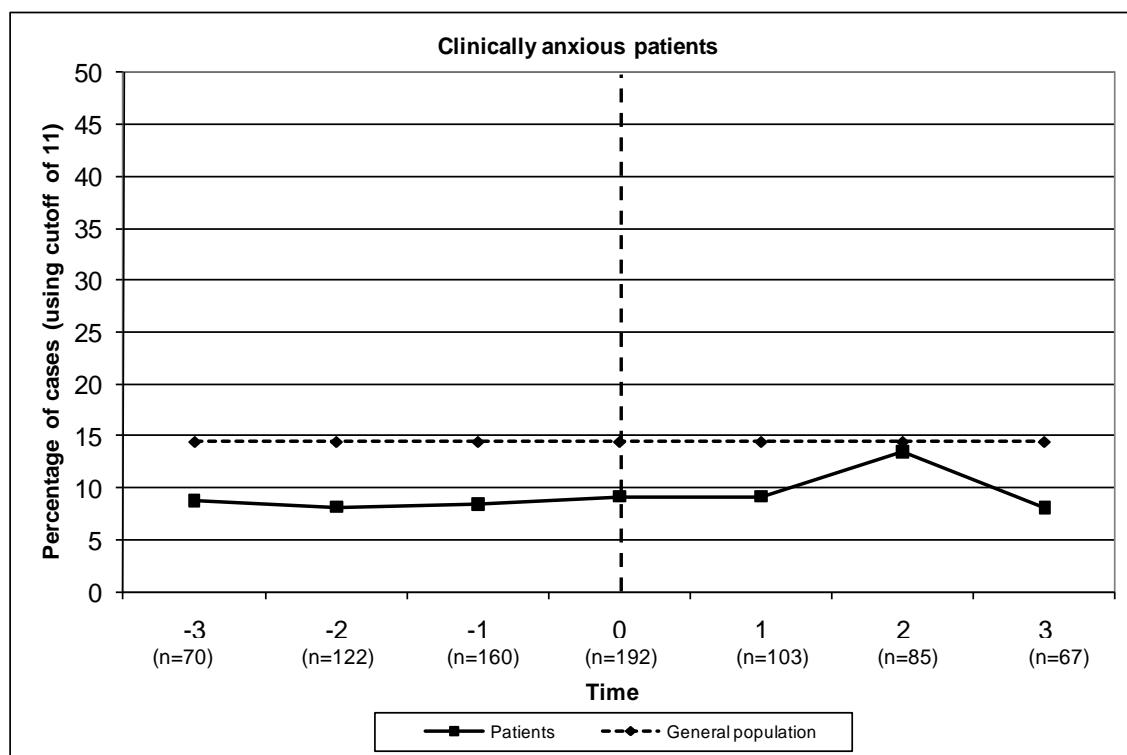


Figure 7.10: Percentages of patients with clinical levels of anxiety compared with Australian general population norms, from six months pre- to six months post-intervention.<sup>i</sup>

### 7.7.5 Baseline prevalence of clinical distress

In the study, 21% of participants were classified as clinically distressed (HADS score of 15+) at study entry. Gender was not associated with levels of distress ( $\chi^2=1.41$   $df=1$   $p=0.24$ ). There was no association between levels of distress and the presence or absence of caregivers ( $\chi^2=1.11$   $df=1$   $p<0.74$ ) or with the level of care-giving provided by the caregivers ( $\chi^2=1.11$   $df=1$   $p=0.29$ ). However, a greater percentage of younger participants (under 65 years of age) reported clinical distress compared with older participants (31% versus 18%,  $\chi^2=3.98$   $df=1$   $p<0.05$ ).

### 7.7.6 Changes in prevalence of clinical distress over time

Figure 7.11 presents the changes in the percentages of patients in the sample with clinical levels of distress (i.e. total HADS score of 15+), from pre- to post-intervention. The GEE analysis was adjusted for confounders, including age, gender, presence of a

<sup>i</sup> (\* $p<0.05$ ; \*\*  $p<0.01$ )

caregiver, time since diagnosis and co-morbidities. The increase in the percentage of distressed patients over the course of the study was not significant. The highest prevalence of clinical distress, which occurred at T3 in this patient sample, was 27.8%.

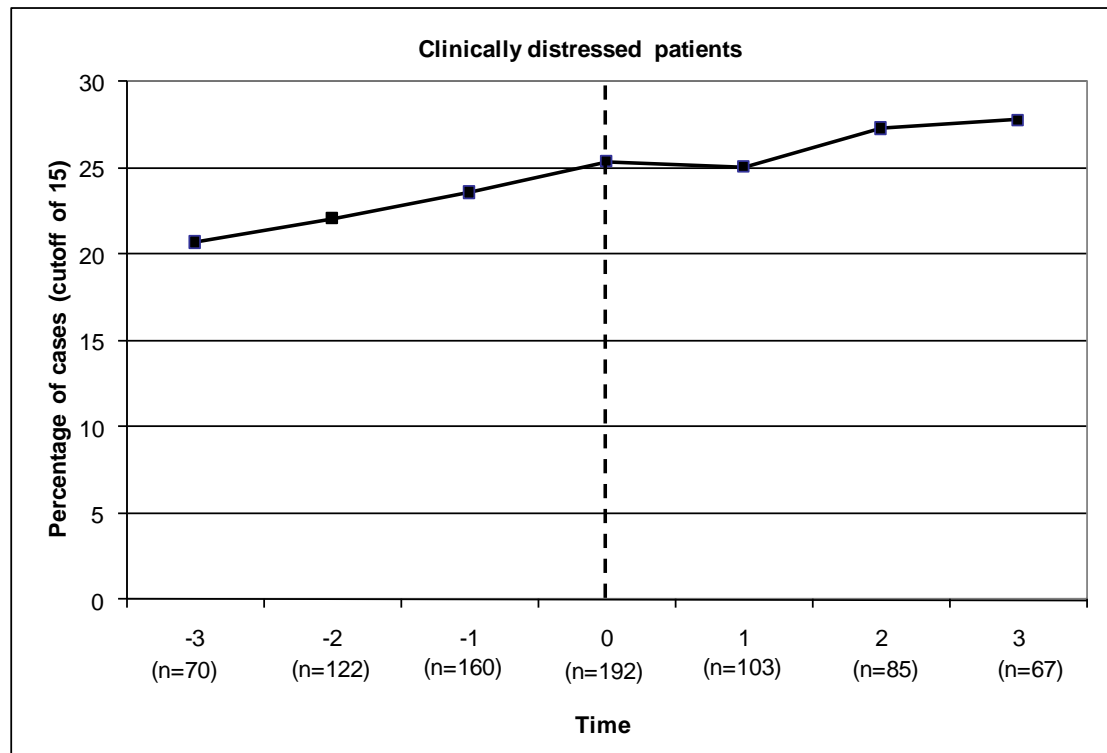


Figure 7.11: Percentages of patients with clinical levels of distress, from six months pre- to six months post-intervention.

## 7.8 DISCUSSION

Literature suggests that advanced cancer is associated with a significant burden of morbidity as patients are poly-symptomatic<sup>20</sup> and often have higher levels of unmet need than those with localised disease.<sup>21</sup> While it is argued that the severity and complexity of the needs of patients may vary throughout the disease trajectory,<sup>22</sup> some may not seek advice for symptoms; so, expressed need may be far less than actual need.<sup>23</sup> In fact, research has shown that patient needs are more likely to be detected through systematic assessment compared with patient self-report.<sup>24</sup> Hence, the importance of assessment methods that are responsive to changes in the types and levels of needs experienced by patients across the complete trajectory of illness have been emphasised.<sup>25-27</sup> In this study, people with advanced cancer were assessed every

2 months for a period of up to 18 months to identify changes in their levels of unmet need, psychological morbidity and quality of life, in response to the implementation of an intervention aimed at improving needs-based care.

Overall, the results suggest that in this population of people with advanced cancer, the use of the *Guidelines* and NAT: PD-C may contribute to a significant reduction in reports of unmet needs, as the percentage of people who reported having moderate or high needs in any of the domains decreased from just over two-thirds at the time of intervention (T0) to approximately half at the post-intervention time points. In particular, the use of the *Guidelines* and NAT: PD-C contributed to a reduction in health system and information needs, and patient care and support needs. Moreover, the use of these resources may have assisted in minimising the anticipated decline in quality of life and increase in physical symptoms and daily living needs that often occur in this population.<sup>14, 21, 28, 29</sup>

The information preferences of patients have been the subject of numerous studies suggesting that the amount of information wanted by people with cancer varies.<sup>30-32</sup> One study found that patients who were told their cancers were not diminishing were more likely to report needs in this domain,<sup>21</sup> while another found advancing disease predicted information needs in men with prostate cancer.<sup>33</sup> In the present study, a greater percentage of people under 65 reported at least one moderate or high health system and information need. Despite the variation in the degree to which information needs remain unmet, the importance of meeting information needs is consistently reported.<sup>34-36</sup> As the most common source of information is the health professional,<sup>37</sup> providing information in line with patients' preferences is an essential part of ensuring high-quality cancer care,<sup>37</sup> and health professionals must be aware of the individual needs in this area in order to provide information adequately. Using the NAT: PD-C can assist in identifying and therefore addressing any problems people may have with the amount and type of information they receive about their diseases, diagnoses, treatments and follow-up.

Previous research has also illustrated the importance of having needs met in the area of patient care and support, especially with regard to having good relationships with health professionals.<sup>36</sup> A greater percentage of people under 65 reported at least one moderate or high need in this area. The percentage of people reporting a patient care

and support need prior to the intervention was lower than those reporting psychological and physical and daily living needs, consistent with previous research.<sup>38</sup> The smaller percentage of people reporting unmet needs post-intervention suggests that, as with health system and information needs, the NAT: PD-C facilitated the identification of problems with physical and emotional care and support by health professionals, and prompted action to address these.

The health-related quality of life of this study sample was significantly lower than the general population at baseline and across the study period; however, it was higher than for previous studies in palliative care populations. While statistical significance is an important consideration when assessing the outcomes of people with cancer, this may not always represent a change that is important to the person.<sup>39</sup> Wyrwich (2005) argues that a “clinically significant change may not lead to a change in treatment or care regimen because the difference represents an improvement that should not be interrupted or a decline that cannot be prevented by other reasonable alternatives”.<sup>39</sup> Rather than an improvement in quality of life, use of the NAT: PD-C may have, in fact, minimised the decline in quality of life that is expected as the disease progresses.<sup>14, 28, 39</sup> As the focus of palliative care is on enhancing the quality of life and comfort of patients, their caregivers and families,<sup>40</sup> this is an important finding.

Despite significant physical impairments such as those often experienced by people with progressive cancer, some literature suggests that an individual's perceived quality of life may not necessarily be influenced by decline in health. This self-levelling phenomenon or response shift, suggests that individuals may change their own standards, values or conceptualisations of quality of life, in order to adapt to changes in their illnesses. As Schwartz (1999) argues, “response shift may serve to attenuate or to exaggerate estimates of treatment effects as patients adapt over time”.<sup>41</sup> Stability in quality of life over time despite declines in physical health has also been reported in other studies of people with life-threatening diseases.<sup>42</sup> This response shift may also explain the stability in the quality of life of the study sample.

Similarly, there is the potential for physical and daily living needs to increase in complexity and severity in people with advancing disease. Physical symptoms such as fatigue, weakness and pain are the most frequently cited problems affecting people with cancer,<sup>43-50</sup> and physical functioning and the ability to perform daily living activities

play important roles in the lives of patients.<sup>45, 51</sup> Being female, having a day-to-day caregiver and having a high co-morbidity score all predicted physical and daily living needs at baseline in this study. Between 30% and 58% of people with varying stages of cancer have reported experiencing physical symptoms and daily living needs;<sup>33, 52, 53</sup> in this study, physical and daily living needs were the most prevalent. However, the percentage of people reporting these needs did not significantly alter during the study period. As with quality of life, the intervention may have minimised the worsening of physical symptoms expected in this population. However, without a contemporaneous control group this cannot be qualified.

The changes that occurred in the remaining patient outcomes as a result of the intervention were less notable. Patients often report higher unmet needs in the psychological domain when compared with other domains.<sup>21, 33, 53</sup> Even so, the degree to which people experience unmet psychological needs may vary, with lower levels of psychological needs reported in other studies of people with advanced cancer<sup>54</sup> and people newly diagnosed.<sup>52</sup> One Australian study examined the impact of a nurse-led intervention on the psychological needs of people with breast cancer, reporting that reductions in psychological needs occurred only in those with high initial needs.<sup>55</sup> In the present study, a greater percentage of younger patients reported having at least one psychological need at baseline. While the percentage of people with psychological needs did decrease over the study period, changes were not significant. The timing of the observed changes does not support the effects observed being directly attributable to the intervention.

Similar findings were identified for the sexuality domain, with a significant decrease in needs occurring prior to the intervention. It has been suggested that sexuality is one of the most poorly addressed areas in cancer care,<sup>56-59</sup> despite the impact of cancer and its treatment on sexual functioning being well-documented in both general cancer and palliative care populations.<sup>60</sup> Sexuality needs are especially prominent in prostate cancer patients, with between a third and a half reporting moderate or high sexuality needs.<sup>33, 61</sup> However, the percentage of people with moderate or high sexuality needs was much lower in the study sample. While there is some evidence that sexuality issues are seen as important, patients who are asked to rate their needs overall rate sexuality needs very low compared with other needs.<sup>51, 62</sup>

It is difficult to determine exactly why the reduction in psychological and sexuality needs of the sample occurred prior to the intervention. There may be some relationship between the needs of the participants and the timing of their diagnoses. For example, time since diagnosis was associated with sexual dysfunction in women with breast cancer; a greater time interval was associated with more dysfunction.<sup>63</sup> However, others have found that length of time since the patient's diagnosis did not predict needs.<sup>29, 64</sup> Perhaps simply discussing these concerns with someone during a telephone interview may have assisted patients in dealing with these issues themselves. There is often an expectation that health professionals will initiate discussions around these issues,<sup>65, 66</sup> and the inclusion of these issues in the survey may have emphasised their importance within this population. Subsequently, patients may have been encouraged to seek advice and assistance from their health professionals, rather than waiting for the health professionals to initiate discussions.

The final need domain addressed was the spirituality domain. More than one-third of patients with cancer report having five or more unmet spiritual needs.<sup>67</sup> Literature suggests that spirituality is often not addressed by health professionals,<sup>68-71</sup> despite its importance to patients,<sup>72-74</sup> and that a majority of patients report that they want their physicians to ask about spirituality.<sup>75</sup> In this study, being less than 65 years of age and being female predicted spiritual needs at baseline. The percentage of the participants who reported spirituality needs remained relatively stable during the study.

Approximately one-third of the study participants reported having no moderate or high needs in any of the domains during their baseline interviews. As expected, this number is lower than the two-thirds of patients who reported having no needs in other studies conducted with mixed-stage patients.<sup>36, 53</sup> However, other studies with advanced cancer patients<sup>29, 76, 77</sup> and mixed-stage patients<sup>21</sup> have reported a higher prevalence of unmet need in items assessing psychological needs, health system and information needs, physical needs and even spirituality needs, than was found in this sample. It has been suggested that these variations in the prevalence of need between studies may be a result of differences in the types of measure used to assess needs and the way unmet need was classified.<sup>78</sup> In fact, Harrison *et al* (2009) in a systematic review found that when “moderate” or “high” need categories were used to classify unmet need, the prevalence of need was lower than when the category, “low” need, was also included.<sup>78</sup>

Other factors have been suggested to influence patient outcomes. Age has been associated with patient-perceived unmet needs,<sup>21</sup> anxiety,<sup>79</sup> depression<sup>80</sup> and quality of life.<sup>16</sup> Older people have been shown to report fewer unmet needs than younger people.<sup>21</sup> Similarly, a smaller percentage of older people (over 65 years) in this study sample reported having moderate or high psychological, health system and information, patient care and support, and spirituality needs during their initial interviews, compared with younger people. Perhaps the older age of the sample meant that people were reporting lower levels of need. As suggested by other authors, the types of needs assessed may be less relevant today than in previous years.<sup>53</sup> For example, Sanson-Fisher (2000) found people reported fewer health system and information needs and argued that this may be a result of improvements in the quality of cancer care in Australia and the greater provision of information.<sup>21</sup> In some cases, the individual items in these domains may have been less relevant than at the time the survey was developed, resulting in fewer people reporting these individual needs.

Geographical residence may negatively affect a person's access to health services and health outcomes;<sup>81</sup> for example, rural patients have been found to report greater unmet needs.<sup>78</sup> Moreover, cancer incidence and mortality may be higher for people living in regional areas compared with those from major cities.<sup>82, 83</sup> However, when people from major cities and regional areas were compared in this sample, the only difference was in the percentages of people with clinical depression. Despite their geographical residence, people were recruited from three major cancer centres in NSW for the study and therefore may have had sufficient access to the services required to meet their needs. In fact, comparisons between recruitment sites on baseline demographic and outcome variables indicated a significant difference only in cancer type. This difference in cancer type was expected, given the different outpatient clinics involved in recruitment at each site. For example, while participants were recruited from haematology clinics at Newcastle Mater Misericordiae and St George Hospitals, only one haematologist at St George Hospital agreed to have patients participate, compared with all haematologists at Newcastle Mater Misericordiae Hospital. Hence, a greater percentage of Newcastle Mater Misericordiae participants had a lymphoid haematopoietic diagnosis.

Cancer type has been reported to predict unmet need.<sup>78</sup> Similarly, cancer type may predict psychological morbidity. In a recent study of over 8000 people with cancer presenting to a USA tertiary cancer centre, higher rates of mixed anxiety/depression symptoms were reported by people with stomach, pancreatic, head and neck, and lung cancers.<sup>84</sup> However, the results of this study found no association between cancer type and level of need at baseline. Moreover, there was no association between cancer type and clinical depression, anxiety, distress or quality of life.

Aside from the unmet needs and quality of life of patients, the impact of the intervention on psychological morbidity was assessed. There is some evidence that level of depression may increase as disease progresses.<sup>85, 86</sup> Depression is argued to be the most persistent symptom in people with advanced cancer.<sup>87</sup> However, identifying depression in the advanced cancer population can be difficult as some symptoms that overlap with the physical systemic changes occurring as a result of cancer progression may be present in the majority of people, while some health professionals may presume that depression is a normal response to advanced disease.<sup>88, 89</sup> Interestingly, a meta-analysis reported that with the exception of depression, psychological concerns of cancer patients are similar to those of the general population.<sup>90</sup>

Importantly, the use of the *Guidelines* and the NAT: PD-C did not worsen psychological distress in participants. However, using these resources did not appear to reduce psychological morbidity, assessed with the measures included in this study. In fact, no significant changes were found in the percentages of people who were clinically depressed, anxious or distressed following the introduction of the intervention. The inclusion of only one item in the NAT: PD-C to assess psychological morbidity may have limited health professionals' sensitivity in identifying depression and anxiety levels of the sample. However, single-item interview questions have been found to be valid in screening for depression in terminally ill patients.<sup>91</sup> Such brevity is also far more likely to be acceptable in clinical practice.

Alternatively, the low prevalence of clinical depression (7%) and anxiety (11%) reported at pre-intervention may have reduced the likelihood of detecting significant reductions in these outcomes post-intervention. In the sample, the percentages of people who were clinically depressed or anxious were lower than those reported in a review of studies with advanced cancer patients,<sup>86</sup> but similar to rates reported with Australian



oncology outpatients using a cut-off score of 11 on the HADS (prevalence rates of 7.1% and 11.5% respectively).<sup>79</sup> Again, without a contemporaneous control group this cannot be qualified.

Aside from the assessment method used, cancer type has also been found to influence prevalence of emotional distress: patients who are diagnosed with cancers that have poorer predicted outcomes and greater burden often have greater distress.<sup>92</sup> Females have been reported to experience greater levels of depression,<sup>19</sup> while anxiety is reported to be more prevalent in female patients,<sup>19, 79</sup> those who are not married,<sup>19</sup> those under the age of 65 years<sup>79</sup> and those who have restricted levels of activity.<sup>79</sup> Reporting of psychological issues is highly context-dependent, with participants potentially more willing to report psychological issues accurately during telephone interviews than during consultations with their health professionals. Hence, these issues may not have been well-identified as a result of using the NAT: PD-C.

## 7.9 STUDY DESIGN AND LIMITATIONS

The *Guidelines* and NAT: PD-C were developed for use in clinical settings, and a “before and after” design was used to test the efficacy and feasibility of the resources in clinical settings. A number of limitations were identified. The response and consent rates for the study were lower than expected. While it was estimated that a total of 407 patients would need to be recruited from all sites for this study, only 219 patients were recruited. Factors contributing to the less than optimal numbers included recruitment staffing issues, gate-keeping by clinicians, lower than expected numbers of eligible patients from all sites, and higher than predicted percentages of patients unable to speak English sufficiently well or deemed ineligible by their treating clinicians because they were unwell, cognitively impaired, unable to speak or too distressed. Bausewein (2004) suggests that “attrition rates as a result of advancing disease or death may be high and compromise internal validity”.<sup>93</sup> In this study, 105 patients had withdrawn or died prior to the intervention being introduced.

*Post hoc* power analyses are reported for the changes observed in this sample for each of the SCNS-SF34 domains from pre-intervention (T0, n=192) to post-intervention (T1, n=103) (Table 7.18). Based on the observed changes in the domains, the power to

detect a change in the percentage of participants with at least one need in each of the domains using this sample size was 13% for physical symptoms and daily living, 6% for psychological, 33% for health system and information, 8% for patient care and support, 9% for sexuality and 5% for spirituality. These findings suggest that the lack of significant findings may have resulted in part from this lack of power. In addition, multiple comparisons using the same data were made, potentially resulting in lower statistical significance.

*Table 7.18: Post hoc power analyses based on the observed changes in percentage of participants with at least one need in each of the domains in the SCNS-SF34 from Time 0 to Time 1*

<b>SCNS-SF34 Domain</b>	<b>Pre-intervention (%)</b>	<b>Post-intervention (%)</b>	<b>Observed change (%)</b>	<b>Power</b>
Physical symptoms and daily living	51	49	5	0.13
Psychological	39	37	2	0.06
Health system and information	28	19	9	0.33
Patient care and support	14	12	2	0.08
Sexuality	6	8	2	0.09
Spirituality	9	9	0	0.05

*NB: The spirituality domain was calculated from items from the Needs Assessment for Advanced Cancer Patients (NA-ACP).*

Attempts were made to address these issues throughout the recruitment period. The eligibility criteria were kept quite flexible to include any cancer diagnosis. Research nurses were employed in two of the three main sites to ensure that disruption and workload issues were kept to a minimum for the clinic staff. Telephone follow-up of non-responding patients was also conducted. After a number of baseline interviews were completed, it was found that the interviews were, in fact, taking less than the expected 40 minutes, and this was reported to potential participants by the research nurses. Negotiations to include other oncology departments and campuses of the participating sites were made difficult, however, due to practical staffing issues and the need to submit to further Human Research Ethics Committees in studies already running, and therefore were not successful.

As previously suggested, the representativeness of the sample and the generalisability of findings to future patients and caregivers are important considerations when promoting the *Guidelines and NAT: PD-C*. The characteristics of the patient sample were compared with a sample of people with cancer from NSW outlined in the most recent Cancer Institute NSW report. Our sample differed from the NSW sample in terms of age and cancer type. While differences existed between the ages of the two samples in the 75+ years and the 65-74 years groups, the differences disappeared when the percentages of people over 65 years in both samples were compared. Hence, the impact on generalisability may have been less than expected, had the difference remained. People with lymphoid and haematopoietic cancers were over-represented in our sample, indicating good uptake by their clinicians, as were females with breast, ovarian and uterine cancer. Males with prostate cancer appeared to be under-represented, perhaps because not all patients with this type of cancer were treated in oncology clinics. People with cancers not classified in the eight diagnosis categories used were also under-represented.

