The development and evaluation of a palliative care admission assessment tool.

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“Life is pleasant. Death is peaceful. It's the transition that's troublesome.”

Isaac Asimov
Abstract

Effective palliative care intervention is contingent upon a comprehensive multidimensional assessment of the patient’s experience of illness. Assessment in palliative care settings must be focused, sensitive, specific and effective in order to minimise discomfort to vulnerable and often highly morbid patients. Optimal assessment can be facilitated by careful choice of tools that allow systematic standardised assessment, are feasible within clinical practice and acceptable to patients.

The aim of this research was the development and testing of evidence based, multidisciplinary, specialist palliative care assessment; accompanying guidelines and training package (the intervention). The tools included in the admission assessment were chosen further to extensive literature review. Mixed methods were utilised to facilitate a comprehensive evaluation pre and post-intervention to test the effectiveness, feasibility and acceptability of the intervention in a busy clinical environment.

Results demonstrated an increase in evidence of assessment across the palliative care domains and in particular in relation to assessment of the patient’s psychosocial distress and assessment of carer’s needs. Post-intervention increased concordance of outcome of clinical assessment with the patients self-rating of pain, nausea, breathlessness and distress is evident in comparison to pre-intervention. Referrals to other disciplines occurred earlier in the admission post-intervention. Staff reported that there was an increase in the assessment of palliative care domains, less need for training and an increased likelihood of assessment of carers needs.

Significant improvement with regard to assessment of patient needs were reported. The admission assessment should be tested in other clinical environments to determine the degree to which the results can be replicated and to investigate concordance with the finding presented here. An adapted version of the assessment should also be developed for the home care and day care services.
Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of PhD is my own work. I have exercised reasonable care to ensure that the work is original and does not to the best of knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

Signature: ________________________

ID No. : _________________________

Date: _________________________
Acknowledgements

I would like to thank my supervisors, Professor David Meagher, Professor Philip Larkin and Dr Marion Conroy for their guidance and advice in the conduction of this work. I owe a huge debt of gratitude to the members of steering committee who worked tirelessly to choose the most appropriate tools for inclusion in the MPCAT and in its implementation.

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I would like to thank all of the patients, who participated in the study. Their time was precious and they gave it generously. I would like to thank all of the staff in the inpatient unit in Milford Care Centre who took part in their study and for sharing their insights with regard to the assessment process and palliative care.

To my husband and my beautiful boys, James and Michael, who have patiently supported me every step of this journey, thank you!

I dedicate this thesis to my parents Bernard and Mary O Reilly, to whom I owe everything.
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List of Abbreviations

AB  Aberdeen Low Back Pain
ADS  Agitation Distress Scale
AKPS  Australian -modified Karnofsky performance status
AQUEL  Assessment of Quality of Life
BAS  Burden Assessment Scale
BASC  Brief Assessment Scale for Caregivers
BCD  Brief Case-Find for Depression
BEDS  Brief Edinburgh Depression Scale
BDI  Beck Depression Inventory
BPI  Brief Pain Inventory
BPI-SF  Brief Pain Inventory – Short Form
CAM  Confusion Assessment Method
CAMPAS-R  Revised Cambridge Palliative Assessment Schedule
CCM  Cancer Care Monitor
CCS  Communication Capacity Scale
CEE  Central and Eastern Europe CEE
CHQ  Caregiver Health Questionnaire
Ci  Cinahl
CIS  Commonwealth of Independent States
CPR  Cardio Pulmonary Resuscitation
CQOLC  Care Giver Quality of Life Index – Cancer
CTD  Cognitive Tests for Delirium
DI  Delirium Index
DOS  Delirium Observation Screening
D-Pap  Palliative Prognostic Score with Delirium
DRS-R-98  Delirium Rating Scale - Revised – 98
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<td>Distress Thermometer</td>
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<td>DTS</td>
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<td>ECOG</td>
<td>Eastern Cooperative Oncology Group Performance Status</td>
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<td>EFAT</td>
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<td>EORTC</td>
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<td>EPCRC</td>
<td>European Palliative Care Research Collaborative</td>
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<td>ERRI</td>
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<td>ESAS</td>
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<td>FACQ-PC</td>
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<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
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<td>IAHPC</td>
<td>International Association for Hospice and Palliative Care</td>
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<td>ICC</td>
<td>Intraclass correlation coefficient</td>
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<td>MCC</td>
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<td>ML</td>
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<td>MMSE</td>
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<td>MOSSSSS</td>
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<td>Memorial Pain Assessment Card</td>
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<td>MPCAT</td>
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<td>MST</td>
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<td>MVCN</td>
<td>Mount Vernon Cancer Network</td>
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<td>NACPC</td>
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<td>NePIQol</td>
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<td>NEST</td>
<td>Needs at the End-of-life Screening Tool</td>
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<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
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<td>NPCP</td>
<td>National Palliative Care Programme</td>
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<td>NPV</td>
<td>Negative Predictive Value</td>
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<td>NRS</td>
<td>Numerical Rating Scale</td>
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<td>PACA</td>
<td>Palliative Care Assessment Scale</td>
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<td>Pain Assessment Questionnaire for a Patient With Advanced Disease</td>
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<td>PPS</td>
<td>Palliative Performance Scale</td>
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<td>PaP</td>
<td>Palliative Prognostic Score</td>
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<td>Palliative Prognostic Index</td>
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<td>PPV</td>
<td>Positive Predictive Value</td>
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<td>SOMCT</td>
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Chapter 1 Introduction

This chapter provides an overview of the contextual basis of the research. The chapter includes an examination of the background of palliative care and carefully outlines the essential elements of an admission assessment within a specialist palliative care setting, highlighting the factors which impact the quality and outcome of the assessment process.

1.1 Palliative care in context

It is considered that the first modern hospice in the world was established at St Christopher’s (London) in 1967, further to the pioneering work of Cicely Saunders and colleagues (Clark, 2007). Saunders and her team introduced the concept of total pain with regard to the distress experienced by patients and which encompasses suffering related to physical, psychological, spiritual and emotional issues and social problems (Clark, 1999). In the interim, there has been rapid growth in respect of the development of palliative care services and there are more than 8,000 palliative care services worldwide (Gomes et al., 2010).

Ireland is one of 35 countries globally in which palliative care services have reached a high degree of integration with the wider health care system (Wright et al., 2008). The first hospices were established in the late 19th century in Our Lady’s Hospice in Dublin and St Patrick’s Hospital in Cork. More recently, inpatient palliative care units were established in Our Lady’s in 1979, Milford Care Centre in 1983 and St Patrick’s Hospital in 1984. The first consultant physician in palliative medicine was appointed in 1989, and in 1995 the Irish Medical Council formally recognised palliative medicine as a specialty. The 1990s also witnessed the establishment of four additional hospices; St Francis Hospice in Dublin; Donegal Hospice; North-West Hospice and Galway Hospice. Blackrock Hospice was opened in 2003 and is provided for under the management of Our Lady’s Hospice. The hospices provide specialist palliative inpatient care, home care and day care services to the population within the local catchment area.
1.2 Palliative care - core elements

The focus of palliative care is the alleviation of suffering and improvement of quality of life of patients at end of life. In accordance with the definition, palliative care also encompasses caring for those who are significant to the patient at end of life.

Palliative care aims to:

- provide relief from pain and other distressing symptoms
- affirm life and regards dying as a normal process
- neither to hasten or postpone death
- integrate the psychological and spiritual aspects of patient care
- offer a support system to help patients live as actively as possible until death
- offer a support system to help the family cope during the patients illness and in their own bereavement
- use a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- enhance quality of life, and where possible 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, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organisation, 2002)

Palliative care is an integral part of clinical practice for many health care professionals (Health Services Executive, 2014). Although commonly associated with end of life care, the scope of palliative care has been broadened to providing palliative care at an earlier stage of the disease trajectory. Although traditionally associated with care of cancer patients, the range of diseases for which patients receive palliative care has widened (The Irish Hospice Foundation, 2008). Palliative care interventions improve symptoms, patient satisfaction, quality of life and reduce caregiver burden (Temel et al., 2010; Smith et al., 2012). A national audit of hospital deaths found that between 20-25% of patients could have died at home if adequate community based supports (such as hospice at home services) were available (McKeown et al., 2010). Such figures
underline the importance of government policy in structuring and organising palliative care services nationally.

1.3 National policy context

The 1994 a health strategy, entitled ‘Shaping a Healthier Future - A Strategy for Effective Healthcare in the 1990s’, highlighted the important role that palliative care services play in improving the quality of life for people with life limiting illness and recommended the structured development of Irish palliative care services (Department of Health, 1994).

The development of the National Cancer Strategy by the Department of Health in 1996 was of fundamental importance to the development of palliative care services in Ireland (Department of Health, 1996). This strategy recognised the critical role palliative care plays in improving quality of life for patients at end of life by recommending the inclusion of palliative care in the educational curriculum of doctors, nurses and allied health professionals. The Cancer Services Forum further defined how palliative care services should be structured and organised within Ireland.

The Irish government’s policy with regard to the provision and structure of palliative care services was delineated in the 2001 report of the National Advisory Committee. In accordance with these recommendations, palliative care is structured within 3 levels:

(i) Level 1 – Palliative care approach: Palliative care principles should be appropriately applied by all health care professionals.

(ii) Level 2 – General palliative care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care.

(iii) Level 3 – Specialist palliative care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. They are involved in the care of patients with more complex and demanding care needs and are analogous to secondary or tertiary health care services.

(National Advisory Committee on Palliative Care, 2001)
The distinction between the three levels of care is based upon the expertise and time dedicated by staff to the care of patients at end of life.

The National Advisory Committee’s report recognised the significance of the voluntary sector’s contribution to the delivery of palliative care services. Recognition of the necessity and importance of the public and voluntary provider interface in the delivery of services was also highlighted in subsequent audits of palliative care provision and government development frameworks (Irish Hospice Foundation, 2006; Health Services Executive, 2009).

More recently, development of palliative care services has been further aligned with Health Services Executive clinical strategy. National Clinical Programmes, including a National Palliative Care Programme (NPCP) have been established to improve the quality of, access to and cost effectiveness of patient care. The NPCP aims to;

“To ensure that patients with life-limiting conditions and families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or diagnosis.”

The objectives of the NPCP include:

1. Improved planning for palliative care services to ensure optimal resource utilisation.
2. Strengthened specialist palliative care services to improve access and quality of care.
3. Strengthened generalist palliative care services in order to strengthen access and quality of care.
4. Improved partnerships in care to improve continuity and quality of care.

This study is located in Milford hospice, a well-established specialist palliative care inpatient unit that provides care to patients with life limiting conditions and palliative care needs irrespective of diagnosis. As specialists in palliative care, staff are focussed on the provision of multidimensional care that is tailored to palliative care needs and as a centre of excellence, aims to provide the highest standard of care.
1.4 Assessment within palliative care

Fundamental to the practice of palliative care is the impeccably assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation, 2002). Formulating a detailed plan to address the often complex and multifaceted problems of palliative care patients is predicated on comprehensive and accurate assessment that is conducted in collaboration with the patient and which considers their physical, familial and social circumstances (Osse et al., 2000; National Institute for Clinical Excellence, 2004; Richardson et al., 2007). All patients therefore require a comprehensive and systematic assessment at initial contact with the service and again as needs change thereafter (Cancer Action Team, 2007). Ideally the assessment process should be a collaborative exercise which identifies patient preferences with regard to their future care and predict potential problems that may arise in the future (Osse et al., 2000; Richardson et al., 2007). The assessment process should both highlight issues and assist in planning management/treatment plans.

