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The Routine Assessment of Unmet Needs in Individuals with Advanced Cancer and the Discussion of Psychosocial Concerns.

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Abstract

Background
Assessing the psychosocial needs of individuals with advanced cancer and their caregivers has become a vital component of care in this stage of the cancer journey. This study explored the modes of administration of a needs assessment tool in oncology consultations, including whether its administration altered the nature and quality of the communication and length of consultations.

Methods
A qualitative analysis was undertaken of audiotaped, outpatient consultations with 20 individuals with advanced cancer and their caregivers who participated in an interrupted time series study of the impact of systematic utilisation of the Palliative Care Needs Guidelines and Palliative Care Needs Assessment Tool (PC-NAT). Across participants, 48 consultations were audiotaped, including 13 baseline recordings where no routine needs assessment was completed and 35 that included completion of the PC-NAT. Audio-tapes were analysed using NVivo and SPSS was sued to calculate impact of using PC-NAT on consultation length.

Results
The routine needs assessment tool was delivered without an explanation of the function of the assessment and in jargonistic terms, and tended not to be integrated into the consultation. The majority of the content of interactions related to physical health issues; however, the number of both physical and psychosocial concerns raised by patients increased from the pre-assessment to post-assessment sessions. The range of empathic responses given by the oncologist in regards to patient and caregiver concerns ranged from low
(denial/disconfirmation) to very high (confirmation), though psychosocial concerns were more often dismissed or not pursued, compared with physical concerns. There was no significant increase in consultation time when the routine needs assessment was included.

Conclusion

There are some differences in the way that physical and psychosocial needs are addressed by oncologists in consultations with individuals with advanced cancer and their caregivers. This difference primarily relates to the expression of empathy by the oncologist in relation to either physical or psychosocial concerns.

Clinical Implications

These results have implications for the training of medical staff in their understanding and the rationale for the use of routine needs assessment tools and how space is created in consultations for the discussion of psychosocial issues.
1 Extended Introduction

1.1 Advanced Cancer in Australia

Cancer is a major cause of morbidity and mortality in Australia with approximately 114,000 new cases diagnosed in 2010 (Cancer Council Australia, 2010). It is the leading cause of death in Australia with approximately 43,000 people dying from the disease in 2010 (Cancer Council Australia, 2010). Fortunately, earlier diagnosis and better treatments have contributed to improved cancer survival rates such that more than half of those diagnosed are now successfully treated (AIHW & AACR, 2012). Nevertheless, the diagnosis, treatment and recovery or progression of cancer is a major life stressor and presents a range of emotional, psychological, physical and practical challenges to those affected by the disease (National Breast Cancer Centre, National Cancer Control Initiative, & NHMRC, 2003).

The five year survival rate is now at 66% of cases; however this means that a large percentage still progress to the advanced stage of cancer (AIHW & AACR, 2012). Advanced cancer or terminal cancer refers to a stage of cancer illness where “curative treatment is no longer useful, the disease is assessed to be incurable and the patient’s condition is progressively deteriorating” (World Health Organisation, 2007). The aim of care for individuals with advanced cancer is often focused on improving quality of life (QOL) by preventing and reducing suffering caused by the illness as it progresses (Palliative Care Australia, 2005b; World Health Organisation, 2007). This is achieved through the assessment and treatment of pain, physical difficulties, psychological or emotional suffering and spiritual issues. (Palliative Care Australia, 2005b; World Health Organisation, 2007). This type of care is often referred to as palliative care. Palliative care is a health care approach, which
seeks to address the problems associated with life threatening illness, in this case advanced cancer, for patients and their families. The World Health Organisation review (World Health Organisation, 2007) of palliative care outlines a number of strategies and core stance taken in the palliative care approach:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor to 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 illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy;
- includes the investigations needed to better understand and manage distressing clinical complications.

The World Health Organisation acknowledges that there are likely gaps in palliative care provision and also limited resources with which to provide this service (World Health Organisation, 2007). In addition, it has also been recognised that all individuals with a terminal illness do not require the same level of palliative care provision. Some patients may not need ‘specialist’ palliative care (Palliative Care Australia, 2005b), so it is vital that they are allocated based on an individual assessment of need (A. Girgis et al., 2006). Not all
palliative care patients have a diagnosis of cancer. Therefore, ‘needs’ assessment is a prerequisite to providing a co-ordinated care for those individuals with advanced cancer. This study explores research into the needs of individuals with advanced cancer patient and their caregivers, their unmet needs and the potential barriers which may inhibit the process of needs assessment.

1.2 The Needs of Patients with Advanced Cancer, and their Caregivers

The palliative care needs of advanced cancer patients and caregivers encompass physical as well as the comprehensive range of psychosocial needs (Palliative Care Australia, 2003; World Health Organisation, 2007). These needs are sometimes referred to as supportive care needs (Janda et al., 2008). There has been an assumption that patients and caregivers will have some level of need and that this should be intrinsically related to service provision, particularly how needs may be met. In looking at the palliative care needs of patients in general, individuals with cancer represent 90% of the palliative caseload (A. Girgis et al., 2006). Results of studies of individuals with advanced cancer in NSW indicate that 95% report some perceived level of need for assistance (Bonevski et al., 2000; Boyes, Girgis, & Lecathelinais, 2009). A review article by Smith et al. (2012) found that individuals with advanced cancer in palliative treatment programs report higher overall QoL and lower levels of depression compared with those individuals whose cancer was also in an advanced stage and who were in usual oncological care (Bakitas et al., 2009; T. Smith et al., 2012). In a similar study using palliative and usual oncological care groups, those individuals with advanced cancer in the palliative treatment program were also found to have improved ‘mood’ (depression and anxiety) in addition to higher overall QoL (Temel et al., 2010). Palliative care for individuals with advanced cancer has also been shown to improve patient satisfaction with care (Davies & Higginson, 2005).
‘Needs’ is an extremely difficult concept to define and operationalise. Needs are dynamic and change with any number of variables experienced by the patient or as services or policy changes (Higginson, Hart, Koffman, Selman, & Harding, 2007). In researching the assessment of ‘needs’ there is great variety in the definition of ‘needs’, even within the field of advanced cancer (White, D'Abrew, Katris, O'Connor, & Emery, 2011). Parry-Jones et al. (2001) completed interviews with a range of health care practitioners including nurses, nursing managers, occupational therapists and social workers working in community care and many meanings were attributed to the word ‘need’. However, common boundaries and definitions were identified, including:

- needs are only formally recognised as such if they fit within eligibility criteria for service provision;
- needs equate with need for a service;
- needs are professionally defined, (i.e., clients can identify their wants, but practitioners identify needs);
- needs should be relative to the client’s own standards (e.g., standards of hygiene) and professionals should not enforce own standards upon client;
- needs are holistic (e.g., need for social contact if not met may affect well-being/ health);
- needs and risk are inextricably linked, (i.e., there may be a need to provide care to minimise risk) and
- needs of scarce resources can be in conflict with clients’ need for preventative treatment.

That is the client might need and benefit from a treatment designed to prevent an illness or disease; however, the resources are so scarce that this service is not possible to deliver. For example public dental waiting lists might be long, which leads to longer waiting
times and conflict between the available resources and the need for preventative health care.

In the present report, needs are considered to be „…the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being” (Sanson-Fisher et al., 2000 p. 227).

There are a large number of ‘needs’ identified in the literature as being important for those individuals with advanced cancer (Rainbird, Perkins, Sanson Fisher, Rolfe, & Anseline, 2009). Because of the great difference that exists between cancer diagnosis, treatment and prognosis for each individual patient there is a great deal of intergroup difference regarding needs (A. Girgis et al., 2006). However, what is clear is that these needs fall into two main categories, 1) physical, and 2) psychosocial needs. Palliative Care Australia (Palliative Care Australia, 2003) outline a range of needs that should be targeted by palliative care interventions, which fit under these headings and each is presented below, pain and physical needs, practical needs, psychological needs, spiritual needs and financial needs (Palliative Care Australia, 2003).

1.2.1 Pain and physical needs.

The largest impact of advanced cancer on patients is the ongoing physical symptoms associated with the continued presence and growth of the cancer (Higginson & Costantini, 2008). The physical symptoms experienced by individuals with advanced cancer vary and are dependent on type and progression of the disease (J Harrison, Young, Price, Butow, & Solomon, 2009). Pain is a common symptom of advanced cancer with a research indicating that in a palliative care population, with 95% being cancer patients, 64% were referred for
pain management difficulties (Potter, Hami, Bryan, & Quigley, 2003). This number does not account for the number of individuals with advanced cancer who experience pain however find that it is managed effectively and so are not referred for this reason. Pain for individuals with advanced cancer can be dependent on the site of the primary tumour with lung cancer the most frequently reported being associated with pain (68%), followed by breast (62%), gastrointestinal (58%), brain (53%), head and neck (52%), gynaecological (50%) and urological (40%) and lymphomas (38%) (Lidstone et al., 2003). Physical conditions include weakness (fatigue), dyspnoea (breathing problems), constipation and gastro-intestinal disturbances. In a population of individuals with advanced cancer referred to SPCS the range of patients reporting physical difficulties, depending on diagnosis, were as follows (Lidstone et al., 2003):

- Weakness of tiredness 63-90%.
- Dyspnoea 35-75%
- Constipation 23-48%
- Gastro-intestinal disturbances 17-62% (nausea 17-25%; weight/appetite loss 30-62%)

As stated above, these figures only capture a part of the actual need level of individuals with advanced cancer, as there may be a higher percentage of individuals who have needs in this area, however their need is met.

1.2.2 Psychosocial needs.

That individuals with cancer require treatment for psychosocial needs in addition to medical treatment is now well-recognised (McIllmurray et al., 2001). Research has shown that both psychosocial and practical needs are important considerations for health professionals, patients and caregivers affected by advanced cancer, particularly as time is
often limited (Van der Lee et al., 2005). The term ‘psychosocial need’ may encompass a number of issues, most often this refers to psychological distress and emotional functioning (hence psychosocial need is often simply referred to as psychological needs). Psychosocial need can be extended to include the physical impact of cancer and treatment and practical needs such as transportation and home duties. McIllmurray et al. (2001) found that physical symptoms and practical issues in a patient with advanced cancer can have a significant impact on levels of distress, anxiety, and depression. Thus, the most often accepted definition of ‘psychosocial need’ is any issue that has a bearing on the ability of a patient to cope with their diagnosis and associated physical symptoms (J Harrison et al., 2009). The main areas of psychosocial needs documented for individuals with cancer advanced cancer are summarised below and include: 1) Activities of Daily Living (ADLs), 2) Information, 3) Psychological, 4) Spiritual, and 5) Financial.

1.2.2.1 Activities of Daily Living (ADLs) needs.

As cancer symptoms and become more difficult to manage as the disease progresses, the ability to perform ADLs declines (Schuit et al., 1998). Fatigue and other physical aspects of cancer and cancer treatment can impact on the patient’s ability to complete ADLs (K. Soothill et al., 2001), particularly in advanced cancer (Osse, Vernooij, Schade, & Grol, 2004). In a study of individuals with head and neck cancer it was determined that there was a significant relationship between weight loss associated with treatment and decline in physical performance and increase in functional dependence (Osse et al., 2004). Despite assistance with ADLs being a significant area of need for individuals with advanced cancer, qualitative research has found that a large proportion of patients are able to compensate for the changes that come with advanced cancer. Whilst they continue to engage in ADLs, this is perhaps not to the same degree (DeSanto-Madeya, Bauer, & Gross, 2007).
1.2.2.2 Information needs.

Information needs relate to what patients want to know and from whom they would like to receive the information (Finney Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Information is generally received from two different sources, 1) primary sources (primary and specialist health providers) and secondary sources (family, friends and support agencies) (Kirk, Kirk, & Kristjanson, 2004). Information is further divided into process (how it is delivered) and content (what information is delivered) (Kirk et al., 2004). The benefits of the information needs of patients being met are summarised by Finney Rutten et al. (2005) as increase involvement in decision making, greater satisfaction with care, improved ability to cope through all stages of cancer journey, reduction in psychiatric morbidity and improved communication with family members.

1.2.2.3 Psychological needs.

Psychological needs may encompass a range of emotional concerns including depression and anxiety. As many as 25% of individuals with advanced cancer in palliative care meet diagnosis for depression, and figure for anxiety can be even higher (Lawrie, Lloyd-Williams, & Taylor, 2004). Psychological concerns are higher for those individuals with advanced cancer who have greater levels of unmet needs (Morasso et al., 1999).

1.2.2.4 Spiritual and existential needs.

McCoubrie and Davies (2006) define spirituality as “life having a purpose, the search for meaning and the attempt to interpret personal illness and death in a way that makes sense” (McCoubrie & Davies 2006 p. 379). These are the issues which are faced by those with terminal illness (McCoubrie & Davies, 2006). One of the most prevalent spiritual needs of individuals with advanced cancer is a need to be with family as they approach end-of-life (Hampton, Hollis, Lloyd, Taylor, & McMillan, 2007). For those individuals with advanced
cancer whose spiritual needs are met there is a significantly lower chance of psychiatric morbidity (McCoubrie & Davies, 2006).

### 1.2.2.5 Financial needs.

Financially the cost of advanced cancer is high and can include the cost of medication, respite and travel as well as medical treatment (Amir, Wilson, Hennings, & Young, 2011; Arozullah et al., 2004). In addition other financial concerns can be related to non-medical support service, prosthesis or aids, support needs at home and loss of income (Butler & Howarth, 1999). Financial pressures add extra strain to those already in a psychologically vulnerable position (Amir et al., 2011). Qualitatively it has been determined that financial burden worries patients, particularly around the loss of savings and hardship for the future (Sherwood, Donovan, Rosenzweig, Hamilton, & Bender, 2008). In addition, patients expressed a great deal of frustration around working with insurance companies and “red tape” associated with these interactions associated with financial burden (Sherwood et al., 2008).

### 1.2.3 Needs of caregivers.

A ‘caregiver’ is defined as a person nominated by the patient as most involved in supporting them through the illness, regardless of family ties, as long as they were not remunerated (C. Thomas et al., 2009). One of the major issues for caregivers is that they are often perceived by the health care team as a “co-worker” rather than a client themselves (Harding, Higginson, & Donaldson, 2003). Caregivers are there for the entire cancer journey, from first symptoms, diagnosis, treatment and post treatment, and in the case of a terminal diagnosis, the passing of the patient (K. Soothill et al., 2001). However, caregivers are often not recognised as having a significant role in the treatment and management of those patients (S Aranda & Peerson, 2001). Although this creates an environment where the consideration of the caregiver’s needs is secondary or not considered, there is increased recognition of the
role of caregivers and that they, like the patient, have significant physical and psychosocial needs also (K. Soothill et al., 2001).

The Australian Bureau of Statistics indicates that there were 2.6 million unpaid caregivers in Australia in 2009 and 770,000 of these caregivers were identified as primary caregivers (Australian Bureau of Statistics, 2011). Caregivers in Australia have reported a number of reasons for taking on the role including “…family responsibility (58%), the carer feeling that they could provide a better quality of care than others (39%) and emotional obligation (34%)” (Ellis, 2009 p. 28). Among those diseases which result in higher levels of informal care provided by caregivers, advanced cancer is represented significantly. The care provided in advanced cancer can be significant, with 20% providing fulltime care (Ellis, 2009; A. Girgis et al., 2006). Caregives are often involved in difficult decision making throughout the patients cancer journey, which includes hospice versus at home care or end of life issues (W.E. Haley, 2003).

Care giving may also involve very difficult and stressful activities including witnessing or managing incontinence, pain, dyspnea, anorexia, cognitive impairment, and death (William E. Haley, LaMonde, Han, Burton, & Schonwetter, 2003). Families generally experience difficulties keeping up with their own Activities of Daily Living (ADLs) and also caring for the patient in the home. In addition they can also experience difficulty in their relationship with the patient particularly in regards to communication as their conversations become less open to avoid the negative (McGrath, 2004). Haley (2003) also writes about the secondary stressors of cancer such as role strain, financial pressures and family conflict.
The range of caregiver needs closely mirror those of patients, including a need for informational support; however caregivers also experience their own unique needs, including requiring psychological support related to losing a loved one. In a review article looking at the needs of caregivers for individuals with advanced cancer, results generally show that most prevalent domains of needs for caregiver include information (i.e., about treatment and care) and psychological support (i.e., counselling for anxiety or grief) (Harding 2003). There appears to be little information regarding the spiritual and existential needs of caregivers.

1.2.3.1 Information needs.

The results of a study of caregivers of those individuals with cancer indicated that the most important needs were related to patient care and honest and understandable information (Friðriksdóttir et al., 2011). In a review of a mixed cohort of cancer related studies ‘treatment-related information’ (91%) and ‘diagnosis-related information’ (81%) were the most frequently cited information needs of caregivers in the reviewed studies (Adams, Boulton, & Watson, 2009). A study of individuals with brain tumours indicated that caregivers need clear information exchange between the treating team in order to manage these difficulties with information needs (Schubart, Kinzie, & Farace, 2008)

1.2.3.2 Psychological needs.

Significant levels of anxiety have been found among primary caregivers of end of life cancer patients (Grovv, Dahl, Moum, & Fossa, 2005). The percentage of caregivers, of those with advanced cancer, with a high level of psychological distress ranges from 41% to 62% (Dumont et al., 2006). A review by Pitceathly (2003) found that psychological distress and psychiatric morbidity increase in caregivers as the patient’s cancer prognosis worsens and they enter into the palliative stage. Compared with those caregivers of patients with treatable cancer, those caring for patients with a terminal illness have a lower quality of life (QoL) and
poorer physical health (A. Girgis et al., 2006). There is little doubt there is significant impact on the caregiver’s psychosocial wellbeing as a result of that role (A. Girgis et al., 2006). For those caregivers of individuals with cancer it may be effective for health care professionals to design communication interventions to enhance emotional support strategies such as active listening, reassurance and validation (Bakas, Lewis, & Parsons, 2001). Caregivers of individuals with advanced cancer have indicated that they require assistance managing anxiety and fatigue (S Aranda & Peerson, 2001) and assistance maintaining previously valued activities (Cameron, Franche, Cheung, & Stewart, 2002). Researchers in both studies recommended that the need for caregivers may be related to gaining assistance in using respite services. A study of caregivers of individuals with brain tumours showed that they need psychological support to manage emotional distress associated with that role (Schubart et al., 2008).

1.2.3.3 Other needs.

Increased pressure on social functioning (Cameron et al., 2002), being required to perform complex medical care (Deekin, Taylor, Mangan, Yabroff, & Ingham, 2003) and financial burden (A. Girgis et al., 2006) all contribute to pressure of the role of caregiver. An examination of the economic burden of cancer care is important in addressing the notion of psychosocial needs. In the US 20% of family members of cancer patients are forced to stop working and 31% of families lose the majority of their savings (Emanuel, Fairclough, & Emanuel, 2000). Economic burden has been associated with physical symptoms, incontinence, older age and low income (Emanuel et al., 2000). It has been suggested that these associated issues are not ones that may be easily ameliorated, and so to some extent the use of empathy and psychosocial interventions are necessary.
Caregivers may also experience a decrease in lifestyle functioning (Cameron et al., 2002). Cameron (2002) found that lifestyle interference can negatively impact on the level of emotional distress of caregivers regardless of the amount of care provided. Emotional distress can also be mediated by the level of social support around the caregiver and the relationship quality the caregiver has with the patient (Pitceathly & Maguire, 2005). Therefore, it was proposed that caregivers may be able to reduce emotional distress by continuing participation in valued activities while providing care.

1.3 Unmet Needs

The assessment of current needs is the first step in the ‘needs assessment’ process, what must also be determined is the extent to which these needs are being met (Bonevski et al., 2000). For example, psychological needs have been found to be higher in cancer patients than other, non-cancer patients, and despite being aware of services to deal with psychiatric needs, only one-third of patients follow through with this service (Fujisawa et al., 2010). Thus, this need remains unmet for a large proportion of patients. Unmet needs are those needs that are “…both important and unsatisfied” (K. Soothill et al., 2001 p. 597), it is a failure to provide action or resources to meet a requirement for QoL of the patient or caregiver. The point of view of health care delivery in advanced cancer ‘needs assessment’ identifies the problem, and ‘unmet needs assessment’ identifies where there is a ‘gap’ in support around these needs. Unmet needs assessment has three advantages (Bonevski et al., 2000):

1) Direct assessment of the patient’s perceived needs so resources may be allocated
2) Prioritizing resources where unmet needs are the highest
3) Identification of groups or individuals who might regularly have higher level needs and could be targeted through early intervention (ie those from lower socioeconomic
backgrounds could be allocated resources to assistance with financial burden sooner).