The experiences of people may vary according to their diagnoses, as some diagnoses have poorer survival rates and shorter disease trajectories compared with others.<sup>83</sup> In fact, levels of need have been found to vary according to cancer type.<sup>21</sup> Cancer type has also been found to influence prevalence of emotional distress, as patients who are diagnosed with cancers that have poorer predicted outcomes and greater burden often have greater distress.<sup>92</sup> For example, people diagnosed with lung cancer have been found to report significantly higher levels of distress when compared with those with breast or colon cancers.<sup>92</sup> There were no significant associations between cancer diagnosis and levels of need, depression, anxiety or quality of life at baseline in the sample. However, the differences in the numbers of people with each diagnosis had the potential to bias the results to participants with more positive outcomes. Having a sample of greater size and equivalent representation of diagnoses, including those with poorer predicted outcomes such as lung cancer, may have made the assessment of unmet needs, clinical depression and anxiety representative of all people with advanced cancer, and changes in needs, depression and anxiety, more achievable following the intervention. At baseline, Newcastle Mater Misericordiae Hospital patients reported a higher quality of life mean score than Liverpool Hospital patients. As

Newcastle Mater Misericordiae patients made up the majority of the patient sample in this study, this had the potential to bias the results to participants with higher self-rated quality of life, thus making improvements in quality of life difficult to achieve.

One study which looked at the changing needs of people with cancer found that the resolution of baseline needs was often offset by the addition of new needs in that area, thus minimising reductions in prevalence of need between baseline and follow-up.<sup>94</sup> In this study, prevalence was reported for at least one need in a domain, a method which has been argued to potentially over-estimate the prevalence of needs.<sup>78</sup> Perhaps people in this study acquired new needs to replace those that were identified and addressed using the NAT: PD-C, therefore minimising any significant reductions in the post-intervention phase for some of the domains.

Finally, it is important to note that multiple comparisons were undertaken using the same data, especially for sample comparisons according to geographical region, recruitment site, presence of a caregiver and number of pre-intervention CATIs performed. Some argue for adjustments to the criteria for significance when performing multiple tests on data, such as Bonferroni adjustments.<sup>95</sup> However, Perneger (1998) argues that adjusting statistical significance for the number of tests that have been performed on study data is unnecessary,<sup>95</sup> as using these adjustments incorrectly assumes that the researcher wants to confirm that all hypotheses are true simultaneously. In addition, making these adjustments assumes that the interpretation of a finding depends on the number of other tests performed and that the likelihood of type II errors is increased when they are used.<sup>95</sup> As the purpose of these comparisons is exploratory and does not set out to confirm that all hypotheses are true simultaneously, no further statistical adjustments to the significance level ( $p < 0.05$ ) were made.

## **7.10 CONCLUSION**

Few studies have examined changes in needs of people with cancer over time.<sup>78</sup> The *Palliative Care Needs Assessment Guidelines* and the Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C) were developed to facilitate a more efficient approach to the ongoing assessment and management of unmet patient needs

in both generalist and specialist settings. The results of this study suggest that in a population of people with advanced cancer, the use of the *Guidelines* and NAT: PD-C may contribute to a significant reduction in the reporting of unmet needs, particularly in health system and information needs, and patient care and support needs. Moreover, the use of these resources may assist in minimising the anticipated decline in quality of life and increase in physical symptoms and daily living needs that often occur in this population. The *Guidelines* and NAT: PD-C can therefore assist health professionals to identify the needs of people with advanced cancer, thereby facilitating the provision of finite palliative care resources to those people who need them most in a more equitable and transparent way.<sup>96</sup>

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# **CHAPTER 8:**

## **IMPACT OF THE PALLIATIVE CARE NEEDS ASSESSMENT INTERVENTION ON CLINICAL ASSESSMENT, RESPONSE AND SERVICE UTILISATION**

## 8.1 INTRODUCTION

The previous chapter described the impact of the systematic and ongoing use of the *Palliative Care Needs Assessment Guidelines* and Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C) on patient outcomes, including unmet needs, quality of life, anxiety and depression. However, determining whether the *Guidelines* and NAT: PD-C offer an opportunity for improving the quality and efficiency of palliative care delivery without placing unnecessary burden on health care providers and services is an important consideration. Hence, the aim of this chapter was to present the findings of the second part of the study, which assessed the impact of the systematic and ongoing use of the *Guidelines* and the NAT: PD-C on patient clinical assessment, response and service utilisation.

## 8.2 FEASIBILITY AND ACCEPTABILITY OF THE NAT: PD-C

### 8.2.1 Completion rate

The feasibility and acceptability of the NAT: PD-C was initially assessed by examining the completion rate of the tool within the outpatient clinic setting. A total of 342 NAT: PD-Cs were completed for 120 patients across all study sites (Table 8.1). There was a significant association between number of NAT: PD-Cs completed in each clinical setting and recruitment site, with 75% of NAT: PD-Cs completed at the Newcastle Mater Misericordiae site ( $\chi^2=27.94$   $df=6$   $p<0.001$ ).

Table 8.1: Number of NAT: PD-Cs completed by different health care providers at each recruitment site

Site	Number of NAT: PD-Cs completed			Total	p-value
	Clinic (%)	GP (%)	SPCS (%)		
Newcastle Mater	188 (73)	45 (17)	25 (10)	258	<0.001
St George	19 (51)	5 (14)	13 (35)	37	
Private clinics	10 (100)	0	0	10	
Liverpool	20 (54)	7 (19)	10 (27)	37	
<b>Total</b>	<b>237(69)</b>	<b>57 (17)</b>	<b>48 (14)</b>	<b>342</b>	

To examine the completion rate of NAT: PD-C within the outpatient clinic setting, the number of NAT: PD-Cs that were due for completion for each patient during the study (depending on the regularity of their appointments) was compared with the number of NAT: PD-Cs that were actually completed. In the outpatient oncology setting, a total of 237 NAT: PD-Cs were completed out of an estimated 373 scheduled for completion (63.5% completion rate). The reasons for non-completion were largely either health professional based (88 NAT: PD-Cs; 64.7%) or procedural (48 NAT: PD-Cs; 35.3%).

The health professional reasons for non-completion of the NAT: PD-C were that the clinician was too busy ( $n=44$ ) or no reason was given ( $n=44$ ). The procedural reasons for non-completion of the NAT: PD-C included the following: changes in patient or appointment status (e.g. the appointment was cancelled or too close to previous appointments where the NAT: PD-C was completed, the patient withdrew from the study or was deceased, or the patient became an inpatient) ( $n=17$ ); the NAT: PD-C was not placed in the patient file prior to the appointment ( $n=20$ ); or the clinician had not yet been trained in the intervention ( $n=11$ ). Overall, this represents a completion rate of 65% (in outpatient oncology clinics). However, when only the health professional factors are taken into account, the completion rate for the NAT: PD-Cs that were actually placed in the files for completion and were appropriate for completion at the designated appointments was 83% (237/285).

### **8.2.2 Length of the consultation**

To examine the impact of the intervention on the length of consultations, a total of 48 consultations (13 pre-intervention and 35 post-intervention consultations) were audio-taped in the oncology setting. The mean consultation time was comparable in consultations where the NAT: PD-C was completed during the consultation *versus* not completed ( $t(46) = 0.50$ ,  $p=0.62$ ) (see Table 8.2).

**Table 8.2:** Comparison of the length of consultations during which a NAT: PD-C was completed versus consultations in which a NAT: PD-C was not completed

	Consultation length (minutes)	
	Without NAT: PD-C (n=15)	With NAT: PD-C (n=33)
Mean length	19.5	18.1
Median length	17.5	17.4
SD	10.5	8.0
Minimum length	9.2	3.5
Maximum length	53.5	40

*NB: Without NAT: PD-Cs group includes baseline consultations, as well as post-intervention consultations in which a NAT: PD-C was not completed (n=2).*

### 8.2.3 Consistency of NAT: PD-C ratings with patient self-reported needs

The Prevalence-Adjusted Bias-Adjusted Kappa (PABAK) statistic<sup>1</sup> was used to determine whether patients and health professionals reported the presence or absence of physical, psychological, information and spiritual needs in the same way, by comparing SCNS-SF34 data from participant interviews and data from NAT: PD-Cs completed within one week of each other (n=67) (Table 8.3). The PABAK values indicated fair agreement between the NAT: PD-C physical item and the SCNS physical symptom and daily living domain item (69% agreement), and moderate agreement between the NAT: PD-C psychological item and the SCNS psychological domain (71% agreement). Agreement between the NAT: PD-C information item and the SCNS health system and information domain was substantial, as indicated by the PABAK value (87% agreement), while the agreement between the NAT: PD-C spirituality item and the NA-ACP spirituality domain was almost perfect (93% agreement).

**Table 8.3:**     *The Prevalence-Adjusted Bias-Adjusted Kappa (PABAK), Cohen's kappa and percentage agreement between the presence (or absence) of needs in the NAT: PD-C and self-reported needs identified during CATIs*

NAT: PD-C domain	Self-reported needs	Consistency	
		PABAK	% agreed
Is the patient experiencing unresolved physical symptoms?	SCNS Physical symptom and daily living	0.38	69%
Are the patient's psychological symptoms interfering with wellbeing or relationships?	SCNS Psychological	0.42	71%
Does the patient have an unmet need for information?	SCNS Health system and information	0.86	87%
Does the patient have concerns about spiritual or existential issues?	NA-ACP Spirituality	0.74	93%

### 8.3 ISSUES OF CONCERN RECORDED USING THE NAT: PD-C

Of the 342 completed NAT: PD-Cs received by the research team, 273 (80%) had at least one issue of concern recorded. A total of 239 NAT: PD-Cs had at least one concern recorded in the *Patient Wellbeing* section, with a total of 441 concerns identified in this section. The majority of concerns identified in the *Patient Wellbeing* section were physical or psychological in nature. While issues of concern were identified across all domains, less than 10% of NAT: PD-Cs recorded concerns relating to information, spiritual, financial or social needs (Figure 8.1). The percentage of completed NAT: PD-Cs that had an action recorded is also reported in Figure 8.1. Hence, for the physical item 59% of the 342 completed NAT: PD-Cs had a need recorded, and 39% of the 342 NAT: PD-Cs had a corresponding action recorded. In addition, any actions that were recorded to address the needs identified in each of the items in the *Patient Wellbeing* section were examined. Of the NAT: PD-Cs that had a need identified, the percentage that also had a corresponding action recorded ranged from 63% in the daily living item to 100% in the social/cultural item.



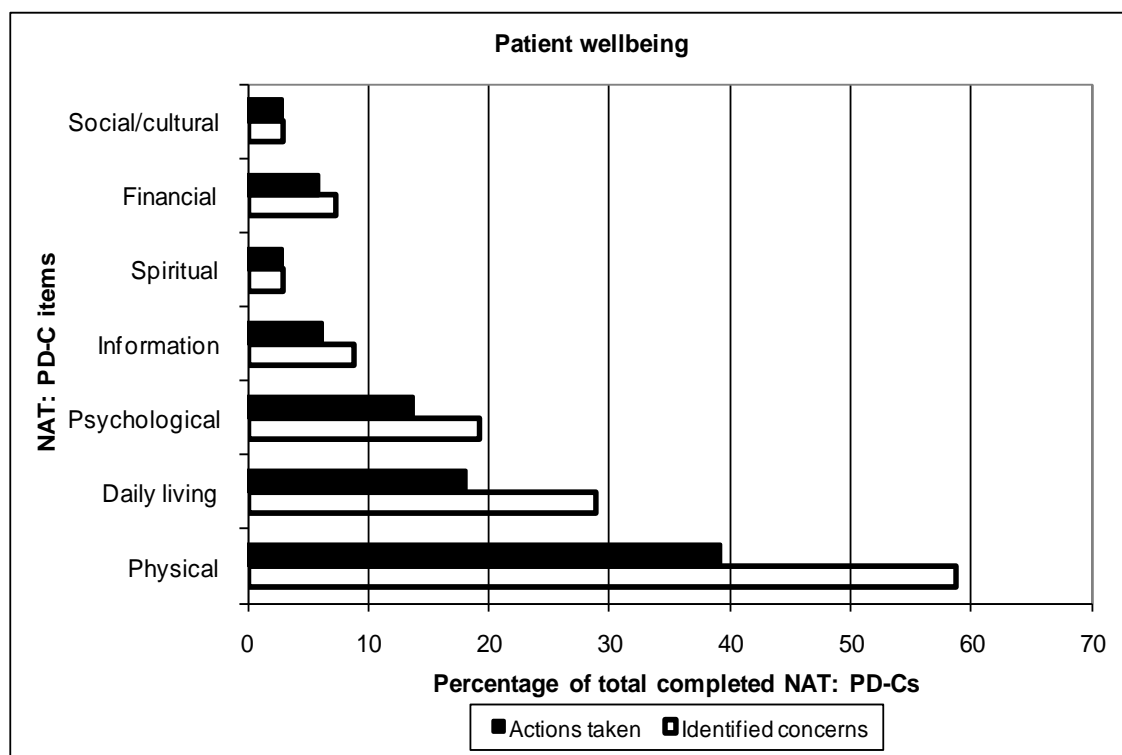


Figure 8.1: Percentage of NAT: PD-Cs in which a need was recorded in the Patient Wellbeing section; and any action recorded to address that concern

A total of 186 NAT: PD-Cs had at least one concern in the *Ability of Caregiver to Care for the Patient* section; overall, a total of 242 concerns were identified in this section. The majority of concerns identified related to the caregiver's distress about the patient's physical symptoms and the caregiver's difficulty with coping (Figure 8.2). The percentage of all completed NAT: PD-Cs with actions recorded is also reported in Figure 8.2. Of the NAT: PD-Cs that had a need identified, the percentages that had a corresponding action recorded ranged from 71% in the physical care item to 100% in the financial item.

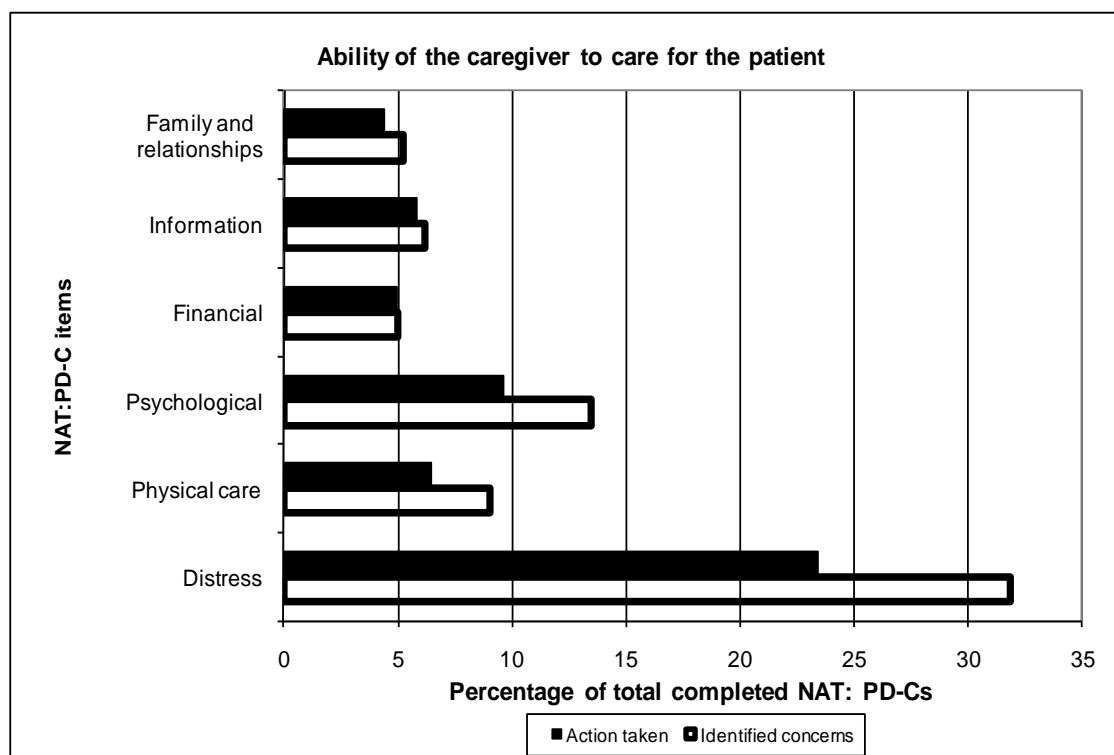


Figure 8.2: Percentages of NAT: PD-Cs in which a need was recorded in the *Ability of the Caregiver to Care for the Patient* section; and any action recorded to address that concern

Finally, a total of 141 had at least one concern in the *Caregiver Wellbeing* section. Just over 10% of completed NAT: PD-Cs recorded caregivers having some or significant concerns of a physical or psychosocial nature, or relating to bereavement grief (Figure 8.3). The percentage of all completed NAT: PD-Cs that had actions recorded is also reported in Figure 8.3. Of the NAT: PD-Cs that had needs identified, the percentage with a corresponding action recorded ranged from 77% in the bereavement item to 80% in the physical and psychosocial item.

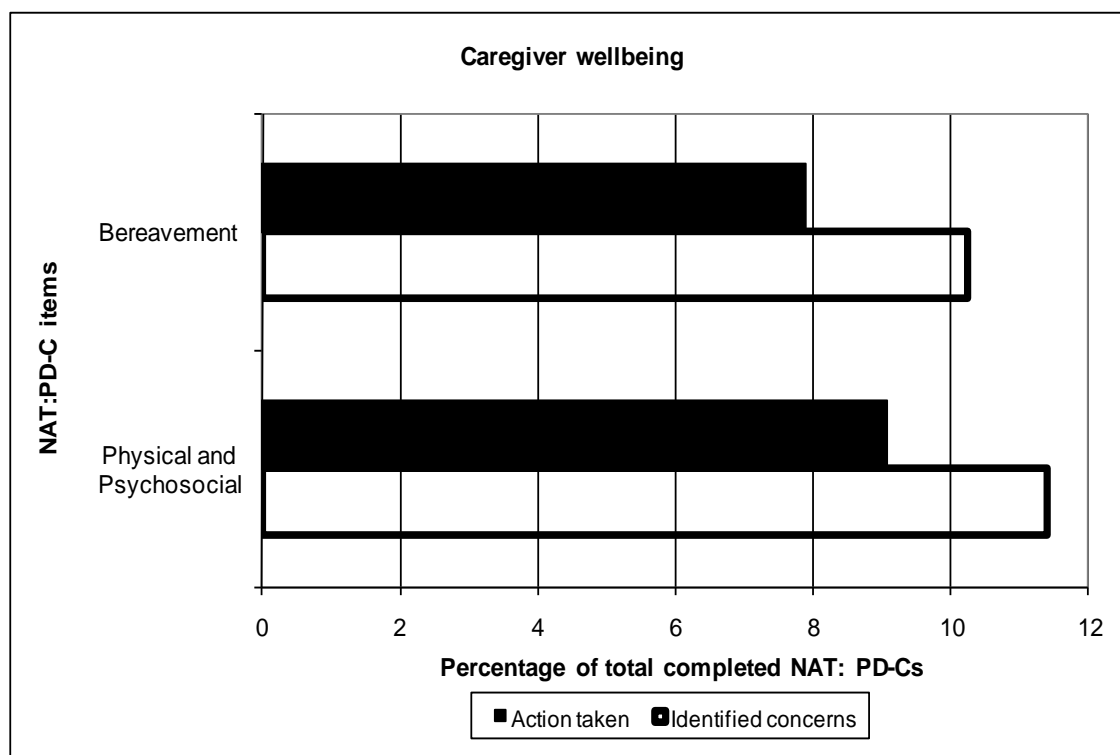


Figure 8.3: Percentage of NAT: PD-Cs in which a need was recorded in the Caregiver Wellbeing section; and any action recorded to address that concern

#### 8.4 RECORDED ACTIONS TO ADDRESS IDENTIFIED ISSUES OF CONCERN ON THE NAT: PD-CS

Of the NAT: PD-Cs that had an issue of concern recorded, the percentage which also had a corresponding action recorded was assessed, for each section of the tool separately. Health professionals directly managed more than half of the issues of concern, whether they related to the patient or caregiver wellbeing or the ability of the caregiver to care for the patient (see Table 8.4). Referrals to other health professionals practising outside the immediate care team were made in 4% to 8% of cases of concern identified across the three sections of the tool. No action was recorded on the NAT: PD-C for 22% to 31% of issues of concern identified.

A total of 33 referrals were made to providers or services outside the clinician's own team, including to specialist palliative care services (32%), social workers (18%),

medical oncologists (15%), psychologists (15%), haematologists (5%), surgeons (5%), physiotherapists (5%), occupational therapists (5%) and dietitians (5%).

*Table 8.4: Percentage of issues of concern identified on the NAT: PD-C for which an action to address that concern was recorded*

NAT: PD-C Section	Type of action taken			No action taken n (%)
	Directly managed n (%)	Managed by other team member n (%)	Referral made n (%)	
Patient wellbeing	160 (52)	40 (13)	12 (4)	95 (31)
Ability of caregiver to care for patient	153 (57)	42 (16)	13 (5)	60 (22)
Caregiver wellbeing	68 (58)	14 (12)	10 (8)	26 (22)

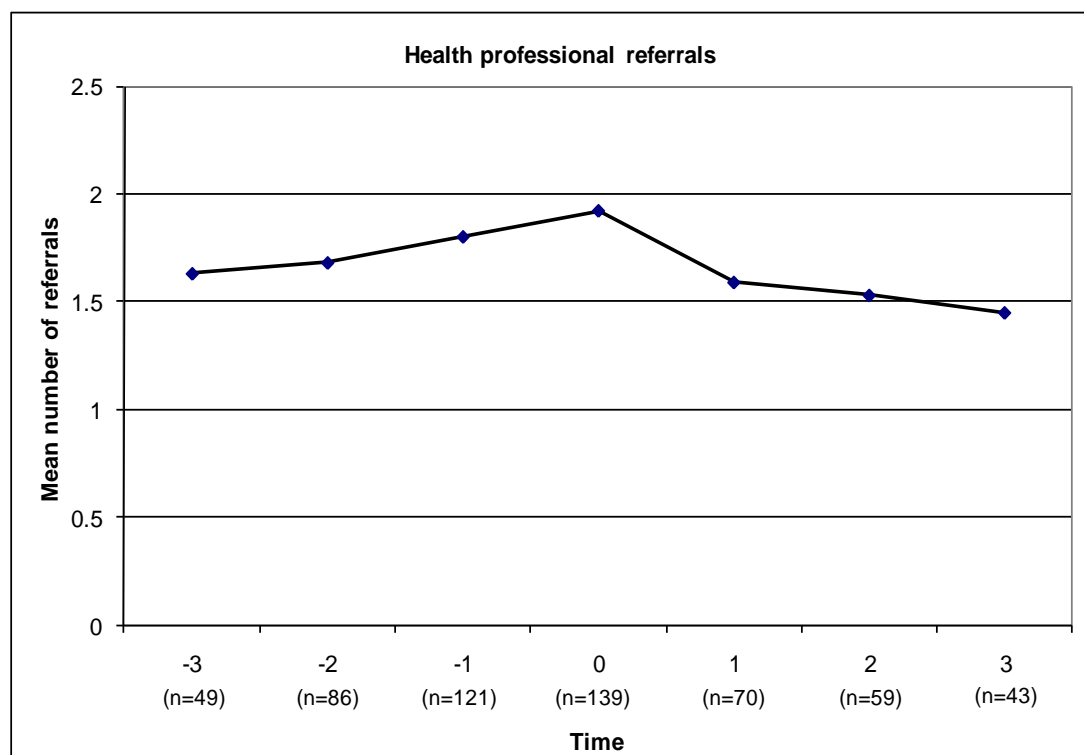
## 8.5 SELF-REPORTED SERVICE USE AND REFERRALS: CATIS

### 8.5.1 Referrals identified in the initial CATI

A total of 370 referrals made to a wide range of health professionals in the month prior to the baseline CATI. The top ten health professionals reported by participants included medical oncologists (20.3%), general practitioners (19.2%), palliative care physicians/services (8.4%), surgeons (7.8%), specialist cancer nurses (7.8%), radiation oncologists (7.8%), community nurses (5.4%), dietitians (4.6%), social workers (3.8%) and psychologists (2.7%). Fifty-six participants (28%) reported receiving no referrals.