A patient-centred approach is fundamental to the assessment process and can assist in identifying those needs which have been highlighted as most troublesome and severe to the patient (Mead and Bower, 2000; Hoekstra et al., 2007). The individual domains of need that shape the patient’s experience of the dying process should also be assessed (Emanuel and Emanuel, 1998; Singer et al., 1999; Della Santina and Bernstein, 2004; Arseven et al., 2005). Within palliative care, these domains include pain, physical symptoms, cognition, adaptive function, the needs of carers, as well as psychological, spiritual and social issues (Osse et al., 2000; Richardson et al., 2007).

Several symptoms may be applicable to the patient within each domain. The most prevalent physical symptoms are pain, fatigue, lack of energy, weakness, appetite loss, weight loss, dry mouth, constipation, insomnia, dyspnea and nausea (Walsh et al., 2000; Teunissen et al., 2007). In addition, early satiety has also been identified as another highly prevalent symptom (e.g. Walsh et al., 2000). It is important to assess all of these symptoms, because of their prevalence and potential to cause distress. Some additional symptoms have been added to the list of essential physical symptoms for assessment including vomiting, coughing, sweating, drowsiness and diarrhoea (Cancer Action Team, 2007; International Association of Hospice and Palliative Care, 2012). Identification of symptom clusters may increase the effectiveness of a systematic
standardised symptom assessment process (Cheung et al., 2009; Tsai et al., 2010; Jiménez et al., 2011).

In addition, assessment of cognitive impairment is recommended. This can be achieved, using brief validated tools (Power et al., 1993; Pereira, 1997). This is justified by its prevalence and the potential for remediation (Leonard et al., 2008). In addition, routine observation is frequently insufficient to detect the presence of cognitive impairment (Irwin et al., 2008). Delirium is present on admission in between 19 – 42% of patients (Lawlor et al., 2000; Durkin et al., 2003) and between 80 - 90% of palliative patients may experience delirium or “terminal agitation” prior to death (Fainsinger et al., 2000; Lawlor et al., 2000). Delirium and other causes of cognitive impairment should be screened for at the time of admission and frequently thereafter in order to detect changes in patient status and allow comparison if the patient’s clinical condition changes.

Patient concerns arising from the illness experience, the associated distress and the impact on quality of life are often of equal importance to the patient as physical symptom severity (Kutner et al., 1999; Arnold, 2011). Spiritual distress and existential suffering can be expressed as physical pain or even be the primary cause of severe analgesic resistant pain (Strang et al., 2004), can affect quality of life (Hampton et al., 2007) and influence treatment choices.

Psychosocial and spiritual concerns which may impact the patient include those relating to the desire to minimise impact on family, anxiety linked to anticipated symptom experience, worries about being a burden to others, or of death itself (Mularski et al., 2007). The resulting distress experienced may range from normal anticipatory grief to psychiatric morbidity (Kelly et al., 2006; Thekkumpurath et al., 2009a; Ziegler et al., 2011). Approximately 50% of patients with advanced cancer meet clinical criteria for psychiatric disorder. The most common are adjustment disorders (11-35%), followed by major depression (5-26%) (Miovic and Block, 2007).

The psychological and social needs of carers should be assessed (National Institute for Clinical Excellence, 2004; Harding and Leam, 2005). Carer’s frequently experience significant psychological distress and their needs for support and information, should be assessed separately to that of patients (Dumont et al., 2006).
Therefore, assessment of need within the context of palliative care is multifaceted and complex. The tools and instruments used as part of the assessment should allow for a multidimensional comprehensive assessment which is targeted, comprehensive and yet is feasible and acceptable to both patients and clinicians (Osse et al., 2004; Arseven et al., 2005). The outcome of the assessment should be used to develop an individualised treatment plan in consultation with the patient, communicate with other clinicians, assure continuity of care and facilitate review of effectiveness of care. Getting the assessment correct has the potential to improve outcomes for the patient and carer alike (Ferris et al., 2002).

However, studies indicate that optimal investigation of a patient’s needs and preferences at end of life does not always occur in clinical practice (Velikova et al., 2001; DesHarnais et al., 2007). This has been linked to a variety of factors that include inappropriate assessment (Cleeland et al., 1994; Bruera, 1996), inadequate staff preparation and education (Lawrie et al., 2004; Thekkumpurath et al., 2009a), underreporting by patients (Cleeland et al., 2000; Wen, 2004), lack of clinician confidence and competence to discuss difficult issues (Block, 2000; Detmar et al., 2000) and time constraints (Osse et al., 2005). Studies indicate that physical symptoms are more likely to be identified than psychological symptoms (Brunelli et al., 1998; Schuit et al., 1998) while psychosocial distress is frequently undetected in clinical practice (Ziegler et al., 2011).

In this context, research into the assessment of the needs of palliative care patients is vital. There are many tools available to support the assessment of patient’s needs that have been developed for and validated in palliative care populations. The number of tools identified and studies describing their validation and use within clinical practice indicate that this is an important area within palliative care and a growing focus for research and clinical practice. Therefore, it is important to examine those studies which have reported improvements to the assessment process and to determine if these can be replicated and/or generalised to other settings.

Evidence suggests that the assessment process is critical to assuring the effectiveness of the admission assessment to a service (Walsh et al., 2000; Strömgren, 2002; Homsi et al., 2006). Standardised systematic assessment using tools which have been
validated in a palliative care population improves symptom identification (Davies and Shah, 2001; Velikova et al., 2001; Homsi et al., 2006; Baile et al., 2011), reduces symptom distress over time (National Institute for Clinical Excellence, 2004) and can reduce the symptom burden experienced by palliative care patients (Hoekstra et al., 2006). Moreover, patient experience of care improves in respect of perception of emotional support received from the physician (Detmar et al., 2002). In particular, identification of symptoms relating to psychological distress (McMillan et al., 2011), emotional needs, fatigue and pain can be improved through systematic assessment (Crooks, 2004). However, it should also be emphasised that the choice of tool is only one element in a complex interaction between the patient and clinician. No assessment tool will substitute for the experience, confidence and competence necessary to investigate highly sensitive and emotionally laden needs with patients at the end of life.

A further important issue is the need to achieve a balance between comprehensive assessment and minimising patient burden, especially in those who are frail or have significant morbidities. It can be a difficult balance between comprehensive inquiry of all possible symptoms without overburdening a patient by an exhausting assessment process. Assessment should therefore emphasise elements of the illness experience which can be relieved by palliative care intervention.

Given the competing demands of busy clinical environments, clinicians must be able to conduct and document the patient assessment and care plan in a succinct and time efficient manner. Consequently, the choice of tools to guide the assessment process is a significant determinant of the quality of the clinical encounter. The feasibility of use in busy clinical settings is also an important consideration in tool selection. Time required to complete the tool (and therefore burden to the patient and the staff) is a significant factor when choosing an assessment tool.

Furthermore, clinician confidence and competence to investigate all domains of need equally, including spiritual, psychosocial and emotional distress may affect the outcome of an assessment. Many clinicians are more comfortable assessing physical need rather than issues such as emotional or spiritual distress, impact of illness on sexual function, financial burden or conflict within families. Lack of clinician confidence and competence have been highlighted as a factor in suboptimal
assessment of psychosocial and spiritual distress (National Institute for Clinical Excellence, 2004).

The documentation process should guide the conduct of the initial admission assessment and offer an aide memoire to staff. The assessment tool should effectively capture the initial assessment for the purposes of development of an individualised treatment plan, communication to other clinicians, and assuring continuity of care and facilitating review of the effectiveness of care. It should contain sensitive, well validated empirically based and feasible tools to support the assessment process.

1.5 Assessment within Milford Care Centre

More locally, a 2006 review of assessment practices in the inpatient unit where this study is located using the Help the Hospices’ National Audit Tool indicated that there was substantial room for improvement in documenting patient’s and carer’s psychological, cultural, social and spiritual needs at time of admission. The audit was conducted retrospectively so it is not clear whether these needs were assessed but not documented, or if there was a lack of assessment. These findings are a cause for concern because of the potential for a lack of effective intervention or treatment of these important domains.

In response to these findings it was undertaken to design a study to develop a tool to facilitate the comprehensive assessment of all palliative care domains of need. The principal objective of this mixed methods research project was to incorporate international best practice into the design and implementation of a new admission assessment tool (the intervention) and to examine the effectiveness of the assessment process in hospice inpatients. In particular, the systematic identification of areas needing evidence-based tools in the assessment process were evaluated.

This mixed methods research evaluated the admission assessment pre-intervention to provide a baseline against which the impact of a new tool can be benchmarked. Furthermore, the pre-intervention evaluation offered an opportunity to engage with clinicians to ascertain their views regarding the critical components of and suggestions for improvements to the specialist palliative care admission assessment process. The effect of the implementation of a novel evidence-based multidisciplinary admission
assessment tool, termed ‘The Milford Palliative Care Assessment Tool’ (MPCAT) is investigated post-intervention.

The anticipated outcome of the research was the development of standardised evidence-based, multidisciplinary, initial inpatient assessment documentation system, with accompanying guidelines and a training package. The study had three principal aims:

1. To develop an agreed evidence-based, multidisciplinary, standardised tool to guide the inpatient assessment, in a specialist palliative care unit.
2. To evaluate the impact of this agreed tool from a patient/carer and staff perspective.
3. To develop and evaluate a training programme to facilitate staff to utilise the standardised protocol for initial inpatient assessment.

1.6 Thesis Structure

Following this introductory chapter, the thesis is presented as follows:

1.6.1 Guide to chapter two

Chapter two outlines in detail the methodology employed in phases one to five of the research. The research strategy was mixed methods in design. In addition, the key ethical considerations that shaped the methodology are described. The decision making process in selecting tools for inclusion in the assessment tool is also explained. Each phase of the research was designed to evaluate the effectiveness of the existing assessment process, used in the specialist palliative care inpatient unit (pre-intervention) and examine the impact of the MPCAT post-intervention. The five phases are detailed below.

Phase 1

(i) A review of literature relating to multidisciplinary admission assessment in palliative care.
(ii) A comparison of multidisciplinary documentation systems used for initial patient assessment utilized in hospices in Ireland and the UK (see 2.5.2) were compared and contrasted.

**Phase 2**

Conduct a comprehensive baseline evaluation of the current admission assessment process within the SPCU using a combination of qualitative and quantitative methodologies. This phase had four distinct elements:

(i) Assess patients and carers needs and determine if these needs are identified at the time of initial admission assessment using validated tools, including the MD Anderson Symptom Inventory (Kwon et al., 2006; Cleeland, 2009), and The Needs Near the End-of-Life Care Screening Tool (Emanuel et al., 2001).