In particular, the use of unmet needs assessment in advanced cancer can allow for timely referral to Specialist Palliative Cancer Services (SPCS). SPCS are usually recommended for patients or caregivers who are experiencing some unmet needs as a part of the advanced cancer diagnosis and this would be assisted by symptom management, psychosocial support, communication, complex decision making, and transition planning (C. Smith et al., 2012). Despite there being a high level of unmet needs, patients close to end of life may actually report lower levels of unmet need than actually present, because it might be too difficult for patients or their caregivers to discuss the issues they are facing and not wanting to discuss death and dying. (Davis, Cowley, & Ryland, 1996). This under reporting may also be due to perceived feelings of embarrassment, that they ‘should’ be coping and also that they feel it is ‘normal’ to have these symptoms at the advanced stage of disease (Hudson et al., 2006; Mitchell, Kaar, Coggan, & Herdman, 2008).

1.3.1 Patient unmet needs.

A recent review of literature found that individuals with advanced cancer in palliative care are amongst those that experience the most unmet needs (J Harrison et al., 2009), with the main domains of unmet needs being:

- Activities of daily living (1-52%)
- Psychological (16-41%)
- Information needs (39%)
- Psychosocial (7-44%)
- Physical (7-89%)
- Spiritual (14-33%)
Researchers conducting research on Australians with cancer found that two thirds reported a moderate to high level of unmet needs at the time of treatment or just after, and then just under half reported a moderate to high level of unmet needs 6 months later (McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010). It is apparent from these findings that during the active treatment phase there is an increased focus on managing these unmet needs. In regards to ongoing unmet needs management, most significant predictor of an unmet need for a patient is the presence of an unmet need previously (McDowell et al., 2010). In a study of individuals with advanced cancer in NSW it was determined that most prominent unmet needs were in the psychological, information, and medical communication domains (Rainbird et al., 2009).

1.3.2 Unmet pain and physical needs.

In a review of needs for individuals with cancer Harrison et al. (2009) determined that physical needs were the most frequently reported for those in the palliative care stage with a range of 7-89%. Physical needs were followed by economic burden (13-60%) and issues with ADLs (1-52%). In a study of individuals with advanced cancer in NSW, it was found that physical needs were on among the most prominent with a moderate/high need for assistance with fatigue (40%), pain (28%) and feeling unwell (27%) (Rainbird et al., 2009). In a European study of individuals with advanced cancer presenting to emergency departments the most commonly stated needs were fatigue (86%), physical function (81%), pain (67%) and loss of appetite (59%) (Soelver, Oestergaard, Rydahl-Hansen, & Wagner, 2012).
1.3.3 Unmet psychosocial needs.

1.3.3.1 Unmet activities of daily living needs.

In a review conducted by Harrison et al. (2009) the most frequently cited domain of need, in the palliative stage of the disease, was Activities of Daily Living (ADLs) (J. Harrison, et al., 2009). The results of a number of studies have indicated that assistance with ADLs is among the highest unmet needs cited by individuals with advanced cancer (K. Soothill et al., 2001) (McDowell et al., 2010) (S. Aranda et al., 2005; A. Girgis, Boyes, Sanson-Fisher, & Burrows, 2000). Regrettably, even if these needs are present these are often overlooked by the treatment team. For example, Waller et al., found that despite 65.8% of patients reporting at least one functional problem, the oncologists’ notes often did not mention this issue (Waller, Girgis, Currow, & Lecathelinais, 2008).

1.3.3.2 Unmet information needs.

Rainbird et al. (2009) determined that information needs are the second most cited needs by individuals with advanced cancer, particularly those related to medical communication and illness information (e.g., ‘Getting information about factors which could influence the course of the cancer’ or ‘To be fully informed about your medical test results as soon as possible’). A review of research from 1980-2003 concerning information needs of individuals with cancer determined that the need for ‘information about treatment’ (38%) was most commonly cited information need across the entire cancer journey, including palliative care phase (Finney Rutten et al., 2005). In a study (Wong et al., 2002) of home palliative care, information needs related to the management of “…pain, fatigue, and home palliative care resources” were most commonly cited (Wong et al., 2002 p. 408). Reasons cited to explain the high prevalence of information needs despite having received information from health care professionals, include that the patients may have forgotten any information given.
to them or may have preferred to avoid information to “…maintain hope” (Rainbird et al., 2009).

1.3.3.3 Unmet psychological needs.

The most commonly cited need by patients in a study of individuals with cancer in NSW was in the psychological domain, namely concern about fear of the cancer spreading or reoccurrence (Waller, A, et al., 2010). Other Australian and international research with individuals with advanced cancer have corroborated that the majority of unmet needs were in the psychological domain namely the fear of a recurrence of the cancer (mainly referring to size of the tumour) and symptoms (S Aranda & Peerson, 2001; J Harrison et al., 2009; Lobb et al., 2009; McDowell et al., 2010; Morrison et al., 2011; K. Soothill et al., 2001).

Prevalence of psychological needs often exceed those of information needs – but together these two domains represent the majority of needs reported by patients with advanced cancer. In the Harrison et al. (2009) review it was determined that individuals with cancer experience a range of need for psychological support from 12-85%, with individuals diagnosed with advanced cancer reporting a range of need of 16-41%. Similarly, in a review article completed by Miovic and Block (2007) it was found that approximately half of advanced cancer patients met criteria for a psychiatric diagnosis (Miovic & Block, 2007). The most common diagnoses were adjustment disorder (11%–35%) and depression (5%–26%). Miovic and Block (2007) indicate that the patients may need pharmacological or psychological assistance in managing these symptoms. A recent review of the literature concerning the psychiatric morbidity of patients in palliative care with cancer determined that 16·5% met criteria for major depression and 9·6% for minor depression, and 9.8% for anxiety disorders and 15.4 % for adjustment disorders (Mitchell et al., 2011). This review also highlights the need for more routine and structured assessment of psychiatric morbidity (Mitchell et al.,
The interplay between the physical symptoms of cancer and psychological distress is also significant. It has been found the level of pain and the way this interferes with functioning increases distress (J. B. Brown, 1999; R. F. Brown, Butow, Dunn, & Tattersall, 2001). No association has been found between psychiatric morbidity and time until death (Cheung et al., 2009).

1.3.3.4 Unmet spiritual needs.

In a qualitative study conducted with individuals with advanced cancer in the last year of their life it was found that spiritual needs are linked to a need to find meaning in their illness, discovering peace, and determining what awaits them after they die (Grant et al., 2004). These findings were corroborated in a study by (Meraviglia, 2004) among individuals with lung cancer. Research indicates considerable variability between individual advanced cancer patients in regards to levels of spiritual need (Hampton et al., 2007). In a study of US cancer patients, 73% indicated that they had at least one spiritual need (Astrow, Wexler, Texeira, Kai He, & Sulmasy, 2007). Spiritual well-being has been found to be a mediating factor for level of distress for advanced cancer at end-of-life as those who consider that their spiritual needs are met report lower psychosocial stress (McClain, Rosenfeld, & Breitbart, 2003). In addition, almost one in five patients with advanced cancer have reported unmet needs in the spiritual domain (Astrow et al., 2007). In another study it was determined that almost three quarters (72%) of individuals with cancer felt that their spiritual needs were being met minimally or not at all by the medical system (Balboni et al., 2007).

1.3.3.5 Unmet financial needs.

In a review of studies on the financial hardship in late stage cancer, financial stress and strain was found in all studies (Hanratty, Holland, Jacoby, & Whitehead, 2007). In a study of a mixed group of Canadians with cancer, it was found that approximately 20% reported
financial burden. Approximately 16% of patients reported significant “out of pocket expenses” and approximately 4% reported these expenses were unmanageable (Longo, Fitch, Deber, & Williams, 2006). From a review of literature, the proportion of patients who had to spend most or all of their savings during their treatment and after was between 17% and 38% (Hanratty et al., 2007). In regards to a individuals with a cancer diagnosis, the results of a study of female breast cancer patients indicted that the financial costs of treatment can be substantial, even for those with insurance (Arozullah et al., 2004). Those patients of a working age who were forced to move from paid employment to sick benefits have been found to be hit harder than those who were not relying on paid employment such as retirees (Amir et al., 2011). For those with advanced cancer, despite a system being in place to cover medication costs in Australia, over half of families (with a member with advanced cancer) have reported that medication and treatment costs was an area of financial burden (Hanratty et al., 2007). It is noted however that purely from a financial perspective those patients who enter a palliative stage the burden is not significant as this stage tends to be fairly limited in duration (Longo et al., 2006).

Patients and their caregivers often find it difficult to access help around these financial strains (A. Girgis et al., 2006). Many patients do not consider the impact of cancer on their financial circumstances (Amir et al., 2011) and it is often family members or caregivers who have a greater understanding of financial difficulties than the patient (Mathews & Park, 2009). This lack of awareness can extend into the treatment phase as patients grapple with the treatment regime and fighting the disease (Amir et al., 2011). Patients have reported that they feel some stigma associated with claiming financial benefits, and there may be some embarrassment in expressing concerns about finances (Chapple, Ziebland, McPherson, & Summerton, 2004; Mathews & Park, 2009). In a qualitative study, lung cancer patients
refused to tell a tax tribunal that they had lung cancer, even though it would have meant their tax bill would have been waived, because they wanted to feel “normal” (Chapple et al., 2004). There was a recommendation that financial circumstances are assessed and reviewed by treating professionals in the spirit of providing more holistic care (Hanratty et al., 2007).

1.3.4 Caregiver unmet needs.

As stated previously, there is a greater recognition that caregivers have needs related to the care of the patient and their own well-being. In a study looking at the unmet needs of caregivers (K. Soothill et al., 2001) it was determined that caregivers have greater levels of unmet psychosocial needs than the patients (K. Soothill et al., 2001). In an Australian study of gynaecological cancer survivors and their partners, partners reported an average of 3.25 needs and almost half had at least one unmet need (Stafford & Judd, 2010). In a UK study, about one third of caregivers of multiple myeloma patients reported unmet supportive care needs (Molassiotis et al., 2011). Researchers in an American study determined that for between 38 and 61% of caregivers their medical, financial, or daily activity needs were unmet 2 months post diagnosis (Kim, Kashy, Spillers, & Evans, 2010). The most commonly cited unmet needs for cancer caregivers were a need for information (Molassiotis et al., 2011; Stafford & Judd, 2010) and psychological support. Higher levels of unmet needs were experienced by partners and caregivers of individuals diagnosed with a brain tumour (Janda et al., 2008) or those in the palliative care phase (Buscemi, Font, & Viladrich, 2010)

1.3.4.1 Caregiver information unmet needs.

Adams et al. (2009) determined that caregivers needed more information related to treatment and prognosis and impact on family (Adams et al., 2009). Similarly, in a review of the impact of unmet need on individuals with breast cancer (mixed groups), the greatest area of unmet need for caregivers was informational need regarding prognosis (Schmid-Buchi,
Halfens, Dassen, & van den Borne, 2008). Conversely, in a study of caregivers of head and neck cancer patients it was determined that 40% perceived that their practical and informational needs were met (Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010). Informational needs are difficult to address, because they are emergent and often do not occur in the middle of a consultation, but rather at home and cannot be addressed and thus met (Schubart et al., 2008).

1.3.4.2 Caregiver psychological support.

In addition to these unmet information needs, like with the patients, caregivers of individuals with cancer identified that a fear of recurrence of the illness was not often addressed (Molassiotis et al., 2011; K. Soothill et al., 2001). Indeed, Park (2010) determined that a quarter of caregivers of individuals with cancer required psychosocial assistance and a further 20% of these caregivers stated that this need was unmet (Park et al., 2010). The need for psychosocial intervention around emotion distress was the most prevalent unmet need for caregivers for many years post treatment (Kim et al., 2010). In an Australian (Molassiotis, et al., 2011) and a UK (Stafford & Judd, 2010) study it was found that one of the most frequently identified unmet needs for caregivers was better access to hospital parking (Molassiotis et al., 2011; Stafford & Judd, 2010).

1.3.5 Variables associated with reporting unmet needs.

1.3.5.1 Patients socioeconomic variables.

In Harrison’s et al. (2009) review those patients found to have higher levels of unmet needs were those living in more rural locations. Similar findings exist for Australian patients regarding those from remote or rural locations (Beesley et al., 2008). Additional predictors of higher rates of unmet needs in an Australian haematological patient population were younger
age and those who were not married (Lobb et al., 2009). In the same study, higher rates of unmet need were significantly related to inability to work (Lobb et al., 2009). In other studies, it was identified that those who have fewer social connections (K. Soothill et al., 2001), are younger (K. Soothill et al., 2001), are more socio-economically disadvantaged and were more likely to have higher level of unmet needs.

1.3.5.2 Illness variables.

Those patients whose cancer was more advanced and had poorer health status more likely to have a higher degree of unmet need (J Harrison et al., 2009). Higher rates of unmet need were also found in those patients who were not in remission and those who had undergone recent treatment (Beesley et al., 2008). Emotional unmet need was found to be a predictor of a large group of other unmet needs, predicted a greater number of unmet needs and was a predictor of QoL scores in an elderly population of veterans (Hwang et al., 2004).

1.3.5.3 Caregiver variables.

As with the needs of caregivers, the rate of unmet need is compounded by a number of variables. It was found that those caregivers who expressed greater dissatisfaction around their needs were those caregivers who did not identify as the partner of the patient, those who had additional caring responsibilities and those who reported poor social contacts (K. Soothill et al., 2001). Other research has found that there are some groups of caregivers that have higher unmet needs and associated burden including wives compared with husbands, those with smaller social groups, those with higher levels of anxiety, with higher levels of anger, those with higher caregiver responsibilities and those caring for an extended period and younger caregivers (A. Girgis et al., 2006). High levels of unmet informational needs were found for those at home care givers compared with those hospital based caregivers (Bee,
There is not a direct correlation between the characteristics of patients and their illness and the ability of the caregiver to cope and manage, and it is for this reason that needs assessment is essential for each caregiver (Deekin et al., 2003).

1.4 Impact of Unmet Needs

The basis of palliative care is that the patients are experiencing some unmet needs around their diagnosis of advanced cancer and this is leading to an increase in distress and a decrease in QoL (A. Girgis et al., 2006). At times, it may even be the late or inadequate referral to SPCS in response to an unmet need that can severely impact distress and quality of life (A. Girgis et al., 2006).

1.4.1 Impact of unmet needs on patients.

The impact of having even just one unmet need can be significant for patients. Having a significant need go unattended leads to increased suffering and distress (A. Girgis et al., 2006; Tsuchiya, 2009). This increase in suffering and distress is in itself a consequence, however this may also lead to further health consequences as the body attempts to cope with this increased stress and this also has an impact on family and caregivers of patients (J Harrison et al., 2009). Cancer patients with moderate to high levels of unmet need have been found to have higher levels of anxiety and depression than those with lower level of need (Newell, Sanson-Fisher, Girgis, & Ackland, 1999). There is evidence that there may be a cyclical relationship between high levels of unmet need around physical symptoms and psychological distress. If physical symptoms are left untreated they can cause an increase in psychological distress, which in turn may impact on perceived levels of physical symptoms (A. Girgis et al., 2006; Vachon, Kristjanson, & Higginson, 1995). For those patients with advanced cancer, despite there being more certainty about prognosis, if their information
needs about other factors such as the future of their family or quality of life are not met this can lead to increased anxiety (S. Aranda et al., 2005; Fujisawa et al., 2010). The risk of severe psychological distress for cancer patients with two to three unmet needs is three times that of those with one or no unmet needs (Fujisawa et al., 2010). Thus, having unmet needs places increase stress and tension, particularly for individuals with advanced cancer who already face an uphill battle (Barg et al., 2007).

Research has found that unmet needs may be an indicator for levels of QoL in individuals with cancer, as such there is an inverse relationship between the number of unmet needs and QoL (J. Harrison, 2010). In a study of advanced breast cancer patients, a significant, negative (range 0.42-0.69) correlation was found between the number of unmet needs and psychological distress and QoL (Uchida et al., 2011). It was hypothesised that if interventions were implemented to reduce the level of unmet needs, there would be improvements in psychological distress and QoL for these patients (Uchida et al., 2011).

1.4.2 Impact of unmet needs on caregivers.

Impact of unmet needs on caregivers can be significant. For example, a caregiver’s psychological wellbeing and distress is closely linked to the amount of information they are able to access about the illness and also the quality of their relationship with the patient (Bee et al., 2008). Having access to information reduces anxiety and fear for the caregiver (Bee et al., 2008). If their information needs remain unmet, this can lead to a “trial and error” approach to home care (Bee et al., 2008) and, in turn, increase stress as caregivers attempt to engage in illness management tasks for which they have not received training (Bee et al., 2008). A greater number of unmet needs for caregivers have been found to be associated with significantly higher levels of both anxiety and depression and poorer mental health (Kim et
al., 2010; Stafford & Judd, 2010). In particular, this can be caused by different unmet needs depending on the phase of survivorship for the patient (Kim et al., 2010). At the early survivorship phase, poorer mental health is related to unmet needs for the patient’s medical care and their own daily activity, and at the mid to long term phase unmet need around financial concerns (Kim et al., 2010). For patients with advanced cancer, it has been found that the quality of end-of-life care and caregivers’ own workplace performance can be negatively affected by higher levels of unmet need (Park et al., 2010). Whilst high levels of unmet need have a negative impact on a number of areas of functioning, having all needs met is not associated with higher levels of QoL (Ross et al., 2010).

That the unmet needs of caregivers can be greater than for patients reflects the lack of attention paid to this aspect of cancer care (K. Soothill et al., 2001). Whilst managing the caregivers’ level of psychosocial morbidity is important, this is also mediated by the level of psychosocial morbidity in the patient, so that higher distress in a patient can lead to higher distress in the caregiver (A. Girgis et al., 2006). Higher unmet need for patients will have a negative impact on families (Sharpe, Butow, Smith, McConnell, & Clarke, 2005). There is a strong relationship between the discrepancy of unmet needs reported by the patient and caregivers for patient needs and reported caregiver burden (Sharpe et al., 2005). Soothill et al. (2001) when investigating patient unmet needs found that good support from family was extremely important (87-91%) and only 1% indicated that this was an unmet need. This may give some indication of the hard work being done by caregivers and an insight into the burden of expectation from patients (K. Soothill et al., 2001). Of course caregivers by nature tend to be “altruistic” and will often turn down offers of assistance despite it being something that would ‘meet their need’ (K. Soothill et al., 2001). It has been suggested that caregivers feel that turning down support for themselves will lead to greater amounts of support being
available for the patient (K. Soothill et al., 2001). The stage of illness has not been shown to be related to level of unmet need for caregivers (Lambert, Harrison, Smith, Bonevski, et al., 2012).

1.5 Assessing Unmet Needs

It is clear that the extent of unmet needs across patients with advanced cancer is significant. What is perhaps less clear is what benefits are seen through a referral to a SPCS and which methods enables for the most accurate and timely identification and assessment of these needs to facilitate referral (Hwang et al., 2004). Evidence has shown that involvement with a SPCS is linked with a significant improvement in physical and psychosocial symptoms (A. Girgis et al., 2006). Earlier referral to SPCS often means the majority of care can be achieved at home, which can be more cost-effective, and readmission rates have been found to be lower (A. Girgis et al., 2006). Involvement with SPCS teams has also been linked with improved outcomes for anxiety, QoL, wellbeing and spiritual wellbeing (A. Girgis et al., 2006). Significant outcomes have been found for caregivers when the patient and caregiver are involved with a SPCS, including reporting fewer unmet needs (A. Girgis et al., 2006). Caregivers are also able to adjust to the passing of the patient with lower levels of anxiety and depression and increased social interaction, if they were involved with a SPCS (A. Girgis et al., 2006). Unfortunately between 40-60% of patients, as reported by family members, did not access SPCS before they died (A. Girgis et al., 2006).