### 8.5.2 Changes in numbers of self-reported referrals over time

Figure 8.4 reports on the mean number of referrals to health professionals reported by participants during each of their interviews. This GEE analysis includes only the participants reporting a referral to at least one health professional in their interviews. Figure 8.4 suggests a relatively stable number of referrals to health professionals across the study period.



*Figure 8.4: Mean number of referrals self-reported by participants in their CATIs over the course of the study*

## 8.6 SERVICE USE AND REFERRALS: AUDIT OF MEDICAL RECORDS

The medical records for 55 deceased patients were audited. The mean numbers of health professionals seen by patients, as well as the mean number of visits to each health professional, were recorded. Figure 8.5 presents data recorded in medical records for the 12 months prior to the participant's death. Figure 8.5 suggests that while the number of health professionals seen was relatively stable in the 12 months prior to death, the number of visits to these health professionals increased as participants approached death.

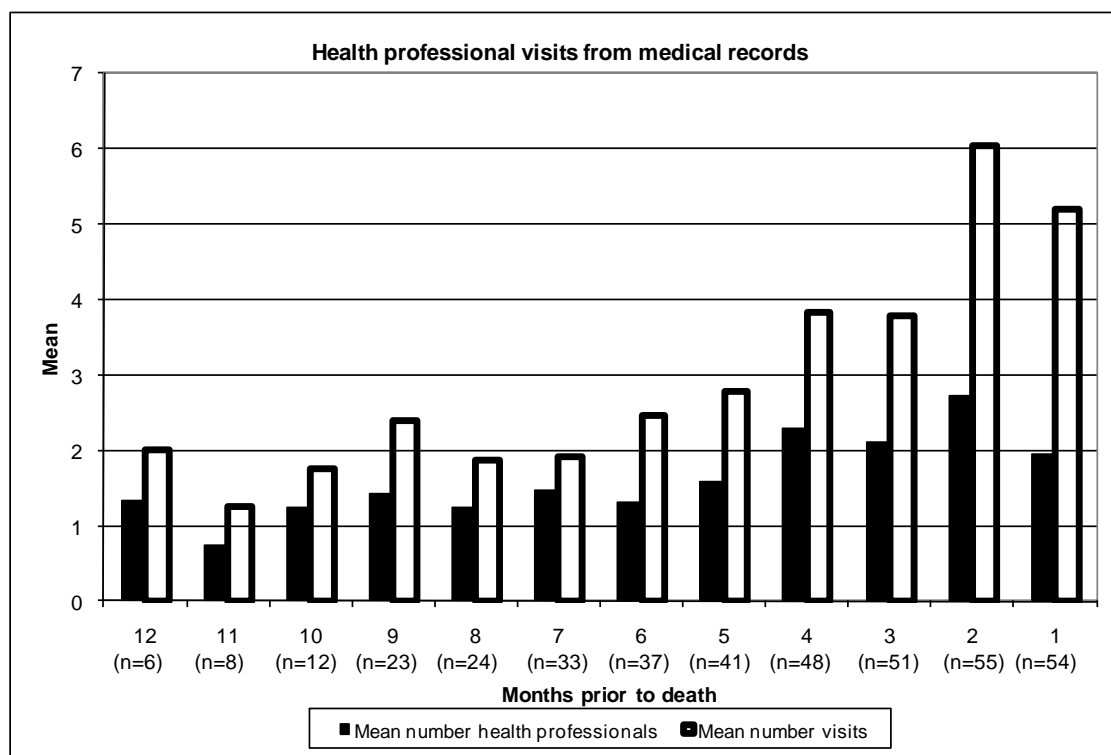


Figure 8.5: Mean number of health professionals seen and visits attended by participants during the 12 months prior to death, as recorded in patient medical records

## 8.7 DISCUSSION

The success of an assessment tool completed by health professionals can depend to a large extent on its feasibility and acceptability within the clinical setting; ensuring optimal compliance has become a primary concern. As Richardson (2005) argues, “practical concerns exist for health professionals and patients involved in the assessment process”,<sup>2</sup> such as the time required to conduct an assessment,<sup>2</sup> and the level of support and training required by staff using the resources.<sup>2, 3</sup> Moreover, while assessment tools may facilitate the identification of unmet patient and caregiver needs, this may subsequently increase the number of referrals made to services, potentially overloading these services. These issues can all impact on the likelihood that a tool becomes part of standard practice.

While newly developed assessment tools must be supported by sound scientific evidence, the implementation of these tools in clinical settings must also be appropriate and feasible. Feasibility can be assessed in a number of ways, one of which is to

assess the uptake rate. In this study, the high uptake rate of the assessment tool in oncology settings indicated a high level of acceptability, especially when only health professional factors associated with non-completion were included. The mode of administration is also an important practical consideration when assessing feasibility of assessment tools. While there is a lack of consensus as to which mode of administration is most suitable in different populations and settings,<sup>4</sup> it has been argued that using caregivers or health professionals to assess needs may affect accuracy in identifying severity and complexity of needs.<sup>5</sup> However, there was good consistency in issues of concern identified by health professionals using the NAT: PD-C, compared with patient self-report. The high uptake rate and consistency between issues of concern identified support the tool's usefulness in a busy clinical setting.

Because of health professionals' high-volume workloads, time is often reported as a factor affecting the accurate and timely identification of needs.<sup>6</sup> Importantly, using the NAT: PD-C during oncology clinic consultations did not appear to increase the length of consultations. In fact, the average consultation time was slightly lower for those consultations in which a NAT: PD-C was used. Similar to findings from other studies which have found that consultation time is not increased and may even be reduced by using tools,<sup>6</sup> the NAT: PD-C may allow health professionals to direct their focus onto relevant problems.

Literature also suggests that health professionals are less likely to identify psychosocial needs in people with advanced cancer, compared with physical needs.<sup>7-10</sup> In fact, oncologists' ability to detect psychological co-morbidity has been found in numerous studies to be unsatisfactory,<sup>8, 11, 12</sup> as has nurses' ability to detect hospice patients' physical and psychosocial concerns.<sup>13</sup> Clinicians (including medical and radiation oncologists and haematologists) are less likely to identify spiritual, social, family, financial, work, self-care or cognitive problems in their patients, compared with patient self-report.<sup>14</sup> For many people with cancer, there is an expectation that these issues will be raised by their health professionals, often because they themselves are uncomfortable in doing so.<sup>15</sup> Previous research has found that using a psychosocial screening instrument can improve the discussion of psychosocial problems and the referral rate to other health professionals.<sup>6</sup> When examining the types of issues identified by health professionals using the NAT: PD-C, it is clear that the majority of concerns identified were physical or psychological in nature. However, needs were

identified in all domains of the NAT: PD-C, suggesting that using an assessment tool may improve the detection of those issues that may not be identified otherwise.

As evidence suggests, the identification of patient or caregiver concerns alone may not lead to the implementation of actions to address these concerns. Aside from assisting health professionals in identifying physical and psychosocial concerns, the NAT: PD-C aims to prompt relevant action to address these concerns, either through the health professional's direct management or through referrals to more appropriate providers. Use of the NAT: PD-C was predicted to improve the identification of participants' concerns, prompting referral to other health services and providers as necessary. The NAT: PD-C data suggest that many of the concerns identified in the consultation using the NAT: PD-C were directly managed by the patient's immediate care team, whether they related to the patient or caregiver wellbeing or to the ability of the caregiver or family to care for the patient.

Up to 70% of the issues were managed either by the clinician or someone else from the team, and referrals to other health professionals practising outside the clinician's own team were made in less than 10% of cases, with a majority of these relating to caregiver wellbeing. Rather than simply increasing the numbers of referrals to specialist providers, use of the NAT: PD-C appeared to assist health professionals who identified unmet needs to meet these needs either themselves or by referring to specialist services. However, it is important to note up to one-third of concerns noted had no action recorded to address them. Whether health professionals, in fact, did not take any action to address the concern or whether an action was taken but simply not recorded on the tool, is difficult to determine.

During their CATIs, participants reported on the types of health professionals or services they had been referred to in the month preceding each of their CATIs, and which of these they had actually seen. In addition, the medical record audits indicated that the numbers of health professionals seen was relatively stable in the 12 months prior to death, even though the numbers of visits to these health professionals increased as participants approached death. Concerns about the NAT: PD-C potentially increasing the number of referrals made and overloading services appeared to be unfounded, with an absence of any significant increase in the number of health professionals seen by patients over the study period. Importantly, the majority of



participants reported having seen the person to whom they were referred. The main reason given for not taking up referrals was that the scheduled appointment had not fallen in the time period prior to their interview, while others reported that they were still waiting for an appointment with the person or service to which they were referred. Only a very small minority of patients had decided that they did not need the referral. The remaining patients reported having had only telephone rather than face-to-face contact with health professionals such as palliative care staff members.

## 8.8 STUDY DESIGN AND LIMITATIONS

A number of limitations in relation to the impact of the intervention on patient outcomes have been discussed in Chapter 7. Despite the apparent benefits of the intervention on clinical assessment and use of services, there are a number of limitations that must be addressed. While this study followed a cohort of people with advanced cancer over time and had minimal eligibility criteria, it was the efficacy of the intervention that was being examined. In this controlled environment, extra support was provided at each site in the form of a research nurse, who was present in the oncology clinics to oversee the completion of the NAT: PD-Cs by clinicians. Each clinician also received training in the use of the *Guidelines* and NAT: PD-C prior to the introduction of the resources. As this extra support is not normally available in these clinical settings, the effectiveness of the intervention in routine clinical care needs further examination. For example, some services and clinicians may perceive the implementation of the *Guidelines* and NAT: PD-C, in the absence of the extra support, as potentially burdensome and be less likely to adopt the resources in everyday practice.

The completion rate of the NAT: PD-C was assessed in the participating cancer centres only, and the presence of a research nurse at each site may have contributed to the high completion rate that was obtained. Moreover, completion rates may have differed in other clinical settings. The participating cancer centres are larger and more established than other services, especially in rural areas. In addition, completion rates in SPCSs and general practice were not formally assessed. In fact, GPs received only a letter and instructions encouraging them to complete the NAT: PD-C on consenting patients.

In terms of the length of consultation, only 13 baseline appointments were audio-taped and these were taped only in the oncology setting. Again, conducting this sub-study with a larger sample size and in different settings may have provided more comprehensive information. However, it is envisaged that the NAT: PD-C will primarily be completed in oncology settings. Therefore, the positive outcomes with regard to feasibility are important findings.

## **8.9 CONCLUSION**

Addressing the “practical concerns of health professionals and patients involved in the assessment process”<sup>2</sup> is an integral step in the development of resources such as assessment tools,<sup>2, 3</sup> as the feasibility and efficiency of the resource will significantly impact on the likelihood that it becomes part of standard practice. The results reported in the previous chapter suggest that the NAT: PD-C can assist busy clinicians to identify issues of concern efficiently, particularly in areas that are not routinely well-addressed. The results of this study suggest that incorporating the tool into standard practice will not place any unnecessary burden on health care providers or services. Overall, the NAT: PD-C is a feasible and efficient tool that can be used by health professionals involved in the care of people with advanced cancer to facilitate the timely provision of needs-based care, including palliative care, especially in primary care and the services that refer to palliative care. A summary of the findings of this research program and a discussion about future research directions are provided in Chapter 9.

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# **CHAPTER 9:**

## **BEYOND THE CONFINES OF WELL- ESTABLISHED ONCOLOGY SETTINGS**

## 9.1 CONCLUSION

The aim of this chapter is to provide a critical review of the research in light of the overall objectives and outline the implications that this research may have for patient care, practice and policy.

The need for improvements in the quality and effectiveness of service delivery in Australian health services has become a major focus in recent times.<sup>1</sup> The Australian health system will continue to be “stretched by an ageing population, the growing burden of chronic illness, and the increasingly outmoded organisation of health services”.<sup>2</sup> Issues such as workforce shortages, the increase in out-of-pocket costs and the role of private and public funding have all impacted on the availability of health care,<sup>2,3</sup> with access to care often based on ability to pay rather than need.<sup>2</sup> In Australia, deaths are often from chronic diseases,<sup>4</sup> and increasingly, the management of chronic diseases such as cancer is lacking in terms of access.<sup>5</sup> The ongoing challenge is to ensure that health care is delivered in an appropriate and equitable manner across the illness trajectory.

Changes in attitudes towards death and dying, changes in demography and an increase in burden of diseases such as cancer have facilitated an increasing interest in the area of palliative care. There is a clear demand by the whole community for people at the end of life to have access to care that matches the complex and ever-changing needs that they encounter; however, there is a disparity between these expectations and current experiences.<sup>6</sup> It is argued that “creative solutions are necessary to address the escalating healthcare demands of chronic conditions” that ultimately lead to death.<sup>5</sup>

The benefits and importance of palliative care are widely recognised.<sup>6-16</sup> Palliative care has been increasingly incorporated into the decisions of policy makers, with “significant changes to the structure, organisation and delivery of palliative care services in Australia, including the role within the wider health care system”.<sup>17</sup> The National Palliative Care Strategy was released in 2000,<sup>1</sup> and Palliative Care Australia (PCA) released a number of policy documents providing advice and information regarding standards of care and service planning.<sup>18,19</sup> These standards outline the expectations

associated with providing care to people with life-limiting illnesses.<sup>17</sup> The need for integration of national standards across all levels of care and care settings to benchmark processes and outcomes of care has been widely recognised.<sup>20</sup> Central to this is the recommendation that palliative care be provided according to the individual needs of the patient, caregiver and family, so that the type and level of care provided, as well as the setting in which it is delivered, are dependent on the complexity and severity of individual needs, rather than prognosis or diagnosis.<sup>19</sup>

At the time of their release, these documents suggested that the “development of well defined and transparent referral and admission protocols and procedures” would facilitate appropriate needs assessment.<sup>19</sup> Similarly, Carlson (2008) argued that the criteria of need must be determined, not only in terms of what constitutes need, but when assessments should take place.<sup>21</sup> The need for change in the delivery of palliative care has been strongly supported in Australia and internationally. This support has been instrumental in providing the framework in which the research reported in this dissertation was conducted.

The intention of this research was to develop and assess a strategy aimed at assisting in the allocation of palliative care resources according to need, within the context of the advanced cancer population. In particular, the research aimed to:

8. Develop and test the psychometric qualities of a new needs assessment tool for use with advanced cancer patients and caregivers; and
9. Assess the impact of the systematic and ongoing use of the Guidelines and needs assessment tool on patient outcomes, clinical assessment, response and service utilisation.

### **9.1.1 Testing the psychometric qualities of the NAT: PD-C**

As part of a wider program of work the *Palliative Care Needs Assessment Guidelines* were developed to assist health professionals in identifying the physical and psychosocial needs of people with advanced cancers, their caregivers and families. Due to the numerous individual patient,<sup>22, 23</sup> health professional<sup>22-25</sup> and organisational<sup>22, 24, 26, 27</sup> barriers that may prevent the uptake of guidelines, identifying a way to facilitate the uptake of these *Guidelines* was a primary concern. Available research advocated a number of different approaches, one of which was the use of

structured tools.<sup>28</sup> The review of existing needs assessment tools in Chapter 3 reported limitations in relation to psychometric properties, clinical feasibility and acceptability for both patient and caregiver tools already available. Importantly, no tools existed to concurrently assess patient, caregiver and professional carer's needs to prompt needs based referrals to palliative care services at the time this research was being undertaken.<sup>29</sup>

Concurrent assessment at multiple time points of patients, caregivers and health professionals is paramount to ensuring that all needs are being met and that the most appropriate course of action with regard to care is being taken. Hence, the Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C) was developed to fill this gap; and two validation studies were undertaken in an attempt to assess the psychometric qualities of this tool. The first study tested the clarity, face validity, content validity, acceptability, and inter-rater reliability of the NAT: PD-C in a simulated setting (Chapter 4). This study found that the NAT: PD-C was easy to administer, covered all areas of needs pertinent to patients with advanced cancer and their caregivers, and was able to differentiate between the different levels of need that may be present.<sup>30</sup> However, the NAT: PD-C was designed for use in clinical practice, so the simulated setting in which this study was undertaken was acknowledged as an important limitation. To address this limitation, the second validation study was undertaken to assess the reliability, validity and acceptability of the NAT in a specialist palliative care clinical setting; and a high level of reliability and validity was reported.

### **9.1.2 Impact of the Guidelines and NAT: PD-C on patient outcomes, clinical assessment, response and service utilisation.**

Building on the evidence base for the resource, the need for patients and their caregivers needed to be assessed at multiple time points using the tool to determine the validity and responsiveness of the NAT: PD-C was an important consideration.<sup>31-33</sup> To provide this evidence, a prospective, multi-site, multi-discipline study was undertaken to assess the feasibility and efficacy of the *Palliative Care Needs Assessment Guidelines* and Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C) and their impact on patient outcomes and service utilisation were assessed (Chapter 7 & 8).

Overall, the research findings suggest that the intervention implemented is an acceptable and useful strategy for facilitating needs-based care for people with advanced cancer being treated in cancer care centres. In terms of patient outcomes, the use of the *Guidelines* and NAT: PD-C contributed to a reduction in health system and information needs, and patient care and support needs. Moreover, the use of these resources may have assisted in minimising the anticipated decline in quality of life and increase in physical symptoms and daily living needs that often occur in this population.<sup>34-37</sup> However, without a contemporaneous control group we cannot reasonably attribute these changes entirely to the intervention. Further work is required to explore the role of the intervention in bringing about such changes.

In terms of clinical assessment, response and service utilisation, the uptake rates of the NAT: PD-C within the outpatient oncology setting indicating a high level of acceptability without any significant burden on consultation time. In fact, the average consultation time was slightly lower for those consultations in which a NAT: PD-C was used. Needs were identified in all domains of the NAT: PD-C, suggesting that using an assessment tool may improve the detection of those issues that may not be identified otherwise. Many of the concerns identified in the consultation using the NAT: PD-C were also directly managed by the patient's immediate care team, rather than being referred to another service.

These findings suggest that at the individual level, the *Guidelines* and NAT: PD-C offer an efficient strategy for systematically identifying the severity and complexity of patient, caregiver and family needs, as well as health care professionals' desire for assistance in providing optimal needs-based care to their patients.<sup>19</sup> At an organisational level, the NAT: PD-C is a feasible and efficient tool that could be incorporated into standard practice without any unnecessary burden on the health care providers or services. There are often serious concerns around the potential for services to be overloaded as a result of greater identification of needs and subsequent increases in the number of referrals made to services. If used systematically in both generalist settings and by specialist palliative care services, the *Guidelines* and NAT: PD-C offer an opportunity to triage care according to level of need, enabling finite palliative care resources to be offered to those people who need them most, in a more equitable and transparent way.<sup>38</sup>



## 9.2 BEYOND THE CONFINES OF ONCOLOGY: OPPORTUNITIES FOR FUTURE RESEARCH

While these findings are promising, there are a number of limitations that must be addressed with regard to the study design and methods. One of the major limitations of this work is that it was conducted with the cancer population only. While non-cancer groups are a smaller percentage of the palliative care population in Australia and internationally,<sup>39-42</sup> there is also a need to ensure that they, too, receive appropriate and timely needs-based palliative care.<sup>43</sup> Future research is required to identify the complexity and severity of needs affecting people with non-malignant conditions, to provide a more accurate determination of the degree of involvement required by generalist and specialist services. There is a need to develop guidelines and assessment tools which can identify the needs and guide appropriate care of people with these conditions. The role these generalised resources can play in identifying and addressing the complexity of needs in people with non-malignant conditions, as well as prioritising limited resources and planning of services, must be examined.

The research was also conducted in large metropolitan cancer centres. Importantly, not all organisations are able to adopt interventions and policies in the same way, and some organisations may lack the relevant resources to provide the same level of care as others with greater resources at their disposal.<sup>44, 45</sup> There is wide variation in Australia in terms of the models of health care services and the capacity of these services. For example, specialist palliative care services are often developed according to needs of the area, may be funded in different ways, and provide varying levels of care involving various disciplines as part of their staff.<sup>38, 46</sup> Rural and regional areas are particularly limited in the ability to ensure that all people who require assistance are provided for. Inequalities for rural populations exist with regard to survival, staging and treatment of cancers.<sup>47</sup> There is greater dependency on generalist providers such as GPs and nurses in these areas and, even then, access cannot be guaranteed.<sup>48, 49</sup> Jong (2005) argues that “conceptually, a well-defined pathway, appropriately tailored to needs, that each person with cancer can easily follow to timely expert care” is required.<sup>47</sup> The feasibility of the *Guidelines* and NAT: PD-C as a strategy for providing timely and appropriate care in rural and remote areas must also be examined further.

While these resources have the potential as a strategy for use in both generalist and specialist settings, this has not been thoroughly tested in this research. Many of the findings, including the data on length of consultation were obtained from cancer centres only. Patients and families report confusion concerning the roles of health professionals involved in providing care,<sup>50, 51</sup> and resent having to be re-assessed, and repeatedly relay information regarding current medications and symptoms to each health professional they see. Effective and timely communication of the patient's situation among health professionals involved in their care is vital.<sup>52</sup> It has been suggested that to sustain this continuity of care, services should develop a common approach to assessment of needs of people with cancer.<sup>31</sup> The *Guidelines* and NAT: PD-C have the potential to be used by health professionals from any care setting and allow for the transfer of similar information in a simple and unified way, thus increasing coordination of care by linking generalist and specialist providers.<sup>31</sup> However, the impact of using these resources in general practice and specialist palliative care settings must be examined further.

The representativeness of the sample and the generalisability of findings suggest that further research with larger sample sizes and varied diagnoses including those with poorer predicted outcomes is required. While using the NAT: PD-C appeared to assist health professionals who identified unmet needs to address these needs either themselves or through other members of their care teams; it is difficult to gauge whether this outcome was the result of using the NAT: PD-C, or whether this may have been due to other barriers to referral that have been acknowledged in the literature. For example, was the health professional aware of the services available, were they willing to refer to these services if necessary and were the services able to take on these patients if they were referred? The extra support provided at each site in the form of a research nurse, who was present in the oncology clinics to oversee the completion of the NAT: PD-Cs by clinicians may also have influenced the outcomes of this study. In addition, each clinician received training in the use of the *Guidelines* and NAT: PD-C prior to the introduction of the resources. Some services and clinicians may perceive the implementation of the *Guidelines* and NAT: PD-C, in the absence of the extra support, as potentially burdensome and be less likely to adopt the resources in everyday practice.

It has been suggested that “replicated findings from interrupted time series designs by different investigators in different settings may provide convincing evidence that an intervention is effective”.<sup>53</sup> Effectiveness and applicability studies within the real-world setting are required to further support the use of the Guidelines and NAT: PD-C. It is important that we ascertain how the resources can be successfully implemented in settings of care, and continue to monitor the subsequent impact these resources have on utilisation and quality of specialist palliative care. Arguably, there may be services in which continued implementation of the resources is less sustainable; if so, ways that the uptake of the resources can be improved must be identified.

### **9.3 IMPLICATIONS FOR POLICY AND PRACTICE**

Translating research findings into health policy is an “active process of dissemination supplemented by a conscious programme of implementation”.<sup>54</sup> Culture change is often an arduous process requiring executive support as well as support from particular individuals or “champions” within organisations to drive new initiatives.<sup>55</sup> Formal and systematic dissemination of these changes within clinical settings is therefore required.<sup>24</sup> Others involved in similar activities to inform changes in practice and policy support the questioning of whether proposed interventions are beneficial, whether the issue is significant and extensive enough to require attention and finally, what the consequences of imposing the change would be.<sup>55</sup> For both government and the public, evidence of quality of services and cost-effectiveness is of paramount concern.<sup>56</sup> Achieving acceptable improvements in quality of care with due consideration to the potential financial and practical concerns of organisations and policy makers is vital if new interventions are to be adopted.