(ii) Determine staff views regarding the initial assessment process and suggestions for how it might be developed.

(iii) Audit documentation of the initial admission assessment for completeness and to determine if all areas of palliative care need are assessed (pre-intervention baseline). The results of the audit of clinician assessments were compared with patient self-ratings to evaluate concordance.

(iv) Monitor referral patterns amongst interdisciplinary team members.

**Phase 3**

The three elements of phase three were:


(ii) Implementation of a training programme to educate staff.
(iii) Implementation of the initial admission assessment protocol in the clinical setting.

Phase 4
The methods utilised in phase 2 were re-applied and compared with the baseline results of phase 2 to determine effectiveness of the MPCAT (post-intervention time 1: 6 months post introduction of the MPCAT).

Phase 5
The integration of the admission assessment protocol to practice was monitored through audit (post intervention time 2: 12 months post introduction of the MPCAT).

1.6.2 Guide to chapter three

Chapter three documents a literature review of assessment tools or scales that have been validated with palliative care patients. A systematic approach was used in searching the literature so that the review might be focussed, feasible and comprehensive. Electronic databases, including Medline, PsycINFO and Cinahl were searched from 2000 to mid 2011. The reference lists of key papers were also reviewed to identify articles which provide details of the psychometric properties of assessment tools.

To aid comparison and decision making, the outcome of the literature review was grouped and presented for each domain of need. A list of all tools, for each domain that had been validated in a palliative care population was generated. Tables (see tables 1-3) were developed for each domain to summarise the results and provide information with regard to:

- The number of items within a tool.
- The response format.
- The tools acceptability to patients and staff if known, in addition to the psychometric data.

The tables were used as a decision making aid when selecting tools for inclusion in the admission assessment tool.
1.6.3 Guide to chapter four

Chapter four describes the results of both the quantitative and qualitative data collected from phases 2, 4 and 5. The quantitative results are presented as follows:

(i) Results of the audit of the admission assessment at three time points, the pre-intervention baseline (phase 2), post-intervention Time 1 (phase 4), and post-intervention Time 2 (phase 5).
(ii) Referral rates and patterns amongst interdisciplinary team members which occurred after the admission assessment process were monitored at the three time points.
(iii) Patient’s self-rated their symptoms and needs using validated tools at two time points, the pre-intervention baseline (phase 2), and post-intervention time 1 (phase 4)
(iv) The clinician’s assessment and the patient’s self-rating of symptoms and issues were compared at two time points, the pre-intervention baseline (phase 2), and post-intervention Time 1 (phase 4). This comparison acknowledged if the clinical assessment process identified the same symptoms and issues as were identified by the patient.
(v) Carers completed a validated tool to evaluate the quality of care received and to identify if their needs had been met at two time points (Time 1).
(vi) A survey of staff perspectives of the admission assessment process and its documentation at two time points, pre-intervention baseline (phase 2), post-intervention Time 1 (phase 4).
(vii) The change in confidence and competence of non-consultant hospital doctors to conduct the psychosocial assessment were evaluated post-intervention to determine effectiveness of the training programme for the MPCAT
(viii) A qualitative review of staff views of the assessment process through semi structured interview at two time points, pre-intervention baseline (phase 2), post-intervention time 1 (phase 4).
1.6.4 Guide to chapter five

Chapter five discusses key findings of the study namely the development of a tool to facilitate the comprehensive assessment of all palliative care domains. Further, the chapter outlines the implications for policy and practice within the hospice movement of the MPCAT assessment tools. The chapter provides a synthesis, analysis of results, critical reflection of and contextualisation of the study findings with regard to the applicable literature. The strengths and limitations of the research are considered. Finally recommendations for future research in the area are proposed.
Chapter 2 Methodology

This chapter describes the methodology used in phases one to five of this mixed methods study. The research evaluated the effectiveness of an admission assessment process conducted in a specialist palliative care inpatient unit (SPCU) to determine if all domains of need of palliative care patients are comprehensively assessed. A baseline evaluation of the admission assessment was conducted pre-intervention. The intervention relates to the development of an admission assessment protocol and accompanying guidelines which was then evaluated after implementation (post-intervention).

2.1 The epistemological approach: A mixed methods research study

This research is a five phase mixed methods study applying quantitative and qualitative approaches to data collection, analysis and interpretation. The research used psychometric scales, quantitative surveys and qualitative interviews. Although complex, this research methodology was identified in consultation with supervisors and the steering committee as appropriate given the complexity of the process that was being evaluated.

The mixed methods approach to research, has become increasingly popular within health care research as it enables a more flexible, responsive approach which can address the ethical considerations of research in a health care environment (Wilde et al., 1994; Creswell et al., 2004; Addington-Hall et al., 2007). Mixed methods are particularly appropriate not only to facilitate evaluation of complex interventions and associated outcomes, but also to palliative care research (Farquhar et al., 2011). When evaluating interventions, mixed methods facilitate a deeper understanding of how an intervention works and of the barriers to implementation (O’Cathain et al., 2007). Mixed methods are responsive to the needs of multiple stakeholders. Stakeholders within palliative care value different outcomes and therefore may have a preference for the results yielded by different methods. For example, administrators may seek quantitative results, whereas patients, their families and staff will focus on the patient experience as the primary outcome – qualitative data (Farquhar et al., 2011).
Mixed methods originated in the late 1980s and has become particularly popular with researchers in education, social science and health science. In the late 1980s authors of evaluation research used definitions of mixed methods which highlighted the mixing of at least one qualitative and one quantitative method and suggested that neither type of method is necessarily linked to a paradigm (Greene et al., 1989). A paradigm has been defined as;

“a worldview, together with the various philosophical assumptions associated with that point of view.” (p 84)
(Teddlie and Tashakkori, 2009)

More recent definitions suggest that mixed methods combines both a method and philosophical orientation.

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

The philosophical basis of the mixed methods research presented in this thesis is the pragmatic world view which facilitates the researcher to collect and analyse both qualitative and quantitative data to gain a more complete understanding of the research problem.

“Pragmatism emphasizes the importance of the research questions, the value of experiences, and practical consequences, action, and understanding of real-world phenomena.” (p 276)
(Creswell, 2011)

Furthermore it has been suggested to be the

“philosophical partner of mixed method research” (p 16)
(Johnson et al., 2007)
The work presented here is a single site study focusing on the admission assessment to a SPCU. This approach allows the researcher freedom to choose methods which are most appropriate to the environment in which the study is situated. Other approaches to the research question may not afford this flexibility to the subject matter under investigation. Furthermore, a mixed methods approach affords an opportunity to extend and expand the understanding of the impact, outcomes of, and barriers to implementation of interventions. The deeper understanding afforded by a mixed methods design is an important aid to replication of the findings. Mixed methods research offers the opportunity to comprehend the experience and perspectives of participants in addition to the objective measurement of variables.

The range of methods available to the researcher is increased by utilising mixed methods as is the validity and reliability of the results and their interpretation (O’Cathain et al., 2007). In essence, by using mixed methods the sum is greater than the constituent modalities of quantitative and qualitative methods (Barbour, 1999).

The manner in which this mixed methods study was designed offered an opportunity to triangulate data in order to increase the validity of findings (Barbour, 1999). This research used a convergent parallel mixed methods design in that both quantitative data (patient structured interviews, staff survey, chart audit) and qualitative data (staff interviews, patient feedback and ward observations) were collected concurrently (Creswell, 2014). The quantitative data are dominant, while there is less emphasis on the qualitative data. Qualitative data provides informative complementary information which can triangulated with the quantitative data. Triangulation of data facilitates a deeper understanding of processes being studied and can increase confidence in findings and enhance the validity of results. The qualitative data affords a greater understanding of the context in which the quantitative results are gathered. For this study a side by side comparison of quantitative and qualitative results was conducted and the results are interpreted and merged in the discussion.

**2.2 Steering committee**

Involvement of practising senior clinicians and educators was a critical combination in integrating the outcomes of the research into the clinical area, . A vital component of
this research was the establishment of the steering committee structure at the initiation of the research.

The committee comprised of;

- Two consultants in palliative medicine,
- Clinical nurse managers from the inpatient unit,
- Head of therapy and social care services,
- Principal social worker,
- Senior physiotherapist,
- Pastoral care worker,
- Day care coordinator,
- Team leader from the hospice at home service.

This committee oversaw the development of the research, supported the application for ethical approval to the Mid-West Regional Scientific Ethics Committee and agreed the tools to be incorporated in the development of the admission assessment tool.

At the outset, it had been hoped that two staff nurses from the unit would also be on the committee. This was felt to be an important element in assuring the integration and practical application of the outcome of the research. However, there were insufficient resources to allow protected time to release staff nurses from duty. In mitigation of this shortcoming it should be noted that both the day care coordinator, team leader of the hospice at home service and the clinical nurse managers are nurses with a considerable number years of practical nursing experience in palliative care settings. The steering committee was of immense support to the researcher, providing encouragement and a critical eye at all stages of the research. Further, the encouragement of the committee was vital, sustaining the researcher through all stages of the research. See Appendix A for the steering committees terms of reference.

### 2.3 Overview of the research methodology

This mixed method study was designed to occur over 5 distinct phases, each with specific objectives and expected outputs which are also illustrated in figure 2.4.1.
2.4 Specific objectives

Below are listed the phases 1 to 5 of the research and the main objectives associated with each.

Phase 1

(1) To review the research literature relating to multidisciplinary admission assessment documentation in palliative care using a systematic approach.

(2) To compare and contrast the multidisciplinary documentation systems used for initial patient assessment utilized in palliative care inpatient units in Ireland and the United Kingdom (UK).

Phase 2

A comprehensive baseline evaluation of the current admission assessment process using a combination of qualitative and quantitative methodologies to:

(1) Assess the needs of patients and evaluate carer’s perspectives on care provided using validated measures to determine if the needs of patient’s are identified at the time of initial admission assessment.

(2) Determine staff views regarding the initial assessment process and suggestions for development/improvement.

(3) Audit the documentation of the initial admission assessment for completeness and to determine if all areas of palliative care needs are assessed.

(4) Monitor referral rates and referral patterns amongst interdisciplinary team members.

Phase 3

(1) To develop a draft evidence-based admission assessment protocol ‘The Milford Palliative Care Assessment Tool’ (MPCAT) and accompanying guidelines based on the outcome of phases 1 and 2.
Achieve consensus of the steering group members regarding tools to be included using an adaptation of the Delphi technique.

Develop and evaluate a training programme to educate staff.

Pilot the initial admission assessment protocol

**Phase 4**

(1) To assess the needs of patients and carers and determine the extent to which these needs are identified during the initial admission assessment.

(2) To evaluate the admission assessment from a staff perspective.

(3) To audit the documentation for completeness and comprehensiveness.

(4) Evaluate the impact of applying a patient rated symptom assessment tool and the effect of the new admission assessment on the volume and timing of referrals to supporting disciplines.

**Phase 5**

(1) To monitor the implementation of the admission assessment protocol through audit.