In Australia palliative care will in the main be delivered by primary health care providers such as the patient’s general practitioner (GP) or the treating oncologist. However, 90% of advanced cancer patients will require an assessment by SPCS, 70% ongoing consultation by SPCS and 30% direct contact (Palliative Care Australia, 2005a). In the UK there are no
standards for referral to SPCS with any health provider the patient consults with able to make the referral (Bestall et al., 2004); however in the US and Australia ultimately the treating oncologist or GP will lead the referral to SPCS to address unmet needs (Friedman, Harwood, & Shields, 2002). In a US study it was found that 79% of referrals to SPCS were made by the treating physician when compared with the patient, caregivers and other service providers (Sanders, Burkett, Dickinson, & Tournier, 2004). These figures indicate that primary health care providers such as the treating oncologist play a large role in the assessment of unmet needs and possible referrals to SPCS.

The assessment of unmet needs can be difficult process for primary health care providers, and a number of barriers can impact on this process, particularly the assessment of unmet psychosocial needs. Medical staff are trained to focus care on the treatment of the illness and often wait for patients to identify needs without formally questioning them (Osse et al., 2004). Australian research has found that there is a strong consideration of physical needs by oncologists when referring to SPCS when compared with psychosocial needs (Johnson, Girgis, Paul, & Currow, 2008). There exist a number of barriers to the assessment of unmet needs including the lack of formal instruments, but perhaps more importantly including assessment as a routine part of care and increasing training around palliative care and recognising the wide range needs, particularly psychosocial concerns, which exist for patients (Johnson et al., 2008).

1.5.1 Routine unmet needs assessment.

Research from the UK, noted that health care providers tended to elicit unmet needs from patients using counselling and questioning rather than using formal tools and questionnaires (Rogers, Clifford, & Lowe, 2011). This would make it more difficult for the treating team to
adhere to guidelines regarding the assessment of needs, without a formal template as offered in formal tools (Rogers et al., 2011). In addition there is a perception that assessing unmet needs requires more time or long personal interviews (Bonevski et al., 2000). Formalising this process using tools can make this process perceptually easier for oncologists and other health care providers (Bonevski et al., 2000).

1.5.2 Recognising unmet needs.

In general, medical oncologists receive little in the way of training in the assessment of psychiatric disorders, despite being confronted with a population of patient who exhibits symptoms of depression more commonly than the general population (Morgans & Schapira, 2011). Because of the potentially life threatening aspect of the illness, many oncologists form the opinion that psychological distress is a normal part of the diagnosis of cancer, and as a consequence might have difficulty recognising negative emotions when they are expressed by patients, unless expressed intensely, beyond what they would consider ‘normal’ (Kennifer et al., 2009).

Often there is an issue with patients taking the initiative to ask for needs to be met, because of various psychological processes, which may include a depressed mood, denial, fear of intervention and loss of independence, not wanting to be seen as someone who complains or a lack of faith in medical staff (Osse et al., 2004). Gender has been found to play a part in their willingness and ability to talk about their problems and concerns. Female patients tend to ask more questions and receive more information than their male counterparts. Similar results have been reported for patients with relatively high levels of education compared with those who are less well educated (Detmar, Muller, Wever, Schornagal, & Aaronson, 2001). Funch (1988) investigating the symptom-reporting behaviour of colorectal cancer patients, found that 54% of experienced symptoms were spontaneously reported, and that chronic,
nonspecific, and mild symptoms were less likely to be discussed than more acute, concrete, and severe symptoms, which suggests that psychosocial issues that may be perceived as secondary concerns are not reported if physical issues are more pressing (Detmar et al., 2001; Funch, 1988).

1.5.3 Approaches to unmet needs assessment.

The aim of unmet needs assessment is then to guide allocation of resources to those patients and caregivers that identify unmet needs (Boyes et al., 2009; K. Soothill et al., 2001). In considering the shift towards the routine assessment of unmet needs in cancer care, health care professionals must negotiate and assess the unclear concept of ‘need’, whether it is ‘unmet’ and manage the outcome of this assessment by rationalizing a referral in an environment of stretched health resources (Parry-Jones & Soulsby, 2001).

To date, self-report has been the preferred approach to ascertain patients’ and caregivers’ needs. In saying this, patients have been found to underestimate their level of unmet needs and so there may be some cause to question the use of self-report tools (Sharpe et al., 2005). Another issue surrounding needs assessment includes the length of the tool, which can create burden for both the patient and caregiver (Deekin et al., 2003). However, because of the burden of any assessment of those in the advanced stage of illness, it can be important to consider what additional information can also be collected so as to capture as much information as possible at one time point (Osse et al., 2004). In addition to the use of self-report measures, needs assessment may be conducted by the oncologist during consultations or a structured interview. In this way the patient and caregiver could be walked through the process by the oncologist and all possible areas of need acknowledged and assessed.
1.5.4 Impact of unmet needs assessment on length of consultation.

Given the constant struggle with shrinking health resources it is vital to understand the impact of unmet needs assessment on the length of consultations. In a systematic review conducted by Harrington et al. (2004) it was found that, of seven studies of interventions to increase doctor patient communication, five found that there was no increase in consultation length. Conversely the Harrington et al. (2004) review presented one study, which found a relatively small increase and one that found a large increase in consultation time (Harrington, Noble, & Newman, 2004). In regards to those studies that are cancer specific it has been found that consultations with oncologists who are more proactive regarding patient participation are actually significantly shorter (R. F. Brown et al., 2001). It has been shown that there is no significant increase in the length of consultations after oncologists have completed training in the use of empathy and then used this training within consultations (Bonvicini et al., 2009). Whilst the time required to conduct an assessment may be seen as a barrier to health professionals, a review completed by Kinnersley et al (2008) assessing interventions completed in oncology consultations designed to improve the flow of information to patients found that, of 17 studies included, only three showed any significant increase in consultation time. The evidence for unmet needs assessment increasing the length of consultation is mixed, as such examination of this issue will be exploratory.

1.5.5 The Palliative Care Needs Assessment Tool (PC-NAT).

A novel tool (Appendix A) recently developed by Girgis et al., (2008) The Palliative Care Needs Assessment Tool (PC-NAT) (Waller et al., 2008) is administered by health care providers and aims to assess unmet needs of both patients and caregivers. The PC-NAT was developed to assist those working in palliative care to identify the psychosocial needs of
individual patients and caregivers to allow for early intervention in the case where these
needs, in particular psychosocial needs, are unmet (Waller et al., 2008).

The strengths of the PC-NAT include that it was designed to be used by any health care
provider caring for someone with advanced cancer. The PC-NAT was developed through the
involvement of 66 palliative care experts and stakeholders on the production of guidelines
surrounding palliative and advanced cancer needs for patients and caregivers. In this way, the
PC-NAT has face and content validity and a study into the use of the PC-NAT has also
shown excellent inter-rater reliability (Waller et al., 2008). The PC-NAT has also shown
strong correlations with other measures associated with quality of life and functioning,
illustrating concurrent validity (Waller, Girgis, et al., 2010). It is the only cancer specific
measure created for use with palliative care patients.

The limitations of using the PC-NAT are that some of the individual items contained in the
assessment have lower inter-rater reliability. These items relate to care-giver distress,
physical concerns and information concerns (Waller, Girgis, et al., 2010). In addition some
health professionals involved in the validation of the measure expressed concern about the
length of time the measure takes to complete and what impact this may have on consultation
times (Waller, Girgis, et al., 2010). This will be explored within this study.

The one-page PC-NAT (Appendix A) includes the following:
1. Section 1: three items – a) absence of a caregiver; b) a patient or caregiver request for
   SPCS referral and c) the health professional’s need for assistance in managing care, which
   if any is endorsed suggests fast track review by a Specialist Palliative Care Service
   (SPCS). The three items are answered “yes” or “no” and the appropriate answered ticked.
2. Section 2: seven items to assess the patient’s well-being, including physical, changes in
   functional status, psychological, information, spiritual/existential, health
beliefs/cultural/social and financial/legal domains. Each of the seven patient areas of well-being were assessed according to the level of concern (‘none’, ‘some’, ‘significant’) they were causing.

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. Each of these items were assessed according to the level of concern (‘none’, ‘some’, ‘significant’) they were causing.

4. Section 4: two items to assess the caregiver’s wellbeing, including physical and psychological issues and bereavement grief. Each of the caregiver/family well-being items were assessed according to the level of concern (‘none’, ‘some’, ‘significant’) they were causing.

5. Section 5: one item to assess whether the health professional thought the patient needed assessment by a SPCS. This required the consultant to indicate which SPCS they believed is required, what level of priority would be assigned to the referral (non-urgent [next available appointment] to urgent [within 24hrs]), and whether the referral has been discussed with the patient and whether they have given permission.

Prompt questions for each item were included on the back page, providing standard language to guide the use of the PC-NAT. 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 to either address identified concerns directly (either personally or through other members of their team) or 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.

1.6 Objectives

The rate of both physical and psychosocial needs for patients with advanced cancer in NSW is high. The needs of each patient and their caregivers are also different and so individual assessment of needs is appropriate. Self-report measures can be both confusing and taxing to patients and carers. Having a tool that can be walked through with the health professional creates an opportunity to reduce confusion and to collect as much information as possible at one time point.

Whilst physical needs are readily discussed in consultations with health professionals, psychosocial needs are often overlooked by health care providers and patients, despite being reported as significantly unmet by patients. It is vital that the impact of prompting health care providers to ask questions about these aspects of care, in addition to any potential barriers, for both doctors, patients and caregivers, are explored. In addition there is a need for further exploration of the potential consequences for resource allocation in completing routine assessment, given the often stretched budgets and long waiting lists of public outpatient services. This aims of this study are to:

1. Examine the approaches used by health professionals to complete the PC-NAT in the consultation setting.
2. Explore the potential of the PC-NAT to facilitate discussion of psychosocial issues.
3. Explore whether use of the PC-NAT by clinicians during consultations with advanced cancer patients alters the length of these consultations.
Abstract

**Background:** People with advanced cancer have high levels of unmet needs and require timely assessment and response to the unmet needs component of their overall care. This study explored the modes of administration of a needs assessment tool in oncology consultations, including whether its administration altered the nature and quality of the communication and length of consultations.

**Methods:** A qualitative analysis was undertaken on audiotaped, outpatient consultations with 20 individuals with advanced cancer and their caregivers, who participated in an interrupted time series study of the impact of systematic utilisation of the Palliative Care Needs Guidelines and Palliative Care Needs Assessment Tool (PC-NAT) on the health outcomes and service utilisation. Forty eight consultations were audiotaped: 13 were “baseline” and 35 included completion of the PC-NAT.

**Results:** The mode of administration of the PC-NAT was sub-optimal, as it was typically administered verbatim and using jargon and completed as an afterthought with little rationale. In all transcripts, codes pertaining to psychosocial issues were used less often compared to those representing medical/treatment issues, an indication that few psychosocial issues were discussed across consultations. Moreover, often psychosocial concerns were assigned codes showing a lower level of empathy than medical concerns. Administration of the PC-NAT did not alter consultation time significantly.
Conclusions: Physical needs dominate oncology consultations. Staff training to enhance understanding and needs assessment as part of routine care is warranted to facilitate discussion of psychosocial issues.
Introduction

Although the five year survival rate for cancer is now at 61%, a significant portion of individuals are still diagnosed with advanced stage cancer (AIHW & AACR, 2007) where the focus of care is no longer on treatment, but on improving quality of life (QOL) (often referred to as palliative care [PC]). Given the limited resources with which to provide PC services (World Health Organisation, 2007), and variations in the level of need for PC for individuals with a terminal illness (Palliative Care Australia, 2005b), allocation of PC resources based on unmet needs assessment is a priority (A. Girgis et al., 2006). Whereas needs assessment identifies required actions or resources, ‘unmet needs assessment’ identifies where there is a gap in support around these needs.

For people with advanced cancer, ongoing physical symptoms can pose a significant burden (Higginson & Costantini, 2008) and can vary depending on type and progression of the disease (J Harrison et al., 2009). Pain is commonly reported in the PC population, as are weakness (63-90%), dyspnoea (35-75%), constipation (23-48%) and gastro-intestinal disturbances (17-62%) (Lidstone et al., 2003). Psychosocial concerns predominantly relate to Activities of Daily Living (ADLs), information, psychological, spiritual and financial issues. A recent review reported that individuals with advanced cancer in PC are amongst those who experience the most unmet needs (J Harrison et al., 2009), including ADLs (1-52%), psychological (16-41%), information (39%), psychosocial (7-44%), physical (7-89%), spiritual (14-33%), communication (34-36%) and economic (13-60%) issues. Unmet needs of caregivers of individuals with advanced cancer closely mirror those of patients, including informational support and assistance with financial burden, psychological difficulties and caring. A recent review by Lambert et al. found that caregivers of patients in PC are more at risk of reporting unmet needs than those of cancer survivors (Lambert, Harrison, Smith,
Bonevski, et al., 2012). The most commonly cited unmet needs for caregivers are for information (Molassiotis et al., 2011; Stafford & Judd, 2010) and psychological support (Lambert, Harrison, Smith, Bonevski, et al., 2012), with caregivers often having greater unmet psychosocial needs than the patients themselves (K. Soothill et al., 2001).

It is recognised that the late or inadequate referral to specialist PC services in response to a patients’ or caregivers’ unmet needs can severely impact distress and QOL (A. Girgis et al., 2006; Tsuchiya, 2009). Furthermore negative impacts on caregivers of patients can be significant (J Harrison et al., 2009), with a caregiver’s psychological wellbeing closely linked to the amount of information they are able to access about the illness and also the quality of the relationship (Bee et al., 2008). In Australia, referral to a specialist PC to address unmet needs is initiated by the treating oncologist or GP (Friedman et al., 2002). However, barriers to effective assessment of unmet needs, particularly psychosocial needs (Johnson et al., 2008), include a lack of a formal structure for undertaking assessments (Bonevski et al., 2000; Rogers et al., 2011) and the ability of professionals to recognise, in particular, psychosocial needs (Ryan et al., 2005). The Palliative Care Needs Assessment Tool (PC-NAT) (Waller et al., 2008) was developed for use by health care professionals involved in the care of people with advanced cancer. This psychometrically sound tool (Waller, Girgis, et al., 2010) facilitates assessment of unmet patient and caregiver needs, through early identification of needs and referral to address these needs (A Waller et al., 2012; A. Waller et al., 2012).

This study aimed to 1) examine the approaches used by oncologists to administer the PC-NAT in the consultation setting, 2) explore the potential of the PC-NAT to facilitate discussion of psychosocial issues, the content of discussions and the level of empathy used by oncologists, and 3) determine whether use of the PC-NAT alters the length of these
consultations.

Method

This (Extended Method Appendix G) study analysed audio-tapes of consultations collected as part of an interrupted time series study (referred to herein as main study) of the impact of systematic utilisation of the Palliative Care Needs Guidelines and PC-NAT on individuals’ with advanced cancer and their caregivers’ health outcomes and service utilisation (A. Girgis et al., 2008; Waller, A, et al., 2010; Waller et al., 2008) (See Figure 1).

Participants

As detailed elsewhere (Waller, A, et al., 2010), the main study included 11 medical oncologists and hematologists, whose patients were eligible if they were: diagnosed with advanced cancer, 18 years or older, had sufficient understanding of English, had emotionally stability and cognitive capacity. The inclusion criteria for caregivers were: nominated by the patient as the primary caregiver and sufficient understanding of English. Of the 45 patients potentially eligible for the audiotaping sub-study, eight were excluded by their treating oncologist. The remaining 37 patients were approached by the research nurse at the time of a scheduled consultation, and 20 (Table 1) consented to having their consultations audiotaped on up to four occasions.
Clinicians at one participating hospital approached to give consent for consultations with their patients and caregivers to be audio-taped (n=45)

Research nurse provided patient with verbal and written information about audio taping, in addition to the main study, and asked for consent (n=37)

Oncologist informed that the next consultation will be audio taped by research nurse

Research nurse contacted patient and asked them when their next appointment was scheduled

Consultation audio taped and analysed (n=20)

Patient withdrew from main study - n=2, judged by clinician to be too ill - n=5, or deceased - n=1

Patient declined, not interested - (n=17)

Figure 1. Participant flow from the main study into the sub-study.
<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>% (number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>30 (n=6)</td>
</tr>
<tr>
<td>Bowel</td>
<td>15 (n=3)</td>
</tr>
<tr>
<td>Myeloma</td>
<td>15 (n=3)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>10 (n=2)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>5 (n=1)</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>5 (n=1)</td>
</tr>
<tr>
<td>Gynaecological</td>
<td>5 (n=1)</td>
</tr>
<tr>
<td>Prostate</td>
<td>5 (n=1)</td>
</tr>
<tr>
<td>Stomach</td>
<td>5 (n=1)</td>
</tr>
<tr>
<td>Bladder</td>
<td>5 (n=1)</td>
</tr>
</tbody>
</table>

**Sex(n); Mean Age, years**

- Female (10) 70 (Age Range 47-89)
- Male (10) 64 (Age Range 44-72)

**Mean age, years** 67 (Age Range 44-89)
**Procedures**

The procedures for the sub-study were embedded within those for the main one for one of the three participating oncology treatment centres. These study participants and their treating oncologists were approached by a research nurse to obtain additional consent to audio-tape up to four consultations.

**Data Collection**

For all patients consenting to the audio-taping of their consultations, the research team aimed to audio-tape one baseline consultation, which did not involve completion of the PC-NAT, and then one to three post-intervention consultations, which were scheduled to have the PC-NAT completed. The research nurse attended the clinic for each consenting participant, started the tape at the beginning of the consultation, left the consultation room, and returned to stop the tape when the patient had left. All tapes were collected by the research nurse and later transcribed verbatim by an experienced member of the research centre.

**Data analysis**

Objectives 1 and 2 were addressed through qualitative analysis of transcribed audio-recordings of the consultation. A ‘thematic survey’ method (Sandelowski & Barroso, 2003) was applied, where utterances related to the research objectives were noted and coded to identify patterns or themes. For objective 1, coding focused on the 1) timing of PC-NAT administration, 2) integration of the PC-NAT in the consultation, and 3) language used when administering the tool. For objective 2, transcripts were coded to identify 1) the types of concerns raised by patients, caregivers and oncologists (i.e., medical versus psychosocial concerns) and 2) the quality of oncologists’ responses. After analysis of six transcripts, it was noted that ‘quality’ of discussion reflected the level of empathy used by the oncologist and additional coding focused on identifying the differential levels of empathy displayed in
response to medical versus psychosocial concerns (Beckman, Markakis, Suchman, & Frankel, 1994; Buylund & Makoul, 2005). The empathy level coded for was based on the work of Buylund and Makoul (2005) and included the seven categories shown in Figure 2. Transcripts were independently coded by two members of the research team. Table 3 summarises strategies used to ensure methodological rigour.

For objective 3, a linear mixed model was completed to assess the difference in means between each time point which included the PC-NAT and those which did not.

![Figure 2. The range of empathic responses coded for in qualitative analysis (Buylund & Makoul, 2005)]
Results

Participants

Of the 20 patients, 14 consulted the same oncologist during all of their audiotaped consultations and 10 had a caregiver present in the consultation. As indicated in Table 2, of the 48 audiotaped consultations, 13 were baseline and 35 included the PC-NAT. Six participants had no baseline recording, but had at least one PC-NAT consultation; and 14 had a baseline consultation, with 11 having at least one PC-NAT consultation (Extended Results Appendix H).

Objective 1 – Approaches used by oncologists to complete the PC-NAT

Oncologists most often administered the PC-NAT in the final third of the consultation, resulting in rushed administration of the tool in a manner that suggested it was an afterthought, rather than an integral part of the consultation.

Oncologist: “Now the other thing which you’re on is this PC-NAT study, which we quickly need to run through.” [10171 Post]

On occasion when the PC-NAT was discussed with patients and caregivers, little preamble was provided regarding the purpose or significance of the PC-NAT. This seemed to constrain the extent to which the PC-NAT was valued and considered an integral part of the consultation.