The *Palliative Care Needs Assessment Guidelines* provide information about the physical and psychosocial needs affecting people with cancer, their caregivers and families, as well as those groups who may be at greater risk because of these issues. The NAT: PD-C operationalises the *Guidelines* and, used routinely by health professionals with a range of clinical expertise, can facilitate needs being identified and addressed in a timely manner. Health care providers who are part of the chain need to feel adequately trained to provide the required care. Generalist and primary care providers, including GPs and allied health professionals, see few patients with life-

limiting illnesses per year and often report a lack of education and training in palliative care.<sup>50, 57-59</sup> Health professionals from disciplines with greater exposure to people with cancer, including oncologists and nurses, report similar issues.<sup>60, 61</sup> In fact, these groups have all acknowledged the need for increased education and training in palliative care.<sup>50, 59, 62</sup> These professionals all play a critical role in providing needs-based care, ensuring that needs are addressed by the most appropriate service provider. Hence, ensuring that adequate education and training in palliative care is available to support these health professionals is imperative for effective palliative care delivery.<sup>18</sup>

Effective dissemination of new resources aimed at changing clinical practice must be supported by an evidence-based approach, including education and training programs for the intended target groups. “Train-the-trainer” workshops, involving the information being taught to individual educators from different services who then conduct in-service classes within their own organisation or clinical setting,<sup>63</sup> have been used to enhance palliative care knowledge of health professionals working in nursing homes,<sup>63</sup> in end-of-life care knowledge in physicians,<sup>64</sup> and in general communication skills training.<sup>65</sup> They offer a feasible option for dissemination as they allow maximum coverage of services and providers. In addition, linking the resources with already established education programs such as the continuing medical education programs of professional organisations including the Royal College of General Practitioners (RACGP), Royal College of Nursing Australia (RCNA) and Australian College of Rural and Remote Medicine (ACRRM), as well as programs for undergraduate medical, nursing and allied health disciplines such as the Palliative Care for Undergraduate Program (PCC4U), could assist in establishing these resources as a vital component of quality cancer care to individuals from a variety of medical, nursing and allied health professions early on in their careers. This is especially pertinent for those, such as primary care professionals, whose main work is not in palliative care.

The sustainability of new initiatives is also highly dependent on linkages with existing infrastructures, policies and systems. In Australia, national policies aimed at improving the delivery of palliative care have been well-established and supported. The wide recognition of the importance of this needs-based approach to care at the national level may be beneficial in promoting the widespread adoption of the resources. Moreover, inclusion of the resources in the National Standards Assessment Program (NSAP),

which supports the “move towards best practice, by developing resources that will support and enhance the ability of palliative care services to improve the quality of care” would be beneficial.<sup>66</sup> Continued evaluation and monitoring are required in order to plan services and assess the workforce required to deliver these services.<sup>67</sup> Importantly, systems are already in place to monitor the utilisation of specialist palliative care services in Australia *via* the Palliative Care Outcomes Collaboration (PCOC) initiative. This initiative enables services to collect standardised patient information, for collation at a national level.<sup>68</sup> Incorporating these resources into established initiatives such as PCOC could provide an important source of information for specialist palliative care settings about the changing needs of people with cancer and their families during their time in the service.

As the NAT: PD-C can be completed by health professionals from a variety of different specialties within multiple clinical settings, it offers a unique opportunity for mapping the patient’s cancer journey and coordinating care between primary and specialist settings. However, strategies for the wide-spread adoption of these resources in settings outside the specialist palliative care setting are also required. According to Palliative Care Australia, a “system-wide infrastructure of established links needs to be in place across the specialist palliative care and primary care service systems to support care”.<sup>17</sup> Initiatives such as the Program for Education in the Palliative Approach have been established for health professionals, whose substantive work is not in palliative care, to receive training within specialist palliative care settings.

This research has identified a potentially efficient and acceptable strategy for supporting needs-based care. However further work is required to confirm the benefits of this approach not only for people with cancer and their families, but also by those delivering care at the generalist and specialist levels. It is hoped that systematic use of the *Guidelines* and NAT: PD-C will assist in providing the correct form of care to people at the time they most need it.

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# APPENDICES

# **APPENDIX 3.1:**

## **SUMMARY OF THE *PALLIATIVE CARE* *NEEDS ASSESSMENT GUIDELINES***

# **Palliative Care Needs Assessment Guidelines Summary**

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**August 2006**



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## ACKNOWLEDGEMENTS

The development of these Guidelines was funded by the Australian Government Department of Health and Ageing and managed through the Centre for Health Research & Psycho-oncology (CHeRP), based at The University of Newcastle, NSW, Australia.

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We extend our sincere thanks to the many individuals and groups across Australia who provided constructive feedback on the draft of these Guidelines.

## Acronyms used in this report

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CALD	Culturally and linguistically diverse
GP	General practitioner
PC	Palliative care
PCA	Palliative Care Australia
QoL	Quality of life
SPC	Specialist palliative care
SPCS	Specialist palliative care service

### The suggested citation for this document is:

Girgis A, Johnson C, Currow D, Waller A, Kristjanson L, Mitchell G, Yates P, Neil A, Kelly B, Tattersall M & Bowman D (2006). *Palliative Care Needs Assessment Guidelines*. The Centre for Health Research & Psycho-oncology, Newcastle, NSW.

## FOREWORD

Community expectations about quality care for someone experiencing a life-limiting illness have continued to evolve rapidly in the last 20 years. There is now a clear demand by the whole community for people at the end of life to have access to care that matches the complex and ever-changing needs that they encounter. Given the range of places in which such care occurs (home, hospital, other community settings) and the wide range of life-limiting illnesses, this requires careful coordination of limited resources and a shared understanding of the goals of care – optimising comfort and function in areas such as physical, emotional, existential, sexual, social and financial care.

Diagnosis and prognosis are poor indicators of need for *this person* in the context of *his/her life*. In palliative care, equitable and timely access to services for people with more complex needs is an imperative. Such an approach is not limited to people for whom active treatment has ceased; these issues need to be raised from the time a life-limiting illness is first recognised.

One audience for the *Palliative Care Needs Assessment Guidelines* are clinicians whose work encounters people with life-limiting illnesses from time to time – general practitioners, community allied health and nursing staff, and doctors from other specialties. For these clinicians, the *Guidelines* can establish whether needs are currently being met, or a specialist assessment may add to the care plan.

For palliative care teams working alongside general practitioners and community nurses, the *Guidelines* can help to determine the complexity of ongoing needs. Are the needs assessed today (not at the time of referral) best met with ongoing specialist input or will these needs continue to be met by generalist clinicians who are already involved in care? This is a dynamic process as the needs of the person and their family changes over time. Such assessments then occur with every encounter to best match needs with the complexity of input.

There is a fundamental challenge in delivering good care for people (and their families) facing an expected death – whose needs are being met currently and whose needs require more input to optimise care? By creating a more transparent and objective mechanism for the decision about who accesses (or does not need to access) specialist services, it is hoped that the care that can be offered for everyone with a life-limiting illness will more equitably address the needs of the tens of thousands of Australians who face this path every year.

Professor David Currow  
President, Palliative Care Australia  
July 2006

## IMPORTANT NOTICE

This document is a general guide to appropriate practice, to be followed subject to the clinician's judgement and the patient's preference in each individual case.

The Guidelines are designed to provide information to assist decision-making and are based on the best evidence available at the time of publication. The accompanying

*Needs Assessment Tool: Progressive Disease-Cancer* is available at

<http://www.newcastle.edu.au/research-centre/cherp/professional-resources/>.

Readers may also find the following module helpful in guiding their discussions with patients about palliative care issues: National Breast Cancer Centre. *Discussing the transition from curative care to palliative care - Evidence from the literature*. 2005 National Breast Cancer Centre, Camperdown, NSW.



## EXECUTIVE SUMMARY

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness. Referral to specialist palliative care services is appropriate at any time in the disease trajectory when a patient with a life-limiting illness, or significant others associated with the patient, have identified needs that are not being adequately addressed, whether these needs are physical, psychological, social or spiritual. However, since not all patients for whom death is expected will need specialist palliative care, the challenge facing managers of health services and policy makers is to develop objective, cost-efficient and needs-based strategies for palliative care resource allocation. This is particularly important given the potential expected increase in the demand for specialist palliative care services, poor articulation about how and when to best refer patients and the likelihood that resources will remain relatively static at least in the foreseeable future.

Palliative Care Australia has argued that central to the development of an integrated plan to deliver quality end-of-life care is the “development of well defined and transparent referral and admission protocols and procedures”. The *Palliative Care Needs Assessment Guidelines* (hereafter referred to as the *Guidelines*), together with the Needs Assessment Tool: Progressive Disease -Cancer, are pivotal to facilitate equity of access, i.e. equal access for equal need, to finite palliative care resources.

The *Guidelines* are intended to provide guidance to those caring for people with life-limiting illnesses and their families, to ensure that they are offered the most appropriate care to meet their specific needs. They cover all aspects of patient, caregiver and primary health care provider characteristics that may influence the decision to provide more specialist palliative care to a particular patient or family. The introduction of the *Guidelines* and Needs Assessment Tool: Progressive Disease - Cancer is expected to reduce the incidence of late and crisis referral and improve referral where psychological, social, physical and spiritual problems are evident. Improved outcomes for patients and families are expected to include improved symptom control, quality of life and satisfaction with care.

Since the cancer patient population currently represents approximately 90% of the palliative care services' caseload, this group has been identified as the most appropriate target population for the first edition of these *Guidelines*. It is planned that the *Guidelines* will be generalised to the non-cancer palliative care population after comprehensive evaluation.

## BACKGROUND & SUMMARY OF KEY EVIDENCE

### • PALLIATIVE CARE

#### World Health Organization definition of palliative care

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing complications.

World Health Organization 2002<sup>1</sup>

*National Cancer Control Programmes: Policies and managerial guidelines 2<sup>nd</sup> Ed, Page 83*

#### Timing of referral to specialist palliative care services

Referral to specialist palliative care services (SPCSs)<sup>j</sup> is appropriate at any time in the disease trajectory when a patient with cancer, or significant others associated with the patient, have identified needs that are not being adequately addressed, whether these needs are physical, psychological, social or spiritual. Local SPCSs may, however, have specific access criteria, which primary health care providers would need to be aware of.

#### Quality of life issues

Promotion of an individual's quality of life (QoL) is a central tenet of PC. The impetus for studies on QoL is linked to treatment advances that have resulted in prolonged survival times with side

<sup>j</sup> Multidisciplinary health care services whose substantive work is with patients who have a life-limiting illness.<sup>2</sup>

effects of treatment that may impact on QoL. In non-curative situations, quality rather than quantity of life becomes important and is considered the primary care outcome to assess. Quality of life is a broad concept that encompasses physical, social, psychological and spiritual domains. A focus on QoL helps to prevent health professionals from separating the patient's body from his/her biography during care.

Although there are different approaches to conceptualising QoL, there is agreement that four aspects of QoL are central: subjectivity, dynamism, multi-dimensionality, and positive and negative dimensions (Level IVb).<sup>3</sup> Subjectivity refers to the notion that the person who is best able to evaluate and reflect upon QoL is the individual him/herself. An external judgement about another's QoL is always second best.

Dynamism refers to the view that perceptions of QoL change over time and are influenced by many factors. The WHO Quality of Life Group (1993)<sup>4</sup> defines QoL as an individual's perception of his/her position in life in the context of the culture and value system in which he/she lives, and in relation to personal goals, expectations, standards and concerns. Therefore, as circumstances change, health status shifts and personal goals are re-aligned, a person's view of QoL changes. Hence, finding a sensitive and trustworthy way to continue to assess an individual's perception of QoL is important in providing responsive PC.

The multidimensional aspect of QoL is a relevant construct when attempting to understand the various domains that comprise QoL: physical, functional, emotional, social and spiritual. Knowing how these various domains inter-relate and shape a person's sense of QoL is helpful in being able to tailor interventions to specific QoL needs that may be a priority. There is also merit in considering a global approach to QoL, inviting a patient to consider his/her overall sense of QoL as a simple cumulative view. In the end stages of a person's life when energy is limited, this type of simple global assessment is often most practical and appropriate.

Finally, it is worthwhile noting that QoL considerations may have both negative and positive dimensions. Some patients may report that although there have been negative aspects of their illness, positive outcomes have also emerged. This attribute of a QoL assessment invites health professionals to consider the strengths and positive capacities of patients in the context of their care, rather than only focusing on issues of loss and distress.

In the context of this review, the concept of QoL is considered to be the over-arching construct that encompasses the domains of care considered here. The key principles that underpin this notion of QoL are apparent throughout the review and help define questions about when to refer to a SPCS.

## DEVELOPMENT OF THE GUIDELINES

### The need for Palliative Care Needs Assessment Guidelines

Late referral, crisis referral, and in some instances non-referral of patients with a life-limiting illness<sup>k</sup> to SPCSs can significantly impact the QoL of patients and their caregivers. Uncertainty regarding when to refer and the reasons to refer are also common amongst the general health professional community. More recently however, there has been a growing recognition that palliative care (PC) services may be appropriate for a wider range of patients than has traditionally been the case.<sup>5</sup>

Given the potential expected increase in the demand for SPCSs, poor articulation about how and when to best refer patients, and the likelihood that resources will remain relatively static at least in the foreseeable future, the challenge facing managers of health services and policy makers is to develop objective, cost-efficient and needs-based strategies for resource allocation. The development of resource allocation strategies will require identifying a) the sub-groups who would most benefit from receiving specialist palliative care (SPC) and ensuring they are offered such care in a timely way; and b) the sub-groups who would gain minimal or no benefit from receiving SPC and offering them alternative care (eg a palliative approach rather than SPC) which is best suited to their needs and strengths.

Palliative Care Australia (PCA) and the Australian Government Department of Health and Ageing have developed the following landmark national policy documents and guides which, together, provide a framework for needs and strengths-based access to quality end-of-life care:

1. PCA (2005) *A Guide to Palliative Care Service Development: A population based approach*<sup>2</sup>
2. PCA (2005) *Standards for Palliative Care Provision*<sup>6</sup>
3. PCA (2003) *Palliative Care Service Provision in Australia: A Planning Guide*<sup>7</sup>
4. Commonwealth Department of Health and Aged Care (2000) *National Palliative Care Strategy: A National Framework for Palliative Care Service Development*.<sup>8</sup>

It is important to note that not all patients for whom death is expected will need SPC. PCA has argued that central to the development of an integrated plan to deliver quality end-of-life care is the “development of well defined and transparent referral and admission protocols and procedures”.<sup>2</sup> The *Palliative Care Needs Assessment Guidelines* (hereafter referred to as the Guidelines), together with the Needs Assessment Tool: Progressive Disease - Cancer (hereafter referred to as the NAT: PD-C), are pivotal to facilitate equity of access, i.e. equal access for equal need, to finite PC resources. The NAT: PD-C will provide a rapid strategy for efficiently and systematically identifying patients who need SPC initially, as well as any change in status over the course of their advancing disease, as outlined in Figure 1.

<sup>k</sup> An illness that can reasonably be expected to cause the death of the patient within a foreseeable future.<sup>2</sup>

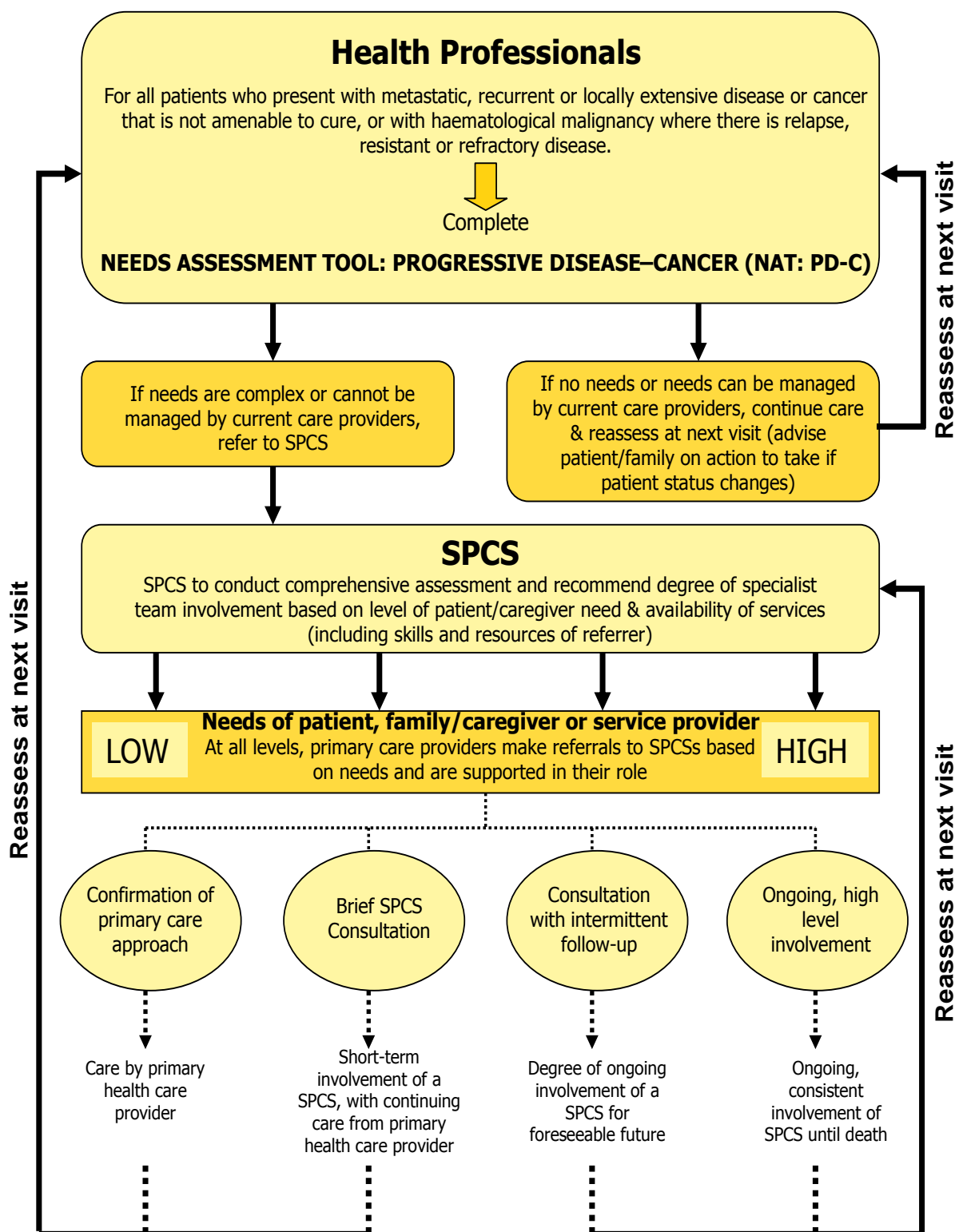
The introduction of the *Guidelines* and NAT: PD-C is expected to reduce the incidence of late and crisis referral and improve referral where psychological, social, physical and spiritual problems are evident. Improved outcomes for patients and families are expected to include improved symptom control, QoL and satisfaction with care.

### **The target groups for the *Guidelines* and Needs Assessment Tool**

Since the cancer patient population currently represents approximately 90% of the palliative care services' caseload, this group has been identified as the most appropriate target population for the first edition of the *Guidelines*. It is planned that the *Guidelines* will be generalised to the non-cancer palliative population after comprehensive evaluation.

The *Guidelines* and NAT: PD-C are intended to be utilised by *any health professionals* involved in the care of a person with advanced cancer. They will:

- Assist health professionals (GPs, community nurses, specialists, allied health professionals, etc, whose primary work is not in PC) to objectively determine whether or not they are currently meeting the needs of individual patients and their families.
- Provide a framework for initial and ongoing assessment of the need for and degree of specialist palliative care team involvement in the care of individual patients and their families.
- Enable an assessment of the areas of strength, as well as the areas of need, across each of the domains of referral. In instances where an assessment of strength or need is difficult to make, the default position would be referral to a SPCS for a more detailed assessment or review of the patient's and family's circumstances.



**Figure 1: Model for needs-based assessment and triage to appropriate level of palliative care service involvement**

## How the *Guidelines* were developed

The *Guidelines* have been developed after a major search and review of the relevant literature. Each study referred to in this document is given a number (referring to the Reference list) and a “level” indicating the type of study undertaken. All retrieved articles were reviewed using the following NHMRC Levels of Evidence.<sup>1</sup>

<b>Level I</b>	evidence is obtained from a systematic review of all relevant randomised controlled trials, usually found in meta-analysis.
<b>Level II</b>	evidence is obtained from at least one properly designed randomised controlled trial.
<b>Level III</b>	evidence is obtained from well-designed controlled trials without randomisation; or from well designed cohort or case control analytic studies, preferably from more than one centre of research; or from multiple time series, with or without the intervention.
<b>Level IVa</b>	evidence is obtained from descriptive studies of provider practices, patient behaviours, knowledge, or attitudes or a systematic review of the descriptive studies.
<b>Level IVb</b>	represents the opinions of respected authorities based on clinical experience or reports of expert committees.
<b>Level QS</b>	Evidence from qualitative studies. [NB: this level has been added to the standard NHMRC levels of evidence given the significant amount of qualitative research on some aspects of palliative care referral.]

Readers should be mindful of the following points when considering the evidence presented in the *Guidelines*:

- Much of the evidence reported in the *Guidelines* is of the incidence or prevalence of physical and psychosocial morbidity and of various practices, for example. In these types of studies, Level IV evidence is the highest level of evidence that can be collected and should therefore be considered the gold standard.
- There are very limited numbers of published population-based studies in the PC area. A majority of the evidence is drawn from research undertaken with specific sub-populations (e.g. in a type of SPCS or with a particular group of patients) and, therefore, may be less readily generalised to whole populations.
- The evidence reported in the *Guidelines* draws from research undertaken in Australia, where possible, as well as research conducted in other countries. It is acknowledged that the health care systems in other countries, particularly the United States of America (USA), are very different from the Australian system and that conclusions drawn from USA research may not be directly applicable to the Australian setting.

<sup>1</sup> NHMRC National Breast Cancer Centre Psychosocial Working Group. Psychosocial clinical practice guidelines: Information, support and counselling for women with breast cancer. 2000.

## OVERVIEW OF THE *GUIDELINES*

The *Guidelines* are intended to provide guidance to those caring for people with life-limiting illnesses and their families, to ensure that they are offered the most appropriate care to meet their specific needs. They cover all aspects of patient, caregiver and primary health care provider characteristics that may influence the decision to provide more specialist PC to a particular patient or family.

Each of the sections of the following table, Summary of key evidence underpinning the *Guidelines*, presents the key evidence relating to each major potential referral domain. The first five sections review the evidence relating to the patient domains, including the physical as well as the psychosocial, spiritual, cultural and other relevant issues; the final two sections review the evidence relating to the caregiver and family and to health professional domains.

In consideration of the different capacities of SPCSs, the *Guidelines* are able to be flexibly applied to the varying settings of care, including rural areas, where access to SPCS is limited. The *Guidelines* review the evidence for alternative modes of delivering support to primary care providers, and detail the common barriers to care. The *Guidelines* also provide an evidence base that may assist in increasing the capacity of all levels of health services to identify needs and deliver appropriate care to patients in the palliative phase of illness.

Readers should be mindful that although the *Guidelines* provide a review of the evidence in each domain separately, there are considerable inter-relationships that exist among the domains covered in each of the sections. For example, there are strong relationships between the patients' physical outcomes and caregivers' psychological outcomes, with uncontrolled physical symptoms in the patient being a major ongoing stressor for caregivers in the home. The quality of family functioning and availability of community services to assist and support "dysfunctional" families may have a significant impact on the fulfilment of a patient's wish to be cared for and/or to die at home. Health professional variables, including their own level of demoralisation, for example, are strongly related to patient variables, including a wish to hasten death.

The cultural diversity of the Australian population must also be taken into consideration when reviewing the evidence presented in the *Guidelines*. Australia is an ethnically diverse nation and, as such, the attitudes and behaviours of patients and families with regard to treatment and end-of-life care may differ depending on their cultural backgrounds. The onus is on health care services, in conjunction with individual health professionals, to promote awareness of these issues so that they are able to identify the culturally specific needs that patients may have and to respond to them with sensitivity. Some of these cultural issues are addressed in the following table of key evidence.