(2) To conduct audit feedback sessions with staff to determine views and recommendations for change.

(3) To adapt the documentation system based on the findings of the audit and implement any recommendations for change.
**Figure 2.4.1 - Methodologies used for each phase**

### Phase 1

**Literature Review**  
**Period:** 2000 – 2011  
**Databases:** Medline, Cinahl, PsychInfo

**Compare and Contrast**  
Milford Care Centre admission assessment procedure with Irish and UK admission assessment procedures. Sample: N=50

**Seek Ethical Approval**  
From Mid West Regional Hospital Scientific Ethics Committee.

**Outcome**  
Identification of clinically feasible evidence based assessment tools appropriate for inclusion in a palliative care admission assessment.

**Outcome**  
Approval to implement research design.

### Phase 2

**Measure 1**  
Administer patient needs/symptom questionnaire (MDSAI) and interview (NEST). Sample: N=35  
Timeframe: within 48/72 hours of admission.

**Measure 2**  
Audit of documentation: Audit tool. Sample: N=35. Patient charts of those patients that have completed the needs/symptom questionnaire and interview.

**Measure 3**  
Administer carers questionnaire. Main carer identified by Patient (FAMCARE2). Timeframe: Within 1 week of admission  
Sample: (N=25)

**Measure 4**  
Qualitative interviews: 50% Doctors (N=2), 30% Nurses (N=11) and 30% Allied Health Professionals (N=7)  
Quantitative staff survey (N=40)

**Outcomes**  
1. Does the current assessment procedure identify the same symptoms and concerns that the patient identifies?  
2. Does the initial assessment prioritise the same symptoms and concerns that the patient does?

**Outcomes**  
3. Does the procedure assess carer needs?  
4. Does the current admission assessment procedure comprehensively assess all domains of need?

**Outcome**  
5. Do carers perceive that their needs are met?

### Phase 3

**Develop:**  
Develop a palliative care admission assessment tool “The Milford Palliative Care Assessment Tool” (MPCAT) based on the outcome of phases 1 and 2.  
Train all staff in the use of the MPCAT.  
Evaluation of the confidence and competence of medical staff to assess. (Time 1)  
Evaluation of the confidence and competence of medical staff to assess. (Time 2)  
Pilot: Revised admission assessment tool for 3 months.  
Evaluation of the confidence and competence of medical staff to assess. (Time3)

**Outcome**  
Development of a clinically feasible evidence-based multidisciplinary admission assessment system with accompanying guidelines. Staff trained in its administration and with an evaluated training programme.
Data from phases 2 and 4 were compared to identify if change occurred and if improvement in the assessment of patient and carers needs were evident.

**Phase 5**

**Audit**

The MPCAT documentation. Sample: N=42. 
Timeframe 12 months post phase 4

Consult with staff in respect of audit results and identify recommendations for change. Method audit feedback workshops.

**Outcome**

To assess whether the change of assessment protocol is to be integrated into clinical practice and be maintained.
2.5 Phase 1

Appraisal of the evidence-based literature and review of the admission assessment documentation from other providers informed the development of the MPCAT.

2.5.1 Planning the literature review

The researcher initially reviewed the guidelines in the Cochrane Handbook for Systematic Reviews of Interventions on developing a systematic review to define the research question and aid development of a search strategy. Further to review, and in accordance with the Cochrane guidelines, the researcher delineated objectives of the study, standards, criteria, participants and interventions appropriate to the study to aid development of a literature review search strategy. This process was informed by an initial literature review, meetings with colleagues and steering group members, discussion with supervisors and the consideration of existing knowledge and practice.

The objectives of the study included:

- To evaluate the initial assessment process of admission to specialist palliative care services (pre and post-intervention), to examine which of the key domains of palliative care are assessed in accordance with best practice.
- To ensure that the initial admission assessment includes evidence-based tools to assess the patient’s physical, psychological, social, cultural and spiritual needs.
- To ensure that the initial admission assessment comprehensively assesses pain and other symptom-control issues and to gather information about family/carers needs in a standardised and systematic manner.
- To ensure that patients and the families/carers are provided with appropriate information about the nature of care to be provided at the time of admission.
- To ensure that after assessment each patient will have an individualised care plan for their specific needs that has been agreed with the patient and their carers, and is effectively communicated to all members of the multi-disciplinary team.
- To ensure that the palliative care team work towards common care goals which are reflective of the patient’s prioritised goals as early as possible in the admission.
• To evaluate the initial assessment process of admission to specialist palliative care services and ensure that the key domains of palliative care are assessed in accordance with best practice.
• To ensure that the initial admission assessment includes evidence-based tools to assess the patient’s physical, psychological, social, cultural and spiritual needs.

Standards relevant to a palliative care admission assessment were derived from:

• Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer: Assessment Guidance (Cancer Action Team, 2007).

The criteria for which are:

• The holistic assessment is conducted in cooperation with patient and family /carer within an agreed timeframe and is coordinated amongst the care/service providers.
• The patient’s total pain and other symptoms are continuously assessed, with appropriate interventions then implemented and evaluated.
• There is a standardised process for assessing patient/client’s physical, psychological, social, cultural and spiritual needs.

Having described the objectives, standards and criteria for the study a key word list was then developed for the literature review search strategy. Advice was sought from a librarian prior to development of the search strategy. The review included searching Medline (Ebsco), Cinahl, PsycINFO databases from January 2000 - July 2011. (This time period forms the basis of the literature of phase 1 however, the literature review continued after 2011 for relevant publications on a periodic basis up to and including 2014.) Other limiters included adult populations and papers published in English. The reference lists of key papers were also reviewed to identify articles which provided details of the psychometric properties of assessment tools.

Search terms for the literature review were derived from the World Health Organisation’s (WHO) definition of palliative care (World Health Organisation, 2002)
including “palliative care”, “life threatening illness”, “pain”, “physical”, “psychosocial”, “spiritual”. Additional key words including “symptom control”, “functional”, “psychological”, “carer” were derived from the areas of need identified for inclusion in the NICE Guidance on Supportive and Palliative Care in combination with terms related to palliative care. Relevant MeSH headings were identified from the Medline (Ebsco), Cinahl, Psychinfo databases (See Appendix B for full search terms used). The references selected were exported to Endnote bibliographic software to facilitate management. The results of the review are reported in Chapter 3.

Data were extracted from the studies using a template which was derived through review of ‘data extraction’ templates in the literature (Richardson et al., 2007). Consequently, data in respect of the following was extracted:

- purpose and population of the tool
- number of items and question/response format
- domains covered
- validity and reliability
- feasibility of the tool in clinical practices

See Appendix C for the data extraction template.

In order to be included, studies had to report data relating to testing the tools validity and/or reliability with palliative care patients. Validity relates to whether or not the tool appears to measure that which it intends to measure. There are many forms of validity including face, content, criterion validity and construct validity. Face and content validity are related and refer to the importance, relevance and appropriateness of the items within the tool with regard to that which is being assessed. Criterion validity relates to correlation of the tool with other tools measuring the same concept and which have already been validated, accepted by experts within the field and are widely used i.e. are the ‘gold standard’. If no ‘gold standard’ has been established construct validity can be established by testing whether the tool fits with the theoretical concept or hypothesis it is measuring.
Reliability refers to the ability to reproduce results with the same population and includes inter-rater and test-retest reliability which can be evaluated by Cohen’s kappa statistical test. Inter-rater reliability refers to the same or similar results being produced when the tool is used with the same patients by different raters. Test-retest reliability refers to the similarity of results produced when the tool is repeated at different times and requires testing under the same conditions. Internal consistency of a tool also relates to reliability and refers to the correlation of individual items of a tool to each other and can be measured by Cronbach’s alpha (Addington-Hall et al., 2007).

The measures, scales and questioning guidelines identified by the literature review are reported in Chapter 3.

2.5.2 Comparison with other admission assessment tools

Specialist palliative care units nationally and internationally (n= 268) were contacted to request permission to access their multidisciplinary initial in-patient assessment documentation. A European Association of Palliative Care taskforce reported that Ireland (5th) and the UK (2nd) are in the top five of forty-seven countries in respect of provision of specific palliative care resources in Europe, including Central and Eastern Europe (CEE) and the Commonwealth of Independent States (CIS) (Centeno et al., 2007). As the other countries listed within the top five were Iceland (1st), Sweden (3rd), Belgium (4th) it was assumed that some assessment documentation from these countries may not be in English. Therefore it was decided to only contact hospices in Ireland and the UK to request a copy of their documentation. The list of hospices in the UK and Ireland was derived from those listed in the Help the Hospices Directory. Children’s hospices were excluded. See Appendix D for a copy of the letters that were sent to the Director of Nursing in the Irish and UK based hospices.

The first five sets of documentation received were reviewed to inform the development of a data collection tool. A data collection tool was then developed to determine the frequency of areas of assessment included in the documentation. The pre-intervention assessment documentation used by Milford Care Centre (MCC) was compared and contrasted against assessments utilised by other specialist palliative care services. The results of the review are reported in Chapter 4.
2.6 Phase 2 and Phase 4

This section outlines phases two and four of the research. Phase 2 is the pre-intervention evaluation. Phase 4 relates to the post-intervention evaluation. Both phases employed the same research methods. Phase 3 describes the development and implementation of the MPCAT including the provision of training (see section 2.12).

2.6.1 Participants and settings

Milford Care Centre is a tertiary level specialist palliative care service in the Mid-West of Ireland. The service is consultant-led comprising of a thirty bedded inpatient unit, a hospice at home service and a palliative day care service operating three days a week. The inpatient unit team is comprised of consultants in palliative medicine, non-consultant hospital doctors, clinical nurse managers, nurses, social workers, pastoral care professionals, pharmacist, physiotherapists, occupational therapists, dietitians, complementary therapist, art therapist, music therapist and a horticulturist.

2.6.2 Patient one to one interviews and carer questionnaires; Pre-intervention

A pilot of the patient interviews and carer’s survey was conducted prior to initiation of phase 2 to test the feasibility, appropriateness of the chosen assessment tools and that they were not excessively burdensome to patients or carers. After each of the five interviews, patients were asked eight questions to evaluate their experience of the process on completion of the interview (See Appendix E.) As no patient found the questions inappropriate or difficult to answer, the measures were not subsequently modified.

This study used a non-probability purposive sampling strategy to collect data from a total of 50 patient and carer dyads, 25 pre-intervention and 25 post-intervention. A sample size of 25 has been reported in previous studies and estimated to facilitate detection of clinically significant differences. All consecutive inpatients who were admitted to the SPCU over a 23 week period were considered for inclusion by the admitting doctor in the pre-intervention evaluation unless any of the exclusion criteria were met (See Appendix F for inclusion/exclusion form). Patients deemed appropriate
by the admitting doctor were approached by the researcher to explain the purpose and nature of the research and to seek their informed consent to participate.

During the time period of the pre-intervention evaluation, 238 persons were admitted, of which 53.1% (n = 127) were male and 47.4% (n = 111) were female. The median age was 68, interquartile range was 19.2. The number of patients deemed too unwell was 101; a subsequent 2 were identified as actively dying. A further 5 patients had either recently experienced a bereavement, had an active and severe mental health issue or were experiencing a family crisis.