Oncologist: “Now, I’ve got to quiz you, because of this thing [PC-NAT] that we’re taping. OK?” [10107 Post]
Table 2

*Number of Baseline and/or Post-Intervention Consultations Audio-Taped for Each Participant % (n)*

<table>
<thead>
<tr>
<th>Number and types of consultations audio-taped</th>
<th>% (n) of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline only</td>
<td>15 (n=3)</td>
</tr>
<tr>
<td>Baseline + 1 Post-intervention</td>
<td>15 (n=3)</td>
</tr>
<tr>
<td>Baseline + 2 Post-interventions</td>
<td>30 (n=6)</td>
</tr>
<tr>
<td>Baseline + 3 Post-interventions</td>
<td>10 (n=2)</td>
</tr>
<tr>
<td>No Baseline + 1 Post-intervention</td>
<td>15 (n=3)</td>
</tr>
<tr>
<td>No Baseline + 2 Post-interventions</td>
<td>5 (n=1)</td>
</tr>
<tr>
<td>No Baseline + 3 Post-interventions</td>
<td>5 (n=1)</td>
</tr>
<tr>
<td>No Baseline + 4 Post-interventions</td>
<td>5 (n=1)</td>
</tr>
</tbody>
</table>

*Baseline consultations were those recorded initially without the PC-NAT. Post-intervention consultations were those that included the administration of the PC-NAT.
<table>
<thead>
<tr>
<th>Qualitative Rigour Criterion</th>
<th>Applied Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td>Audio recording (Rubin &amp; Rubin, 2005) - A record of how the transcripts were created from the audio files has been maintained. Transcripts were written verbatim from audio files</td>
</tr>
<tr>
<td></td>
<td>Thematic log (Rubin &amp; Rubin, 2005) - A record was created of how the code book was developed and how it evolved over time with subsequent iterations</td>
</tr>
<tr>
<td></td>
<td>Transcript (Rubin &amp; Rubin, 2005) - Segments of participant quotes are included in the report</td>
</tr>
<tr>
<td></td>
<td>Peer debriefing (Streubert Speziale &amp; Carpenter, 2003) – Approaches and findings were discussed monthly between research team members throughout the duration of this study</td>
</tr>
<tr>
<td>Transferability</td>
<td>Predetermined research questions (Reige, 2003) - Research objectives/questions established prior to research</td>
</tr>
<tr>
<td></td>
<td>Cross case analysis (Reige, 2003) - Analysis was performed on multiple cases and participants (oncologists, patients and caregivers)</td>
</tr>
<tr>
<td></td>
<td>Specific coding procedures (Reige, 2003) - Code book formed through iterative analysis, and direct quotes utilised</td>
</tr>
<tr>
<td></td>
<td>Simultaneous literature review (Reige, 2003)</td>
</tr>
<tr>
<td>Dependability and</td>
<td>Field journal/Auditing (Reige, 2003) - Audit trail kept including iterations of codebooks and initial hand coding</td>
</tr>
<tr>
<td>Confirmability</td>
<td></td>
</tr>
</tbody>
</table>
Most often, oncologists administered the tool by reading each prompt on the PC-NAT verbatim, rather than tailoring the needs assessment to match patients’ and caregivers’ situation.

**Objective 2– Potential of the PC-NAT to facilitate discussion of psychosocial issues**

**Content**

Across the 48 transcripts analysed, the majority of interactions related to medical/treatment issues, with little to no discussion of psychosocial concerns (regardless of whether the PC-NAT was used or not). The oncologist generally began by asking an open-ended question regarding well-being, which was most often interpreted and responded to by patients as concerning physical health.

Oncologist: “How are you?”

Patient: “Oh, not too bad. I had a bit of a rough trot [difficult time] the last fortnight. Every time I eat, about 3 hours later I end up with bad pains in the stomach and I’d end up in care [emergency department] and it didn’t matter what I ate.” [10053 Baseline]

Similarly, the majority of interactions between the oncologists and the caregivers also related to medical and treatment issues.

Despite no discernible difference in codes pertaining to discussion about psychosocial issues from baseline to PC-NAT consultations, the overall number of concerns (physical and psychosocial) coded for seemed to increase as time passed. For instance, it was typical to only code for 2-3 issues at baseline, whereas in PC-NAT consultations up to 10 concerns could be coded for. This pattern was also evident for caregivers. For the six patients who
consulted with the same oncologist throughout, more codes pertaining to psychosocial concerns were being used with time.

**Quality**

None of the oncologist responses reached the highest level of empathy of ‘sharing experiences’. The highest level of empathy in response to medical and psychosocial concerns was ‘confirmation’; and the most frequent level of empathy coded for was ‘pursuit’ (Figure 1), (i.e., oncologists requesting further information, answering a question).

However, it was noted that the code ‘dismissed’ seemed to be more commonly applied to psychosocial concerns than medical concern.

Patient: “12 months, yeah [time since finishing work]. I do not know, it’s just boring”

Oncologist: “OK, do you want to take your shirt off?”

Patient: “I tell you what, this stuff, [Jesus] Christ [expression of surprise], it’s given me some body hair!” [10053 Post 3]

**Objective 3: Length of Consultation**

There was no significant difference in the mean length of PC-NAT consultations (18.1 minutes, range= 3.5 to 53.51) and baseline consultations (19.5 minutes, range= 9.5 to 24.1) (F[4, 34.5] = 0.49, p = .74). The within subjects correlation r = 0.15 indicated no correlation between time points for each patient, so there was no effect of patient or caregiver being likely to have “long” or “short” consultations.
Discussion

Identification of psychosocial needs is a cornerstone of routine cancer care (Holland, Watson, & Dunn, 2011). Four findings from this study are notable: 1) the mode of administration of the needs assessment tool was not optimal for the identification and discussion of psychosocial concerns, as the PC-NAT was typically administered verbatim and using jargon and completed as an afterthought, 2) in all transcripts, codes pertaining to psychosocial issues were applied less often compared to those representing medical/treatment issues, an indication that few psychosocial issues were discussed across consultations, 3) whilst overall level of empathy coded for was similar across psychosocial and medical/treatment issues, often psychosocial issues were assigned codes showing a lower level of empathy than medical concerns, and 4) there was no significant increase in the length of consultation when the PC-NAT was administered. Each of these findings are discussed in turn.

Use of Jargon during Administration of the PC-NAT – Review of transcripts revealed PC-NAT need items and prompts intended for health care providers were read verbatim to patients and these included jargon. It is well-documented that jargon creates a barrier in communication between the oncologist and patients, particularly when discussing complex medical results or procedures (Deuster, Christopher, Donovan, & Farrell, 2000; Sevinc, Buyukberber, & Camci, 2005), which can (West & Baile, 2010) lead to “noncompliance, frustration, dissatisfaction… unrealistic expectations of treatment efficacy… may adopt an overly optimistic picture of the impact of therapy… may undermine shared decision making” (West & Baile, 2010 p. 217). Similar to a study by Ford (Ford, Fallowfield, & Lewis, 1996), it was noted in the present study that the use of jargon seemed lead to oncologist-led, one way, hurried communication and limit patients’ and caregivers’ responses. Thus, findings from this study suggest that health care provider administered tools for the assessment of
psychosocial needs should avoid jargon altogether as to discourage its use by oncologists.

Whilst the use of jargon might have adversely influenced the extent to which psychosocial issues were explored, it should be noted that the results of the larger interrupted time series study indicated that the systematic use of the PC-NAT was associated with improvements in patient-reported unmet needs and a slowing of the deterioration of QOL (A Waller et al., 2012; A. Waller et al., 2012). This suggests significant potential for this tool to facilitate detection and provision of psychosocial care, if administered more systematically and as an integral part of the consultation.

Few psychosocial issues were discussed across consultations- This finding is consistent with a number of studies (Detmar et al., 2001; Fagerlind et al., 2008; Taylor et al., 2011), including research reporting the analysis of audiotaped medical consultations, where not only did patients give out twice as many ‘information’ (e.g., ‘I really don’t know much about the different treatments’) than ‘emotion’ cues (e.g., ‘I get so upset sometimes that I can’t stop crying.’) in a consultation, but doctors also responded more to ‘information’ than ‘emotion’ cues (28% compared to 72% of information cues) (P. Butow, Brown, Cogar, Tattersall, & Dunn, 2002). A study by Taylor et al. (2011) reported that while 50% of oncology physicians stated they discussed emotional concerns in consultations ‘often-almost always’, only 18% of patients agreed with this level of discussion of emotional concerns (Taylor et al., 2011). Fostering an environment where psychosocial discussion occurs routinely requires consideration of potential barriers. There are a number of barriers that might influence the discussion of psychosocial, despite the use of a needs assessment tool, including:

- Perceived lack of time to discuss psychosocial needs when medical issues must be discussed (Hudson et al., 2006). Although the PC-NAT was designed for use in
outpatient clinic settings, these are run behind time and oncologists might simply be “too busy” to discuss emotional concerns (Ryan et al., 2005).

- Lack of relational continuity of care. In the present study, and typical of an outpatient clinic, not all patients consulted with the same oncologist across consultations, which may have affected the relational continuity of care and compromised the integration of the PC-NAT and communication of psychosocial concerns (Fagerlind et al., 2008)

- Perceptions about whose role it is to raise and also discuss psychosocial concerns or willingness of both patients and oncologists to discuss these issues (ie patient embarrassment). Whilst oncologists and patients are both willing to discuss QOL and emotional issues, it is also apparent that both perceive it to be the other party’s role to raise such issues (Detmar, Aaronson, Muller, & Schornagal, 2000).

_Psychosocial concerns were assigned codes showing a lower level of empathy then medical concerns_ - Empathy has been shown to strengthen the patient-physician relationship, increase patient satisfaction, decrease the need to restate concerns, and makes patients more likely to disclose future concerns and adhere to treatment plans (Morse, Edwardsen, & Gordon, 2008; Pollack et al., 2007; Zachariae et al., 2003). It has also been shown to be correlated with a decrease in distress and increase in self-efficacy for oncology patients (Zachariae et al., 2003). However, despite the potential benefits of empathy, the present study, as well as others (P. N. Butow et al., 2008; Fallowfield et al., 2002; Kennifer et al., 2009; Morse et al., 2008; Pollack et al., 2010; Pollack et al., 2007), have shown that this remains a challenging area for oncologists, particularly in relation to psychosocial concerns. Kennifer et al. (2009) has suggested that oncologists feel more comfortable providing medical advice, as a way of reassuring patients than validating their experience (Kennifer et al., 2009). Thus, further communication skills training might focus on providing health care
providers with strategies to respond to emotional concerns (Barth & Lannen, 2011; P. N. Butow et al., 2008). Bonvicini has found higher levels of empathy was reported in a trained group of physicians compared with a control group (Bonvicini et al., 2009).

No increase in length of consultation - One of the major concerns with the examination of doctor patient interaction is that any strategies implemented to improve communication might lead to an increase in already stretched consultation time. Importantly, administration of the PC-NAT did not lengthen consultation time, a finding, which is consistent with previous research (Detmar et al., 2001; Morse et al., 2008), and supports the use of structured assessments to streamline the content and focus of consultations (Kinnersley et al., 2008).

Limitations
The mean length of consultation times was similar between this study and others at approximately 18 minutes (Pollack et al., 2007); however, the response rate (54%) was low compared to other audiotaping studies (71% to 90.5%) (P. Butow et al., 2002; Detmar et al., 2001). Whilst meeting criteria for advanced cancer, patients were of mixed cancer diagnosis. The sample was drawn from one hospital over a time limited period, therefore the results cannot be generalised to other oncology settings around the country or other oncology specialists outside the medical and haemotology specialties. Methodologically, the content of the consultation was analysed by third party observers using audiotape coding, which relies on verbal behaviour and fails to account for the role and value of non-verbal expressions (Bonvicini et al., 2009).

Future Directions
The PC-NAT was developed to routinely assess the needs of individuals in the advanced stage of their cancer where the goal is to improve QOL. Future research should explore needs assessment in populations with non-malignant conditions. Also, the assessment of needs in those with poorer predicted outcomes in the inpatient setting requires attention. It would also be useful to determine the impact of intensified training procedures on the administration of the PC-NAT.

This study was completed in a metropolitan setting. Future research needs to consider issues specific to rural areas, where PC is often provided by general practitioners rather than specialist PC services (Evans, Stone, & Elwyn, 2003; Kelley, 2007). Studies have indicated difficulty in accessing training and education for service providers in rural locations (Arnold, 2011; Evans et al., 2003), with other research indicating that such training would improve abilities to meet PC needs (Kelley, Habjan, & Aegard, 2004).

Conclusion
The issue of needs assessment and the discussion of psychosocial needs are important for individuals with advanced cancer where the focus of care is on maintaining quality of life. This qualitative study explored the use of the PC-NAT with individuals with advanced cancer and their caregivers. Key findings included 1) the routine needs assessment was not rationalised to patients and was often delivered in a verbatim manner using a degree of jargon, 2) discussion of psychosocial issues was minimal in comparison to medical issues, 3) the degree of empathy used to respond to the psychosocial concerns and medical concerns raised by patients and caregivers was similar; however, psychosocial concerns were often dismissed or ignored during these consultations, and 4) the length of the consultation was not affected by the administration of the PC-NAT. Further research is needed to determine how more extensive training for oncologists in the understanding and use of needs assessment
tools might facilitate increased discussion of psychosocial issues. In addition, understanding the patient's perspective about the discussion of such issues is vital, as this might not be the forum in which they wish to discuss such difficulties.
References


3 Extended Discussion

The assessment and discussion of psychosocial needs between health care providers and patients with cancer has attracted more and more attention, particularly since the importance of assessing and addressing the psychosocial needs of patients and caregivers is now a clear standard for cancer care (Holland & Weiss, 2008). This study examined how psychosocial needs were discussed by oncologists with patients with advanced cancer and their caregivers, in an outpatient setting, where a needs assessment tool was used. The objectives were as follows:

1. Examine the approaches used by health professionals to complete the PC-NAT in the consultation setting.
2. Explore the potential of the PC-NAT to facilitate discussion of psychosocial issues.
3. Determine whether use of the PC-NAT by clinicians during consultations with advanced cancer patients alters the length of these consultations.

Across these aims, four findings are noteworthy and will be discussed in turn:

1. Related to aim 1, the prompts within the needs assessment tool, initially written for health care providers to facilitate the discussion of the range of needs it covers, were used verbatim, which seemed to not always be understood by patients and limit meaningful exploration of any concerns.

2. In terms of the potential of the PC-NAT to facilitate discussion of psychosocial issues (aim 2), it was noted that the majority of the codes used pertained to medical issues, rather than psychosocial issues. The discussion of psychosocial issues was often solely prompted by the PC-NAT administration; however, this was completed almost as an afterthought towards the end of the consultation. In the majority of the consultations
where the PC-NAT was used, no rationale was given for completing the tool.

3. It was also found that oncologists’ responses to patients’ and caregivers’ concerns were coded as different attempts to understand or validate these concerns and were coded as ‘empathy’. Whilst the style of empathy coded for medical and psychosocial concerns was comparable, more often, codes reflecting dismissing or denying the concern were used for psychosocial concerns rather than medical concerns. Given the missed opportunities to discuss patients’ and partners’ psychosocial issues, this discussion will consider modes of administration and barriers to discussion of psychosocial concerns in greater detail. Recommendations to assist with potential future uptake of this needs assessment tool will also be presented.

4. A last important finding from this research was that the use of the needs assessment tool in the clinical consultation did not significantly lengthen those consultations (aim 3). This finding has implications for the clinical utility of needs assessment tools like the PC-NAT and is consistent with a number of other reports (Detmar et al., 2001; Morse et al., 2008).

3.1 Main Finding 1: The Use of Jargon during Administration of the PC-NAT

The results provided insight into how supportive care needs were assessed using the PC-NAT and associated issues, which seemed to mainly include reading the needs assessment items and prompts (both which included jargon) verbatim to patients and caregivers. As these included jargon, it seemed to hinder understanding and limit the detail of answers provided. Jargon has been defined as the “specialized language of a trade, profession, or similar group” that is “not likely to be easily understood by persons outside the profession” (Deuster et al., 2000 p. 1947). In recent years there has been increased attention to the practice of oncologists in relation to patient communication. Training programs are now being developed in the field
of oncology, which incorporate education about “avoiding jargon”, particularly in the area of ‘breaking bad news’ (Baile et al., 1999; R. Brown, Bylund, Eddington, Gueguen, & Kissane, 2010; Fukui, Ogawa, & Fukui, 2010). Whilst there has been an increase in training for oncologists in reducing jargon, there is little evidence to suggest whether this is adhered to as the oncologist continues in their career (Deuster et al., 2000). Jargon creates a barrier in communication between the oncologist and patients, particularly when discussing complex medical results or procedures (Deuster et al., 2000; Sevinc et al., 2005), which can lead to “noncompliance, frustration, dissatisfaction… unrealistic expectations of treatment efficacy… may adopt an overly optimistic picture of the impact of therapy… may undermine shared decision making” (West & Baile, 2010 p. 217). As noted in the present study, the use of jargon can lead to one way hurried communication from the oncologist to the patient and/or caregiver (Ford et al., 1996). In a study looking at the jargon used in breast and prostate cancer screening interviews it was found that the use of jargon was widespread, and if there were explanations given for these terms they lagged behind the use of the jargon (Deuster et al., 2000). In some cases it has been suggested that these jargonistic phrases are so ingrained that oncologists are unaware that the majority of patients and caregivers fail to understand their meaning (Miller, 2010) and it is those oncologists who use jargon more frequently who are considered good practitioners (Sevinc et al., 2005). Thus, based on findings from this study and those of others, tools for the assessment of psychosocial needs or any other issue in oncology where the patient’s view is gathered should avoid jargon so as to discourage its use by oncologists. Tools should utilise prompts which are written in the language of the patients and not weighted in medical/psychological terms.
3.2 Main Finding 2: Psychosocial Concerns Were Not the Focus of Consultations

The qualitative analysis explored the discussion of psychosocial issues and noted that there was less focus (if any) on this aspect of care when compared with medical/treatment issues. In addition, this study found that individuals with advanced cancer and their caregivers raised fewer concerns about psychosocial concerns compared with medical concerns. This finding is consistent with other Australian research analysing the content of audiotaped medical consultations which reported that not only did patients give out twice as many ‘information’ cues (e.g., ‘I really don’t know much about the different treatments’) than ‘emotion’ cues (e.g., ‘I get so upset sometimes that I can’t stop crying.’) in a consultation, but doctors also responded more to ‘information’ than ‘emotion’ cues (28% compared to 72% of information cues) (P. Butow et al., 2002). Like the present study, similar studies reported that psychosocial needs are generally discussed in less than one third of oncology consultations (Detmar et al., 2001; Taylor et al., 2011). (Fagerlind et al., 2008). This is despite 75% of oncology physicians stating that they would feel comfortable initiating discussion about psychosocial issues in consultations (Taylor et al., 2011) and almost all oncologists surveyed agreed they provided some psychosocial care (Muriel et al., 2009). A study by Taylor et al. (2011) emphasised that oncology physicians seem to overestimate the extent to which they discuss emotional concerns with 50% stating that they discussed emotional concerns in consultations ‘often-almost always’, whilst only 18% of patients agreed with this level of discussion of emotional concerns (Taylor et al., 2011). Detmar et al. (2001) audio-taped consultations and found that oncologists devoted 64% of time to medical issues and only 23% of time to Health Related Quality of Life (HRQoL) issues (13% related to process and social communication), whilst patients devoted 41% of their time to medical and 48% to HRQoL issues (11% to process and social communication) (Detmar et al., 2001). Similarly, Taylor, 2011 (Taylor et al., 2011) found that 59% of patients would be willing to raise psychosocial
issues. Findings from Detmar et al. (2001) and Taylor et al. (2011) challenged those of this study, which found that the discussion of these factors by patients was rare. This finding was further echoed by Anderson et al. 2008 who found that among patients with advanced cancer in oncology consults it was found that only 17% of consultations contained discussion of psychosocial concerns. The Taylor et al. (2011) study determined that the majority of psychosocial concerns raised by patients included fear of the future and uncertainty and anxiety. Other research has also found that anxiety and depression are among the most frequent psychosocial concerns discussed by patients in oncology consultations (Taylor et al., 2011; Warrington & Velikova, 2011). It has also been suggested that when a consultation is with a “well” patient (e.g., relatively low level symptoms, minimal distress), these are less emotionally charged and can be shorter than consultation with more unwell patients. Unwell patients in the advanced stage of illness often express more expression of emotional concerns; however, there is often less time to address these issues, as there are a number of competing clinical (medical) care concerns (Buckman, 2010).