**Summary of key evidence underpinning the *Guidelines***

<b>Key evidence: Physical symptoms and functional status</b>	<b>Highest level of evidence</b>	<b>Relevant references</b>
Fatigue and weakness are reported as the most prevalent problems encountered by patients with advanced cancer.	III <sup>m</sup>	9-18
Younger age (<65 years) is associated with a higher prevalence of pain and may also be associated with severity of pain.	IVa	19, 20
Problems with dyspnoea, nausea, vomiting and pain are reported more frequently and are of higher intensity as performance status decreases.	III	21
There is a decline in physical function and ability to perform daily activities that occurs in parallel with increasing symptom burden. There may be an increased need for assistance in personal care and activities of daily living at this time.	IVa	22
Towards the end of life, expressed need may be far less than actual need, with some patients not seeking advice for symptoms despite their severity. Periodic reviews of the whole patient situation to assess the impact of the disease may highlight unmet needs.	IVa	23
Patients with unmet needs in physical symptom control, occupational functioning, nutrition, sleep and personal care demonstrate higher symptom distress and psychological distress.	IVa	24
Patients with more intense symptoms are more likely to be depressed, suggesting that psychological distress may result in magnification of physical symptoms, or that physical symptoms may have a role in the development of mood disorders in patients with advanced cancer.	IVa	25
The use of non-pharmacological interventions can serve as an adjunct to existing pharmacological pain management practice, reducing pain and improving quality of life.	I	26-28
The inclusion of allied health professionals may enhance the provision of care at the primary care level and help maintain physical function.	II	29-34

<sup>m</sup> Levels III and IVa are considered the highest levels of evidence for prevalence data.

Key evidence: Psychological issues	Highest level of evidence	Relevant references
Psychosocial morbidity often goes undetected in cancer patients. Assessment using standardised measures and feedback about patients' self-reported wellbeing is useful to clinicians, increases clinicians' perceived awareness of their patients' concerns, and improves doctor-patient communication.	I	35-43
A diagnosis of depression may be missed in situations in which depression is presumed to be a normal response to the situation, and when staff are unskilled in the diagnosis of psychological disorders.	IVa	44, 45
A <i>desire</i> to hasten death is not necessarily synonymous with a <i>request</i> to hasten death. People may tire of the symptoms and burden of decreasing ability and, in the face of depression, poor symptom control and lack of support mechanisms, these feelings become dominant. However, few terminally ill people sustain over time a desire to hasten death.	III	46-48
Cancer patients perceive sexuality as an important aspect of their quality of life. Patients prefer the health professional or nurse to initiate discussions regarding sexual issues.	III	49-51
Patients reporting loss of dignity are far more likely to report psychological distress, symptom distress, higher dependency needs, loss of will to live, depression, hopelessness, anxiety, issues with their appearance and desire for death. Dignity-preserving care incorporates physical, psychological, social and existential elements of the person.	IVa	52, 53, 54
Acute cognitive impairment is a significant burden in the PC population, affecting almost half of all patients prior to death. It may be the result of prescribed medications, sepsis, brain metastases, organ failure, hypercalcaemia or hyponatraemia. If recognised and treated, significant improvements in cognition may be achieved.	III	20, 55-58
Patients reporting better communication with their doctors, especially regarding decision-making and psychosocial and spiritual needs, are less likely to have high levels of death distress, a measure of anxiety and depression specifically linked to death and dying.	IVa	59

Pre-existing post-traumatic stress disorder (PTSD) in patients with cancer may be complicated by depression, grief, substance abuse, anxiety and adjustment disorders. Be alert to more severe symptoms of PTSD in patients with more advanced disease, more recent treatment, more intrusive treatment and cancer recurrence.	II	60-62
<b>Key evidence: Cultural and social issues</b>	<b>Highest level of evidence</b>	<b>Relevant references</b>
As with families and patients, health professionals regard language as one of the main barriers to providing adequate care. Use of interpreter services may overcome some of these difficulties.	IVa	63
The family's level of involvement in the patient's illness varies across cultures, as does the family's attitudes toward the provision of information. An understanding of cultural practices and beliefs may assist in providing optimal care to people of culturally and linguistically diverse backgrounds.	IVa	64-69
While PC teams need to consider the rituals and practices of different cultural groups, it is important to maintain an individualised approach to the treatment of patients, as membership of a particular cultural group does not necessarily imply that the individual shares all of that group's culture, beliefs and values.	IVb	65, 70
Social support helps reduce emotional distress. Lack of social support has been significantly associated with wish to hasten death. As well as encouraging patients to utilise available support systems, health professionals and volunteers are an important source of support.	IVa	46, 71, 72, 73-75
Different types and levels of support may be appropriate to offer to different groups of patients: a) Female cancer patients report greater unmet support needs than male patients. b) Younger patients and their families have greater unmet social needs than older patients. c) Practical information regarding services, treatment options, accommodation and travel are especially important for patients in rural areas as they often spend time away from intimate support networks.	IVa	14, 76, 23, 77-80

Formal support groups can provide social support for patients where they can feel empathy and gain information about methods of coping, stress reduction techniques and problem-solving skills. Social support groups improve the mood of patients and may reduce anxiety and depression.	II	81-83
<b>Key evidence: Spiritual issues</b>	<b>Highest level of evidence</b>	<b>Relevant references</b>
Hope is an important coping mechanism for patients. Families have been shown to have lower levels of hope than palliative care patients, and older family members may experience higher levels of hopelessness and fatigue than younger family members. Health professionals play an important role in nurturing hope, balanced with truth, in patients and their families.	IVa	84-86
For patients with advanced cancer, existential concerns are as prevalent as physical and psychological symptoms and include feelings of isolation, hopelessness and uncertainty.	IVa	87, 88
Spiritual wellbeing is associated with higher quality of life and life satisfaction and lower rates of depression, anxiety, hopelessness and death distress. Patients with greater spiritual wellbeing may also experience less symptom distress.	II	46, 59, 87, 89-91
The attitudes of health professionals towards facilitating the provision of spiritual needs of patients and their families have a significant impact on the delivery of these services.	IVa	92, 93
Almost all family physicians believe spiritual wellbeing is an important component of holistic care for patients with cancer; yet, few are likely to address the spiritual needs of patients. Barriers to health professionals providing spiritual care include a lack of time, a lack of training, difficulty identifying who needs to discuss spiritual issues and fear of projecting own beliefs onto patients.	IVa	93-95
<b>Key evidence: Other issues</b>	<b>Highest level of evidence</b>	<b>Relevant references</b>
Australian research has identified the costs of caring for patients at home to be substantial. These may include the costs for medications, respite care, other health care costs (e.g. podiatry, dental), hiring or buying specialist equipment and aids, housing alterations and maintenance, special food or clothing and continence products.	IVa	96, 97

The need to travel for specialist services, gap payments for treatment, loss of income (for the patient and caregiver) and upfront costs such as running two households if the patient has relocated, all further complicate financial issues for patients from regional, rural or remote areas.	IVa	78-80, 98
Despite the significant financial impact of care-giving, few people are aware of government caregiver benefits, and many have difficulty accessing payments, do not meet criteria, are given incorrect advice or experience delays.	IVa	96
Health professionals need to be aware of the financial situation of their patients with advanced cancer, and patients and families need to be informed of services and programs that may assist with meeting the costs of palliative care.	IVb	Consensus
If an advanced care directive is in place, the likelihood of doctors following patients' wishes may be significantly increased. This best follows comprehensive discussions regarding treatment options and likely outcomes.	IVa	99-104
Developing and implementing advance care planning and creating Advance Directives can result in increased patient satisfaction, patients knowing that their doctors have a better understanding of their wishes, greater comfort in making end-of-life decisions, continued discussion of patients' concerns with their families, and increased likelihood of discussing future health plans with doctors.	II	105-108
Barriers to discussing advance care planning include time constraints, discomfort on the part of the patient, family or health professional, fear about being unable to change one's mind, a lack of knowledge, and for Indigenous and Torres Strait Islander patients and patients from culturally and linguistically diverse groups, language.	IVa	65, 68, 109
<b>Key evidence: Caregiver and family issues</b>	<b>Highest level of evidence</b>	<b>Relevant references</b>
Cancer is one of the 10 most common health conditions resulting in the need for informal care-giving in Australia. Care may be equivalent to a full-time job, with 20% of caregivers providing full-time or constant care. Almost 80% of caregivers live with the person receiving the care; 43% of all caregivers are partners; 25% are children; and 21% are parents of the persons receiving care.	III	110-112

There are numerous health implications for caregivers, with increased morbidity and mortality associated with care-giving. Caregivers of patients receiving palliative care have lower quality of life (impairment in physical functioning, general health and vitality) and worse overall physical health than caregivers of patients receiving curative or active treatment. As patients deteriorate physically, caregiver quality of life worsens, suggesting a greater need for support at this time.	III	113, 114
<p>Many caregivers feel positively about caring and derive deep satisfaction in this role. However, the impact of care-giving on psychological wellbeing includes:</p> <ul style="list-style-type: none"> <li>• possible increased risk of depression and anxiety, increasing in incidence with proximity to death</li> <li>• traumatic stress and post-traumatic stress disorder</li> <li>• increased risk of complicated grief</li> <li>• feelings of sadness, anger, resentment and inadequacy.</li> </ul>	III	96, 115-129
There may be significant social, financial and employment implications for caregivers, including increased social isolation and loneliness; impact on holidays and personal time; changes in family and other relationships; limited time for personal relationships; a financial burden for family members, both from out-right expenses and from lost income and benefits; reduced chance of being employed, being unable to work or having to work in lower paid jobs or for fewer hours; and loss of superannuation and savings for retirement.	IVa	96, 97, 110, 112, 130-132
<p>Health professionals should be aware of the caregiver groups who are at risk of poorer psychological outcomes and higher levels of caregiver burden and facilitate appropriate assistance for them. These groups include:</p> <ol style="list-style-type: none"> <li>1. caregiver wives, who have higher levels of depression and poorer health than caregiver husbands</li> <li>2. those with smaller social networks</li> <li>3. those with lower perceived caregiver satisfaction and higher perceived levels of stressful behavioural problems and self-care problems of the patient</li> <li>4. those with higher levels of anxiety</li> <li>5. those with higher levels of anger</li> </ol>	III	133-137

6. those who care for patients with higher levels of need		
7. those caring for longer periods		
8. caregivers who are younger (<65 years)		
9. caregivers with limited social networks and more restrictions in their daily activities due to care-giving.		
Lack of adequate information is a major concern for caregivers and families. Understanding details relating to the illness helps caregivers cope and reduces fear, stress and anxiety. Written and verbal information, as well as opportunities for discussion and clarification, are important for family understanding and satisfaction with care.	IVa	96, 116, 138-140
Caregivers' psychological wellbeing is predicted by the quality of the relationship with the patients and by a lower Karnofsky score of the patients at the time of referral to SPCS, suggesting a need for earlier referral to reduce caregiver burden.	III	141
Unresolved psychological problems in caregivers may place the caregivers at risk of medical as well as psychological illness.	III	142
Recognition and treatment of psychological morbidity in patients may not only improve the patients' quality of life, but also has implications for the long-term psychological morbidity of surviving partners. Unrelieved psychological symptoms of patients appear to increase the risk of caregivers' psychological morbidity.	III	135
The level of palliative care received by the patient and his/her family improves the psychological wellbeing of the caregiver and family during bereavement.	III	143
Involvement of specialist palliative care services in the care of people with advanced cancer may be associated with increased survival of bereaved spouses.	III	144
Caregivers have lower levels of depressive symptoms if they perceive that the doctors listen to them about the patients' needs and consider their opinions regarding the patients' illnesses and medical treatments.	IVa	136
Families (including children) of people with advanced cancer experience similar psychological problems to caregivers. Physical problems of the family members as well as of the patient can have a negative effect on the psychological health of the family, including poorer mental health and cognitive functioning during and after the patient's illness.	III	116-118, 143, 145-148

Functioning of the family is important, since poor communication among family members may lead to higher family anxiety. Families with open communication, less conflict and high expressiveness have fewer mood disturbances and are more able to share their fears, anxiety and frustrations and solve problems together, leading to lower distress for members.	III	82, 149, 150
<b>Key evidence: Health professional issues</b>	<b>Highest level of evidence</b>	<b>Relevant references</b>
Health professionals are ideally placed to provide information and proactively assess the need for referral to specialist palliative care services.	IVa	151-153
General practitioners are ideally situated to coordinate care for patients with advanced cancer; and a formalised team approach to care can potentially improve patient outcomes.	IVa	154, 155
High levels of psychological morbidity are found in oncology doctors and nurses, oncologists, specialist palliative care providers and allied health professionals.	III	34, 156-159
Health professionals report that both formal and informal sources of emotional support are important aspects in aiding them to provide adequate palliative care; oncology staff, GPs, nurses and allied health professionals all report a paucity of formal support.	III	154, 156, 158, 160-165
Higher levels of professional burnout may be found in health professionals who spend a greater amount of time with patients, and in younger nurses and hospice staff. Reasons for burnout, other than emotional distress, include insufficient personal and/or vacation time, continuous exposure to fatal illness, frustration with limited therapeutic success, uncertainty of reimbursement for physician service, and lack of opportunities for other professional activities such as teaching, research or administration.	IVa	164-168
Doctors who report deficiencies in or absence of communication skills training, even when they have postgraduate training in a medical specialty, manifest the most anxiety and least confidence when dealing with patients' problems. These doctors also have higher prevalence of depersonalisation, lower personal accomplishment and the greatest risk of burnout.	IVa	157



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## APPENDICES

### APPENDIX A: ORGANISATIONS AND GROUPS INVOLVED IN REVIEW OF DRAFT *GUIDELINES*

Australasian Chapter of Palliative Medicine, RACP  
Australasian College for Emergency Medicine  
Australia Government Department of Health and Ageing  
Australasian Society for HIV Medicine Inc.  
Australia & New Zealand Haematology Society  
Oncology social Workers Australia  
Australian Council of community Nursing Services  
Australian Council on Healthcare Standards  
Australian Divisions of General Practice  
Australian Health Ethics Committee  
Australian Music Therapy Association  
Australian Physiotherapy Association  
Australian Psychological Society  
Australian Practice Nurses Association  
Australian Psychological Society  
Australian Thoracic Society  
Breast Cancer Network of Australia  
Cancer Nurses Society Australia  
Cancer Voices NSW  
Carers Australia  
Caritas Christi Hospice  
Centre for Health Service Development  
Centre for Mental Health  
Centre for Palliative Care Research & Education  
Centre for Rural and Remote Mental Health  
Centre for Health Economic Research and Evaluation (CHERE)  
Centre for Health Research & Psycho-oncology (CHeRP)  
Clinical Oncological Society of Australia (COSA)  
College of Emergency Nursing Australasia  
Consumers' Health Forum of Australia  
Council on the Ageing (Australia)

Curtin University of Technology  
Dietitians Association of Australia  
Diversional Therapy Association National Council  
Division of Palliative Care  
Haematology Society of Australia & New Zealand  
Health Economists  
Health Informatics Society of Australia Ltd  
Health Planner  
Indigenous Coordination Centre  
Medical Oncology Group of Australia  
National Palliative Care Nurses  
National Rural Health Alliance  
Occupational Therapists Australia  
Palliative Care Australia  
Palliative Care Inter-Governmental Forum  
Pastoral Care Workers  
Royal Australian College of Surgeons  
Royal College of Nursing, Australia  
Speech Pathology Association of Australia  
Territory Palliative Care  
The Australian Pain Society  
The Cancer Council – NSW  
The Pharmacy Guild of Australia  
The University of Queensland  
University of Sydney  
University of Western Australia  
Rural Palliative Care Program

## APPENDIX B: NATIONAL CONSENSUS MEETING ATTENDEES

Organisations Represented	Attending representative
Australasian Chapter of Palliative Medicine, RACP	Associate Professor Richard Chye
Australasian Society for HIV Medicine Inc	Ms Kelly Tank
Australian and New Zealand Society of Palliative Medicine	Professor Paul Glare
Australian Association of Social Workers, Palliative Care Social Workers – the Children’s Hospital Westmead	Ms Cay Camden
Australian Council of Community Nursing Services	Ms Anne Oakley
Australian Council on Healthcare Standards	Ms Anne Rauch
Australian Government Department of Health and Ageing	Ms Jennie Della
Australian Government Department of Health and Ageing	Ms Rita Evans
Australian Music Therapy Association	Dr Clare O’Callaghan
Australian Pain Society	Mr Paul Gray
Australian Physiotherapy Association	Ms Kay Matthews
Australian Psychological Society	Ms Eva Fera
Breast Cancer Network of Australia	Ms Lyn Swinburne
Cancer Nurses Society of Australia	Dr Catherine Jones
Cancer Voices NSW	Ms Sally Crossing
Carers Australia	Ms Fran McArdle
Centre for Health Economics Research & Evaluation	Mr Kees Van Gool
Centre for Health Research & Psycho-oncology	Professor Afaf Girgis
Centre for Health Research & Psycho-oncology	Ms Amy Waller
Centre for Health Research & Psycho-oncology	Ms Claire Johnson
Centre for Health Research & Psycho-oncology	Ms Deborah Bowman
Centre for Health Service Development	Ms Maree Banfield
Centre for Palliative Care Research & Education	Professor Patsy Yates
Clinical Oncological Society of Australia	Professor Stephen Ackland
College of Emergency Nursing Australasia	Mr Cyril Dixon
Consumer Representative	Mr George Dreimanis
Consumer Representative	Ms Mireille Dreimanis

Consumer Representative	Mr Paul Burns
Consumer Representative	Ms Midori Burns
Consumer Representative	Mr John Newsom
Consumer Representative	Ms Glenys Fist
Consumer Representative	Ms Susan Chung
Consumer Representative	Ms Janelle Huxley
Consumer Representative	Ms Linda Guthrie
Consumer Representative	Ms Pat Booth
Dietitians Association of Australia	Ms Jane Kellett
Division of Palliative Care	Ms Lynne O'Brien
Facilitator	Dr Norman Swan
Haematology Society of Australia and New Zealand	Mr Hamish Holewa
Health Planner	Ms Meran Lethbridge
National Cancer Control Initiative	Professor Brian McAvoy
National Cancer Strategies Group	Dr David Woods
National Palliative Care Nurses	Professor Margaret O'Connor
National Rural Health Alliance	Ms Mary Miles
Occupational Therapists Australia	Ms Deirdre Burgess
Oncology Social Work Australia	Ms Angela Cotroneo
Palliative Care Australia	Ms Angela Magarry
Palliative Care Inter-governmental Forum	Ms Susan Hanson
Pastoral Care Worker	Dr Bruce Rumbold
Royal Australian and New Zealand College of Psychiatrists	Dr Cathy Mason
Royal Australian and New Zealand College of Radiology	Dr Tanya Holt
Royal Australian Children's Hospital, Melbourne	Dr Jenny Hynson
Royal College of Nursing, Australia	Ms Peta McVey
Rural Palliative Care Program	Mr Ian Hatton
South Eastern Sydney and Illawarra Area Health Service	Professor Sue Hanson
South Western Sydney Area Health Service	Associate Professor Trish Davidson
Palliative Care Australia	Professor David Currow
Speech Pathology Association of Australia	Ms Nadine Manison
Territory Palliative Care	Mr Simon Murphy

The Cancer Council NSW	Ms Gillian Batt
The Pharmacy Guild of Australia	Mr Harvey Cuthill
The University of Queensland	Associate Professor Geoff Mitchell
University of Newcastle	Dr Amanda Neil
University of Sydney	Professor Martin Tattersall
University of Western Australia	Dr Lorna Rosenwax
WA Centre for Cancer and Palliative Care	Professor Linda Kristjanson

# **APPENDIX 4.1:**

## **PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT) PILOTED VERSION**

**PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT)**  
(COMPLETE ALL SECTIONS)

PATIENT NAME: ..... ASSESSMENT DATE: .....

SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT	Yes	No	If any yellow boxes are ticked, consider referral to SPCS for comprehensive assessment
1. Does the patient have a caregiver? (tick yes/no)			
2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)? (tick yes/no)			
3. Would you as a health professional like assistance in managing the care of this patient or his/her family? (tick yes/no)			

SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance in assessing each domain)		Level of concern (tick one)		
Domain of need		None	Some	Significant
Physical	Is the patient experiencing unresolved physical symptoms?			
Changes in functional status	Does the patient need help with daily living activities?			
Psychological	Are the patient's psychological symptoms interfering with his/her wellbeing or relationships?			
Information	Does the patient have unmet needs for information?			
Spiritual & existential	Does the patient have concerns about spiritual or existential issues?			
Financial & legal	Does the patient or family have financial or legal concerns that are causing distress or require assistance?			
Health beliefs, cultural & social	From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?			

SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance in assessing each domain)		Level of concern (tick one)		
Domain of need		None	Some	Significant
Physical	Is the caregiver or family distressed about the patient's physical symptoms?			
Changes in functional status	Is the caregiver or family having difficulty providing physical care?			
Psychological	Is the caregiver or family having difficulty coping?			
Information	Does the caregiver or family have unmet needs for information?			
Family and relationships	Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?			

SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance in assessing each domain)		Level of concern (tick one)		
Domain of need		None	Some	Significant
Physical & psychosocial	Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?			
Bereavement	Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?			

SECTION 5: GLOBAL ASSESSMENT	Yes	No	Not sure
Does this patient need further assessment by a SPCS? (tick)			

### ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

#### PATIENT WELLBEING

##### Physical

- Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, vomiting/nausea, pain, constipation, sleep problems, diarrhoea, or loss appetite?

##### Changes in Functional Status

- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
- Is there a caregiver to assist the patient?

##### Psychological

- Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?
- Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?
- Is the patient requesting a hastened death?

##### Information

- Does the patient want more information about the course and prognosis of the disease and treatment options?
- Is the patient aware of the various care services available to assist them and do they need assistance in accessing these?

##### Spiritual/Existential

- Is the patient feeling isolated or hopeless?
- Does the patient feel that life has no meaning or that his/her life has been wasted?
- Does the patient require assistance in finding appropriate spiritual resources or services?

##### Financial/Legal

- Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?
- Is the family socio-economically disadvantaged?
- Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advanced care plans?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?

##### Health Beliefs, Social and Cultural

- Are there any language difficulties? Does the patient or family require a translator?
- Is the family preventing information about prognosis from being disclosed to the patient?
- Does the information have to be passed on to a particular member of the family or cultural group?
- Is the patient or family feeling socially isolated?
- Does the family live more than 50km from the primary service provider?
- Is the patient of Aboriginal or Torres Strait Islander descent?
- Is the patient over 75 years of age? (NB: older patients are under-represented in SPCs.)
- Does the patient or family have beliefs or attitudes that make health care provision difficult?

#### ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT

##### Physical

- Are the patient's physical symptoms causing the caregiver and family distress?

##### Changes in Functional Status

- Is the caregiver having difficulty coping with activities of daily living, medical regimes or practical issues such as equipment and transport?

##### Psychological

- Is the caregiver having difficulty coping with the patient's psychological symptoms?
- Is the caregiver requesting a hastened death for the patient?

##### Information

- Does the caregiver or family want more information about the course and prognosis of the disease and treatment?
- Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these?

##### Family and Relationships

- Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles?
- Is the patient particularly concerned about the impact of the illness on the caregiver or family?

#### CAREGIVER WELLBEING

##### Physical and psychosocial

- Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances?
- Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed?
- Does the caregiver have spiritual/existential issues that are of concern?

##### Bereavement Grief (pre and post death)

- Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?



# **APPENDIX 4.2:**

## **PILOT STUDY PARTICIPANT INFORMATION LETTER**



[Date]

Dear Participant

**INFORMATION ABOUT THE RESEARCH PROJECT:  
Pilot testing of the Palliative Care Needs Assessment Tool (PC-NAT)**

You are invited to take part in the pilot study for the evaluation of the Palliative Care Needs Assessment Tool (PC-NAT) that is being conducted by the Centre for Health Research & Psycho-oncology (CHeRP). CHeRP is the behavioural research unit of The Cancer Council NSW, and is based within the Faculty of Health at the University of Newcastle. CHeRP's research focus is on primary and secondary prevention of cancer as well as on the behavioural aspects of the consequences of cancer and the care of cancer patients.

Amy Waller, from CHeRP, is conducting this research, under my supervision, as part of her Doctorate of Philosophy at the University of Newcastle.