The total number of patients identified as suitable to participate at the time of admission pre-intervention was 131. The condition of 10 patients, who were initially identified as well enough to be approached, deteriorated post admission. A further 12 patients were repeat admissions during the pre-intervention data collection phase and had previously participated. The number of patients admitted for less than 72 hours was 3, and 10 patients could not be accessed in the first 48/72 hours of admission, (time frame specified by the research design) due to a variety of reasons including attendance for radiotherapy treatment, inclusion exclusion form not signed, or the researcher being on leave. Consequently, 96 patients were approached within the first 72 hours of the admission. Of these, 36 patients agreed to participate in the research, one of whom was too fatigued to complete it. In total 60 patients declined to participate in the research. The families of 25 of the patients who participated in the research returned surveys.

2.6.3 Post-intervention

A sample of 46 inpatients was included in the post-intervention evaluation. All consecutive inpatients admitted to the SPCU in a 24 week period were considered for inclusion in the post-intervention evaluation. The same inclusion/exclusion form was used in the post-evaluation as had been used in the pre-intervention.

During the period of the post-intervention evaluation, 249 persons were admitted, 47.2% (n = 118) were male and 53.3% (n =131) were female. The median age was 71, with an interquartile range of 20. The number of patients deemed inappropriate to be
approached was 116; 105 were too unwell, 7 were identified as actively dying. A further 4 patients had as before a mental health issue or did not understand English. Therefore, 133 patients were identified as appropriate to be approached. The condition of a further 3% (n=8) of patients, who were initially identified as well enough to be approached, deteriorated post-admission. A further 6% (n=14) were repeat admissions during the pre-intervention data collection phase and had previously participated. Two percent (n=5) were admitted for less than 72 hours and 14% (n=19) could not be accessed in the first 48/72 hours of admission, (time frame specified by the research design) due to attendance for radiotherapy treatment, inclusion exclusion form not signed, or the researcher being on leave. Consequently, 65% (n=87) of those identified as appropriate to be approached were within the first 72 hours of the admission. Of these 87 patients, 54% (n=47) agreed to participate in the research; one person completed half of the interview, but was too fatigued to complete it. A further 46% (n=40) of patients declined to participate in the research. The families of 25 patients who participated in the research returned surveys, a response rate of 54%.

2.6.4 Identification of tools

A literature review was conducted to identify measures that could be employed in the research. An adapted Delphi technique (Rowe and Wright, 1999) was used to aid choice of measures as it is a particularly useful method of facilitating group discussion and achieving consensus with experts, through a series of rounds or questionnaire and feedback to participants (Powell, 2003; Iqbal and Pipon-Young, 2009). The Delphi technique was used as a mechanism to structure the steering group’s choice of tools for the research. This study did not include an “idea generation round” as the tools presented to the steering group were validated tools derived from the literature. It has been suggested that a two round Delphi method is sufficient if the subject matter being considered has a defined literature base (Petry et al., 2007; Iqbal and Pipon-Young, 2009).

In addition to the two rounds of questionnaire, techniques of the Delphi methodology that were used included:
- Establishment of a panel of clinical experts (the steering committee), to reach consensus regarding choice of evidence-based tools (Iqbal and P hipon-Young, 2009).
- Anonymity of responses of the participants (Rowe and Wright, 1999).
- Ranking of responses according to a pre-determined criteria (Jairath and Weinstein, 1994).
- Presentation of individual responses in the context of overall responses.

The panel consisted of eleven members from diverse professional backgrounds with extensive experience of specialist palliative care. Heterogeneity of panel members, who are clinical experts in the area of intervention under review, has been evidenced to improve outcome when using the Delphi technique (Jones and Hunter, 1995; Linstone and Turoff, 2002). The anonymity of responses reduces influence of dominant personalities on a group response (Rowe et al., 1991).

A number of ‘quality of life’ measures and ‘symptom assessment/needs assessment’ measures for use with patients with palliative care needs and their carers were identified by the systematic reviews (Teno, 2000; Mularski et al., 2007; Richardson et al., 2007). A summary of the tools was circulated to members of the steering committee, who were asked to rank the 3 preferred measures (in order of preference e.g. 1st 2nd 3rd) utilising the following criteria:

- How comprehensively it covers all keys domains of palliative care, rated 0-5 (5 being the most preferred).
- How complicated and burdensome its use is to the patient, rated 0-5.
- Whether the measure reviewed a similar time period to the admission assessment, rated 0-5.
- How well the tool clarifies physical/spiritual/ psychological/social issues, rated 0-5.
- It’s relevance to the project (e.g. questions would be similar to that the admission assessment facilitating matching the symptom list to documentation audit), rated 0-5.
• Whether it includes patient self-identification of priorities for intervention, rated 0-1.

2.6.5 Measures – patient interviews

For the patient interview stage of the research patients were asked to:

• Complete a validated symptom assessment measure, the MD Anderson Symptom Assessment Inventory (MDSAI; 19 items).
• Respond to scripted questions derived from an amended Needs Near the End-of-Life Care Screening Tool (NEST). The questions, included two additional items from the Assessment of quality of Life questionnaire (AQEL), one from Functional Assessment of Chronic Illness Therapy – Palliative Care (Facit–Pal) and one bespoke question after the initial assessment has been completed, but within 2/3 days of completion of admission to the SPCU.

(See Appendix G for a copy of the MDSAI and Appendix H for a copy of the adapted NEST Screening Tool utilised.)

The MDSAI is a 19 item patient self-administered symptom assessment questionnaire. The questionnaire includes 13 symptoms, the severity of which are rated on an eleven point numerical scale, (0-10), 0 meaning "not present" and 10 meaning "as bad as you can imagine”. Additionally, there are six interference items rating the impact of symptoms on a 0-10 numerical rating scale, 0 meaning “did not interfere at all”, 10 meaning “interfered completely”. Each item is rated at its worst in the preceding twenty four hours.

A component score for the MDASI symptom severity scale is obtained by taking the average of the 13 items. A prorated total score can be obtained when patients score at least 7 of the 13 items using the formula: (sum of items answered x 13) / number of items answered.

The MDASI was initially developed for cancer patients (Cleeland et al., 2000). However, it has been validated in a palliative population (Kwon et al., 2006). Kwon reported that the internal consistency as measured by Cronbach’s alpha was 0.90 for all
19 items, 0.85 for the 13 symptom items and 0.89 for the 6 interference items, 0.84 for
general symptom subscales and 0.72 for gastrointestinal symptom subscales indicating a
high level of reliability for these sets of items.

A further study validated the MDASI in 108 Taiwanese adolescents with cancer (Tseng
et al., 2008). Construct validity was established by principal component analysis, which
resulted in a 2-factor solution for the 13 MDASI symptom items: a general symptoms
factor (pain, fatigue, sleep disturbance, distress, shortness of breath, difficulty
remembering, drowsiness, dry mouth, sadness, and numbness) and a gastrointestinal
symptoms factor (nausea, vomiting, and lack of appetite). These two factors explained
52% of the total variance. Hierarchical cluster analysis results were consistent with the
factor analysis.

The Needs Near the End of Life Screening Tool (NEST) was developed as a screening
tool for use in the clinical setting and was based upon literature review, interviews and
focus groups with patients, carers and professional experts.

The NEST contains four domains:

- screening for social needs; (4 items: finances, access to care, closeness, caregiving needs).
- existential (4 items: distress, spirituality, settledness/personal acceptance, sense of purpose).
- symptoms, (2 items: physical issues and anxiety/depression).
- therapeutic relationship (3 items: patient/clinician relationship, information needs/clinician communication and goals of care).

This 13 item version is a screening tool if the cut off score for any of the questions is
reached. There are additional questions to facilitate further assessment of need. The
NEST is rated from 0 – 10 similar to the MDASI. For the purposes of the research, the
questions relating to finances, closeness, distress, spirituality/religiousness, settledness
/personal acceptance, sense of purpose and goals of care were utilised. The question
relating to information needs/clinician communication was slightly amended in that the
words “At the time of admission” were added to the question. The questions relating to
physical issues and anxiety/depression were not used as there were similar questions in the MDASI. The questions relating to care-giving needs and access to care were not used as the patient participants were inpatients. The question relating to patient/clinician relationship was also not used as it focused only on doctors and nurses rather than all team members. A question regarding the patients perception of their quality of life was adapted from the Assessment of Quality of Life in Palliative Care (AQEL) (Axelsson, 1999). The patient’s perception of their quality of life is a key measure of the quality of care provided (Mularski et al., 2007; Parker and Hodgkinson, 2011). A question concerning worries shared with any family member taken from the AQEL was added to the NEST interview. A question relating to satisfaction with family communication about the illness was adapted from FACIT–PAL (Lyons et al., 2009). These questions were included as the patient’s sources of social support and opportunities to share concerns with family members have been identified as key issues that impart the patient’s psychological well being (Mularski et al., 2007; Rosenblatt and Meyer, 2012). An open question relating to identification of symptoms and concerns that the patient would most like help with was added at the end. Therefore, the adapted interview schedule comprised of 12 scripted questions which were rated from 1-10 with verbal descriptors at each end and one open question, See appendix H.

2.6.6 Inclusion and exclusion criteria for patient interviews

Given the nature of population included in this research, it was essential that participants were sufficiently well to engage and that participation would not excessively burden or unduly fatigue them. Minimisation of burden to research participants is a key ethical requirement in palliative research (Cassarett and Karlawish, 2000; Wohleber et al., 2012). Consequently, inclusion and exclusion criteria were agreed with the medical team. The inclusion/exclusion criteria were as follows:

- Patients were aged over 18.
- Patients could understand English.
- Patients had to be physically and psychologically well enough to participate.
2.6.6.1 Patients were aged over 18 and could understand English

The age limit of 18 ensured that no minors were involved in the study. Patients who could not understand English were excluded as there were insufficient resources available to employ a professional interpreter. Although, a number of patients had family members who could interpret for them, it was felt inappropriate to request them to do so given that a number of the questions related to the patients satisfaction with family communication and support from family members. It was also felt that family members acting as interpreters might influence the responses from patients and potentially cause distress or conflict within the family.

2.6.6.2 Patients had to be physically and psychologically well enough to participate

The researcher did not wish to add to the burden of any patient who was too unwell, might fatigue too easily, or whose condition might be made worse through participation in the research (Addington-Hall, 2002). Consequently, the nature and duration of the research was explained to all admitting doctors who then made a decision, based on clinical judgment, as to whether it was appropriate to approach a patient to participate in the research. Admitting doctors were requested to exclude any patient who was too unwell, cognitively impaired, delirious or was actively dying. Patients with an acute mental health issue, an unrelated family crisis or who had experienced bereavement within the last three months were also excluded.