There are a number of barriers that may have influenced the raising and then discussion of psychosocial concerns in the oncology consultations reviewed for this study, despite the use of a needs assessment tool, including:

- Perceived lack of time to discuss psychosocial needs when medical issues must be discussed (Hudson et al., 2006)
- Lack of relational continuity of care
- Perceptions about whose role it is to raise and also discuss psychosocial concerns
- Willingness of both patients and oncologists to discuss these issues (ie patient embarrassment).

Within the context of the present study the perceived lack of time and lack of relational
continuity of care seemed the most pertinent barriers and have implications for the use of a needs assessment tools such as the PC-NAT, as it was designed for use in outpatient clinic settings, which are often busy, running behind time and staffed by a changing workforce of specialists and registrars. The perceptions of oncologists and patients are also discussed as a potential barrier to the discussion of psychosocial issues in regard to the use of the PC-NAT where it was determined that it was administered almost as an afterthought, late in the consultation and with no rationale.

3.2.1 Perceived lack of time to discuss psychosocial issues.

For both oncologists and patients there is a sense that the consultation is used for discussion of medical issues and there is little time to discuss psychosocial issues (Detmar et al., 2001). Time is certainly a factor for busy outpatient clinics, such as the one in this study, and overwhelmed oncologists and patients have a perception that oncologists are “too busy” to discuss emotional concerns (Ryan et al., 2005). In fact, it has been noted that less discussion of psychosocial issues occurs in in consultations that start behind time (Detmar et al., 2001). Whilst time constraints can be a factor in discussion of psychosocial issues this should not stop a brief empathic statement being given by the oncologist (Pollack et al., 2007). The consequences of not responding to these concerns can mean the patient restates the concern and this in turn actually increases the length of consultation (Pollack et al., 2007). It is worth considering research from other areas of medicine that has suggested that by increasing the length of a consultation for other issues, one might be able to reduce the length of future consultations or even the frequency of future consultations (Welch, 2010).

3.2.2 Perceived lack of relational continuity of care leading to reduced discussion of psychosocial issues.
Only a portion of patients in this study were able to see the same oncologist through their recorded consultations and thus perceived relational continuity of care might have been one of the major barriers to effective communication between the oncologist and patients (Fagerlind et al., 2008). Relational continuity of care is the ongoing relationship between a health care provider, patient and caregiver that continues over time (Kristiansen, Tjornhoj-Thomsen, & Krasnik, 2010) and over important events (Heller & Solomon, 2005). It was noted that more codes pertaining to discussing psychosocial concerns were assigned to transcripts of the post-intervention session compared with the baseline session for those patients with the same oncologist. This finding suggests that having contact with a familiar oncologist may facilitate patients expressing psychosocial concerns. In the oncology setting at times the turnover of medical staff might adversely affect continuity of care (Nazareth et al., 2008), which in turn has been shown to negatively impact on the extent to which emotional concerns are discussed with professionals (Kristiansen et al., 2010). Relational continuity is essential in building trusting relationships through which emotional support can be sought (Botti et al., 2006; Kristiansen et al., 2010). Relational continuity of care and the relationships that are fostered by it were also found to be correlated with perceived quality of care by caregivers (Heller & Solomon, 2005). In a qualitative study of individuals with a diagnosis of cancer those who experienced a high turnover of staff felt that this would make the provision of emotional support difficult in the future (Kristiansen et al., 2010). In a qualitative study of women with gynaecological cancer it was found that women felt that they needed a consistent person to understand and guide them through the health care system (Walton, Reeve, Brown, & Farquhar, 2010).

3.2.3 Oncologists’ and patients’ perceptions of role in the discussion of psychosocial issues.
This study has found that little rationale was given for the assessment of needs and it was generally completed as an afterthought. One of the major barriers to discussion of psychosocial issues in oncology consultations might be the perception that it was not the role of the oncologist to assess or discuss these issues (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Hudson et al., 2006). This view appears to be shared by both patients and oncologists. In Detmar et al. (2000) study just under half of the oncologist’s surveyed indicated that their role in assessing the psychosocial aspects of their patients should be shared with other health care providers such as general practitioners. It has been found that when oncologists do not feel entirely responsible for discussing psychosocial issues, these issues are less likely to be explored during oncology consultations (Detmar et al., 2001). Often there is an expectation or assumption from the health care provider that a patient shares their focus on treatment of the disease above all other needs (Horden & Street, 2007). This attitude may account for the way that the routine assessment of needs was presented to patients in this study and suggest that other health care professionals (e.g., nurse) might find that this type of assessment fits more naturally in their roles and responsibilities. The concern is that when oncologists continue to fail to respond to expressions of concern from the patient, these expressions often become less frequent (Suchman, Markakis, Beckman, & Frankel, 1997).

The patient also has a role to play in the encouragement of discussion of psychosocial needs. In this study patients were quick to move conversation away from emotional issues, and this has been found in other research (Kennifer et al., 2009). This reinforces the belief that the oncologists’ role does not include dealing with emotional issues. Similar to the present findings, patients in a study by Butow et al. (2002) were found to give more cues regarding information needs than emotion needs and in return the oncologist was more likely to respond to informational cues than emotional cues. Studies have determined that advanced
cancer patients consider the role of outpatient consultations by oncology staff to be strictly for biomedical treatment and consider the primary care provider (general practitioner) as the professional with whom psychosocial issues are discussed (Anderson et al., 2008).

3.2.4 Willingness to discuss psychosocial issues.

Despite these perceptions of role, oncologists have acknowledged the importance of assessing and managing emotional distress and have reported working within guidelines regarding referrals for psychosocial difficulties in cancer care (Absolom et al., 2011). Issues raised by the patient around end of life can cause “concern and confusion” for oncologists and they can feel they don’t know what to say (Hudson et al., 2006). For this study the motivation and willingness of oncologists and patients to discuss psychosocial issues is unknown and may still be a barrier. Both oncologists and patients have generally been found to be willing to discuss Health Related QoL issues (which included emotional functioning); however, the barrier to this seemed to be each party’s thoughts on who should initiate the discussion, with patients and oncologists leaving it to the other to raise psychosocial issues (Detmar et al., 2000). Almost all patients want to discuss physical (95%) and psychosocial issues (90%) with their oncologist, but only a quarter were willing to discuss psychosocial issues if it was raised by the oncologist (Detmar et al., 2000). Despite patients expressing willingness to discuss emotional concerns and expressing these concerns verbally, which is commonly associated with self-reported psychological distress (Ryan et al., 2005), they may also express concerns in an indirect or non-verbal way which might be difficult for oncologists to interpret (Ryan et al., 2005). Similarly in this study, the psychosocial concerns expressed by patients were not direct or overt displays of distress. Even around end of life issues, despite patients citing that emotional support and understanding are important skills for physicians to have (Fagerlind et al., 2008), they do not often express concerns about dying
(Anderson et al., 2008). Studies have shown that there are however oncology and primary care patients for whom the idea of discussing psychosocial issues with their oncologist evokes feelings of embarrassment, that they “should be coping” (Hudson et al., 2006; Mitchell et al., 2008). A review of literature has found that almost a half of distressed cancer patients in a study of general practice patients did not disclose this distress, because they felt embarrassed or did not want to burden the physician with these concerns (Ryan et al., 2005). Embarrassment for the patient may be a function of thoughts about the “obviousness” of emotional distress around advanced cancer or that these feelings are unreasonable (Ryan et al., 2005). Cultural factors can play an important part in these feelings of embarrassment around psychosocial issues, particularly for those cultures which encourage stoicism (Tang, de Groot, & Bultz, 2009). For the current study it is conceivable that both oncologists and patients’ willingness to discuss psychosocial concerns was low and so was not made a priority for the consultation.

3.3 Main Finding 3: Psychosocial Concerns Addressed with a Lower Level of Empathy than Medical Concerns

As stated above, codes assigned to the concerns raised by patients and caregivers reflected that fewer psychosocial concerns compared with medical concerns were raised. Psychosocial concerns, or psychosocial empathic opportunities, expressed by patients and caregivers were often addressed by the oncologist at a lower level of empathy than medical empathic opportunities. This is a finding that emerged from the analysis of the initial transcripts and was not anticipated at the outset of this study. The large number of medical concerns raised in this study within the short time of the consultation, could certainly have been a factor, which affected the oncologist’s ability to attend psychosocial concerns raised.
Empathy is the idea that patients can arouse in the health care provider projections of their own feelings (Hojat et al., 2002; Spiro, 1992), which are then conveyed back to the patient by the oncologist (Coulehan et al., 2001; Hojat et al., 2002). As opposed to sympathy which might be “I want to help you”, empathy is “I am you” (Spiro, 1992). Examples of empathic response that might be expected of clinician include acknowledging emotions (especially when expressed indirectly) and clarifying understanding of a concern (e.g., “It sounds like you’re feeling scared, is that right?”) and communicating that understanding to patients” (McCormack et al., 2011). Coulehan et al. (2001) described a three step empathic process:

1. The clinician listens to the “perspective and experience” of the other person, still with a clinical detachment.
2. The clinician has an emotional response, which resonates with their experience.
3. The clinician then checks back with the person to determine whether they have heard and experienced a similar feeling, in this way providing feedback.

Empathy allows the patient/caregiver to feel “understood, respected, and validated” (Coulehan et al., 2001). Empathy has been shown to strengthen the patient-physician relationship, increase patient satisfaction, decrease the need to restate the negative emotion, and may make patients more likely to disclose future concerns and adhere to treatment plans in cancer treatment (Morse et al., 2008; Pollack et al., 2007; Zachariae et al., 2003). Effective use of empathy by oncologists has also been shown to be correlated with a decrease in distress and an increase in self-efficacy for oncology patients (Zachariae et al., 2003). Oncologists share a belief that responding to emotional concerns in an empathic way will be helpful to patients (Pollack et al., 2007). However, similar to the findings in the present study, previous research has shown that oncologists do not do well in responding empathically to negative emotions expressed by patients (P. N. Butow et al., 2008; Fallowfield et al., 2002;
Morse et al., 2008; Pollack et al., 2010; Pollack et al., 2007). This is of concern, as patients have been found to only express 50% of their emotional concerns to oncologists (Heaven & Maguire, 1997; Maguire, 1999) and if an opportunity to be heard and validated is missed it might inhibit the patient or caregiver offering any further expression (Pollack et al., 2007). Other research (Morse et al., 2008) has suggested that individuals with cancer in palliative care will actually provide several opportunities to give empathy, if the oncologist does not respond initially, and this was also noted in the present study. Patients with cancer have been found to be more likely to receive an empathic response based on the theme of their emotional concern, so that those concerns about the health care system would receive an empathic response more often than one related to distress (Morse et al., 2008). Interestingly despite the available knowledge related to the benefits of empathy specifically for cancer patients, the present study has determined that this is still a challenging area for oncologists, with a number of psychosocial empathic opportunities being dismissed by the oncologist. This finding is similar to those of others where it was found that when an oncologist is provided with an empathic opportunity they dismiss the concern in 73% of the time (Pollack et al., 2007). The concern is that non-empathic language has been found to almost always terminate discussion about that issue (Kennifer et al., 2009). There are a number of factors that contribute to the findings that psychosocial empathic opportunities are responded to with little validation and in a way which limits further discussion. These factors include (Pollack et al., 2010):

- The ability of the oncologist to recognise a psychosocial empathic opportunity
- Training of the oncologist in communication skills
- Oncologist workload
- Age of the oncologist
In view of these challenges the most pertinent ones in the context of the current study are the ability of the oncologist to recognise a psychosocial empathic opportunity as opposed to a medical empathic opportunity and their training in communication skills. As most of the oncology workforce is older (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007) and workload high (Poulsen, Poulsen, Asaduzzaman, Poulsen, & Khan, 2011) it is plausible that these issues could have affected the level of empathy used.

3.3.1 The challenge of recognising a psychosocial empathic opportunity.

In this study oncologists received a small amount of training in the use of the Palliative Care Needs Guidelines and also the PC-NAT. The recognition of psychosocial needs was not part of that training, and so may be a consideration in discussing the lower levels of empathy for psychosocial concerns. The difficulties associated with recognising psychosocial empathic opportunities are related to the ‘normal’ grief reaction of a cancer diagnosis and also the somatisation of emotional symptoms (Ryan et al., 2005). Oncologists have the knowledge and training to manage physical symptoms associated with diagnosis and treatment, however it is often the case that emotional symptoms mimic these physical symptoms. For example nausea may be a side effect of medication and also a symptom of anxiety. Approximately three quarters of patients with a diagnosis of anxiety or depression present with one or more symptoms of somatisation (Ryan et al., 2005). Difficulty in recognising expressions of emotion by the oncologist may also be due to being busy with other tasks such as thinking about diagnosis or treatment options (Morse et al., 2008).

3.3.2 Providing training to improve the use of empathy.

As stated above oncologists received some training as a part of this study, but by no means did this focus on how oncologists should respond to psychosocial concerns. There is a vast
spectrum of approaches to psychosocial issues in oncology from very empathic and understanding communication to denial and a focus on medical issues (Stiefel, Favre, & Despland, 2006). Because the concerns expressed by patients are so often anxiety and fear related to future concerns (e.g., “Does this test result mean the cancer has returned”), oncologists often respond to the question to reassure the patient and reduce psychosocial distress rather than providing an empathic response that acknowledges the distress (Anderson et al., 2008; Kennifer et al., 2009; Morse et al., 2008). It has been suggested that oncologists feel more comfortable providing medical advice, such as the statistical success of a treatment, as a way of reassurance rather than validating the experience expressed by the patient (Kennifer et al., 2009). This was seen throughout the consultations in the present study where the oncologist would focus a medical aspect of care rather than acknowledge the distress or emotional concern of the patient or caregiver. In addition the level of empathy used did not reach the level of ‘shared feeling or experience’ or personal disclosure. The ability to convey empathy involves the health professional being able to imagine what it might be like for the patient to experience a particular issue and convey this back to the patient, and so in some cases a powerful way to do this is to use self-disclosure (Keller & Carroll, 1994). Whilst self-disclosure is still often considered a boundary violation (Nadelson & Notman, 2002), and in some cases, if used, it causes interruptions and moves the consultation away from the patient’s concerns (McDaniel et al., 2007). McDaniel et al. (2007) determined that 34% (n=113) of physician-patient visits included some self-disclosure, with no evidence of positive impact on the interaction (McDaniel et al., 2007).

More intensive Communication Skills Training (CST) has been found to improve communication skills and effectively increase the ability to respond to emotional concerns for oncology clinicians (Barth & Lannen, 2011; P. N. Butow et al., 2008). A study of oncology
physicians found that a training group used higher levels of empathy at follow-up compared with a group who received no training (Bonvicini et al., 2009). Using a rating scale it was found that levels of empathy expressed increased by 37% in the training group. A randomised control trial completed by Fallowfield et al. (2002) found that a focused CST program saw an 69% difference in expressions of empathy between the intervention and control group post CST (Fallowfield et al., 2002). The best outcomes can be found for those CST programs which occur over a greater period of time with smaller groups of clinicians (Gysels, Richardson, & Higginson, 2005). In light of the findings from the current study, for future use of the PC-NAT consideration perhaps should be given to increasing the length and detail of training.

3.3.3 The challenge of workload in providing empathy to psychosocial concerns.

There is a perception that burnout in Australian oncology professionals is high (A Girgis, Hansen, & Goldstein, 2009) and it has been found that one third of oncology workers surveyed in Queensland, reported having significant burnout (Poulsen et al., 2011). Approximately one third of Australian oncology clinicians with direct patient contact have high levels of emotional exhaustion (EE); however, less than 10% experience depersonalisation which is the hardening against emotion and treating patients like objects (A Girgis et al., 2009). In a study from Canada, 53% of oncologists were found to have high levels of emotional exhaustion (Dougherty et al., 2009) and from a review, one third of oncology clinicians were found to have high levels of EE and one third experienced depersonalisation (Trufelli et al., 2008). All these factors contribute to oncologists having lower confidence in their ability to communicate with their patients (Emold, Schneider, Meller, & Yagil, 2011; Schofield, Green, & Creed, 2008). In a study of medical students it was determined that empathy was inversely related to burnout, and specifically for medical
residents there was a negative correlation between depersonalisation and empathy (M. Thomas et al., 2007). In a study of medical residents, 76% met criteria for burnout, and for those residents they were significantly more likely to engage in an occasion of sub-optimal care monthly (e.g., “I did not fully discuss treatment options or answer a patient’s questions”) (Shanafelt, Bradley, Wipf, & Back, 2002).

3.3.4 The challenge of age in providing empathy to psychosocial concerns.

Another significant finding from research into empathy in oncology is that younger oncologists have been found to give empathic responses (‘continuers’) more frequently than older oncologists (Pollack et al., 2007). The age of the oncologists is not considered in this study however may be a factor. This finding could be a representation of recent changes in medical training which promote the use of empathy and having better communication skills (Pollack et al., 2007). Another hypothesis is that a younger clinician will have experienced less challenges, and so as a consequence will have a lower level of burnout (Pollack et al., 2007).

3.4 Length of Consultation

One of the major concerns with the examination of doctor patient interaction is that any strategies implemented to improve communication might lead to an increase in already stretched consultation time. This study determined that the introduction of the PC-NAT did not significantly increase the length of consultations. This finding supports the idea that exploration of patient psychosocial issues does not necessarily add time to consultations. To date there does not appear to be any evidence which suggests that clinician training in an intervention has a significant impact on consultation time either to increase or decrease it (Kinnersley et al., 2008).
3.5 Strengths and Limitations of Study

The main strength of this qualitative study was that it allowed for an in depth and exploratory analysis of the interactions between the patients, caregivers and oncologists. The mean length of oncology consultation times was similar between this study and others at approximately 18 minutes (Pollack et al., 2007). The response rate of this study (54%) was low compared with similar studies into individuals with cancer. Other studies which included the audio taping of oncology consultations had a response rate ranging from 71% to 90.5% (P. Butow et al., 2002; Detmar et al., 2001). However, for a population of individuals with advanced cancer this response rate was relatively high. Whilst this study has a heterogeneous sample in terms of primary disease site, obtaining a homogeneous sample would be difficult and limiting in regards to the scope of this study and not representative of the outpatient clinic in question. All participants had a non-curable cancer and some transitioned to palliative care during the time of the study.

A limitation of this study was that the population of patients sampled was limited to those initially attending an outpatient clinic. The sample of oncologists for this audio-taping sub-study was also drawn from one hospital site over a time limited period, therefore caution is needed when generalising results to other oncology settings around the country or other oncology specialists outside the medical and haematology specialties. The method used to study the content of discussion and the concept of empathy was to use third party observers using audiotape coding. This method assumes that empathy is a verbal behaviour and does not account for the non-verbal expression of empathy, which could be facilitated by touch or body movements or facial expression (Bonvicini et al., 2009).

A limitation of this study was that no account was made of the patient’s perspective of their
psychosocial needs to determine whether the patient wanted more time to discuss these issues. Taylor et al. (2011) study asked patients and oncologists how much they believed psychosocial issues were discussed in session, which gave some insight into their perspectives and therefore not relying solely on an objective view of the interactions. In addition assessing the psychiatric morbidity prior to consultations would have given an indication of how often oncologists were able to facilitate a referral for psychiatric assistance based on the conversation generated by administering the PC-NAT (P. Butow et al., 2002). Some account has also been taken in previous studies of whether oncologists have received past communication training (Pollack et al., 2007). This variable would help determine whether any increase in discussion of psychosocial issue was an effect of communication training.

Studies into advanced cancer in the United States looked at both the expression of emotional concerns by patients and the rate to which oncologists responded empathically from a quantitative perspective (Anderson et al., 2008). Building further on the results of this study Kennifer et al. (2009) looked at the intensity of the emotional expressions from patients and determined what impact this had on the rate of empathic responses from oncologists. This added another dimension to the analysis of empathic responses by oncologists in providing information about the types of empathic opportunities which would garner an empathic response. It was determined that oncologists provided higher levels of empathy when the patients’ emotional intensity was higher. Similarly research has been conducted looking at the whether the type of emotion (eg anger/sadness) impacts on the likelihood of an oncologist providing an empathic response (Sheldon et al., 2009). Pollack et al. (2007) explored whether the gender of oncologist was a factor in the frequency of empathic responses and found that female oncologists were more likely to respond with an empathic continuer. No measures of
the intensity of the empathic opportunity or the gender of the oncologist were made, which would have added more detail to the findings.