**Why is the research being done?**

Late referral, crisis referral and in some instances, non-referral of patients to specialist palliative care services (SPCS) impacts significantly on the quality of life of cancer patients and their carers. Uncertainty regarding when to refer and the reasons for referral are also common amongst the general health professional community. The introduction of the Palliative Care Needs Assessment Tool (PC-NAT) is expected to reduce the incidence of late referral and improve referral where psychological, spiritual, social, and physical problems are evident. Hence, the main objective of this study is to pilot test the reliability and validity of the PC-NAT for use by health professionals.

**Who can participate?**

The project involves medical and radiation oncologists, palliative care specialists, haematologists, general practitioners, social workers and nurses who have contact with advanced cancer patients and their caregivers. As potential referrers to specialist palliative care services, your participation will provide much needed feedback on the acceptability and useability of the PC-NAT with advanced cancer patients. A member of your organisation expressed interest in participating in this research during a National Consensus meeting held in August 2005 and has extended this invitation to you.

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The health professionals who have been invited to participate in this pilot study have access to the *Palliative Care Needs Assessment Guidelines* and other materials that are not yet widely available.

### **What choice do you have?**

Participation is entirely your choice. Whether or not you decide to participate, your decision will not disadvantage you in any way and will not affect your relationship with your organisation. If you do decide to participate you may withdraw at any time without giving a reason. You are also free to discontinue participation in the group discussion at any time and to decline to answer any questions that you wish.

### **What would you be asked to do?**

Also included with this Information Letter are a) a summary of the SPCS Referral Guidelines, b) a short demographics survey and c) a Consent Form. If you agree to participate you would be asked to:

1. Read the summary Guidelines before attending a 1-hour group session.
2. Complete the demographic survey and Consent Form and bring them with you to the group session for collation by the research team.
3. During the group session, you would watch a DVD of three 10-minute consultations with simulated patients with advanced cancer and their caregivers, and complete the PC-NAT for each consultation.
4. Once you have completed the three PC-NATs, you would participate in a group discussion aimed at giving the researchers feedback about the PC-NAT. The discussion will be facilitated by Prof Afaf Girgis from CHeRP.

We are seeking your consent to make a videotape of the discussion, to allow us to transcribe it at a later date. Any identifying information in the transcript will be removed and videotapes will not be made available to any person apart from the research team and the transcriber. Should you wish to review the recording or transcript and edit or erase parts of the discussion, we will forward the recording or transcript to you. We ask that you be mindful of your obligation of confidentiality to your client group and avoid identifying patients or caregivers in any discussion.

### **How will your privacy be protected?**

All information received will be treated confidentially, and no participants will be identifiable in the resulting reports. A database of participants and contact details will be kept on a password-protected database for dissemination and tracking purposes only. Transcripts of group discussions will be identified by an identification number only. Consent Forms with contact details will be kept by the researcher in a locked filing cabinet in a locked room. Transcripts and electronic data will be stored in a locked storage facility for a minimum of five years on completion of the project.

Information will be presented in a doctoral thesis submitted by Amy Waller and may be published in scientific journals. Individual participants will not be identified in any reports arising from the project.

### **What do you need to do to participate?**

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have any questions, please contact the researchers.

To participate, you will need to sign and return the attached Consent Form to the researchers when you attend the group session. The session will take place on the 25<sup>th</sup> May 2006 at the Radiation Oncology Unit Mater Centre.

### Results

On completion of this pilot project, a summary of results will be made available to those who would like a copy at the group session. If you would like a copy of the summary of results please notify the researchers at the group discussion. If you would like more information about this research project you may contact Amy Waller (Ph: 02 4924 6338 or email: [Amy.Waller@newcastle.edu.au](mailto:Amy.Waller@newcastle.edu.au)) or Afaf Girgis (Ph: 02 4924 6376 or email [Afaf.Girgis@newcastle.edu.au](mailto:Afaf.Girgis@newcastle.edu.au)).

Any help you can give us in this important research work would be most appreciated.

Yours sincerely

Centre for Health Research & Psycho-oncology (CHeRP)

Professor Afaf Girgis  
Director

Amy Waller  
PhD Student

**The CHeRP Research Team:**

Prof Afaf Girgis, Director  
Ms Amy Waller, Candidate,  
Doctor of Philosophy

**Project Advisory Group:**

Professor David Currow, Flinders University, Adelaide, SA  
Professor Linda Kristjanson, Edith Cowan University, WA  
Professor Patsy Yates, Queensland University of Technology, QLD  
A/Professor Geoff Mitchell, University of Queensland, QLD  
Professor Martin Tattersall, University of Sydney, NSW  
Professor Brian Kelly, The University of Newcastle, NSW  
Dr Amanda Neil, The University of Newcastle, NSW  
Ms Claire Johnson, CHeRP

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-144-1105. Should you have 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 the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone 02 49216333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).

# **APPENDIX 4.3:**

## **PILOT STUDY PARTICIPANT CONSENT FORM**



**CONSENT FORM FOR THE RESEARCH PROJECT:**

**Pilot testing of the Palliative Care Needs Assessment Tool (PC-NAT)**

Researchers: Afaf Girgis, Amy Waller

Version 3: 03/05/06

*Please read the information and invitation letter before completing this consent form. If there is anything in the information letter that you do not understand or if you have any questions regarding the study, please contact the researchers on (02) 49246338 or (02) 49246376.*

*Please **tick one box** to indicate if you would like to take part in this study and return to researchers at the group session.*

☐ **I agree to participate in the above research project and give my consent freely.**

I understand the project will be conducted as described in the information statement, a copy of which I have retained. I understand I can withdraw at any time and do not have to give a reason for withdrawing. I also understand I can withdraw my data at any time.

I consent to:

- Read the Summary Guidelines document and complete a short survey about myself prior to the group discussion.
- Watch the DVD containing three consultations of simulated patients with advanced cancer and their caregivers.
- Complete the Palliative Care Needs Assessment Tool (PC-NAT) for each consultation.
- Participate in a face-to-face group discussion that will take a maximum of 15 minutes.

I understand that my personal information will remain confidential and accessible only to the researchers. I have had the opportunity to have any questions answered to my satisfaction. I understand that I should maintain the confidentiality of any discussion and not divulge the specific content of such discussion to outside parties.

☐ **No, I would not like to take part in this study. I understand the researchers will make no further contact with me regarding this study.**

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

I have informed the above person about this research and am sure that they understand both the content of the information statement and the additional information I have provided.

Signed: \_\_\_\_\_

# **APPENDIX 4.4:**

## **PILOT STUDY PARTICIPANT DEMOGRAPHIC SURVEY**



## DEMOGRAPHIC SURVEY

Please complete the following questions and return to the researchers with your assessment of the two simulated consultations.

1. Are you: Male? Female? **(Please circle)**

2. What is your year of birth?

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3. In what country did you complete your undergraduate training?

1. Australia

2. Other **(Please specify)** \_\_\_\_\_

4. Do you have any specific qualifications (e.g. postgraduate) in palliative care?  
**(Circle one)**

1. No

2. Yes **(Please specify)** \_\_\_\_\_

5. In what year did you complete training for the specialty or type of practice in which you are primarily now working (e.g. oncology, general practice, nursing, etc)?

--	--	--	--

6. How would you best describe the setting in which you currently practise?  
**(Circle one)**

- Regional
- Metropolitan
- Rural
- Remote
- Other (please specify) \_\_\_\_\_

7. During the past 12 months, approximately how many patients have you cared for in some way that had/have advanced cancer? **By advanced cancer we mean cancer that is not amenable to cure, with either locally extensive or metastatic disease, or haematological malignancy where there is relapse, or resistant or refractory disease.**

\_\_\_\_\_

**Thank you for your participation.**



# **APPENDIX 4.5:**

## **SUMMARY OF PATIENT HISTORY:**

### **ANDREW DONATI**

## Appendix 4.5

Name	Andrew Donati
Age	25
Occupation	Freelance music journalist
Marital status	Single
Caregiver	Julie (mother) aged 55, works full-time.

Andrew presented about x months ago with a persistent cough. His GP found a widened mediastinum, and chest and abdo CT confirmed the presence of enlarged mediastinal and retroperitoneal lymph nodes. A cervical lymph node biopsy confirmed intermediate-grade lymphoma.

He had initial chemotherapy which induced a remission lasting 8 months. Andrew noticed recurrent abdominal pain, and CT confirmed recurrence of the disease.

Salvage chemotherapy did not generate a response, and was complicated by his “brain going to mush” and his hearing being affected permanently. Platelets were low and he had delays in chemo cycles and multiple transfusions. He had a bout of “shingles” which caused severe pain in his side.

He has persistent post-herpetic neuralgia, significant lethargy, and persistent thrombocytopaenia. He presents with his mother because he has run out of pain tablets. You are aware that he used to live independently, but he has moved back with his parents. He appears flat and somewhat withdrawn.

# **APPENDIX 4.6:**

## **SUMMARY OF PATIENT HISTORY:**

### **BARRY WHITE**

Name	Barry White
Age	65
Occupation	Retired CEO of Gold Coast real estate firm
Marital status	Married to Barbara, aged 60
Children	Two grown-up children and three grandchildren

Barry is driven, ambitious and restless and retired last year. He built up a successful real estate business into a thriving operation. The firm is known as a go-getter operation, driven by bottom line sales practices. To competitors he is known to be neither entirely honest nor scrupulous. Barry is not very self-aware. When he had angina pain five years ago, he ignored the symptoms until his wife drove him to the GP herself. That led to an emergency triple bypass operation. He recovered and for nearly a year was a changed man. But after about a year, the old Barry began to show.

Barry experienced 3 months of rectal bleeding. Eventually, he mentioned it to his wife, and Barry found himself seeing the GP. The GP organised a colonoscopy that showed colon cancer. The GP referred him on to a colorectal surgeon. When the pathology results came back, it showed that the cancer had already spread to two lymph nodes in the pelvic area. The surgeon recommended chemotherapy to try to stop further spread. Barry cuts short the attempts of the oncologist to explain his prognosis and lots of information about side-effects. He was worried that chemo might affect his sexual function but a bit embarrassed to ask.

He began the chemo and had a terrible time. He felt nauseous for several days after the treatment, in part because he did not take the prescribed tablets. He developed mucositis about the time the nausea began to abate: there was a burning soreness in the mouth followed by painful mouth ulcers. Whether because of the mucositis or the treatment, he lost his appetite, causing great drama for Barbara who sat him down to eat whether he felt like it or not. Barry became lethargic, suffered a lot of diarrhoea (once again, he did not take the tablets they had given him), and pins and needles in his fingers.

Ten days ago he developed a very mild cough. Barbara steered him straight back to the GP who organised a chest X-ray and CT chest. The X-ray showed multiple small cancers in the lungs. The GP made an urgent appointment with the oncologist. The oncologist recommended some oral chemotherapy with Xeloda (capecitabine) since Barry was unwilling to go back on IV chemo. Barry is aware that his time is running out. He has come to the GP to ask for a medical certificate to allow him to access his superannuation early, so that he can sort out some of his convoluted finances.

# **APPENDIX 4.7:**

## **SUMMARY OF PATIENT HISTORY:**

### **DENISE BLACKWELL**

## Appendix 4.7

Name	Denise Blackwell
Age	34
Occupation	Interior decorator
Marital status	Married
Caregiver	Steven Grayson, aged 39, high school teacher (History and English)
Children	Joanna aged 10 and Joel aged 9 when Denise first discovered her lump

Denise found a lump in the left breast while showering. She went to her GP who sent her off to have a mammogram, which came back “suspicious.” The GP referred her on to a breast surgeon at the local hospital.

After a needle biopsy, the surgeon confirmed that the lump was cancer. The doctor recommended a lumpectomy as the biopsy showed invasive cancer. Five of the 15 nodes that the surgeon excised showed spread of cancer. After initial chemotherapy, things were good for 3 ½ years.

Most recently, there has been evidence that the cancer has recurred in her lungs, liver and bones. She is concerned that despite several types of chemotherapy in quick succession, she is noticing that she is getting weaker each week.

She is increasingly breathless, especially at night, causing Steve and Denise a great deal of anxiety. Even showering and dressing have become exhausting tasks.

Denise is also worried about her children who are now 12 and 13. They have not yet discussed how quickly things are changing and how the future looks. The children have also had to pitch in with the chores, which has reduced their leisure time and time with friends. Joanna in particular is resentful of this responsibility. Joanna has begun acting out at school.

Steve has had to cut down the hours at his job to four days a week to cope with the extra household chores. Their neighbour stays with Denise on the days that Steve has to work. However, Denise feels embarrassed relying on the neighbour to “babysit” her.

# **APPENDIX 5.1:**

## **PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT)**

### **REVISED VERSION**

# **PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT)** COMPLETE ALL SECTIONS

PATIENT/ADDRESS LABEL

PATIENT NAME: \_\_\_\_\_

DATE: \_\_\_\_\_ DIAGNOSIS: \_\_\_\_\_

## **SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT**

	Yes	No	If yellow boxes are ticked, consider assessment by SPCS
1. Does the patient have a caregiver readily available if required?			
2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?			
3. Do you require assistance in managing the care of this patient and/or family?			

## **SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)**

	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the patient experiencing unresolved physical symptoms?						
2. Does the patient need help with daily living activities?						
3. Are the patient's psychological symptoms interfering with wellbeing or relationships?						
4. Does the patient have an unmet need for information?						
5. Does the patient have concerns about spiritual or existential issues?						
6. Does the patient have financial or legal concerns that are causing distress or require assistance?						
7. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?						

COMMENTS: \_\_\_\_\_

## **SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)**

	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the caregiver or family distressed about the patient's physical symptoms?						
2. Is the caregiver or family having difficulty providing physical care?						
3. Is the caregiver or family having difficulty coping?						
4. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?						
5. Does the caregiver or family have unmet needs for information?						
6. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?						

COMMENTS: \_\_\_\_\_

## **SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)**

	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?						
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?						

COMMENTS: \_\_\_\_\_

## **IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS SECTION**

1. Referral to: (Name and Specialty) \_\_\_\_\_

2. Priority of assessment needed: ☐ Urgent (within 24 hours) ☐ Semi-Urgent (2-7 days) ☐ Non-Urgent (next available)

3. Have you discussed the referral with the client? ☐ Yes ☐ No

4. Has the client given consent for the referral? ☐ Yes ☐ No

5. Referral from: Name: \_\_\_\_\_ Position: \_\_\_\_\_ Signature: \_\_\_\_\_



## PALLIATIVE CARE NEEDS ASSESSMENT TOOL (PC-NAT)

### ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

#### PATIENT WELLBEING

##### Physical

- Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, vomiting/nausea, pain, constipation, sleep problems, diarrhoea, or loss appetite?

##### Changes in Functional Status

- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
- Is there a caregiver to assist the patient?

##### Psychological

- Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?
- Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?
- Is the patient requesting a hastened death?

##### Information

- Does the patient want more information about the course and prognosis of the disease and treatment options?
- Is the patient aware of the various care services available to assist them and do they need assistance in accessing these?

##### Spiritual/Existential

- Is the patient feeling isolated or hopeless?
- Does the patient feel that life has no meaning or that his/her life has been wasted?
- Does the patient require assistance in finding appropriate spiritual resources or services?

##### Financial/Legal

- Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?
- Is the family socio-economically disadvantaged?
- Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advanced care plans?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?

##### Health Beliefs, Social and Cultural

- Does the patient or family have beliefs or attitudes that make health care provision difficult?
- Are there any language difficulties? Does the patient or family require a translator?
- Is the family preventing information about prognosis from being disclosed to the patient?
- Does the information have to be passed on to a particular member of the family or cultural group?
- Is the patient or family feeling socially isolated?
- Does the family live more than 50km from the primary service provider?
- Is the patient of Aboriginal or Torres Strait Islander descent?
- Is the patient over 75 years of age? (NB: older patients are under-represented in SPCSs.)

#### ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT

##### Physical

- Are the patient's physical symptoms causing the caregiver and family distress?

##### Changes in Functional Status

- Is the caregiver having difficulty coping with activities of daily living, medical regimes or practical issues such as equipment and transport?

##### Psychological

- Is the caregiver having difficulty coping with the patient's psychological symptoms?
- Is the caregiver requesting a hastened death for the patient?

##### Information

- Does the caregiver or family want more information about the course and prognosis of the disease and treatment?
- Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these?

##### Family and Relationships

- Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles?
- Is the patient particularly concerned about the impact of the illness on the caregiver or family?

#### CAREGIVER WELLBEING

##### Physical and psychosocial

- Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances?
- Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed?
- Does the caregiver have spiritual/existential issues that are of concern?

##### Bereavement Grief (pre and post death)

- Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?

# **APPENDIX 5.2:**

## **PALLIATIVE CARE OUTCOMES COLLABORATION (PCOC) DATASET**

## Appendix 5.2

Person giving score	Signature	Date Phase Start	Phase	Pain	Other symptom	Psycho social / spiritual	Family / Carer	RUG-ADL Score 1-5					Symptom Assessment Scale Score 0-10								AKPS	Provider Type	Model of Care at phase end	Date Phase End
P=Patient N= Nurse F=Family/ carer D=Doctor			1 Stable 2 Unstable 3 Deteriorating 4 Terminal 5 Bereaved	Score 0-3 0 Absent 1 Mild 2 Moderate 3 Severe	Score 0-3 0 Absent 1 Mild 2 Moderate 3 Severe	Score 0-3 0 Absent 1 Mild 2 Moderate 3 Severe	Score 0-3 0 Absent 1 Mild 2 Moderate 3 Severe	Eating	Bed mobility	Toileting	Transfers	Total	Difficulty sleeping	Appetite problems	Nausea	Bowel problems	Breathing problems	Fatigue	Pain		Score 0-100	6 Interdisciplinary (level 2 & 3 PCA)	3 Consultation / liaison with another service provider	
																					6	3		
																					6	3		
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																					6	3		

1	Stable phase: Symptoms are adequately controlled by established management.		
2	Unstable phase: Development of a new unexpected problem or a rapid increase in the severity of existing problems, either of which require an urgent change in management, or emergency treatment.		
3	Deteriorating phase: Gradual worsening of existing symptoms or the development of new but expected problems. These require the application of specific plans of care and regular review but not urgent or emergency treatment.		
4	Terminal care phase: Death is likely in a matter of days and no acute intervention is planned or required.		
5	Bereaved phase: Death of the patient has occurred and the family/carers are grieving. Note: Record only one bereavement phase per patient – not one for each carer/family member.		
AKPS			
100	Normal; no complaints; no evidence of disease	40	In bed more than 50% of time
90	Able to carry on normal activity; minor signs or symptoms	30	Almost completely bedfast
80	Normal activity with effort; some signs of symptoms of disease	20	Totally bedfast and requiring extensive nursing care by professionals and/or family
70	Cares for self; unable to carry on normal activity or to do active work	10	Comatose or barely arousable
60	Requires occasional assistance but is able to care for most needs	0	Dead
50	Requires considerable assistance and frequent medical care		

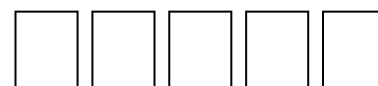
RUG-ADL							
EATING		BED MOBILITY		TOILETING		TRANSFER	
1	Independent or supervision only	1	Independent or supervision only	1	Independent or supervision only	1	Independent or supervision only
2	Limited assistance	3	Limited physical assistance	3	Limited physical assistance	3	Limited physical assistance
3	Extensive assistance/ total dependence/ tube-fed	4	Other than two persons physical assist	4	Other than two persons physical assist	4	Other than two persons physical assist
		5	Two or more persons physical assist	5	Two or more persons physical assist	5	Two or more persons physical assist
PROBLEM SEVERITY SCORES      0 = Absent    1 = Mild    2 = Moderate    3 = Severe							
Psychological/Spiritual: Overall degree of psycho/spiritual problems of the patient (e.g. anxiety/fear, anger, request to die, depression/sadness, confusion, agitation)							
Family/Carer: Overall degree of family/carers problems (e.g. denial, caregiver fatigue, unrealistic goals, anger, legal issues, difficult communication, anxiety)							
Pain: Overall degree of pain symptoms							
Other symptoms: Overall degree of other symptoms (e.g. nausea/vomiting, anorexia, constipation/diarrhoea, wound/ulcer, dysphasia, incontinence, weakness/fatigue, dyspnoea, confusion/delirium)							

# **APPENDIX 5.3:**

## **VALIDATION STUDY HEALTH PROFESSIONAL ACCEPTABILITY SURVEY**



Sir Charles Gairdner Hospital



## **Validation of the Palliative Care Needs Assessment Tool (PC-NAT)**

### **Health professional Acceptability Survey**

#### **Instructions**

Thank you for recently completing the Palliative Care Needs Assessment Tool (PC-NAT). We would be pleased if you would help us again by giving us your views about completing the PC-Nat within your clinical setting.

When you have finished answering the questions please mail your completed survey to:

Amy Waller  
Locked Bag 10  
Wallsend NSW 2287

#### **Thank you for completing this survey**

If you have any questions or concerns, please contact Amy Waller at the Centre for Health Research & Psycho-oncology by telephone on (02) 4924 6070, fax on (02) 4924 6208 or email: [amy.waller@newcastle.edu.au](mailto:amy.waller@newcastle.edu.au).

- The following statements ask about the PC-NAT in general. For each statement, please tell us how much you agree or disagree with the statement, by choosing the number that best describes your views.

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Don't know
• The PC-NAT was generally easy to complete	1	2	3	4	9
• The time it took me to complete the PC-NAT was reasonable within a clinical setting	1	2	3	4	9
• The prompts provided on the back page were helpful when completing the PC-NAT	1	2	3	4	9
• The PC-NAT would be useful to use routinely in this clinical setting	1	2	3	4	9
• The items included in the PC-NAT were comprehensive and relevant	1	2	3	4	9

- Are there any items that you feel are important that have not been included in the PC-NAT? If so, please write them here. *(Please go over the page if this space is insufficient)*

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- Which, if any, of the items were difficult to assess? If any, can you please describe what made them difficult to assess, so that we can improve these for future uses of the PC-NAT? *(Please go over the page if this space is insufficient)*

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- For the future, we are interested to know how often you think it would be useful to complete the PC-NAT for patients with advanced cancer, to detect changes in needs.

Once a week 1  
Once a month 2  
Other (please describe) 3

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- The PC-NAT was developed so that it could be completed by any health professional involved in the care of people with advanced cancer or their families, including clinicians, nurses, social workers and occupational therapists. Are there any groups you think would not be able to complete it and, if so, why not? *(Please go over the page if this space is insufficient)*

Yes	1
No	2

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- If you would like to make any other comments about the PC-NAT, including the layout, response options, time taken or content, please write them here. *(Include both positive and negative comments. Please go over the page if this space is insufficient.)*

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# **APPENDIX 5.4:**

## **VALIDATION STUDY PATIENT INFORMATION LETTER**



**Sir Charles Gairdner Hospital**



**Centre for Health Research  
& Psycho-oncology (CHeRP)**

**INFORMATION ABOUT THE RESEARCH PROJECT:**

**Testing of the Palliative Care Needs Assessment Tool (PC-NAT)**

**Version 1: 13/02/08**

**The Project Research Team:**

Professor Afaf Girgis, Chief Investigator

Wendy Scott, Sir Charles Gairdner Hospital, WA

Ms Amy Waller, Candidate, Doctor of Philosophy, University of Newcastle, NSW

Dr David Sibbritt, University of Newcastle, NSW

*Please take time to read the following information carefully and discuss it with your friends, family and general practitioner if you wish. Ask any questions if some parts of the information are not clear to you or you would like more information. Please do this before you sign the consent form.*

You are invited to take part in a study that is being conducted by the Centre for Health Research & Psycho-oncology (CHeRP) and funded by the Australian Government Department of Health and Ageing. CHeRP is the behavioural research unit of The Cancer Council NSW, and is based at the University of Newcastle. CHeRP is interested in improving the quality of care for people with cancer.

Amy Waller from CHeRP is conducting this research, under the supervision of Professor Afaf Girgis, as part of her Doctorate of Philosophy studies in the School of Medicine and Public Health at the University of Newcastle.