2.6.7 Carer questionnaire

Questionnaires or measures which enabled assessment of carer’s needs, quality of life of carers, or carer satisfaction with service delivery were identified through literature review. In order to be considered, data relating to testing the validity and reliability of the measure with a palliative care population had to be available within the literature. Questionnaires identified included:

- Quality of Life in Life Threatening Illness – Family Care Version (QOLLTI-F) (Cohen et al., 2006)
• Problems and Needs in Palliative Care Questionnaire - Care Giver Form (Osse et al., 2006)
• Care Giver Quality of Life Index – Cancer (CQOLC) Scale (Weitzner and McMillan, 1999)
• Care Giver Quality of Life Index (CQLI) (McMillan and Mahon, 1994)
• Families evaluation on management, care and disclosure for terminal stage cancer patients (Mystakidou et al., 2002b)
• Care Giving at Life’s End Questionnaire (Salmon et al., 2005)
• Family Inventory of Need (FIN) (Kristjanson et al., 1995; Hwang et al., 2003)
• FAMCARE (Ringdal et al., 2003) and the FAMCARE - 2 (Aoun et al., 2011)

Tools or questionnaires that had 20 or less items were prioritised in order to strike a balance between a comprehensive carer perspective and minimisation of burden to the carer. Tools which asked the caregiver to consider their present situation or the time period over the last 2/3 days to 1 week were also prioritised as this time scale was consistent with the time duration of contact with the hospice service.

The FAMCARE - 2 was developed to measure carer’s satisfaction with the care provided by the palliative care multidisciplinary team in an inpatient setting and was chosen as the measure of carer’s perception of care provided in this study. The FAMCARE - 2 is a revision of the FAMCARE (Hwang et al., 2003) which was developed to measure carer’s satisfaction with community or home based palliative care services. The tool contains seventeen items, with a five point Likert rating scale ranging from 1 - 5 (very satisfied to very dissatisfied), and a sixth response option of “not relevant to my situation”. The tool was validated in 2010 (Aoun et al., 2010) which identified four factors through factor analysis, including:

• Management of physical symptoms and comfort.
• Provision of Support, support to the family and provision of psychological care to the patient.

Aoun et al’s (2010) study reported that the FAMCARE - 2 had a Cronbach’s alpha coefficient of 0.93, indicating high reliability, and an item to item correlation coefficient of 0.49–0.72.
Additional demographic questions were added at the beginning of the FAMCARE - 2 tool including; age, gender and relationship of the respondent to the patient to facilitate comparison of demographic variables. Additionally, bespoke questions were designed by the researcher and agreed with the steering committee, relating to; efforts made to help with financial concerns, advise about additional supports, clarity of explanation received about the nature of the service provided by the unit, and satisfaction that the first meeting with the doctor and the nurse was conducted in a way that was manageable and acceptable. These questions were added to the end of the FAMCARE - 2 tool.

The patient was asked to identify the family member or friend who was most appropriate to complete the questionnaire from a carer’s perspective. The questionnaire was then given to the carer after three to five days of the patient’s admission. An addressed envelope was included for return to the researcher. Pre-intervention the response rate was 71% (n=25) as 35 questionnaires were issued. Post-intervention 46 questionnaires were issued and 25 were returned which resulted in a response rate of 54%.

2.6.8 Staff views

Information regarding the views of staff about the admission assessment, its component parts, how well it was working and aspects that required improving was sought pre and post-intervention through quantitative and qualitative enquiry.

2.6.8.1 Staff surveys

A short staff survey was developed further to consultation with the steering group to collect quantitative data. A convenience sample of all professional staff who worked in the SPCU received postal questionnaires and were invited to return them, pre-intervention (n = 65) and post-intervention (n = 67). Staff names and titles were identified from the human resources department of the palliative care unit. Staff were requested to return the questionnaires within three weeks of their receipt. They were issued a reminder through their email and line managers. A total of 77 staff returned questionnaires, 62% (n =40) pre-intervention and 55% (n = 37) post-intervention.
2.6.8.2 Staff interviews

All staff were invited to participate in short qualitative interviews of approximately 30 minutes duration. It was explained in the introductory letter that the first twenty participants to return a consent form would be interviewed. Sixty five staff were working in the inpatient unit at the pre-intervention stage (7 doctors, 40 nurses and 18 therapy and social care staff) and sixty seven were working in the inpatient unit at the post-intervention stage (9 doctors, 40 nurses and 18 therapy and social care staff). The aim was to interview approximately thirty percent of each discipline. Thirty percent was chosen as it was viewed as feasible sample size from each discipline and it was anticipated that saturation would be reached in that sample. A total of 20 staff agreed to participate in the pre-intervention evaluation interviews (2 doctors, 11 nurses and 7 therapy and social care staff) and were subsequently interviewed by the researcher. A total of 16 staff agreed to participate in the post-intervention evaluation interviews (3 doctors, 8 nurses and 5 therapy and social care staff). Those respondents who were interested in participating completed and returned the consent form which outlined details of their profession, the length of the experience in palliative care and the length of their experience in palliative care in MCC, (see Appendix I). The interviews were scheduled at a time convenient to the interviewee and conducted in private.

A protocol for conducting the interviews was developed for the purposes of consistency and to help guide the interview (see Appendix J). A semi-structured interview schedule was developed (see Appendix K). The use of individual interviews as a method of collecting data can be useful as it allows for greater nuances in the responses and affords new angles of approach to questioning. The interview questions were developed after careful deliberation and in consultation with the chair of the steering group. Two pilot interviews were conducted to test the relevance of the questions and the researcher’s interview style. The interviews were conducted by the researcher at a time and place convenient to the interviewee. Interview duration varied from fifteen minutes to thirty five minutes. All interviews were taped with the consent of the interviewee and transcribed using a transcription kit.
2.6.9 Audit of the admission assessment

An audit of the admission assessment documentation was conducted at phase 2, 4 and 5. Two mini audits were also conducted during phase 3 to further refine and inform the admission assessment process and documentation. A literature review of palliative care standards was conducted to identify standards relevant to an initial admission assessment. (See Appendix L for the outcome of the literature review used to identify audit criteria).

Two questions were asked of each criterion relating to symptoms or issues in the audits in phases 1 and 2. The first question explored the evidence of assessment of the symptom or issue. The second question related to relevance to the patient, i.e. was the patient experiencing the symptom of issue. In the audit in phase 5, only evidence of assessment of the symptom or issue was sought.

The audit tool was piloted and completed independently by three individuals, the researcher, a consultant in palliative medicine and a clinical nurse manager. This ensured validity. Any discrepancies in how criteria were scored were discussed until consensus was reached. The audit was then conducted through retrospective chart review and the data collected on an excel spread sheet. All results were then exported to SPSS (v19.0) for analysis. (See Appendix M for the audit tool).

The results of the audits were presented to the steering group and to the staff working on the unit. Suggestions for improvement to the process and documentation of the admission assessment were collated during the staff feedback sessions and documented. The suggestions were then discussed with the steering group to determine if they would be accepted or rejected. In this way, the development of the admission assessment process and its documentation was an iterative process involving cycles of audit, principles of quality improvement, consultation with staff and critical appraisal and reflection (Curry et al., 2009).
2.6.10 Ethical considerations

Ethical approval was received from the Mid-West Regional Hospital Scientific Research Ethics Committee and was conducted in accordance with the World Medical Association’s Declaration of Helsinki – Ethical Principles for Medical Research involving human subjects (World Medical Association, 2008). A number of ethical issues were considered in the development of the research design.

2.6.10.1 Participation in research may be too distressing and burdensome for patients

Burden to participants due to participation in research has been explored by a number of investigators, who have found that the majority of participants do not typically find such activities burdensome, and many experience benefit through participation (Paci et al., 2001; Takesaka et al., 2004; Pessin et al., 2008).

2.6.10.2 Participants might feel obligated to participate in the research

Patients and carers may feel compelled to participate due to a feeling of indebtedness to the service or concern that non-participation might negatively impact on care provided to the patient. Staff may be concerned that they would be viewed negatively by their supervisors if they did not participate.

Prospective participants, including patient’s carers and staff, were assured of their right not to participate in the research both verbally when the research was being explained and in writing in the patient information leaflet. A reassurance was also provided that there would be no negative impact due to non-participation.

2.6.10.3 Informed consent

All participants (patients, carers and staff) were requested to consent in writing prior to participation in the evaluation. Information leaflets were provided to patients, their family members and staff, which described why they were being approached, the purpose of the research, what the research entailed, how long it would take and what would happen to the data. Patients also received a verbal explanation from the
researcher. It was emphasised both verbally and in writing that there was no obligation to participate.

The researcher always introduced themselves to patients as a researcher who was working under the supervision of the clinical team. This was an effort to convey accurate information to patients that the researcher did not have a clinical role, would not be providing care or interventions and that, where applicable, information would be relayed back to the clinical team. The verbal explanation also emphasised that participation would be of no direct benefit to patients. The researcher wished to ensure that patients did not feel a sense of coercion, obligation to participate or be concerned that they were displeasing clinicians through non participation. The researcher highlighted that they worked with, but were not part of, the clinical team and emphasised the lack of direct benefit to the patient for these reasons.

During the verbal explanation, the researcher provided patients with a description of the nature of the questions that would be asked in simple language and checked the understanding of patients prior to giving them the information leaflet. All participants were offered an opportunity to ask questions for clarification and a period of time alone to consider whether they would like to take part. It was particularly important that the patients understand that questions might be invasive - for example asking about communication within the family, impact of the illness on finances, support received from religious or spiritual beliefs and other issues. By explaining the nature of the questions in advance the patient was provided with forewarning and was facilitated to make an informed choice as to whether or not they wished to give consideration to or answer such questions. (See Appendix N, O, and P for information leaflets for patients, carers and staff. See Appendix Q and R for consent forms for patients and carers).

Implied consent was presumed from staff who returned surveys. Although, implied consent could not have been presumed from carers and not all carers returned their consent form with the surveys, it was important to include a carer’s consent form as it highlighted that information contained in completed questionnaires would be communicated to relevant clinicians, if appropriate. This happened on six occasions,
relating to areas of dissatisfaction on two occasions and requests for information on four occasions.

2.6.10.4 Informing the patient that their completed questionnaires are available for review by the clinical team may influence how questionnaires are completed.

It was necessary to ensure that the clinical team was informed of any issues identified in the questionnaires which had not been identified at the initial time of admission. Consequently, copies of completed questionnaires were filed in the patient chart immediately after completion and highlighted to either the medical or nursing team post completion. In instances where an issue might be most appropriately dealt with by a different member of the multidisciplinary team (such as social work or pastoral care) the identified need was also communicated to the relevant member of the team if the patient consented for the information to be communicated.

Concern has been expressed that if the patient was aware that the doctor would be reviewing the questionnaire, it may prevent the patient or carer being truthful or introduce a bias in answers (Strömgren et al., 2001). For example, social desirability bias may result in the patient wishing to communicate certain messages through the responses to the questionnaire, e.g. that symptoms improve more than they actually do. However, it was felt that the necessity of ensuring that all symptoms identified were treated as quickly as possible outweighed the concern regarding influencing a patient’s completion of questionnaires. To assure clarity, the fact that issues were to be communicated to clinicians as appropriate was communicated in the verbal description, the information leaflets and again highlighted in the patient and carer consent forms.