3.6 Meaning of the Study: Recommendations for Clinicians or Policymakers

Our research revealed that the mode of administration of the needs assessment tool in the clinical consultation was not conducive to the identification and discussion of psychosocial concerns of the patients and their caregivers; and that psychosocial issues received less focus in the consultations than physical issues. However, despite this, the published findings of the patient outcomes from the larger trial of this needs assessment tool indicate that the systematic use of the tool was associated with some improvements in patient-reported unmet needs and a slowing of the deterioration of quality of life in the group of patients with advanced cancer (A Waller et al., 2012; A. Waller et al., 2012). Hence, this suggests significant potential for this tool to improve the detection and provision of psychosocial care if administered more systematically and as an integral part of the consultation. It is now well accepted that the identification of psychosocial needs should be part of routine cancer care (Holland et al., 2011). Systematic assessment of all patients can assist both oncologists and patients in overcoming potential barriers of the stigma associated with identifying psychosocial issues (Holland et al., 2011). There seems to be a three part process to the assessment of psychosocial needs of individuals with advanced cancer. 1) The creation of a tool, which allows the assessment to occur without the use of jargon and with a sense of purpose and rationale, 2) the training of oncology staff in conducting an assessment of needs in a manner which empathically encourages conversations around these issues, and 3) ensuring that this assessment process is a routine part of cancer care. The focus of this study has been the implementation of needs assessment and the manner in which psychosocial needs are discussed in oncology consultations.
3.6.1 Creating a Tool

Needs assessment tools must take into account the time constraints facing oncology departments and also ensure that needs assessments are conducted in a manner which promotes the importance of the process and allows for patients to understand the process. As the administration and completion of the PC-NAT was generally the role of the oncologist in this study, a suggestion might be that the patients are given a copy of the PC-NAT and asked to complete this prior to entering the session. They could then be asked to report any thoughts or concerns which have been raised as a result of completing the assessment without the time pressure of the consultation. Completion of the PC-NAT by the patient and caregiver prior to the session may also reduce any cultural factors (adjusting for language), where they may feel more free to raise psychosocial issues.

3.6.2 Training Staff and Making Needs Assessment a Routine Part of Treatment

Training oncology staff in the use of needs assessment tools is essential; however, what seems more important is training around the rationale for needs assessment, as this study demonstrates, despite training in use of the tool the oncologists conducted the assessment without a rationale or language to facilitate this process for the patient.

In helping to foster an environment where psychosocial discussion is a norm, considerations need to be made regarding the relational continuity of care and the length of time allocated for advanced cancer consultations, where more time might be dedicated to discussion of these issues. In addition, transparent conversation about the importance of discussion of
psychosocial issues would be important to provide space for these concerns to be raised by both the patient and oncologist. When creating an environment where discussion occurs it is essential that, if raised, any emotional concerns are dealt with in a fashion which encourages further exploration and future collaboration on these issues. Oncologists need to be able to address concerns in a way which validates distress and illustrates the importance of treating the psychological aspects of the individual’s disease. Ryan et al. (2005) outline a number of strategies which could be used by oncologists to facilitate discussion of psychosocial issues. These include strategies designed to increase doctors’ understanding of the importance of patient distress and also their knowledge in order to assess the presence of distress (Ryan et al., 2005). Specifically in relation to being able to assess cues of distress doctors would also be trained in active listening and having a patient centered approach (Ryan et al., 2005). Ryan et al. (2005) also discussed the need to facilitate and encourage patients to divulge psychosocial issues. Recommendations have been made around creating space for patients to be able to communicate this aspect of their health and for doctors to respond in an empathic style including using emotional words to reflect the patient’s descriptions. In addition to training programs for communication training, programs in helping clinicians managing their own mental health have shown to be helpful in improving the clinician’s ability to relate to the patient. A mindfulness based program used with primary care physicians has been shown to significantly improve the ability of physicians to be empathic with patients (Krasner et al., 2009). Receiving external support and supervision can mediate against burnout (Schofield et al., 2008). Furthermore, in order for training to be effective in changing oncologist’s behaviour, it needs to be ongoing, repetitive and on an individual basis (Bonvicini et al., 2009).
3.7 Unanswered Questions and Future Research

The PC-NAT was developed to routinely assess the needs of individuals in the palliative stage of their illness where the goal is to improve quality of life. As such this research focuses solely on those individuals with a diagnosis of advanced cancer, and does not explore needs assessment with other non-malignant conditions such as individuals with HIV/AIDS, motor neurone disease, muscular dystrophy, multiple sclerosis and end-stage dementia (Department of Health and Ageing, 2012). While these represent a smaller percentage of the palliative care population, the issues associated with these different diagnoses, symptoms and treatment are significantly different and require exploration. In addition this study focused on those individuals with advanced cancer and their caregivers whom had not entered a hospice and were receiving palliative care as an outpatient. The way that needs are assessed and psychosocial needs are discussed in those with poorer predicted outcomes requires attention. It would be useful to determine any impact on the administration of the PC-NAT if training procedures were intensified and the tool’s prompts altered to include more colloquial language.

This study was completed in one health care setting and so the recommendations of this study may not viable or possible in other centres. The differences may be more significant for those health care organisations in rural areas, given this study was completed in a metropolitan centre. Care for those in the terminal stage of an illness is very complex (Arnold, 2011) and palliative care is a unique area of practice (Robinson et al., 2009). However in rural areas of Australia care is often provided to palliative care patients by general practitioners rather than SPCS (Evans et al., 2003; Kelley, 2007). Studies have indicated that there is a great deal of difficulty accessing training and education for these service providers in rural locations (Arnold, 2011; Evans et al., 2003), with other research indicating that such training would
improve abilities to meet palliative care needs (Kelley et al., 2004). Rural health providers also experience a lack of resources to provide palliative care (Kelley, 2007; Kelley et al., 2004), particularly around emotional concerns and bereavement (Evans et al., 2003). Therefore it is important that the use of routine needs assessment in rural and remote areas is explored in order to understand how this takes place in these areas.
4 Conclusion

The issue of needs assessment and the discussion of psychosocial needs are important for individuals with advanced cancer where there is no curative treatment and the focus is maintaining quality of life. This study is unique in that it allowed for an in-depth qualitative exploration of the use of a routine needs assessment tool with individuals with advanced cancer and their caregivers. It was found that there is less discussion of psychosocial issues when compared with medical issues in these consultations. The routine needs assessment was not rationalised to patients and was often delivered in a verbatim manner using a degree of jargon. The degree of empathy used to respond to the psychosocial concerns and medical concerns raised by patients and caregivers was similar; however, psychosocial concerns were often dismissed or ignored during these consultations. Further research is needed to determine how more extensive training for oncologists in the understanding and use of routine needs assessment tools might facilitate increased discussion of psychosocial issues. In addition understanding the patient’s perspective about the discussion of such issues is vital, as this might not be the forum in which they wish to discuss such difficulties.
5 References


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Appendix A. PC-NAT

A reproduction of the Palliative Care Needs Assessment Tool (PC-NAT) as used in the study.

<table>
<thead>
<tr>
<th>SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does the patient have a caregiver readily available if required? Yes</td>
</tr>
<tr>
<td>2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)? Yes</td>
</tr>
<tr>
<td>3. Do you require assistance in managing the care of this patient and/or family? Yes</td>
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<table>
<thead>
<tr>
<th>SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)</th>
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</thead>
<tbody>
<tr>
<td>Level of Concern</td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Is the patient experiencing unresolved physical symptoms? Yes</td>
</tr>
<tr>
<td>Does the patient need help with daily living activities? Yes</td>
</tr>
<tr>
<td>Are the patient's psychological symptoms interfering with wellbeing or relationships? Yes</td>
</tr>
<tr>
<td>Does the patient have an unmet need for information? Yes</td>
</tr>
<tr>
<td>Does the patient have concerns about spiritual or existential issues? Yes</td>
</tr>
<tr>
<td>Does the patient have financial or legal concerns that are causing distress or require assistance? Yes</td>
</tr>
<tr>
<td>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? Yes</td>
</tr>
</tbody>
</table>

COMMENTS: 

<table>
<thead>
<tr>
<th>SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)</th>
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</thead>
<tbody>
<tr>
<td>Level of Concern</td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Is the caregiver or family distressed about the patient's physical symptoms? Yes</td>
</tr>
<tr>
<td>Is the caregiver or family having difficulty providing physical care? Yes</td>
</tr>
<tr>
<td>Does the caregiver or family have financial or legal concerns that are causing distress or require assistance? Yes</td>
</tr>
<tr>
<td>Does the caregiver or family have unmet needs for information? Yes</td>
</tr>
<tr>
<td>Is the family currently experiencing problems that are interfering with their functioning or interpersonal relationships, or is there a history of such problems? Yes</td>
</tr>
</tbody>
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COMMENTS: 

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<thead>
<tr>
<th>SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Concern</td>
</tr>
<tr>
<td>-------------------</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning? Yes</td>
</tr>
<tr>
<td>Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning? Yes</td>
</tr>
</tbody>
</table>

COMMENTS: 

<table>
<thead>
<tr>
<th>IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE PLEASE COMPLETE THIS SECTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral to (Name and Specialty)</td>
</tr>
<tr>
<td>Priority of assessment needed: [ ] Urgent (within 24 hours) [ ] Semi-Urgent (3-7 days) [ ] Non-Urgent (next available)</td>
</tr>
<tr>
<td>Have you discussed the referral with the client? [ ] Yes [ ] No</td>
</tr>
<tr>
<td>Has the client given consent for the referral? [ ] Yes [ ] No</td>
</tr>
<tr>
<td>Referral from: Name: __________________ Position: __________________ Signature: __________________</td>
</tr>
</tbody>
</table>
ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

PATIENT WELLBEING

Physical
- Does the patient present with unresolved physical symptoms such as dizziness, fatigue, vomiting, headaches, pain, constipation, sleep problems, diarrhea, or loss of 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, irritability, anger, tearfulness 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 concerns 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 healthcare 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? (NE older patients are under-represented in SPCRs.)

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 B. Patient Information Letter

Patient Information Letter for the study.

INFORMATION ABOUT THE RESEARCH PROJECT:
Evaluation of a Needs Assessment Intervention
Version 1 (HNEH): 25/10/07

OPTION TO CONSENT TO AUDIO-TAPING OF CONSULTATIONS:
You have consented to take part in the Evaluation of a Needs Assessment Intervention.
Study as outlined in the Patient Information letter (Version 5: 23/08/07). You are now invited to take part in a smaller study which will look at the impact of the Needs Assessment Tool on consultation time and content.

Why is the research being done?
Using assessment tools can help health professionals to identify the needs of people with cancer; however, the time taken to complete these tools may determine whether they are actually used. By audio-taping consultations with your doctor, we can find out how using the recently developed Needs Assessment Tool affects consultation time. We would also like to see how the issues that were recorded on the Needs Assessment Tool were discussed between you and your doctor during the consultation. Audio-taping consultations can also provide you with a record of the information discussed in the consultation that you can review as needed, or share with your family.

Who can participate?
We are inviting people to participate who have already agreed to take part in the Evaluation of a Needs Assessment Intervention study. As you are participating in this study, you are nominated as a possible participant in this audio-taping research.

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. You will also be able to continue your participation in the Evaluation study. 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.

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.
- Give permission for 2.4 of your consultations to be audio-taped by the research team. These recordings will be transcribed by the research team. A copy of the tape will also be available to you upon request.

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. Copies of the PC-NAT, interview transcripts and tapes will also be stored in a locked filing cabinet and will be identified by a code number and any identifying information will be removed. Data will be stored in a locked store room for a minimum of seven 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. 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 questions, please ask the research nurse or 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, the research nurse will contact you to find out when your next appointment will be. You have been given a copy 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 nurse 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
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 please contact the Social Work Department at the Mater Hospital on 4521 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 Weller, Amy.Weller@newcastle.edu.au, Claire Johnson: Claire.Johnson@newcastle.edu.au or myself: AtaGirgis@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 AtaGirgis
Chief Investigator

Professor David Currow
Principal Investigator

Complaints
This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 06/06.27.4.01. Should you have concerns about your rights as a participant in this research, or if an independent person is preferred, to Dr Nicole Gerrand, Professional Officer (Research Ethics), Hunter New England Health Ethics Committee, Hunter New England Health, Locked Bag 1, New Lambton NSW 2305, telephone (02) 4921 4500, email Nicole.Gerrand@hneh.health.nsw.gov.au

The Project Research Team:
Professor AtaGirgis, Chief Investigator
Professor Stephen Ackland, HNEH, University of Newcastle
Professor David Currow, Flinders University, Adelaide, SA
Ms Claire Johnson, CHerP
Ms Amy Weller, Candidate, Doctor of Philosophy
Appendix C. Patient Consent Form

Patient Consent Form as used in the study.

ID number: [redacted]

PATIENT CONSENT FORM:
Evaluation of a Needs Assessment Intervention
Audio-taping sub-study
Researchers: Abaf Gagis, Stephen Ackland, David Currow,
Claire Johnson, and Amy Walker
Version 1 (HNEH): 25/10/07

The Cancer Council
New South Wales
Centre for Health Research & Psycho-oncology (CheRP)

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 769 016.

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 statement (Version 1 dated 25/10/07), 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 having 2-4 of my consultations with my doctor(s) audio-taped by the research team. I understand that a copy of the tape(s) will be made available to me on my request.

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 or to the research nurse in person.

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 contact details are:
Telephone: ___________________________ Mobile: ___________________________

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: ___________________________

The Cancer Council
New South Wales
Centre for Health Research & Psycho-oncology

Langworth Avenue
Wollongong NSW 2227 Australia
Locked mail bag 10
Wollongong NSW 2227
Telephone (02) 4224 6372
Facsimile: (02) 4224 6266
e-mail: CheRP@newcastle.edu.au
Appendix D. Clinician Information Letter

Clinician Consent Form as used in the study.

INFORMATION ABOUT THE RESEARCH PROJECT:
Evaluation of a Needs Assessment Intervention
Version 1 [RHEH]: 25/10/07

OPTION TO CONSENT TO AUDIO-TAPING OF CONSULTATIONS
You are invited to take part in a study that is being conducted by the Centre for Health Research & Psycho-oncology (CHoRP). This study is a sub-study of the Evaluation of a Needs Assessment Intervention Study, which aims to find out how helpful the Needs Assessment Guidelines and Assessment Tool are in improving the care of patients and caregivers by assessing and addressing their unmet needs earlier. You are now invited to take part in this study looking at the impact of the Needs Assessment Tool on consultation time and content.

Why is the research being done?
Research has shown that practical concerns are important considerations for health professionals and patients involved in the assessment process, particularly as time is often limited. In fact, the time required to conduct an assessment may act as a barrier to the use of assessment tools. By audio-taping consultations with your patients, we can find out how using the recently developed Needs Assessment Tool affects consultation time. We would also like to see how the issues on the Needs Assessment Tool are discussed within the consultation. Finally, providing patients with audio-tapes of their consultations improves patient recall and understanding of information, caters for varying levels of information needs and allows for flexible information review for patients as well as their families, without detrimental psychological effects.

Who can participate?
We are inviting medical oncologists and haematologists whose patients are involved in the Evaluation study to take part in this sub-study. You have been nominated as a possible participant in this research.

What choice do you have?
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 and request that the information you have already provided be destroyed. Eligible patients from consenting doctors will be approached for their individual consent to participate only after their doctor has given consent.

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.
- Give permission for some of your consultations to be audio-taped by the research team. These recordings will be transcribed by the research team. A copy of the tape will also be available to you upon request.
- A research nurse will attend the clinic for each consenting participant, start the tape at the beginning of the consultation then leave the consultation room. She will remain in the clinic waiting area to stop the tape when the consultation ends (i.e. when the patient leaves the room).
- If the research nurse is not able to be present at the time the consultation takes place, you will be asked to start and stop the tape and give this tape to the research nurse. A reminder note will be placed in the files of participating patients to prompt you to tape these consultations.

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. Copies of the PC-NAT, interview transcripts and tapes will also be stored in a locked filing cabinet and will be identifiable by a code number and any identifying information will be removed.
Data will be stored in a locked store room for a minimum of seven 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. 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 questions, please ask the research nurse or 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. You have been given a copy 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 nurse 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 or would like more information about the study
If you would like more information about this research project, please feel free to contact us by telephone on 1800768016, or by emailing us. (Amy Waller: Amy.Waller@newcastle.edu.au, Claire Johnson: Claire.Johnson@newcastle.edu.au or myself. Ataf.Girgis@newcastle.edu.au) You can also contact a member of the research team to raise any concerns.

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 Ataf Girgis  Professor David Currow
Chief Investigator  Principal Investigator

Complaints
This project has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 05/06.274.01. 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 Gerrard, 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 4590, email Nicole.Gerrard@hnehealth.nsw.gov.au

The Project Research Team:
Professor Ataf Girgis, Chief Investigator
Professor Stephen Ackland, HNEH, University of Newcastle
Professor David Currow, Flinders University, Adelaide, SA
Ms Claire Johnson, CHeRP
Ms Amy Waller, Candidate, Doctor of Philosophy
Appendix E. Clinician Consent Form

Clinician Consent Form as used in the study.

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 766 816.

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 (Version 1 dated 25/10/07), 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 having 2-4 consultations per consenting patient audio-taped by the research team. I understand that a copy of the tape(s) will be made available to me on my request. I also understand that a copy of the tape(s) will be made available to the patient on their request.

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 or to the research nurse in person.

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:
Telephone: ___________________________ Mobile: ___________________________

Centre for Health Research & Psycho-oncology
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Appendix F. Code Book

Final version of the code book used to conduct the qualitative analysis.

Code Book

**Objective 1:** Determine method used by HCPs to complete PC-NAT

1.1 **Timing:** Denotes when during the consultation the PC-NAT is administered.

1.1.1 Start of Consultation

1.1.2 During Consultation

1.1.3 End of consultation

<table>
<thead>
<tr>
<th>1.1 Timing</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1.1 Start of Consultation:</td>
<td>This is coded if the PC-NAT is delivered in the first third of the consultation.</td>
</tr>
<tr>
<td>1.1.2 During Consultation:</td>
<td>This is coded if the PC-NAT is delivered in the middle third of the consultation.</td>
</tr>
<tr>
<td>1.1.3 End of consultation:</td>
<td>This is coded if the PC-NAT is delivered in the last third of the consultation.</td>
</tr>
</tbody>
</table>

1.2 **Integration in Consultation:** Denotes technique used by the oncologist to implement the PC-NAT within the session.

1.2.1 Facilitated conversation

1.2.2 Non-facilitated conversation

<table>
<thead>
<tr>
<th>1.2 Integration in Consultation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.2.1 Facilitated conversation</td>
<td>This is coded if the PC-NAT is administered in a less formal and structured manner than if it was read verbatim. Indications of this may include the use of more lay terms to elicit response and if the PC-NAT is more integrated into the entire consultation.</td>
</tr>
<tr>
<td>1.2.2 Non-facilitated conversation</td>
<td>This is coded if the PC-NAT is administered in a manner which indicates that the health professional is reading the items verbatim or very close to</td>
</tr>
</tbody>
</table>
conversation verbatim. An indication of this would be the use of similar wording in the question as is found in the PC-NAT and if the items are asked in the order they appear on the PC-NAT.

1.3 Language used (translation of concepts): The language used by the doctor during administration or discussion of the themes outlined in the PC-NAT.

1.3.1 Jargon
1.3.2 Lay Terms

<table>
<thead>
<tr>
<th>Language used</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.3.1 Jargon</td>
<td>This is coded if the PC-NAT is delivered in a manner which includes the use of jargonistic terms which are outlined on the PC-NAT form. This may include the use of such terms as ‘existential’ or ‘psychological symptoms’.</td>
</tr>
<tr>
<td>1.3.2 Lay Terms</td>
<td>This is coded if the PC-NAT is delivered in a manner which includes the use of more basic and understandable terms than those outlined on the PC-NAT form. This could include when asking about psychological symptoms questioning how the patient is “coping”?</td>
</tr>
</tbody>
</table>

Objective 2: Determine whether the content of the consultation includes an increase in discussion of psychosocial issues in those sessions which incorporate the PC-NAT compared to those do not. This would be determined by an increase in the time spent discussing themes related to psychosocial issues. In addition, using the PC-NAT will also facilitate more empathic communication and shared understanding by medical staff in response to patient and caregiver concerns.