**Why is the research being done?**

People with cancer may have a range of unmet needs in relation to physical, emotional, social and spiritual issues. Unfortunately, not everybody receives the type of help they need with such issues at the time they most need it. To help health professionals to identify their patients' needs better, we have developed a Needs Assessment Tool, and are undertaking a study to find out whether this Tool measures your level of need accurately.

**Who can participate?**

We are inviting people with cancer who have been referred to the Sir Charles Gairdner Palliative Care Service to take part in the study. By using the Needs Assessment Tool, members of the health care team may be able to identify what sorts of help you need, and assist you to get suitable help at the time you most need it. However, we cannot and do not guarantee or promise that you will receive any benefits from this study.

**Centre for Health Research  
& Psycho-oncology**

Longworth Avenue  
Wallsend NSW 2287 Australia

Locked mail bag 10

Wallsend NSW 2287

Telephone (02) 4924 6372

Facsimile (02) 4924 6208

e-mail: CHeRP@newcastle.edu.au

### **What choice do you have?**

Participation is entirely your choice. If you decide not to take part, your decision will not affect your treatment, your relationship with those treating you or with the Sir Charles Gairdner Hospital in any way.

If you do decide to participate, you may withdraw from the study at any time and request that the information you have already provided and the assessment tools relating to your treatment and completed by Hospital staff be destroyed. You may also refuse to answer any questions that you are asked in the tool.

### **What would you be asked to do?**

Included with this information letter is a consent form. If you agree to participate you would be asked to:

- 7.4.1 Fill out the Consent Form and return it to a Hospital staff member.
- 7.4.2 Give permission for two palliative care staff members to complete a Needs Assessment Tool. This will take approximately 10 minutes for each of the two times.
- 7.4.3 Give permission for researchers to obtain copies of the completed Tools, which will have information about your level of need and cancer diagnosis.
- 7.4.4 Give permission for researchers to obtain information collected by the palliative care service relating to your diagnosis, date of birth and gender, as well as information about your symptoms and your wellbeing.

### **How will your privacy be protected?**

All information you give us will be kept strictly confidential and will be stored according to strict privacy guidelines. Only authorised research staff, who understand that it must be kept confidential, will have access to the information. Consent forms with your contact details will be kept in a locked filing cabinet and room at the CHeRP site in Newcastle. Data will be stored in a locked store room for a minimum of seven years on completion of the project, and may be destroyed any time thereafter. The information we collect from you will only be identified by a code number and any identifying information will be removed. The results of the research will be presented in a doctoral thesis submitted by Amy Waller and may be published in scientific journals and at scientific meetings. All information published will be grouped information only, so you will not be able to be identified in any reports about the project.

### **What do you need to do to participate?**

Please read this Information Letter and make sure you understand it before you agree to take part. If there is anything you do not understand, or you have any questions, please contact the researchers listed at the end of the letter. To take part, you will need to sign and return the Consent Form. By signing the Consent Form you indicate that you have understood the information, and that you agree to take part in the study. You have been given a copy of the Information Letter to keep as a record.

### **Results**

A summary of results will be available at the end of the study. If you would like a copy to be sent to you, please fill out the Summary of Results Form included with this Information Letter and return it with your Consent Form.

**Who has reviewed the study?**

The Sir Charles Gairdner Hospital and University of Newcastle Human Research Ethics Committees have reviewed this study and have given approval for the conduct of the research. This procedure ensures that the study conforms to the principles set out by the National Statement of Ethical Conduct of Research involving humans and the Good Clinical Practice Guidelines.

**If you have problems during the research**

During the completion of the Needs Assessment Tool you will be asked questions about your cancer experience, which can sometimes be difficult. If you find that you would like to talk to someone about any problems or concerns that you may have after participating, please contact the Cancer Helpline on 131120. You can also contact the research team by telephone, email or by mail to raise any concerns.

**More information about the study**

If you would like more information about this research project, please feel free to contact us by telephone on 1800766016, or by emailing us: [Amy.Waller@newcastle.edu.au](mailto:Amy.Waller@newcastle.edu.au) or [Afaf.Girgis@newcastle.edu.au](mailto:Afaf.Girgis@newcastle.edu.au). You may also contact Wendy Scott on (08) 9346 2551 (email: [wendy.scott@health.wa.gov.au](mailto:wendy.scott@health.wa.gov.au)).

Any help you can give us in this important research work would be most appreciated.

Yours sincerely

Centre for Health Research & Psycho-oncology (CHeRP)

Professor Afaf Girgis  
Chief Investigator

Wendy Scott  
Site Investigator

Amy Waller  
PhD Candidate

**Complaints**

The Sir Charles Gairdner Hospital Human Research Ethics Committee has given ethics approval for the conduct of this project (Approval No: 2008-027). Should you have 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, you can contact the secretary of the Sir Charles Gairdner Hospital Human Research Ethics Committee on telephone (08) 9346 2999.

This project has also been approved by the University of Newcastle's Human Research Ethics Committee, Approval No. H-2008-0044. Should you have concerns about this research, you may also contact the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone 02 49216333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).

# **APPENDIX 5.5:**

## **VALIDATION STUDY PATIENT CONSENT FORM**



Sir Charles Gairdner Hospital



# **INFORMATION ABOUT THE RESEARCH PROJECT:**

## **Testing of the Palliative Care Needs Assessment Tool (PC-NAT)**

### **The Project Research Team:**

Professor Afaf Girgis, Chief Investigator

Ms Wendy Scott, Sir Charles Gairdner Hospital, WA

Ms Amy Waller, Candidate, Doctor of Philosophy, University of Newcastle, NSW

Dr David Sibbritt, University of Newcastle, NSW

- I have been given clear information (verbal and written) about this study and have been given time to consider whether I want to take part. I have retained copies of the Information Letter and Consent Form.
- I have been told about the possible advantages and risks of taking part in the study and I understand what I am being asked to do.
- I have been able to have a member of my family or a friend with me while I was told about the study. I have been able to ask questions and any questions have been answered satisfactorily.
- I know that I do not have to take part in the study and that I can withdraw at any time during the study without giving a reason and without affecting my future medical care. My participation in the study does not affect any right to compensation, which I may have under statute or common law.
- I give permission for:
  - 9.1 two palliative care staff members to complete a Needs Assessment Tool
  - 9.2 researchers to obtain copies of the completed Tools, which will have information about level of need and cancer diagnosis
  - 9.3 researchers to obtain information collected by the palliative care service relating to my diagnosis, date of birth and gender, as well as information about my symptoms.

**If you are unclear about anything you have read in the Participant Information Sheet or this Consent Form, please speak to your doctor before signing this Consent Form.**

Name of Participant: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Investigator: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

The Sir Charles Gairdner Hospital Human Research Ethics Committee has given ethics approval for the conduct of this project. If you have any ethical concerns regarding the study you can contact the secretary of the Sir Charles Gairdner Hospital Human Research Ethics Committee on telephone (08) 9346.2999.

Centre for Health Research  
& Psycho-oncology  
Longworth Avenue  
Wallsend NSW 2287 Australia  
Locked mail bag 10  
Wallsend NSW 2287  
Telephone (02) 4924 6372  
Facsimile 02) 4924 6208  
e-mail: CHERP@newcastle.edu.au

# **APPENDIX 5.6:**

## **VALIDATION STUDY REQUEST FOR RESULTS FORM**





Sir Charles Gairdner Hospital



**Evaluation of a Needs Assessment Intervention  
Request for summary of results**

Version 1: 14/02/08

If you would like a summary of the results of this study to be forwarded to you on completion of the project, please complete this form and return to the researchers with your consent form. Results will be available in a minimum of two years.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

# **APPENDIX 5.7:**

## **VALIDATION STUDY HEALTH PROFESSIONAL INFORMATION LETTER**



**Sir Charles Gairdner Hospital**



### **INFORMATION ABOUT THE RESEARCH PROJECT:**

#### **Testing of the Palliative Care Needs Assessment Tool (PC-NAT)**

**Version 1: 13/02/08**

#### **The Project Research Team:**

Professor Afaf Girgis, Chief Investigator

Ms Wendy Scott, Sir Charles Gairdner Hospital, WA

Ms Amy Waller, Candidate, Doctor of Philosophy, University of Newcastle, NSW

Dr David Sibbritt, University of Newcastle, NSW

*Please take time to read the following information carefully. Ask any questions if some parts of the information are not clear to you or you would like more information. Please do this before you return the survey.*

You are invited to take part in a study that is being conducted by the Centre for Health Research & Psycho-oncology (CHeRP) and funded by the Australian Government Department of Health and Ageing. CHeRP is the behavioural research unit of The Cancer Council NSW, and is based at the University of Newcastle. CHeRP is interested in improving the quality of care for people with cancer.

Amy Waller from CHeRP is conducting this research, under the supervision of Professor Afaf Girgis, as part of her Doctorate of Philosophy studies in the School of Medicine and Public Health at the University of Newcastle.

#### **Why is the research being done?**

People with cancer may have a range of unmet needs in relation to physical, emotional, social and spiritual issues. To help health professionals to identify their patients' needs better, we have developed a Needs Assessment Tool and are undertaking a study to test the validity and acceptability of the tool.

#### **Who can participate?**

We are inviting staff from the Sir Charles Gairdner Palliative Care Service to take part in the study. Assessing the acceptability of the Needs Assessment Tool to members of the health care team is an integral part of evaluating assessment tools to be completed by health professionals. However, we cannot and do not guarantee or promise that you will personally receive any benefits from this study.

#### **What choice do you have?**

Participation is entirely your choice. If you decide not to take part, your decision will not affect your relationship with the Sir Charles Gairdner Hospital in any way. If you do decide to participate, you may withdraw from the study at any time and request that the information you have already provided be destroyed. You may also refuse to answer any questions.

Centre for Health  
Research & Psycho-  
oncology  
Longworth Avenue  
Wallsend NSW 2287 Australia  
Locked mail bag 10  
Wallsend NSW 2287  
Telephone (02) 4924 6372  
Facsimile (02) 4924 6208  
e-mail: CHeRP@newcastle.edu.au

**What would you be asked to do?**

Included with this information letter is a copy of the acceptability survey. If you agree to participate you would be asked to:

- complete the survey assessing the acceptability of the Palliative Care Needs Assessment Tool (PC-NAT). Return of this survey to the research team will be taken as consent.

**How will your privacy be protected?**

All information you give us will be kept strictly confidential and will be stored according to strict privacy guidelines. Only authorised research staff, who understand that it must be kept confidential, will have access to the information.

Acceptability surveys will be kept in a locked filing cabinet and room at the CHERP site in Newcastle. Data will be stored in a locked store room for a minimum of seven years on completion of the project, and may be destroyed any time thereafter. The information we collect from you will only be identified by a code number, and any identifying information will be removed. The results of the research will be presented in a doctoral thesis submitted by Amy Waller and may be published in scientific journals and at scientific meetings. All information published will be grouped information only, so that you will not be able to be identified in any reports about the project.

**What do you need to do to participate?**

Please read this Information Letter and make sure you understand it before you agree to take part. If there is anything you do not understand, or you have questions, please contact the researchers listed at the end of the letter. To take part, you will need to complete and return the acceptability survey. By returning the survey you indicate that you have understood the information, and that you agree to take part in the study. You have been given a copy of the Information Letter to keep as a record.

**Results**

A summary of results will be available at the end of the study. If you would like a copy to be sent to you, please fill out the Summary of Results Form included with this Information Letter and return it with your survey.

**Who has reviewed the study?**

The Sir Charles Gairdner Hospital and University of Newcastle Human Research Ethics Committees have reviewed this study and have given approval for the conduct of the research. This procedure ensures that the study conforms to the principles set out by the National Statement of Ethical Conduct of Research involving humans and the Good Clinical Practice Guidelines.

**If you have problems during the research**

If you find that you would like to talk to someone about any problems or concerns that you may have after participating, please contact the research team by telephone, email or by mail to raise any concerns.

**More information about the study**

If you would like more information about this research project, please feel free to contact us by telephone on 1800766016, or by emailing us:

[Amy.Waller@newcastle.edu.au](mailto:Amy.Waller@newcastle.edu.au) or [Afaf.Girgis@newcastle.edu.au](mailto:Afaf.Girgis@newcastle.edu.au).

Any help you can give us in this important research work would be most appreciated.

Yours sincerely

Centre for Health Research & Psycho-oncology (CHeRP)

Professor Afaf Girgis  
Chief Investigator

Wendy Scott  
Site Investigator

Amy Waller  
PhD Candidate

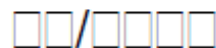
**Complaints**

The Sir Charles Gairdner Hospital Human Research Ethics Committee has given ethics approval for the conduct of this project (Approval No: 2008-027). Should you have 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, you can contact the secretary of the Sir Charles Gairdner Hospital Human Research Ethics Committee on telephone (08) 93462999.

This project has also been approved by the University of Newcastle's Human Research Ethics Committee, Approval No. H-2008-0044. Should you have concerns about this research, you may also contact the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone 02 49216333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).

# **APPENDIX 6.1:**

## **EVALUATION STUDY COMPUTER ASSISTED TELEPHONE INTERVIEW (CATI) PATIENT QUESTIONS**



## **Evaluation of a Needs Assessment Intervention**

### **Patient Interview Questions**

Please retain a copy of this questionnaire with your information letter  
Do not fill out this survey. It is for your information only.

Evaluation of a Needs Assessment Intervention

- ☒ It may be helpful to keep this copy of the questionnaire near the telephone so you can read along with the interviewer during the interview.
- ☒ You may discontinue the interview at any time and reschedule a more convenient time to complete it.
- ☒ If you are asked a question you would prefer not to answer, just tell the interviewer and that question can be skipped.

### Lifestyle Questions

We would like to ask some questions about you and your lifestyle. Some questions may seem personal but it is important that you try to answer each question. We are asking everyone the same questions. All information will be handled with the strictest confidence. To answer, please choose the option that best describes your situation.

Q1. In what year were you born?

19 \_\_\_\_

Q2. Are you:

Male	1
Female	2

Q3. What is your current marital status?

Married	1
Defacto or living with a partner	2
Separated or divorced	3
Widowed	4
Never married or single	5

Q4. What is the highest level of education that you have completed?

Primary school	1
Secondary school	2
Certificate or Diploma	3
University Degree	4



**Q5. Which of the following best describes your employment situation for the majority of the 12 months or so before you were diagnosed with cancer?**

Paid full-time employment	1
Paid part-time employment	2
Self-employed	3
On leave with pay	4
On leave without pay	5
Not employed – retired	6
Not employed – disabled	7
Household duties	8
Student	9
Unemployed	10
Volunteer	11
Other (please specify.....)	12

**Q5B. Is this your current employment situation?**

Yes	1	[go to Q8]
No	2	[go to Q6]

**Q6. Which of the following best describes you current employment situation?**

Paid full-time employment	1
Paid part-time employment	2
Self-employed	3
On leave with pay	4
On leave without pay	5
Not employed – retired	6
Not employed – disabled	7
Household duties	8
Student	9
Unemployed	10
Volunteer	11
Other (please specify.....)	12

**Q7. Has your work situation changed as a result of your cancer diagnosis or treatment?**

Yes	1	[go to Q7B]
No	2	[go to Q8]

**Q7B. Can you describe how your work situation has changed?**

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**Q8. Do you currently have private health insurance?**

No – Medicare only	1
Yes – hospital cover only	2
Yes – ancillary (extras) cover only	3
Yes – hospital and ancillary (extras) cover	4

**Q9. What is your present gross family income each week (that is, before tax)?**

Less than \$300 per week	1
Between \$300-\$499 per week	2
Between \$500-\$799 per week	3
Between \$800-\$1000 per week	4
More than \$1000 per week	5

**Q10. Can you tell us how long ago you were diagnosed with cancer?**

Years:
Months:

**Q10B. Can you tell us what type of cancer it was?**

Lung	1
Breast	2
Prostate	3
Bowel, colon or rectum	4
Melanoma	5
Skin	6
Don't know	7
Other (please specify.....)	8

**End of Lifestyle questions**

## Your Health Questions

**Q11.** The following questions are about other illnesses that you may have. For each of the illnesses please answer yes or no as to whether your doctor has ever told you that you have the condition and whether any of your current activities are limited by the condition?

	Has a doctor ever told you that you have this condition?			If "yes", has the condition limited activities you would do during a typical day? For example: work, working around the house or garden, bathing or dressing yourself, social activities.			If "yes", how severely has the condition limited your activities? Please choose a number from 1 which is slightly limited to 7 which is severely limited.							
	Yes	No	Don't know	Yes	No		Slightly			Severely				
A. Arthritis or rheumatism	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
B. Diabetes or high blood sugar	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
C. Inflammatory bowel disease, colitis or Crohn's disease	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
D. Bleeding from stomach ulcers	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
E. Asthma, Chronic lung disease, bronchitis or emphysema	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
F. Heart failure	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
G. Stroke or brain haemorrhage	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
H. High blood pressure	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
I. Heart attack or myocardial infarction	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
J. Chest pain or angina	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
K. Liver disease or cirrhosis	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7
L. Depression or anxiety	1	2	3	If yes	1	2	If yes	1	2	3	4	5	6	7

**M. Have you ever been told that you have any other major illnesses?**

Yes	1	[go to QM1]
No	2	[go to Q12]

**M1. Please list the other major illnesses you have been told you have and indicate if the condition limits your activities.**

Name of illness	Has the condition limited activities you would do during a typical day?		If "yes", how severely has the condition limited your activities?	
	Yes	No	Slightly	Severely
	1	2	if yes 1 2 3 4 5 6 7	
	1	2	if yes 1 2 3 4 5 6 7	
	1	2	if yes 1 2 3 4 5 6 7	
	1	2	if yes 1 2 3 4 5 6 7	

## Quality of Life

The next two questions ask about your overall health and quality of life in relation to your cancer. There are no 'right' or 'wrong' answers – you should just select the response that best applies to you. Choose the number between 1 and 7 that best applies to you. 1 represents very poor and 7 represents excellent.

**Q12. How would you rate your overall health during the past week?**

1 2 3 4 5 6 7  
Very poor Excellent

Q13. How would you rate your overall quality of life during the past week?

1      2      3      4      5      6      7

Very poor    Excellent

### End of health and quality of life questions

You have now finished one-third of the survey – Thank you

## Needs Questions

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item indicate whether you have needed help with this issue within the last month as a result of having cancer. Choose the option which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

- 1 = No need:**      **Not applicable**  
This was not a problem for me as a result of having cancer.
- 2 = No need:**      **Satisfied**  
I did need help with this, but my need for help was satisfied at the time.
- 3 = Some need:**    **Low need for help**  
This item caused me little concern or discomfort. I had little need for additional help.
- 4 = Some need:**    **Moderate need for help**  
This item caused me some concern or discomfort. I had some need for additional help.
- 5 = Some need:**    **High need for help**  
This item caused me a lot of concern or discomfort. I had a strong need for additional help.

In the last month, what was your level of need for help with:		No need		Some need		
		Not applicable	Satisfied	Low need	Moderate need	High need
1.	Pain	1	2	3	4	5
2.	Lack of energy/tiredness	1	2	3	4	5
3.	Feeling unwell a lot of the time	1	2	3	4	5
4.	Work around the home	1	2	3	4	5
5.	Not being able to do the things you used to do	1	2	3	4	5
6.	Anxiety	1	2	3	4	5
7.	Feeling down or depressed	1	2	3	4	5
8.	Feelings of sadness	1	2	3	4	5
9.	Fears about the cancer spreading	1	2	3	4	5
10.	Worry that the results of treatment are beyond your control	1	2	3	4	5
11.	Uncertainty about the future	1	2	3	4	5
12.	Learning to feel in control of your situation	1	2	3	4	5
13.	Keeping a positive outlook	1	2	3	4	5
14.	Feelings about death and dying	1	2	3	4	5
15.	Changes in sexual feelings	1	2	3	4	5
16.	Changes in your sexual relationships	1	2	3	4	5

Patient interview questions

7

In the last month, what was your level of need for help with:		No need		Some need		
		Not applicable	Satisfied	Low need	Moderate need	High need
17.	Concerns about the worries of those close to you	1	2	3	4	5
18.	More choice about which cancer specialists you see	1	2	3	4	5
19.	More choice about which hospital you attend	1	2	3	4	5
20.	Reassurance by medical staff that the way you feel is normal	1	2	3	4	5
21.	Hospital staff attending promptly to your <u>physical</u> needs	1	2	3	4	5
22.	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	1	2	3	4	5
23.	Being given written information about important aspects of your care	1	2	3	4	5
24.	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
25.	Being given explanations of those tests for which you would like explanations	1	2	3	4	5
26.	Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5
27.	Being informed about your test results as soon as feasible	1	2	3	4	5
28.	Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
29.	Being informed about things you can do to help yourself to get well	1	2	3	4	5
30.	Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
31.	To be given information about sexual relationships	1	2	3	4	5
32.	Being treated like a person not just another case	1	2	3	4	5
33.	Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
34.	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5
35.	Setting new priorities in your life	1	2	3	4	5

Patient interview questions

8

In the last month, what was your level of need for help with:		No need		Some need		
		Not applicable	Satisfied	Low need	Moderate need	High need
36.	Accepting your relationship with God or a higher being	1	2	3	4	5
37.	Dealing with the spiritual issues of death or dying	1	2	3	4	5
38.	Trying to find meaning in your cancer experience	1	2	3	4	5
39.	Being able to choose the place where you spend your final days	1	2	3	4	5
40.	Assistance having your spiritual needs met	1	2	3	4	5
41.	Having the opportunity to talk to someone who is sharing a similar experience	1	2	3	4	5
42.	Receiving accurate medical judgements from medical staff	1	2	3	4	5
43.	Being able to have open discussion with your doctors	1	2	3	4	5
44.	Getting adequate information from medical staff about your prognosis	1	2	3	4	5

**Q45.** Were there any other issues or needs that you would have liked help with?

Yes	1	[go to Q45B]
No	2	[go to Emotional Wellbeing questions on p10]

**Q45B. For each of these other issues or needs, please describe what it was and how much help you needed with it? Please use the same categories as used in the rest of the Supportive Care Needs Survey:**

Please describe the need	Some need		
	Low need	Moderate need	High need
A.	1	2	3
B.	1	2	3
C.	1	2	3
D.	1	2	3
E.	1	2	3
F.	1	2	3

End of Needs questions

You have now finished two-thirds of the survey – Thank you



## Emotional wellbeing questions

The next few questions ask how you have been feeling in the last week. To answer, please choose the option that best describes how you have been feeling in the last week. Don't take too long over your answers; your immediate reaction to each question will probably be more accurate than a long thought out answer.

<b>1. I feel tense or 'wound up':</b> Most of the time 1 A lot of the time 2 From time to time, occasionally 3 Not at all 4	<b>8. I feel as if I am slowed down:</b> Nearly all the time 1 Very often 2 Sometimes 3 Not at all 4
<b>2. I still enjoy the things I used to enjoy:</b> Definitely as much 1 Not quite as much 2 Only a little 3 Hardly at all 4	<b>9. I get a sort of frightened feeling like 'butterflies' in the stomach:</b> Not at all 1 Occasionally 2 Quite often 3 Very often 4
<b>3. I get a sort of frightened feeling as if something awful is about to happen</b> Very definitely and quite badly 1 Yes, but not too badly 2 A little, but it doesn't worry me 3 Not at all 4	<b>10. I have lost interest in my appearance:</b> Definitely 1 I don't take as much care as I should 2 I may not take quite as much care 3 I take just as much care as ever 4
<b>4. I can laugh and see the funny side of things:</b> As much as I always could 1 Not quite so much now 2 Definitely not so much now 3 Not at all 4	<b>11. I feel restless as if I have to be on the move:</b> Very much indeed 1 Quite a lot 2 Not very much 3 Not at all 4
<b>5. Worrying thoughts go through my mind:</b> A great deal of the time 1 A lot of the time 2 From time to time but not too often 3 Only occasionally 4	<b>12. I look forward with enjoyment to things:</b> As much as I ever did 1 Rather less than I used to 2 Definitely less than I used to 3 Hardly at all 4
<b>6. I feel cheerful:</b> Not at all 1 Not often 2 Sometimes 3 Most of the time 4	<b>13. I get sudden feelings of panic:</b> Very often indeed 1 Quite often 2 Not very often 3 Not at all 4
<b>7. I can sit at ease and feel relaxed:</b> Definitely 1 Usually 2 Not often 3 Not at all 4	<b>14. I can enjoy a good book or radio or TV program:</b> Often 1 Sometimes 2 Not often 3 Very seldom 4

End of Emotional Wellbeing questions

Patient interview questions

11

## Health Care Providers and Services

The final section asks some questions about other treatment and health care providers that you may have been referred to by your treatment team in the last month. We would also like to know if you have used any support services or complimentary or alternative medicine or services.