2.6.10.5 Patients may be too ill to participate

Authors have raised concerns that asking palliative care patients to participate in research will potentially further deplete energy levels, can reduce the time available to spend with loved ones or to complete unfinished business. The admitting doctor identified if a patient was well enough to participate in the research, based on clinical judgement. Patients were made aware that they were free to withdraw at any time and for any reason. Patients were reassured that withdrawal would not impact their care.
2.6.10.6 Dealing with disclosures

It was anticipated that there might be situations during the data collection where a disclosure might be made to the researcher. Such disclosures were to be handled on a case-by-case basis, and all such disclosures were to be documented fully and formally reported to the appropriate staff member in accordance with the relevant MCC policy.

2.6.10.7 Requirement to maintain information in a confidential manner

All data was processed confidentially, ensuring that identification of persons who participated in the interviews, or returned surveys or patients whose charts are audited did not occur. A unique ID number was assigned to each audit sheet, returned questionnaire etc. Any identifying information was removed from returned questionnaires. The master list of persons contacted was held separately to the data or hardcopy questionnaires in locked filing cabinets. The soft copy of the master list was password protected.

2.6.10.8 Accessing Patients

Previous authors have discussed that accessing palliative care patients for the purposes of research can be difficult for a multitude of ethical reasons (Duke and Bennett, 2010). These include ‘gate keeping’, difficulty in determining if a patient has capacity to consent and difficulties in recruiting adequate sample sizes to detect change (Steinhauser et al., 2006a; Addington-Hall et al., 2007). Strategies employed to remediate the potential for ‘gate keeping’ were reviewed at the stage of research design (Addington-Hall, 2002; Harris et al., 2008b; Duke and Bennett, 2010). The research design was developed through extensive consultation with the steering committee which included senior clinical decision makers. This included consideration of the research process on the ward, how and when the research would be conducted as well as measures and analysis methodology to be utilised. Additionally, this process of careful consideration fostered relationships between the researcher and the clinicians and a shared ownership of, and commitment to the research.
Four presentations were conducted with frontline staff over a three week period to explain the methodology of the research design in advance of its initiation. Such presentations offered opportunities to delineate the aims and relevance of the research to clinical practice and to give reassurance that patients and carers would be offered every opportunity to opt out of participation and would not be unduly burdened. Examples of literature which had discussed palliative care patient’s response to participation in research were provided. Part of the research design was to interview patients who consented to participate within the first 48-72 hours of admission. Consequently, it was important to ensure that doctors signed the inclusion form as quickly as possible after the admission assessment. The researcher enlisted the help of the ward clerks in the unit, who agreed to include the inclusion form as part of the admission documentation to facilitate ease of completion by the doctors.

The ward clerks were contacted on a daily basis to identify new admissions. Subsequently, the admitting doctor was contacted on the evening of the admission or early the following morning to ensure the inclusion form had been completed. This method afforded two full days to approach the patient to seek consent, allow them time to consider the request and to complete the interviews. Patients were most commonly approached in the morning immediately after the ward round or after lunch in order to avoid disrupting the patients time with visitors. There is no restriction on visiting hours in the unit, however most visitors attend in the afternoon. By liaising with clinicians immediately post-interviews to share the ratings specified by the patient, the researcher demonstrated to clinicians that participation was feasible and did not negatively impact the patients. There were occasions when the interviews provided information that had not previously been known about the patient.

2.6.10.9 Welfare of patients

The patient interview concluded with the question “That is the end of all my questions, how was that for you?” If the patient said little in response, a prompt asking “Did the interview cause any difficulty or distress? and/or Was there any question you would prefer was not asked?” was added.
The researcher communicated the outcome of the interviews and in particular the effect on the patient during and after the interviews to either the doctor or nurse on duty. The researcher made contact with all patients the day after interviews to thank them for participation. The researcher used this opportunity with all persons, particularly those who had become upset during the course of the interview, to check how they were, and to determine if they required support.

2.6.10.10 Welfare of the researcher

The welfare of the researcher was also considered at the research design stage, given the nature of the interviews, which included asking patients with terminal conditions to reflect on the impact of their illness and its effect on their values, meaning within their lives, and effect on their family life. Studies have noted that research of this nature may be emotionally draining and that measures to promote positive mental health for researchers are necessary (Seymour and Skilbeck, 2002; Steinhauser et al., 2006a).

The researcher could access support through a mentor, the head of therapy and social care services at MCC and who was on the supervising committee, overseeing the research design. Support from the mentor was used on two occasions post interviews. The first occasion was because the researcher had become upset during an interview as a patient recounted their experiences. The researcher had acknowledged that they were becoming overly emotional to the patient who was particularly articulate and open about the impact of their disabling condition on their lives and lives of their family. There was no indication the patient was distressed. This was confirmed after the interview by checking with patient. However, the researcher was concerned that it might reoccur and felt this may be inappropriate or burdensome to patients. The researcher was given an opportunity to discuss the concerns with the mentor and provided with reassurance. The researcher did not become distressed again during interviews.

The second occasion related to a patient who had initially kept the interview at a very superficial level using humour as a means of deflection when discussing his symptoms. For example, this patient referred to ascites as “the twins” repeatedly. However, when it came to the question relating to the “How much does this illness seem senseless and meaningless”, the patient became extremely upset and cried for an extended period of
time. This patient talked about how sad he was to be leaving his family, that he couldn’t understand why he had gotten sick, as he felt he had lived healthily and that he had anticipated another “half of life”. The researcher remained quietly by the patient’s bedside, occasionally touching their arm, offered tissues and listened while they cried and talked. When the crying had abated the researcher suggested a break or that the interview be discontinued. The patient preferred to continue the interview. On immediate review of the interview the patient described the interview as follows:

“It was tough going there, there was no question that shouldn't have been asked; I'm glad I got it out.”

At the end of the interview the patient made a request that copies of the carer’s survey would be given to their spouse and young adult children and that they (the patient) would be then given copies of the children’s completed surveys to see how they felt. The patient explained his concerns that one of his children might be in denial as they would not discuss the illness. The researcher initially agreed to this request, largely because of the strength of the emotion that had been shown by the patient and misguided desire to help. The researcher explained the availability of pastoral care and social workers and their skill in supporting families to have difficult conversations with each other. The patient consented to both pastoral care and social work being contacted by the researcher. The researcher then communicated the outcome of the interview to the nurse on duty. The researcher discussed the issue with the mentor due to concerns of confidentiality and consent. The mentor suggested that blank copies could be provided to the patient to give to the adult children and they could be used as a vehicle for discussion within the family. The researcher went back to the patient to see how they were and to explain that it would be inappropriate to allow access to completed copies of the surveys without the consent of the children. The patient agreed to the use of blank copies as a vehicle for discussion with the children. The researcher enquired how the patient felt after the interview. The patient acknowledged that it was emotional:

“.....it was there, it was good to get it out, it was a release.”

The patient was followed up by both pastoral care and social work.

In addition to the support of a mentor, the researcher was in regular contact with their supervisor through phone, email and face to face communications. The researcher also
kept a research journal to facilitate reflection and the processing of thoughts (see 2.6.8.3). Also, if necessary, a staff support service provided by a psychologist, was available at Milford Care Centre, although this was never used.

### 2.7 Data analysis

This section details methods of analysis of the questionnaires, staff interviews, reflexivity (as a tool to increase objectivity), qualitative data and the analysis of phases.

#### 2.7.1 Questionnaires

The completed patient (MDSAI and adapted NEST), carer (FAMCARE - 2) and staff questionnaires (bespoke) were coded and entered into SPSS (version 19). Analysis of data included testing for normality and descriptive and inferential tests (such as chi-squared tests and Mann Whitney U tests). Answers to open-ended questions were collated and thematically analysed. The data collected through patient chart audit and staff quantitative questionnaires was described using frequencies and percentages. A chi-square statistic was used to determine if there was an association/difference between percentage documented evidence of assessment and the phase of the intervention. A chi-square statistic was also used to determine if there was an association/difference in the respondent’s ratings on the staff questionnaire and the phase of intervention.

The data collected through the patient interviews pre and post-intervention were tested for normality using the Kolmogorov-Smirnov statistic. The results of all tests indicated that the data collected on the symptoms and issues queried was non-normal in distribution. Therefore the statistical test utilised was a non-parametric test. A Mann Whitney U test was then used to check if there were differences in patient ratings pre and post-intervention for all symptoms and issues that were not normally distributed.

The data collected from carers via the FAMCARE 2 tool was tested for normality and as it was not normal, the Mann Whitney U test was utilised to investigate if there was a difference pre and post-intervention between the total scores or the factor scores.
The data collected from the staff regarding their confidence and competence was tested for normality using the Shapiro-Wilk W test as the sample size was below 50. As the data was non-normal in distribution, the Friedman test was used to determine if there was a change in confidence and competence over three time points, prior to receipt of training (Time 1), immediately after receipt of training (Time 2), and three months post receipt of training (Time 3). Where significant change in scores over the three time periods was evidenced the Wilcoxon rank test was used as a post-hoc test to check for difference in scores between Time 1 and Time 2 and between Time 2 and Time 3.

2.7.2 Staff interviews – Analytical method

Thematic analysis was chosen as the method for analysis of staff interviews. Thematic analysis facilitates the identification, organisation, analysis and reporting of themes within qualitative data (Braun and Clarke, 2006). Thematic analysis was chosen as it is sufficiently flexible to be used with a number of epistemological perspectives. It affords review of the significant features of a large body of data and facilitates delineation of similarities and differences within a data set, which is appropriate in the context of a pre and post-evaluation.

2.7.3 Reflexivity

The researcher employed reflexivity as a tool to increase objectivity during data collection and analysis. Reflexivity relates to the;

“…capacity of any system of signification to turn back upon itself, to make itself its own object by referring to itself” (p. 307).

(Myerhoff and Ruby, 1992)

The research was conducted at the researcher’s place of employment. The intervention that was being evaluated post-intervention was developed by the researcher in consultation with the steering group. Therefore, the researcher is part of social cultural and hierarchical milieu in which the research was set. The reflexive journal was a tool to aid acknowledgement of, and manage impact of, the researcher on outcome of the
research and to minimise the impact of the research on the researcher. In order to minimise bias and maximise the rigour and validity of the research the reflexive researcher wishes to;

‘become more consciously reflexive by thinking about our own thinking, by noticing and criticizing our own epistemological pre-understandings and their effects on research, and by exploring possible alternative commitments.’(p 129)

(Johnson and Cassell, 2001)

Consideration of both the researcher’s and the participant’s perspective is critical in the context of the qualitative research. This is particularly important in the context of the use of qualitative enquiry in this research as it was aimed at illuminating the participant’s opinion of the product of the researcher’s work.