Goal of coding: code communication and interaction between patient and MD to be able to identify extent to which psychosocial issues are discussed and how?

2.1 Content of Discussion: The themes discussed during the consultation. Coded for each utterance is whether a question is asked (open or closed), whether information is given or the doctor is providing counselling and for each what theme is being raised medical condition, therapeutic regime, lifestyle, psychosocial or another undefined theme.

Mode:
• **Asks Closed-Ended Question:** A closed ended question is one which is “interrogative” (Beckman 1984) and limits the responder to a specific or a specific range of responses (Beckman 1984). It is one that asks for specific information (Ford 1996). An example of this form of question “Are you on something to thin your blood out?”

• **Asks Open-Ended Question:** A inquiry which is “…non-specific(ity)” and “probing nature” and allows the patient, caregiver or doctor to give a more detailed answer. These questions often start with “what”, “why” or “how” (Ford 1996). An example of an open question “Tell me how you've been feeling since I last saw you”

• **Gives Information:** Statements which give factual information, delivered in a neutral tone with no direction given to the other participants. May convey information regarding “…actions to be taken by speaker or others” (Miller 2005). An example of ‘gives information’ would be “Um the main side-effects, is tingling in the fingers when you touch something cold.”

• **Counsels:** “Statements that suggest or imply some resolution or action to be taken by the other person (usually the patient)” (Miller 2005). An example of ‘counsels’ would be “Certainly, it’s worth having a go knowing that if you don’t tolerate it, you don’t like it, you don’t have to have another one”

**Content:**

• **Medical Condition:** The content of the utterance focuses on the diagnosis, physical health and tests/results for the patient. In regards to physical health, includes communication between oncologist/health professional and/or patient and/or caregiver which focuses on the physical health of the patient. These would include discussions of the physical health impact of the cancer and may include issues such as pain and fatigue (e.g., “How are you?”, “Yeah, first happened in Townsville. I had both legs were huge”). In regards to tests and results includes communication between oncologist/health professional and/or patient and/or caregiver which focuses on test results, the facts and figures (“How was my last test yesterday?”, “Blood tests still look pretty good. Just let me have a look at your last Para protein – from – I think when we looked at it, it was still”).

• **Therapeutic Regime:** The content of the utterance focuses on the treatment of the patient in regards to their diagnosis and includes therapeutic regimes, side effects from treatment and treatment history. In regards to treatment, includes communication between
Lifestyle: The content of the utterance focuses on the everyday functioning of the patients, their ability to perform Activities of Daily Living (ADLs) and includes communication between oncologist/health professional and/or patient and/or caregiver which focuses on the ability of the patient to perform Activities of Daily Living (ADLs) which include toileting, cleaning, showering, bathing, or food preparation and also extends to discussion of what difficulty the patient may have in performing other tasks they we once able to complete fully (e.g., “...interfering with your ability to function and doing daily things?”, “When you’re shaving or trying to comb your hair”).

Psychosocial: Content of utterance focuses on psychosocial issues and may include themes related to psychological functioning, needs for information, spiritual issues, financial and legal issues, health beliefs and supports. In regards to psychological functioning, includes communication between oncologist/health professional and/or patient and/or caregiver which focuses on the psychological aspects of the patients care which includes distress, mood, anxiety and any emotional difficulty they maybe.
experiencing at the time of their diagnosis and treatment. This would also include any
calls for a hastened death or suicide. Also included would be any relationship issues for
the patient (e.g., “Any psychological symptoms interfering – well, hard not to be.”, “If I
give her the sh*ts, she nicks off”). In regards to need for information, includes
communication between oncologist/health professional and/or patient and/or caregiver
which focuses on the seeking of or offering of more information about course and
prognosis of the disease and treatment options and also other services which may be of
assistance. These discussions would centre around a blatant request or offer of additional
information and would not be coded for questions about course and prognosis of the
disease and treatment options and also other services which may be of assistance (“Do
you feel like you need more information about what’s going on?”, “We would like some
more information regarding palliative caregiver services”). In regards to spiritual issues,
includes communication between oncologist/health professional and/or patient and/or
caregiver which focuses on the spiritual and existential issues for the patient. These would
include discussions of afterlife or what happens after death, what the patient feels about
their “life” and discussions of spiritual services available (“I would just rather sit there
looking at the lake or sit there with a rod in my hand with a fish on the end and saying,
hooroo, that’s it, I’m off.”, “I believe in miracles, so something may happen, you never
know.”). In regards to financial and legal concerns, includes communication between
oncologist/health professional and/or patient and/or caregiver which focuses on the
financial or legal concerns of the patient and caregiver. Topics of discussion may include
loss of income or costs of treatment, travel expenses, or equipment and also accessing
services which may assist with these aspects of care. Legal issues may extend to end of
life issues (“Any financial or legal concerns?”, “I haven’t even thought about my will
yet”). In regards to health beliefs, includes communication between oncologist/health
professional and/or patient and/or caregiver which focuses on the beliefs or attitudes that
may make health care provision difficult. This may also include language barriers or
social/cultural issues which impact on health/treatment (“...from a health delivery point
of view, do you have any health beliefs, cultural or social factors that make things more
complex”, “Well what I would like to do, is to discuss it with the family and the kids.”).
In regards to supports, includes communication between oncologist/health professional
and/or patient and/or caregiver which focuses on the discussion of the supports that the
patient has in their life and also discussions of whether further supports would be appropriate (“My GP calls me in when he suspects that I’m not travelling well.”).

- **Other:** Content of utterance focuses on issues not covered by the above mentioned categories of content, and this can include communication between oncologist/health professional and/or patient and/or caregiver which focuses on building rapport and discussing aspects of the health professional’s and patient/caregiver’s lives not associated with cancer diagnosis, treatment or prognosis. This could be considered as social banter between the parties involved in the consultation. *(e.g., “Alright, so you went for a little trip to the NT and how did it go?”).*

<table>
<thead>
<tr>
<th>2.1 Content of Discussion</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1.1 Asks Closed-Ended Question</td>
<td>Medical Condition</td>
</tr>
<tr>
<td>2.1.2 Asks Closed-Ended Question</td>
<td>Therapeutic Regime</td>
</tr>
<tr>
<td>2.1.3 Asks Closed-Ended Question</td>
<td>Lifestyle</td>
</tr>
<tr>
<td>2.1.4 Asks Closed-Ended Question</td>
<td>Psychosocial</td>
</tr>
<tr>
<td>2.1.5 Asks Closed-Ended Question</td>
<td>Other</td>
</tr>
<tr>
<td>2.1.6 Asks Open-Ended Question</td>
<td>Medical Condition</td>
</tr>
<tr>
<td>2.1.7 Asks Open-Ended Question</td>
<td>Therapeutic Regime</td>
</tr>
<tr>
<td>2.1.8 Asks Open-Ended Question</td>
<td>Lifestyle</td>
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<tr>
<td>2.1.9 Asks Open-Ended Question</td>
<td>Psychosocial</td>
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<tr>
<td>2.1.10 Asks Open-Ended Question</td>
<td>Other</td>
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<tr>
<td>2.1.11 Gives Information</td>
<td>Medical Condition</td>
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<tr>
<td>2.1.12 Gives Information</td>
<td>Therapeutic Regime</td>
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<td>2.1.13 Gives Information</td>
<td>Lifestyle</td>
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<td>2.1.14 Gives Information</td>
<td>Psychosocial</td>
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<tr>
<td>2.1.15 Gives Information</td>
<td>Other</td>
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<tr>
<td>2.1.16 Counsels</td>
<td>Medical Condition/Therapeutic Regime</td>
</tr>
<tr>
<td>2.1.17 Counsels</td>
<td>Lifestyle/Psychosocial</td>
</tr>
</tbody>
</table>

**2.2 Initiation of Concerns:** Denotes the consumer who raises a concern, patient or caregiver, and whether this concern is related to medical or psychosocial issues. Concerns are statements or questions raised by the patient or caregiver which express some form of uncertainty, anxiety or worry. Within each concern it is also coded as to whether the concern is a primary concern or a secondary concern. A **primary concern** is one that is raised without prompting from another problem (e.g., “The pain in my stomach has been much worse since our last appointment”), whereas a **secondary concern** is one where an issue has already been raised and this concern is a direct result of that problem (e.g., “I am getting very anxious about the time it is taking for my results to come back”).

2.2.1 Patient (Medical/Therapeutic Regime)
2.2.2 Patient (Lifestyle/Psychosocial)
2.2.3 Caregiver (Medical/Therapeutic Regime)
2.2.4 Caregiver (Lifestyle/Psychosocial)
| 2.2.1 Patient | Initiating discussion of concern (medical) | An item of concern is raised by the patient which pertains to physical health. This includes questions or statements which indicate some level of worry or uncertainty about issues such as medication, treatment, tests, pain, fatigue or any other physical health issue. This concern may be raised in regards to an issue for the patient or caregiver.  
“…going to make me feel crook, and I don’t want to do that”  
“Is that a port there?” | Primary Concern: | Secondary Concern: |
| 2.2.2 Patient | Initiating discussion of concern (psychosocial) | An item of concern is raised by the patient which relates to the psychosocial aspects of care and functioning. These concerns may extend to those psychosocial such as psychological wellbeing, daily functioning, information needs, financial and legal concerns, health and cultural beliefs and issues about supports and relationships. Often this concern will be the secondary impact of the cancer diagnosis and treatment such as the distress caused by a palliative treatment option. This concern may be raised in regards to an issue for the patient or caregiver.  
“If I give her the sh*ts, she nicks off”  
“If I could afford to travel, I would travel forever. But that’s not going to happen. ” | Primary Concern: | Secondary Concern: |
### 2.2.3 Caregiver

**Initiating discussion of concern (medical)**

An item of concern is **raised by the caregiver** which pertains to **physical health**. This includes questions or statements which indicate some level of worry or uncertainty about issues such as medication, treatment, tests, pain, fatigue or any other physical health issue. This concern may be raised in regards to an issue for the patient or caregiver.

“He’s having a few falls, too. Nasty falls.”

“first have to establish a trust and they don’t trust us because you’re in there asking for morphine”

<table>
<thead>
<tr>
<th>Primary Concern:</th>
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<td>Secondary Concern:</td>
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### 2.2.4 Caregiver

**Initiating discussion of concern (psychosocial)**

An item of concern is **raised by the caregiver** which relates to the **psychosocial aspects** of care and functioning. These concerns may extend to those psychosocial such as psychological wellbeing, daily functioning, information needs, financial and legal concerns, health and cultural beliefs and issues about supports and relationships. Often this concern will be the secondary impact of the cancer diagnosis and treatment such as the distress caused by a palliative treatment option. This concern may be raised in regards to an issue for the patient or caregiver.

“Oh, no I do with the dressing and that a bit. He can’t get”

“Just a bit worried when I have the hip done, that’s all”

<table>
<thead>
<tr>
<th>Primary Concern:</th>
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<tr>
<td>Secondary Concern:</td>
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### 2.3 Empathy (Quality of Interaction): A behavioural rating of empathy provided by the oncologist in response to a concern raised by a patient or caregiver.

<p>| | |</p>
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<td>2.2.3</td>
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<td>2.2.4</td>
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<tr>
<td>2.3.1</td>
<td>Shared feeling or experience</td>
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<td>2.3.2</td>
<td>Confirmation</td>
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<tr>
<td>2.3.3</td>
<td>Pursuit</td>
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<td>2.3.4</td>
<td>Acknowledgement</td>
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<tr>
<td>2.3.5</td>
<td>Implicit recognition</td>
</tr>
<tr>
<td>2.3.6</td>
<td>Perfunctory</td>
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<tr>
<td>recognition response, giving the empathic opportunity minimal recognition</td>
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<tr>
<td>2.3.7 Denial/Disconfirmation</td>
<td>This was coded when oncologist either ignored the patient’s empathic opportunity or makes a disconfirming statement.</td>
</tr>
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Appendix G. Extended Method

Extended Method, which describes in greater detail the approach used to conduct the analysis.

Method

This study analysed audio-tapes of consultations collected as part of an interrupted time series study (referred to herein as the main study) of the impact of systematic utilisation of the Palliative Care Needs Guidelines and PC-NAT on individuals’ with advanced cancer and their caregivers’ health outcomes and service utilisation (A. Girgis et al., 2008; Waller, A, et al., 2010; Waller et al., 2008) (See Figure 1).

Participants
The main study recruited 219 outpatients across four hospitals in New South Wales (NSW), Australia. Inclusion criteria for patients in the main study were: diagnosed with advanced cancer, aged 18 years or older, sufficient understanding of English, and emotionally and cognitively capable of participating in the study as judged by the treating staff. The inclusion criteria for caregivers were: nominated by the patient as the primary caregiver and sufficient understanding of English. For pragmatic reasons, the site in closest proximity to the research team was selected for the present audio-taping, sub-study with all of the 45 patients and caregivers who were recruited from this site considered for inclusion in the sub-study.

Procedures
The procedures for the sub-study were embedded within those for the main one. Initially, for the main study, an eligible participant was identified, through the outpatient clinic lists, by an on-site research nurse. The research nurse then assessed the criteria in discussion with the
treating oncologist before asking participants for consent (Appendix B & C). For the sub-study, consent was also gained from potential participants’ treating oncologist (Appendix D & E) to audio-tape the consultations. Of the 45 potentially eligible patients at the sub-study site included, eight were excluded by their treating oncologist (two had withdrawn from the main study, five required inpatient admissions during the sampling period of the sub-study and so were no longer eligible and one was deceased). The remaining 37 patients were approached to participate in the main study by the research nurse at the time of their scheduled consultation, and 20 consented to having their consultations audio recorded on up to four occasions for the purpose of the sub-study. These 20 patients were seen in consultations by one of 11 oncologists. Of the 20 patients 14 were able to see the same oncologist at all of their recorded consultations, seven saw two different oncologists. 10 of the 20 patients brought a caregiver with them to sessions. Participants were recorded during a “baseline consultation” which did not include the PC-NAT and then subsequent “post intervention” consultations which included the PC-NAT. The seventeen who declined to participate stated that they were not interested in participating. Figure 1 provides a summary of the flow of participants from the main study into the sub-study, where a patient withdraws from the main study they are also withdrawing from the sub-study.

For the purpose of the study, it was decided that an academic detailing approach would be used to inform health professionals about the importance of the Palliative Care Needs Guidelines and the PC-NAT, as well as provide initial training in the use of these resources. Academic detailing sessions are brief, focused and delivered in the health professionals’ own environments and health professionals have expressed preference for this method. In this study, both individual and group sessions were used, depending on the availability of health professionals and their perceived degree of involvement in working with patients and
caregivers at the treatment centres (i.e., those less involvement with patients would require only detailing through a group session).

**Data Collection**

For all patients consenting to the audio-taping of their consultations, the research team aimed to audio-tape one baseline consultation, which did not involve completion of the PC-NAT, and then one to three post-intervention consultations, which were scheduled to have the PC-NAT completed. The research nurse attended the clinic for each consenting participant to start the tape at the beginning of the consultation then left the consultation room. The research nurse remained in the waiting room and re-entered the consultation room once the patient had left, to stop the audio-tape. If the research nurse was unavailable at the time of the consultation, a reminder note was placed into the patient’s file as a prompt to the oncologist to tape the consultation. All tapes were collected by the research nurse and later transcribed verbatim by an experienced member of the research centre.

**Data Analysis**

Qualitative analysis was the main approach used to explore the interactions between the oncologist, patient and caregiver and address objectives 1 and 2. Quantitative methods were utilised to address objective 3. The main advantage of using qualitative methods to address objectives 1 and 2 is that inductive analysis allowed for the specific details of an interaction between palliative cancer patients, caregivers, and oncologists to be examined before moving to a ‘general understanding’ of the consultations (Streubert Speziale & Carpenter, 2003), both with and without the PC-NAT. In addition, qualitative methods allowed for an in-depth analysis of the processes used by oncologists to complete the PC-NAT and the context in which it is used (Streubert Speziale & Carpenter, 2003). The qualitative method utilised was ‘thematic survey’ (Sandelowski & Barroso, 2003), which aims to identify participants’ patterns of responses or themes associated with specific topics. In the context of this sub-
study, themes were identified by characterising the quality and nature of the topics raised during the consultation and then categorising trends using codes (Sandelowski & Barroso, 2003).

Initial coding was carried out using methods proposed by several other researchers (Fonteyn, Vettese, Lancaster, & Bauer-Wu, 2008; McQueen, McLellan, Kay, & Milstein, 1998; Tong, Sainsbury, & Craig, 2007). First, an initial three transcripts were independently coded by two members of the research team. Each transcript was read once in its entirety to gain an understanding of the content and determine what aspects were of note in regards to the study objectives before undertaking line-by-line coding. When utterances related to the research objectives were noted, a code was assigned to convey the meaning of that text. A code was a brief description of a behaviour or instance that allowed the data to be sorted into categories (Burman & Margolin, 1992). For example, when the content of an utterance was in regard to past treatments the code assigned was: ‘Focus/Topic of communication – Medical - Treatment history’. The initial iteration of the code book emerged from the coding of these initial transcripts and was reviewed by the research team to discuss the coding structure and compare codes. Discrepancies between the coders were resolved through discussion until a consensus was reached. Further coding of other transcripts was undertaken by the candidate and patterns of response or behaviours identified during coding were compared to what has been documented in the patient-health care provider communication literature to further guide the labelling of codes and additional analyses. The main additions to the coding scheme after this literature review were the integration of codes related to the type of communication (eg open versus closed questions) (Roter, Hall, & Aoki, 2002) and the level of empathy expressed by the oncologist (eg Denial/disconfirmation-Shared understanding) (Buylund & Makoul, 2005).
Continued review of the coding book by the research team through trialling of the code book on additional transcripts occurred until the final coding scheme was formed. Coding was then completed by the candidate for the remaining 6 transcripts and no new codes emerged. The final code book (Appendix F) was divided into three sections and mirrored the study objectives.

**Objective 1: Examine the approaches used by oncologists to complete the PC-NAT in the consultation setting.**

The code book aimed to capture variations in the process of completion of the PC-NAT by coding for the 1) timing of the administration of PC-NAT, 2) integration of the PC-NAT in the overall consultation, and 3) language used by the oncologist when administering the tool.

**Objective 2: Explore the potential of the PC-NAT to facilitate discussion of psychosocial issues.**

To address objective 2, transcripts were coded to identify 1) the types of concerns raised by patients, caregivers, and oncologists and 2) the quality of oncologists’ response to patients’ and caregivers’ concerns. For types of concerns raised, the code book divided the content of the consultations into discussions pertaining to medical versus psychosocial concerns. Within the medical code, discussion was coded as medical condition (eg pain), therapeutic regime (eg treatments) or other (eg social conversation). Within the psychosocial domain discussion was coded as lifestyle (eg ADLs), psychosocial (eg mental state) or other (eg social conversation). The way each participant (patient, caregiver or oncologist) expressed his/her thoughts was also coded (eg open/closed question, giving information). For the quality of the discussion was considered, as in the initial three transcripts it was recognised that the quality of the discussion reflected the level of empathy used by the oncologist, codes assigned mainly reflected differential levels of empathy doctor displayed in
regards to the medical and psychosocial concerns raised by patients and caregivers. (Beckman et al., 1994; Buylund & Makoul, 2005). The level of empathy the The level of empathy coded for was based on the work of (Buylund & Makoul, 2005) and ranged from 'Denial/Disconfirmation’ (no empathy expressed) to ‘Shared Feeling or Experience’ (maximum expression of empathy) (Figure 2). To ensure methodological rigour of this qualitative study, the study met the criteria of credibility, dependability, confirmability and transferability (Reige, 2003; Streubert Speziale & Carpenter, 2003) and used the guidelines as reported in Tong et al. 2007. The techniques used to ensure methodological rigour are presented in Table 3.

**Objective 3 – Assess the impact of completion of the PC-NAT on consultation length.**

The ‘length of consultation’ was the amount of time that had passed from the time the conversation began between the oncologist and patient/caregiver, regardless of the nature of the conversation, until the conversation had finished and the appointment was ended. The mean length of consultations in minutes was determined for all consultations and a linear mixed model was completed to assess the difference in means between each time point which included the PC-NAT and those which did not. Linear mixed-effects modelling allows for handling of correlated data which occurs with the repeated measurements of instruments such as with the patients in this sample. A general linear model was appropriate as it assumes independence of the data. Statistical Package for Social Sciences (SPSS) was used to analyse the data.
Appendix H. Extended Results

Extended Results, which describes in greater detail the results of the study.