Firstly, has your treatment team suggested that you see a particular health care provider in response to any needs or concerns you may have had over the last month?

For example, you may have been referred to a social worker for help in accessing financial benefits or community services, an occupational therapist for help with physical concerns or equipment needs, or a counsellor for help with emotional issues such as anxiety.

1. In the last month, have you been referred to any of the health care providers listed below?

General practitioner	1
Surgeon	2
Medical oncologist	3
Radiation oncologist	4
Palliative care physician or service	5
Specialist cancer nurse	6
Psychologist, counsellor, psychiatrist	7
Social worker	8
Physiotherapist	9
Occupational therapist	10
Dietician or nutritionist	11
Community nurse	12
Community mental health worker	13
Respite	14
Other (please specify.....)	15

- 1A. Of the health care providers that you were referred to during the last month, were there any that you did not actually see?

Yes	1	[go to 1B]
No	2	[go to 2 on page 13]

- 1B. Please list each health care provider that you were referred to and did not see, and state the reason why for each of these.

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**2. Have you used any of the following support services in the last month?**

Cancer Helpline	1
Cancer Connect	2
Support group	3
Tele-group counselling	4
Living with cancer education program	5
Peer one on one support	6
Community health centre	7
Other services (please specify.....)	8
None	9

**3. Have you used any complementary or alternative medicine services?**

Acupuncture	1
Aromatherapy	2
Art, Music, or dance therapy	3
Chiropractic manipulation	4
Enema or colonic irrigation	5
Herbal medicines eg. Bach plants, Iscador or Mistletoe	6
Homeopathy	7
Hypnosis	8
Laetrile or amygdaline	9
Massage	10
Meditation, imagery or visualisation	11
Microwave or Tronado therapy	12
Naturopathy	13
Nutritional supplements eg. Vitamins, minerals, enzymes	14
Osteopathic manipulation	15
Ozone therapy	16
Prayers or spiritual practices	17
Progressive muscle relaxation	18
Reiki	19
Shark cartilage	20
Special diets and foods eg. Macrobiotic, Gawler, vegetarian	21
T'ai chi	22
Traditional Chinese medicine	23
Yoga	24
Other (please specify.....)	25
None	26

End of health care providers questions

## Your current circumstances

1. Are there any circumstances or recent events that have influenced the way you have answered the questions in this questionnaire, compared to how you would normally have answered them? For example, have you been away on holidays, or is it a holiday period for the care team? There may be other things that have affected the type of help and support you have needed.

Yes	1	[Go to Q2]
No	2	[go to GP Question below]

2. Please describe how your current circumstances are different from usual?

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That is the end of the questions about you.

1

## Caregiver participation in the study

You may have indicated earlier that you didn't have a caregiver or that they were not interested in joining the study. A caregiver may be a partner, son or daughter, or other family member or friend, who supports you through your illness and can help you with practical or emotional support if you need it now or in the future. They do not necessarily live with you.

1. Do you have a caregiver now, or someone of that description who might be a caregiver in the future?

Yes	1	[Go to Q2]
No	2	[Go to GP question]

2. Would you like us to send you another copy of the caregiver pack to hand on to the appropriate person?

Yes	1
No	2

## GP participation in the study

As part of this study, we are aiming to encourage GPs and other health care providers to assess their patient's needs and to help them with any concerns they identify. To help evaluate the usefulness of the Needs Assessment Tool, we would like to send a copy to your GP to complete during a consultation with you. You are most welcome to discuss your participation in this study with your GP, if you would like to.

1. Can we have your permission to send a Needs Assessment Tool to your GP to complete during your consultation and return a copy to us for our records?

Yes	1	[Go to Q2]
No	2	[You have finished]

2. Please provide your GPs name and contact details.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Telephone No: \_\_\_\_\_

**You have now finished the interview questions. Thank you for your participation.**

If you have any further questions about the study – please do not hesitate to ring the researchers on 1800766016.

If you feel that you would like to talk to someone else about the issues we have talked about or any other concerns that you may have please call the Cancer Helpline on 131120 or talk to your treatment team or general practitioner

# **APPENDIX 6.2:**

## **EVALUATION STUDY PATIENT INFORMATION LETTER**

**INFORMATION ABOUT THE RESEARCH PROJECT:  
Evaluation of a Needs Assessment Intervention  
Version 6 (HNEH):22/11/07**



You are invited to take part in a study that is being conducted by the Centre for Health Research & Psycho-oncology (CHeRP). CHeRP is the behavioural research unit of The Cancer Council NSW, and is based at the University of Newcastle. CHeRP is interested in improving the quality of care for people with cancer and their caregivers.

**Why is the research being done?**

People with cancer and their caregivers may have a range of unmet needs in relation to physical, emotional, social and spiritual issues. Unfortunately, not everybody receives the type of help they need with such issues at the time they most need it. To help health professionals to identify their patients' needs better, we have developed Needs Assessment Guidelines and a Needs Assessment Tool. We are undertaking a study to find out how helpful these Guidelines and Assessment Tool are in improving the care of patients and caregivers by assessing and addressing their unmet needs earlier.

**Who can participate?**

We are inviting people with cancer and their nominated caregivers to take part in the study. You have been nominated as a possible participant in this research. By using the Needs Assessment Guidelines and Tool, members of the health care team may be able to identify what sorts of help you need, and assist you to get suitable help at the time you most need it.

**What choice do you have?**

Participation is entirely your choice. If you decide not to take part, your decision will not affect your treatment, your relationship with those treating you or with the Mater Hospital in any way. If you do decide to participate, you may withdraw from the study at any time and request that the information you have already provided and the assessment tools relating to your treatment, completed by your doctor, be destroyed. You may also refuse to answer any questions that you are asked in the surveys.

**What would you be asked to do?**

Included with this information letter is a Consent Form. If you agree to participate you would be asked to:

- Fill out the Consent Form and return it to the research team in the reply paid envelope.
- Provide us with your address and a telephone number where we may reach you to conduct the interviews and send you up-dates about the research project.
- Take part in up to seven, 40-minute telephone interviews over a period of two years. The interviews include questions about your health, your needs, and your use of health services. In addition, you will be asked to answer some general background questions about yourself.

Centre for Health  
Research & Psycho-  
oncology  
Longworth Avenue  
Wallsend NSW 2287 Australia  
Locked mail bag 10  
Wallsend NSW 2287  
Telephone (02) 4924 6372  
Facsimile 02) 4924 6208  
e-mail: CHeRP@newcastle.edu.au

- Give permission for your health care providers to give the researchers copies of the Tool they complete in your consultation(s) which will have information about your level of need and cancer diagnosis.
- Give permission for researchers to access your medical records to ascertain your diagnosis, stage of disease and date of initial diagnosis, and to track your health status. In addition, we would like to check the dates you used health services. No other information will be extracted from your record for study purposes.

### **How will your privacy be protected?**

All information you give us will be kept strictly confidential and will be stored according to strict privacy guidelines. Only authorised research staff will have access to the information. Consent Forms with your contact details will be kept in a locked filing cabinet in a locked room. Data will be stored in a locked store room for a minimum of seven years on completion of the project. The information we collect from you will only be identified by a code number, and any identifying information will be removed. Information will be presented in a doctoral thesis submitted by Amy Waller and may be published in scientific journals. All information published will be grouped information only, and so you will not be able to be identified in any reports about the project.

### **What do you need to do to participate?**

Please read this Information Letter and make sure you understand it before you agree to take part. If there is anything you do not understand, or you have questions, please contact the researchers listed at the end of the letter. To take part, you will need to sign and return the Consent Form in the reply paid envelope.

By signing the Consent Form you indicate that you have understood the information, and that you agree to take part in the study. Once the researchers have received your Consent Form, they will contact you to make a time with you to conduct the interview. You have been given copies of the Information Letter and Consent Form to keep as a record.

If we do not hear from you within 10 days we will telephone you to see if you have any questions and to remind you about the study. If you do not wish to receive the reminder call, you may inform the research officer in the clinic or return a blank Consent Form in the reply paid envelope.

### **Results**

A summary of results will be available at the end of the study. If you would like a copy to be sent to you, please fill out the Summary of Results Form included with this Information Letter and return it with your Consent Form.

### **If you have problems during the research**

During the telephone interviews you will be asked questions about your health and the care you have received. Talking about your cancer experience can sometimes be difficult. If you find that you would like to talk to someone about any problems or concerns that you may have after completing an interview, please contact the Social Work Department at the Mater Hospital on 4921 1298. You may also discuss the issues with your treatment team or call the Cancer Helpline on 131120. You can also contact a member of the research team by telephone, email or by mail to raise any concerns.



**More information about the study**

If you would like more information about this research project, please feel free to contact us by telephone on 1800766016, or by emailing us (Amy Waller: [Amy.Waller@newcastle.edu.au](mailto:Amy.Waller@newcastle.edu.au), Claire Johnson: [Claire.Johnson@newcastle.edu.au](mailto:Claire.Johnson@newcastle.edu.au) or Afaf Girgis: [Afaf.Girgis@newcastle.edu.au](mailto:Afaf.Girgis@newcastle.edu.au)).

Any help you can give us in this important research work would be most appreciated.

Yours sincerely

Centre for Health Research & Psycho-oncology (CHeRP)

Professor Afaf Girgis  
Chief Investigator

Professor David Currow  
Principal Investigator

**Complaints**

This project has been approved by the Hunter New England Human Research Ethics Committee, Reference 06/06.27/4.01. Should you have concerns about your rights as a participant in this research, or you have a complaint about the way 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 Ethics), Hunter New England Human Research Ethics Committee, Hunter New England Health, Locked Bag 1, New Lambton NSW 2305, telephone (02) 4921 4950, email [Nicole.Gerrand@hnehealth.nsw.gov.au](mailto:Nicole.Gerrand@hnehealth.nsw.gov.au)

# **APPENDIX 6.3:**

## **EVALUATION STUDY PATIENT CONSENT FORM**



**PATIENT CONSENT FORM:**  
**Evaluation of a Needs Assessment Intervention**  
Researchers: Afaf Girgis, Stephen Ackland,  
David Currow, Claire Johnson, and Amy Waller  
**Version 4 (HNEH): 22/11/07**

*Please read the Information Letter before completing this Consent Form. If there is anything in the Information Letter that you do not understand or if you have any questions regarding the study, please contact the researchers on 1800 766 016.*

I agree to participate in the above research project and give my consent freely. I understand the project will be conducted as described in the Information Letter (Version 4 dated 20/11/06), a copy of which I have retained. I understand I can withdraw at any time and do not have to give a reason for withdrawing. I also understand I can withdraw my data at any time.

I consent to participate in up to 7 telephone interviews of approximately 40 minutes each, over the next two years. I also consent to my health care providers providing the researchers with copies of the Tool completed in my consultation(s) which will have information about my level of need and cancer diagnosis.

I consent to researchers accessing my medical records for the purpose of ascertaining my diagnosis, stage of illness and date of initial diagnosis, tracking my health status and checking the dates I used health services.

*To indicate your consent to take part in this study, please sign below, complete your contact details and return to researchers in the reply paid envelope provided.*

I understand that my personal information will remain confidential and accessible only to the researchers. I have had the opportunity to have any questions answered to my satisfaction.

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

**My details are:**

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ Mobile: \_\_\_\_\_

The best day(s) to contact me: \_\_\_\_\_

The best time(s) to contact me: \_\_\_\_\_

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood.

Researcher's Name: \_\_\_\_\_ Date: \_\_\_\_\_

Signature: \_\_\_\_\_

# **APPENDIX 6.4:**

## **EVALUATION STUDY PATIENT MEDICAL RECORD AUDIT FORM**

**Patient medical record audit form**

Participant Name

Address

Date of consent

Date deceased

Intervention date

Service/health professional	Date/s of referral	Occasions of service (dates dd/mm/yy)
Medical oncologist		
Haematologist		
Radiation oncologist		
GP		
Palliative Care Service		
PC nurse		
PC physician/specialist		
Pain service		
Community nurses		
Specialist nurse (specify) .....		
Physiotherapist		
Occupational therapist		

## Appendix 6.4

Clinical psychologist or psychiatrist		
Dietitian		
Social worker		
Counsellor		
Community Mental Health Worker		
Community Health Centre		
Cancer Council Helpline		
Peer support/self-help groups		
Pastoral carer		
Financial counsellor		
Other (Specify) .....		
Other (Specify) .....		
Other (Specify) .....		
Other (Specify) .....		

Appendix 6.4

1. Inpatient admissions (dates) 2. Length of stay (days) 3. Doctor admitted under					
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**Comments**

# **APPENDIX 7.1:**

## **SUPPORTIVE CARE NEEDS SURVEY**

### **SHORT FORM-34 (SCNS SF-34)**

#### **LIST OF MODERATE OR HIGH NEEDS**



**The Supportive Care Needs Survey items for which patients reported a moderate or high need for help in the month preceding the baseline interview**

<b>SCNS items</b>	<b>% with moderate /high need</b>	<b>Domain</b>
Not being able to do the things you used to do	33.0	Daily living
Concerns about the worries of those close to you	27.9	Psychological
Lack of energy/tiredness	26.2	Daily living
Work around the home	23.0	Daily living
Uncertainty about the future	21.4	Psychological
Pain	20.9	Daily living
Worry that results of treatment are beyond your control	19.4	Psychological
Fears about the cancer spreading	18.8	Psychological
Feeling unwell a lot of the time	17.3	Daily living
Anxiety	15.3	Psychological
Learning to feel in control of your situation	15.3	Psychological
Feeling down or depressed	13.8	Psychological
Feelings about death and dying	12.8	Psychological
Feelings of sadness	12.2	Psychological
Changes in your sexual relationships	10.2	Sexuality
Having one member of hospital staff with whom you can talk about all aspects of your condition, treatment and follow-up	9.6	Health and information
Getting adequate information from medical staff about your prognosis	9.6	NA-ACP
Keeping a positive outlook	9.6	Psychological
Being able to have open discussion with your doctors	9.2	NA-ACP
Changes in sexual feelings	8.6	Sexuality
Being informed about things you can do to help yourself to get well	8.1	Health and information
Receiving accurate medical judgements from medical staff	7.7	NA-ACP
More choice about which cancer specialists you see	7.6	Patient care
Being given written information about important aspects of your care	7.1	Health and information
Being adequately informed about the benefits and side-effects of treatments before you choose to have them	7.1	Health and information
Trying to find meaning in your cancer experience	6.6	Spirituality

Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	6.6	Health and information
Reassurance that the way you feel is normal	6.6	Patient care
Hospital staff attending promptly to your physical needs	5.6	Patient care
Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	5.6	Health and information
Having the opportunity to talk to someone who is sharing a similar experience	5.6	NA-ACP
Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	5.1	Patient care
Being treated in a hospital or clinic that is as physically pleasant as possible	5.1	Health and information
Being informed about your test results as soon as feasible	4.6	Health and information
Setting new priorities in your life	4.6	Spirituality
Being able to choose the place where you spend your final days	4.6	Spirituality
Being given explanations of those tests for which you would like explanations	4.6	Health and information
Being informed about cancer which is under control or diminishing (that is, remission)	4.1	Health and information
To be given information about sexual relationships	4.1	Sexuality
More choice about which hospital you attend	3.6	Patient care
Being treated like a person not just another case	3.6	Health and information
Accepting your relationship with God or a higher being	2.6	Spirituality
Dealing with the spiritual issues of death or dying	2.0	Spirituality
Assistance having your spiritual needs met	2.0	Spirituality

# **APPENDIX 9.2:**

## **NEEDS ASSESSMENT TOOL:**

### **PROGRESSIVE DISEASE – CANCER**

#### **(NAT: PD-C) FINAL VERSION**

## NEEDS ASSESSMENT TOOL: PROGRESSIVE DISEASE – CANCER (NAT: PD-C) USER GUIDE

### Purpose of the NAT: PD-C

- Used in both generalist and specialist settings to support the recommendations in the Palliative Care Needs Assessment Guidelines, the Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C) can assist in matching the types and levels of need experienced by people with advanced cancer and their caregivers with the most appropriate people or services to address those needs.
- In generalist settings (eg general practice and oncology), the NAT: PD-C can be used to determine which needs may be met in that setting and which needs are more complex and may be better managed by specialists.
- In specialist settings (eg specialist palliative care services), the NAT: PD-C can assist in determining when complex needs have been met and act as a discharge planning tool, or to identify the need for ongoing support.
- The NAT: PD-C is an important tool for facilitating communication between primary and specialist care providers about patient needs and actions taken to address these.

### Completing the NAT: PD-C

The NAT: PD-C is a one-page assessment tool that can be completed by health professionals across a range of disciplines. When completing the NAT: PD-C, the following steps should be followed:

1. **ASSESS** patient/caregiver level of concern **FOR EVERY ITEM**, using the response options: "none", "some/potential for" or "significant".
2. **CONSIDER** the range of issues within each domain that apply to a person at this stage of their illness. Prompts are provided on a separate page to help you.
3. **ACT** on each need where you identified some concern ("some/potential for" or "significant"). Your actions may include: directly managed by you, managed by another member of your care team, or referral to someone outside your care team. Record your action on the NAT: PD-C.
4. **REFER** if required by completing the referral section at the bottom of the tool, ensuring that information regarding the type of referral, the priority of the referral and client knowledge of the referral is included.
5. **INFORM** other members of the care team of the outcomes of the needs assessment by:
  - a. Filing one copy of the NAT: PD-C in the patient's medical file.
  - b. Sending a copy to the person's GP/oncologist/other specialist.
  - c. If a referral is required, forwarding a copy to the referee.
6. **REASSESS** needs by completing the NAT: PD-C approximately monthly or when the patient's or family's situation, or functional status changes.

# NEEDS ASSESSMENT TOOL : PROGRESSIVE DISEASE CANCER (NAT: PD-C)

COMPLETE ALL SECTIONS

PATIENT NAME: \_\_\_\_\_

DATE: \_\_\_\_\_ DIAGNOSIS: \_\_\_\_\_

PATIENT/ADDRESS LABEL

## SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT

	Yes	No	If yellow boxes are ticked, consider assessment by SPCS
1. Does the patient have a caregiver readily available if required?			
2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?			
3. Do you require assistance in managing the care of this patient and/or family?			

## SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)

	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the patient experiencing unresolved physical symptoms (including problems with pain, sleeping, appetite, nausea, bowel, breathing or fatigue)?						
2. Does the patient have problems with daily living activities?						
3. Does the patient have psychological symptoms that are interfering with wellbeing or relationships?						
4. Does the patient have concerns about spiritual or existential issues?						
5. Does the patient have financial or legal concerns that are causing distress or require assistance?						
6. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?						
7. Does the patient require information about (tick any options that are relevant):						
<input type="checkbox"/> The prognosis <input type="checkbox"/> The cancer <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Social/emotional issues						

COMMENTS: \_\_\_\_\_

## SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)

Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the caregiver or family distressed about the patient's physical symptoms?						
2. Is the caregiver or family having difficulty providing physical care?						
3. Is the caregiver or family having difficulty coping?						
4. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?						
5. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?						
6. Does the caregiver or family require information about (tick any options that are relevant):						
<input type="checkbox"/> The prognosis <input type="checkbox"/> The cancer <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Social/emotional issues						

COMMENTS: \_\_\_\_\_

## SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)

Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?						
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?						

COMMENTS: \_\_\_\_\_

## IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS SECTION

1. Referral to: (Name) \_\_\_\_\_

2. Referral to: (Specialty) ☐ General practitioner   ☐ Social worker   ☐ Psychologist   ☐ Specialist palliative care service  
☐ Medical oncologist   ☐ Radiation oncologist   ☐ Haematologist   ☐ Other \_\_\_\_\_

3. Priority of assessment needed: ☐ Urgent (within 24 hours)   ☐ Semi-Urgent (2-7 days)   ☐ Non-Urgent (next available)

4. Discussed the referral with the client: ☐ Yes   ☐ No

5. Client consented to the referral: ☐ Yes   ☐ No

6. Referral from: Name: \_\_\_\_\_ Position: \_\_\_\_\_ Signature: \_\_\_\_\_

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## ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

PATIENT WELLBEING
<p><b>Physical symptoms</b></p> <ul style="list-style-type: none"> <li>Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnoea, vomiting/nausea, pain, constipation, sleep problems, diarrhoea, or loss appetite?</li> </ul> <p><b>Activities of daily living</b></p> <ul style="list-style-type: none"> <li>Is the patient having difficulty with toileting, showering, bathing, or food preparation?</li> <li>Is there a caregiver to assist the patient?</li> </ul> <p><b>Psychological</b></p> <ul style="list-style-type: none"> <li>Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?</li> <li>Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?</li> <li>Is the patient requesting a hastened death?</li> </ul> <p><b>Spiritual/Existential</b></p> <ul style="list-style-type: none"> <li>Is the patient feeling isolated or hopeless?</li> <li>Does the patient feel that life has no meaning or that his/her life has been wasted?</li> <li>Does the patient require assistance in finding appropriate spiritual resources or services?</li> </ul> <p><b>Financial/Legal</b></p> <ul style="list-style-type: none"> <li>Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?</li> <li>Is the family socio-economically disadvantaged?</li> <li>Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?</li> <li>Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?</li> </ul> <p><b>Health Beliefs, Social and Cultural</b></p> <ul style="list-style-type: none"> <li>Does the patient or family have beliefs or attitudes that make health care provision difficult?</li> <li>Are there any language difficulties? Does the patient or family require a translator?</li> <li>Is the family preventing information about prognosis from being disclosed to the patient?</li> <li>Does the information have to be passed on to a particular member of the family or cultural group?</li> <li>Is the patient or family feeling socially isolated?</li> <li>Does the family live more than 50km from the primary service provider?</li> <li>Is the patient of Aboriginal or Torres Strait Islander descent?</li> <li>Is the patient over 75 years of age? (NB: older patients are under-represented in SPCs.)</li> </ul> <p><b>Information</b></p> <ul style="list-style-type: none"> <li>Does the patient want more information about the course and prognosis of the disease and treatment options?</li> <li>Is the patient aware of the various care services available to assist them and do they need assistance in accessing these? (eg financial and legal assistance, psychological services, support groups, pastoral care.)</li> </ul>
ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT
<p><b>Physical symptoms</b></p> <ul style="list-style-type: none"> <li>Are the patient's physical symptoms causing the caregiver and family distress?</li> </ul> <p><b>Providing physical care</b></p> <ul style="list-style-type: none"> <li>Is the caregiver having difficulty coping with activities of daily living, medical regimes or practical issues such as equipment and transport?</li> </ul> <p><b>Psychological</b></p> <ul style="list-style-type: none"> <li>Is the caregiver having difficulty coping with the patient's psychological symptoms?</li> <li>Is the caregiver requesting a hastened death for the patient?</li> </ul> <p><b>Family and Relationships</b></p> <ul style="list-style-type: none"> <li>Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles?</li> <li>Is the patient particularly concerned about the impact of the illness on the caregiver or family?</li> </ul> <p><b>Information</b></p> <ul style="list-style-type: none"> <li>Does the caregiver or family want more information about the course and prognosis of the disease and treatment?</li> <li>Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these? (eg respite, financial and legal services, psychological services, support groups, pastoral care.)</li> </ul>
CAREGIVER WELLBEING
<p><b>Physical and psychosocial</b></p> <ul style="list-style-type: none"> <li>Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances?</li> <li>Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed?</li> <li>Does the caregiver have spiritual/existential issues that are of concern?</li> </ul> <p><b>Bereavement Grief (pre and post death)</b></p> <ul style="list-style-type: none"> <li>Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?</li> </ul>

Funded by the Australian Government Department of Health and Ageing and Cancer Council NSW

Further copies are available at: <http://www.newcastle.edu.au/research-centre/charp/professional-resources>