Results

Participants
Of the 20 participants involved in the sub-study, 10 were female and 10 were male. All patients had a diagnosis of advanced cancer, with other characteristics shown in Table 1. The 20 participants had a mix of baseline and/or post PC-NAT consultations audio-recorded. The breakdown of these consultations can be seen in Table 2. A total of 48 audio recordings or transcripts were reviewed: 13 baseline and 35 post-PC-NAT. As shown in Table 2, six participants had no baseline recording (i.e., without PC-NAT), but these participants did have at least one post PC-NAT consultation. As detailed in Table 2, 14 participants had a baseline consultation, and 11 of these had at least one follow-up consultation where the PC-NAT was implemented.

Table 4.
Total Number of Audio-Recordings at Each Study Phase.

<table>
<thead>
<tr>
<th>Consultation</th>
<th>Percent of Total Number of Audio-Recordings % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>27.1 (n=13)</td>
</tr>
<tr>
<td>Post Intervention 1</td>
<td>37.5 (n=18)</td>
</tr>
<tr>
<td>Post Intervention 2</td>
<td>25 (n=12)</td>
</tr>
<tr>
<td>Post Intervention 3</td>
<td>6.2 (n=3)</td>
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<tr>
<td>Post Intervention 4</td>
<td>4.2 (n=2)</td>
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</table>

The results for Objective 1 have been found using the 35 post intervention recordings, the recordings where the PC-NAT was utilised. These 35 recordings were completed with n=17
patients and n=7 caregivers. In regards to baseline recordings, 10 of these 17 participants had had at least one prior consultation with an oncologist, where the tool had not been used (ie ‘baseline’), but the remaining 7 had not. The results for Objective 2 have been found using all 48 audio recordings, with n=20 patients and n=10 caregivers. The breakdown of these recordings can be viewed in Table 4. The results for Objective 3 have been determined by comparing the mean times at each time point. The numbers of audio recordings for each time point can be seen in Table 4.

**Objective 1: Examine the Approaches Used by Oncologists to Complete the Palliative Care Needs Assessment Tool (PC-NAT) in the Consultation Setting**

When studying the mode of the PC-NAT administration it became apparent that oncologists most often administered the PC-NAT in the final third of the consultation. This seemed to result in rushing through the PC-NAT and using the PC-NAT appeared to be an afterthought, rather than an integral part of the consultation.

Oncologist: “Now the other thing which you’re on is this PC-NAT study, which we quickly need to run through.” [10171 Post]

It was observed during the first post intervention consultations when the PC-NAT was discussed for the first time with patients and caregivers, little preamble was provided as to the purpose or significance of the PC-NAT. It was often introduced as a requirement, given study participation. This seemed to constrain the extent to which patients’ and caregivers’ needs were explored or the extent to which the PC-NAT was a valued and integral part of the consultation.
Oncologist: “Now the other thing which you’re on is this PC NAT study, which we quickly need to run through. Previously I think Steve said that things were going along well, um, he’s always ticked no concerns.” [10171 Post 1]

Oncologist: “Now Alan you also consented to a Palliative Care Needs Assessment Tool Study – is that right?”
Patient: “Yeah, I suppose so. Yeah, if that’s what I’ve done, then yeah, I’ve done it!”
Oncologist: “OK, so there’s a few things I need to ask OK so, do you normally have a caregiver?” [10053 Post 1]

In subsequent post intervention session, again little explanation was given regarding the unmet needs assessment, and the patient appeared to view the discussion as a hurdle requirement, with little meaning to their treatment.

Oncologist: “OK. I’m going to ask you a few questions.”
Patient: “Oh, we’re going to run through our sheet again!” [10015 Post 3]

Oncologist: “Now, I’ve got to quiz you, because of this thing [PC-NAT] that we’re taping. OK? Are you experiencing any unresolved physical symptoms” [10107 Post 3]

Most often, oncologists assessed needs by reading through each prompt on the PC-NAT. As a result the PC-NAT was also delivered almost verbatim from the text on the tool and administered in a style that did not seem to match patients’ and caregivers’ knowledge. The PC-NAT includes language that would not routinely be used by patients or caregivers.
(jargon), as it was developed to guide oncologists’ assessment of the issues during consultation rather than be used to direct questions verbatim to patients and caregivers.

Oncologist: “Any psychological symptoms interfering with the wellbeing or relationships? …Do you have any concerns about spiritual or existential issues? …Do you have any financial or legal concerns that are causing distress or are persistent?” [10053 Post]

The verbatim reading of the PC-NAT prompts appeared to confuse some patients or caregivers and detract from the importance of the needs assessment. This confusion or misunderstanding, sometimes expressed as jokes, was not often addressed by the oncologist nor was clarification provided regarding the nature of the question or the area of needs assessment. The following exchange illustrates this point:

Oncologist: “Do you have any concerns about spiritual or existential issues?”
Patient: “No, I haven’t seen any ghosts or anything!”
Oncologist: “Do you have any financial or legal concerns that are causing distress or are persistent?” [10053 Post]

There were occasions when the oncologist would answer the questions for the patient. As apparent in the following quote, this seemed to limit the extent to which patients could then raise their needs. Often patients would simply confirm the thoughts of the oncologist or the oncologist moved onto the next question.
Oncologist: “Um, from a health delivery point of view, do you have any health beliefs, cultural or social factors that make things more complex – I don’t think so.”

Patient: “No.”

Oncologist: “From the health delivery point of view, are there any health beliefs, cultural or social factors involving the patient? No, I didn’t think so. You’re totally independent?”

Patient: “Yes.”

Oncologist: “You don’t have a carer?”

Patient: “Yeah, my wife. Yeah, yeah, I mean she does help me with certain things.”

Oncologist: “Does the patient need help with daily living activities? No. You don’t, you think?” [10171 Post]

**Objective 2: Explore the Potential of the PC-NAT to Facilitate Discussion of Psychosocial Issues**

**The content of discussion: Physical and psychosocial health.**

Although the main aim of the PC-NAT is to facilitate discussion of the range of physical and psychosocial issues, when the consultations were reviewed it seemed that the majority of interactions between the oncologist and patients related to medical and treatment issues, regardless of whether the PC-NAT was used or not and with little to no discussion of broader psychosocial concerns. The primary concern of the oncologists, patients, and caregivers was physical health. In the majority of consultations, the oncologist began by asking a general, open-ended question regarding well-being, which could be interpreted as concerning either physical or psychosocial health, but patients often responded by raising concerns pertaining to their physical health.

Oncologist: “How are you?”
Patient: “Oh, not too bad. I had a bit of a rough trot [difficult time] the last fortnight. Every time I eat, about 3 hours later I end up with bad pains in the stomach and I’d end up in care [emergency department] and it didn’t matter what I ate.” [10053 Baseline]

Similarly, when the consultations were reviewed from the point of view of the caregivers, the majority of interactions between the oncologists and the caregivers related to medical and treatment issues.

Caregiver: “He’d had terrible cramps in his hand, and the pain was so bad, and then he fell to sleep and I was sitting next to him and thought he was having his afternoon sleep, and then he woke up and he sort of didn’t know where he was or anything and he’d wet himself – absolutely saturated himself, and that’s not like.” [10115 Post 4]

Also observed was that the caregiver was rarely asked for their opinion regarding the patient’s or their own needs, whether medical or psychosocial. When listening to the audiotapes and reviewing the transcripts, it was often unclear that a caregiver was present until he/she spoke and expressed a thought or opinion about the patient’s care. The caregiver would often have to interrupt the discussion to express an opinion or ask a question rather responding to an invitation by the oncologist.

Oncologist: “OK, sounds like we should give you some antibiotics.”

Caregiver: “And she hasn’t – she’s just been laying more in bed than – she hasn’t got any strength to sit up. She wants to be laying down in bed all the time. She’s very lethargic.”
Patient: “And I can’t sort of get up and walk around like I did. I’ve got to have my walker. But I was only on my stick before. I was going good. Yeah. But I’ve just got to get my confidence back.” [10028 Post]

Often the issues raised by the caregiver were new issues and, whilst the patient agreed with them, it appeared these would not have been mentioned without the input of the caregiver.

It was observed that patients seemed to raise more and more physical and psychosocial concerns from the baseline session to the post-intervention sessions. At times there were only 2-3 concerns expressed in the baseline session for a patient and then 10+ concerns raised in the subsequent post-session. This finding was also noted for caregiver in regards to medical and psychosocial concerns. In addition it was noted that for the six patients whom had the same oncologist from the baseline to first post-intervention session, there was on average an increase in the number of psychosocial concerns raised. Below is a quote from a post-intervention session where during the needs assessment with the PC-NAT there is participation from the caregiver.

Oncologist: “Are the patient’s psychological symptoms interfering with wellbeing or relationship?”

Patient and Caregiver: “No.”

Oncologist: “You’re not cranky?”

Caregiver: “Of course he is! He’s irritable. Bit shorter [more quick tempered] than he used to be but he’s manageable! No – he’s fine.” [10123 Post]
Quality of the discussion of psychosocial issues: The role of empathy.

The range of empathic responses across transcripts ranged from a “denial or disconfirmation” of the issue raised to “confirmation” of the issue or concern (i.e., reflecting that a concern is valid). No responses to concerns raised offered some shared experience, therefore not reaching that highest level of empathy. When patients expressed a concern that was related to medical status or treatment the highest level of empathy coded for was confirmation, and similarly the highest level of empathy coded for psychosocial concerns. An example of confirmation is given below:

Patient: “I get down. I think it’s the mind games that I have trouble with because it’s you know, eating and things like that – I’m good. I just feel sorry for myself occasionally…."

Oncologist: “It’s always hard when people have fatigue too because as you said yourself, there can be many reasons for that.” [10168 Baseline]

Although confirmation was the highest level of empathy coded for in response to medical concern, the most often level of empathy noted was “pursuit” (Figure 2) that is oncologists were often requesting further information, either engaging in answering the patient’s question or providing information on treatment options and pursuing further information.

Patient: “Oh, for about 10 days I put up with it. And I came into casualty [emergency department] last Monday.”

Oncologist: “Because it was getting worse and worse?” [10053 Baseline]

When a psychosocial concern was raised by a patient, the highest level of empathy coded for was also confirmation (see Figure 2). However, most often, psychosocial concerns raised by
the patient were not confirmed or pursued and the concern was altogether dismissed, a level
of empathy consistent with ‘denial/disconfirmation’. The following quote illustrates this level
of empathetic response. Although the patient expressed how challenging it is not being able
to work, the oncologist does not acknowledge this concern and seemed to want to focus on
physical/practical aspects, steering the patient away from psychological concerns.

Patient: “12 months, yeah [time since finishing work]. I do not know, it’s just
boring”

Oncologist: “OK, do you want to take your shirt off?”

Patient: “I tell you what, this stuff, [Jesus] Christ [expression of surprise], it’s
given me some body hair!” [10053 Post 3]

When the concern expressed by the patient was dismissed, the patient appeared to follow the
oncologist’s lead and did not raise the concern again. Only when patients restated their
psychosocial concern did the oncologist respond to that concern. As shown below, the patient
continued to seek reassurance from the oncologist, even after the oncologist told the patient
“don’t worry about it”.

Patient: “Oh, yeah, but I think that’s arthritis, you know, you’re shooting pains –
but only this hand and I just go like that – my fingers have been very, very sore,
but maybe because we had a bit of red wine later and I better cut that out and
maybe that’s it?”

Oncologist: “Oh, I wouldn’t blame it on the red wine [laughs].”

Caregiver: “Do you like red wine too?”
Patient: “You’ll do me! [expressing delight that doctor might also enjoy red wine]”

Oncologist: “So, no, no, I mean was that [arthritis] present there before you were on Thalidomide?”

Patient: “Yes, yes, don’t worry about it. No.”

Oncologist: “I won’t worry too much about it.”

Patient: “For some reason I thought something’s not right – I don’t know why I felt it. Usually I’m competent, I know, because I think in a lot of ways we are our own doctor. We know how we feel. I’m sleeping, I certainly haven’t lost my appetite – so everything’s great so – good so nothing’s shown up, nothing to be concerned about because otherwise I reckon Michael [usual oncologist] will be seeing me.”

Oncologist: “I’m very happy, Michael (usual oncologist) has seen the results as well, so yeah he wasn’t worried.” [10107 Post 1]

Caregivers’ medical concerns were usually met with the same level of empathy as those of patients: ‘pursuit’. In this way the oncologist worked to validate the caregiver’s concern and worry by directly providing information, as illustrated by the interaction below.

Caregiver: “So, are you able to still treat her without it [port-a-cath]?”

Oncologist: “Oh, well she’s got some veins. A few. It makes it [treatment] much more difficult obviously.” [10028 Post 3]

Although the level of empathy coded for patients and caregivers concerns was the same, there were differences in the way that oncologists approached providing empathy to patients and
caregivers. Overall, concerns raised by caregivers seemed more often to be met with ‘denial/disconfirmation’. During many interactions with caregivers, the oncologist rarely pursued the concern that was raised. Often the oncologists responded by turning the conversation back towards the patient. In the interaction below, where the PC-NAT was used, the caregiver raised that she needed assistance with the patient’s activities of daily living. However, despite this being a part of the PC-NAT the exact nature of this need was not further explored before moving onto the next question in the assessment.

Caregiver: “Oh, no, I do (help the patient) with the dressing and that a bit. He can’t get [to it]?”

Oncologist: “Oh right, he can’t [reach].”

Caregiver: “And when you have a shower and trying to do your back with one hand.”

Patient: “Clothing, yeah.”

Oncologist: “Scratching your back!”

Patient: “I can do one side, half clean on the other half.”

Oncologist: “OK. Any unmet needs for information?” [10015 Post 4]

It was also noted that all codes reflecting ‘confirmation’ (i.e., highest level of empathy noted) were used in the baseline transcripts. The highest level of empathy coded for in post-intervention consultation transcripts reflected mainly pursuit. A finding consistent across medical and psychosocial concerns. No trend for the psychosocial concerns of caregivers was observed, as no caregiver psychosocial concerns were coded for in the baseline sessions.

**Objective 3: Length of Consultation**
The mean time length of those consultations where a PC-NAT was completed by the
oncologists was 18.1 min (range = 3.5 to 53.51) and the mean time for those consultations where no PC-NAT was completed (Baseline) at 19.5 min (range = 9.5 to 24.1). Using a linear mixed model to test the difference in means overtime, no significant difference was found between the each data collection point Baseline to Post Intervention 5 F(4, 34.5) = 0.49, p = .74. A repeated measures ANOVA like analysis was used but all data points were retained by the mixed model as missing values do not affect the estimation by dropping subjects. The covariance structure chosen for the residual matrix was compound symmetry. The within subjects correlation was r = 0.15 indicated that there was no correlation between time points for each patient, so there was no effect of patient or caregiver being likely to have “long” or “short” consultations.
Appendix I. Journal of Palliative Medicine Requirements

Overview of the Journal of Palliative Medicine and instructions given to authors. These instructions direct the writing of the manuscript portion of the submission.

Overview
Journal of Palliative Medicine (http://www.liebertpub.com/overview/journal-of-palliative-medicine/41/) is the premier peer-reviewed journal covering medical, psychosocial, policy, and legal issues in end-of-life care and relief of suffering for patients with intractable pain. The Journal presents essential information for professionals in hospice/palliative medicine, focusing on improving quality of life for patients and their families, and the latest developments in drug and non-drug treatments.

The companion weekly eNewsletter, Briefings in Palliative, Hospice, and Pain Medicine & Management, delivers the latest breaking news and information to keep clinicians and health care providers continuously updated. Journal of Palliative Medicine coverage includes:

- The latest medical advances in pain and symptom management
- Evidence-based protocols
- Model palliative care programs
- Clinical case reports
- Guidance for working with patients and their families
- Psychological and spiritual aspects of end-of-life care
- Roundtable discussions with leading experts in the field

Journal of Palliative Medicine is under the editorial leadership of Editor-in-Chief Charles F. von Gunten, MD, PhD, Provost, Institute for Palliative Medicine San Diego Hospice and other leading investigators.
**Audience:** Physicians and pediatricians, pharmacists, nurses, nurse practitioners, physician assistants, social workers, psychologists, pain medicine specialists, and hospice and nursing home staff, among others.

**Instructions for Contributors**

**Statement of Purpose and Policy**
Journal of Palliative Medicine will accept original manuscripts that contain material that has not been reported elsewhere, except in the form of an abstract of no more than 400 words. Prior abstract presentations should be described in a footnote to the title. Submissions should be accompanied by a letter requesting evaluation for publication.

**Preparation of Original Manuscript**

Original manuscripts may NOT exceed 3,000 words, excluding references, tables, figures and appendixes. Original manuscripts are generally reports of completed research studies. There are ample sample sizes, statistical analyses, and firm conclusions from the work can be drawn. Submissions over 3,000 words will be returned to the author. Leave ample margins on both sides, top, and bottom of manuscript text file. A structured abstract of 250 words or less, using the following guidelines, must be included and should be self-explanatory without reference to the text:

- Background (Why was this report needed)
- Objective (What did you set out to do?)
- Design (How did you go about doing it)
- Setting/Subjects (If this was a clinical trial, in what setting was it done and who were the subjects)
- Measurements
• Results (What did you discover)
• Conclusions

Number pages consecutively, including the title page. Do not place author names anywhere in the manuscript. A separate cover page should be uploaded with information for all authors, including degrees, affiliations and contact information for corresponding author.

**Preparation of Brief Report**
In contrast with Original Manuscripts, brief reports may not exceed 1500 words. This category is for research that is less well-developed than reported in an original manuscript. The results of preliminary studies, pilot programs, or small series on which an hypothesis can be formulated and tested in a subsequent study are good candidates for this category. The Journal of Palliative Medicine is particularly interested in fostering the careers of junior investigators, or those new to the field of palliative medicine research. This category fills a need for those reports worthy of dissemination, but not worthy of 3,000 words to tell the story. Please include a structured abstract as for an original manuscript.

**Preparation of a Letter**
Results of research or the development of ideas that do not fit the criteria for a brief report may be reported in a letter. Not more than 500 words, letters are often the richest source of new insights or serendipitous observations on which the future of the field may turn. This section is meant to transmit information that is much more ‘raw’ or ‘untested’, but holds promise in furthering the field through stimulating further research, discussion, or resolving controversy. A small number of references, usually no more than 5, may accompany a letter.

Preparation of an Editorial or Special Report
From time to time, an unsolicited report from an important group or meeting, or a description of a phenomenon in the field, or a particular point of view deserves publication. These decisions rest solely with the editor-in-chief.

**Preparation of a Personal Reflection**

One of the most widely read features in the journal, the personal reflections are written in a way that illustrates the personal engagement with the field—either its struggles or its joys or the complex combination of the two. Prose and poetry have all found a place here.

Acceptance is at the sole discretion of the Managing Editor and Editor.

**Tables and Illustrations**

Prepare each table and its title in a separate file. Use Arabic numerals to number tables. Each table must stand alone (i.e., contain all necessary information in the caption, and the table itself must be understood independently of the text). Details of experimental conditions should be included in the table footnotes. Information that appears in the text should not be repeated in a table, and tables should not contain data that can be given in the text in one or two sentences.

Figures/images should be presented according to these guidelines:

- Do not include any illustrations as part of your text file.
- Do not prepare any figures in Word as they are not workable.
- Black and white line illustrations (bar charts and line graphs) must be submitted at 900 DPI.
- Halftones and color photos should be submitted at 300 DPI.
- Please submit only TIFF or EPS files.
- Color art must be saved as CYMK not RGB. If RGB files are submitted, the files will be converted to CYMK, and some slight color variation may occur.
• Do NOT prepare any files in PowerPoint or Excel. These files cannot be uploaded in Manuscript Central.

• When naming your files, please label them with your last name and “Fig1.” (For example, Smith.Fig1). Label figures and tables inside the files in addition to naming the file with the figure or table number.

**Abbreviations**
Abbreviations of journal titles should follow MEDLINE.

**References**
References should be presented in numerical order and in the following style:


If it is necessary to cite an abstract, this should be designated. Authors are responsible for the accuracy of the reference, and are reminded that inaccurate references are highly frustrating to the reader, the cited author, and indexing services.

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