“Understanding something about the position, perspective, beliefs and values of the researcher is an issue in all research, but particularly in qualitative research where the researcher is often constructed as the ‘human research instrument’(p 333)

(Cohen and Crabtree, 2008)

2.7.4 Analysis of qualitative data

The staff interviews were transcribed, read and re-read. The transcripts of the interviews were then loaded to NVivo 10. Within qualitative research, the NVivo software is used as an analytical tool for the purposes of efficiency and transparency. Use of such software does not absolve the researcher of their hermeneutical responsibility. Since the researcher controls the inquiry and analysis. The software is the medium through which the inquiry, analysis, thought process and decision making of the researcher can be registered or chronicled.
2.7.5 Phases of analysis

As the interviews were transcribed by another person for reasons of time efficiency, each interview was re-listened to by the interviewer and checked against the transcript for accuracy. Any words or phrases that were missing were reinserted by the researcher. Initial notes concerning observations and possible codes were also made on the typed transcripts at this stage. This is an important first phase of analysis to facilitate familiarisation with the data.

The transcripts were subjected to thematic analysis which included three rounds of coding or data extraction. The first round of open coding was used to extract basic or fundamental codes in a systematic manner and required reading the transcripts and coding of the transcripts to categories which described the content. Each category was initiated by delineating a definition as to its content. This level of coding largely corresponded with the interview questions and additional codes to describe the data.

The second round of coding, interpretative coding, included collating the codes to more abstract themes and sub themes which described the content and facilitated further analysis of the content to inform the evaluation. This round of coding required a further full review of the data sets. Some data extracts were coded to more than one theme at this stage. A mind map was created to visually represent the codes and aid the organisation of codes to themes.

The third round of coding included refinement of themes and sub themes. The coded data extracts were further reviewed to determine if they were appropriate to the themes. This stage facilitated a further opportunity to identify if any important data had not been coded or needed to be recoded, a process that is known as validating the themes. Themes were refined, merged and re-categorised via data reduction for the purposes of consolidation and development of a meaningful summary or conceptual framework to illustrate and clarify the content. Themes were renamed and their definitions revised to assure that they were explicit, representative of the data and clearly communicated to the reader.
Finally the extracts which were most illustrative of the identified themes were chosen to be included in the results section (see chapter 4).

2.8 Phase 3.

Phase 3 describes the development and implementation of the MPCAT.

2.8.1 Development of the revised admission assessment process

The outcome of phases 1 and 2 were used to develop the admission assessment process and proforma. A series of pre-scheduled meetings were established with the steering group to agree the tools, scales or questioning format to be included in the admission assessment and to identify the professional most appropriate to complete each element. The pre–scheduling of a series of meetings in advance was used to facilitate the attendance of members with particular expertise, such as social workers in respect of assessment of psychosocial needs and pastoral care in respect of assessment of spiritual distress. Members of the steering group were not expected to attend all meetings.

The meetings were scheduled according to the domains of need as follows:

- assessment of pain and physical symptoms (three meetings)
- cognitive issues (one meeting)
- psychosocial issues (two meetings),
- spiritual need (one meeting),
- assessment of carers need (two meetings),

The data extraction summaries developed in phase 1 and justification summaries were circulated to steering group members at least one week in advance of the meeting. Subgroup meetings were also held to redevelop certain sections of the admission assessment such as activities of daily living with nursing personnel, assessment of manual handling and ‘falls risk’ with physiotherapists and nursing personnel.

An adapted Delphi technique was utilised to request the group to rank their first, second and third choice of tools or scales in order of preference in advance of attendance at the
meeting using an excel form that had been circulated by the researcher. Criteria used to rate tools included:

- How comprehensively it covered the palliative care domain, rated 0-5 (5 being the most preferred).
- How complicated and burdensome to the patient, rated 0-5.
- Whether the period of review of the measure was similar to the admission assessment, rated 0-5.
- Whether it elicits specificity from the patient, rated 0-5.

The group members were requested to return the completed excel spreadsheet on the morning of the meeting to be collated by the researcher. Where agreement was not reached at the first meeting, the list of tools or measure was shortlisted and a second Delphi round occurred. Three final meetings focused on refining and reformatting the admission assessment proforma as a single document with associated guidelines.

### 2.8.2 Training the staff

Once agreed, the researcher arranged appointments with all nursing, medical, social worker and pastoral care staff on the ward. Small groups typically involving two or three staff at a time were held. The theoretical background and scoring guidelines of all included tools was provided. The sessions explored the rationale for the choice of tools and questioning format. These sessions emphasised the need to conduct the assessment in response to patient cues and in the context of the patient’s presenting condition and willingness to participate in the assessment of the various domains. A folder which included an example of the admission assessment document, the papers validating the evidence-based tools included and the scoring guidelines of the tools included was provided at each nurse’s station (See Appendix S for an example of the hand outs provided at the training session).

Training also included workshops relating to psychological and spiritual assessment facilitated by a principal social worker and a pastoral care professional. Guidelines to assure the safety and appropriateness of the assessment process included that:
• The assessment may be conducted on Day 1 of the patient’s admission. However, it may be more appropriate that the assessment flows over a period of 48 – 72 hours (Day 1 – 3) in the majority of instances to avoid over burdening the patient.

• The psychosocial, spiritual and carer’s assessment may be completed on day 1 but can also be completed over days two and three by a doctor or nurse, if felt to be more appropriate in the context of the patient’s presenting condition.

• Instances where conducting the assessment over 48 – 72 hours is not possible as the patient is either unable or unwilling to participate should be recorded. Explore the potential to conduct the assessment over the following 48 hours i.e. Days 4 and 5.

• Social work can be contacted to request them to contribute to or complete the psychosocial or carer’s assessment in instances where the early involvement is warranted.

• A summary of the proposed domains of the assessment should be provided for the patient in order that they make an informed choice as to their preference concerning participation.

• Staff shall communicate an outline of the areas that will be covered to the patient and the possible length of the initial assessment. Also, they should seek the patient’s consent that all areas of the assessment are conducted.

• Pastoral care staff conduct the spiritual assessment. Medical personnel conduct the spiritual screen if appropriate.

• In instances of a patient expressing a preference that an aspect of the assessment not be conducted, e.g. psycho-social domain or spiritual assessment, these wishes should always be respected. The patient should be advised that this decision will be revisited periodically to offer opportunities of assessment.

• Staff should ensure that sections on completion are signed and dated with professional title and time of entry. Reviews of documentation on subsequent days are asterixed, signed, dated and timed by the documenting clinician.

• All members of the team who are documenting within the patient chart are to document their name, title and signature on the signature page.
Further to provision of training, the assessment process was then piloted for a period of 3 months.

2.8.3 Training evaluation

All non-consultant hospital doctors who received training in respect of the revised admission assessment were asked to complete a questionnaire to evaluate their confidence to communicate around difficult issues which commonly arise in dealing with palliative patients. This data was collected post-intervention only. The questionnaire included 14 questions with 0 - 10 numerical rating scales (Fallowfield et al., 2001; Wilkinson et al., 2008) (See Appendix T). The doctors were asked to complete the questionnaires prior to receipt of training, immediately after receipt of training and three months post-receipt of training. All other staff who received training had an opportunity to rate their need for additional training pre and post the development of the admission assessment as part of the quantitative survey.

2.9 Summary

The epistemological approach to this research is a mixed methods research study. This mixed methods study was designed to occur over five distinct phases, each with specific objectives and expected outputs which are illustrated in figure 2.4.1. A vital component of this research was the establishment of the steering committee structure at the initiation of the research. This committee was critical as an aid to the development and delivery of the research throughout its tenure and the acceptance of the MPCAT tool within MCC. In the development of the MPCAT specialist palliative care units nationally and internationally (n= 268) were contacted to request permission to access their multidisciplinary initial inpatient assessment documentation. A literature review using a systematic approach was conducted to identify tools in the literature relevant to the area of admission assessment protocols for palliative care patients. An adapted Delphi technique was used as a mechanism to structure the steering group’s choice of tools for the research. Ethical approval was received from the Mid-West Regional Hospital Scientific Research Ethics. The methodology also addressed issues of inclusion and exclusion criteria of patients. These criteria were rationalised and validated to ensure, appropriate selection of patients and carers. These methods also served as to not ‘over burden’ patients in trials of MPCAT. Feedback in the form of staff interviews and
audits in the developed tool also informed the research. Methods of analysis of the questionnaires, staff interviews, reflexivity (as a tool to increase objectivity), qualitative data and the analysis of phases provided solid foundations to the analysis of results. The implementation and effectiveness of the training programme for the MPCAT was also evaluated.
Chapter 3 Literature review

This chapter documents a literature review of assessment tools or scales that have been validated within palliative care services. A systematic approach was used in searching the literature so that the review might be focussed, feasible and comprehensive. Electronic databases, including Medline, PsycINFO and Cinahl were searched from 2000 to mid 2011. The reference lists of key papers were also reviewed to identify articles which provide details of the psychometric properties of assessment tools. Searching the literature resulted in the identification of evidence based guidelines, screening and assessment tools suitable for use in the admission of palliative care patients to an inpatient service. The outcome of the literature review was used to inform the development of the Milford Palliative Care Assessment Tool (MPCAT).

3.1 The importance of a literature review

Assessment within palliative care requires consideration of the multi-dimensional nature of the patient experience supplemented by an assessment of carer’s needs. Given that palliative care patients are commonly polysymptomatic, the number of issues to be assessed is broad and includes complex interplay between physical, social, spiritual and psychological needs. A systematic approach to searching the relevant literature allows a focussed feasible and comprehensive review. To aid comparison and decision making a list was compiled for each domain, comprising tools that had been validated in a palliative care population. Tables were developed for each domain to summarise the results. The tables provide information with regard to the number of items within each tool, the response format, its acceptability to patients and staff if known, as well as psychometric data. After careful analysis this information along with a recommendation from the researcher was shared with members of the steering group. The data helped to inform the steering group’s decision in selecting/identifying suitable tools for inclusion in the assessment proforma.

The electronic search identified 7,479 hits when the search terms were applied. Of these, 3,992 originated from Medline, (Med) a further 1,776 in PsycINFO (Psych) and 1,711 in Cinahl (Ci). The full list of search terms is included in Appendix B. Further to
review of the titles and abstracts, 441 articles were initially selected from the electronic search, 191 from Medline, 172 from PsycINFO and 78 from Cinahl. After exclusion of duplicates, 334 articles remained. Table 3.1.1 shows a summary of the outcome of the search.

Abstracts and titles of papers were screened to determine if they should be included in the review by the researcher. In instances of uncertainty the full paper was reviewed. The abstracts were screened against predefined inclusion and exclusion criteria which included searching for articles relating to validation of assessment measures, tools, or scales, used in patient assessment and assessment of carers need in inpatient palliative care, end of life, terminal care or hospice settings. Further details of inclusion and exclusion criteria employed are delineated in Table 3.1.2

**Figure 3.1.1** Systematic literature review results
Table 3.1.2 Inclusion and exclusion criteria for the literature review

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Studies relating to initial assessment of adult inpatients with palliative care needs.</td>
<td>• Studies specifically to palliative care in outpatient, day care or community settings.</td>
</tr>
<tr>
<td>• Studies relating to measures for use in clinical care.</td>
<td>• Studies relating to non palliative care specific environments such as Nursing Homes and Intensive Care units.</td>
</tr>
<tr>
<td>• Studies which provided details of the psychometric data of assessment tools or measures for use in inpatient palliative care setting.</td>
<td>• Studies relating to specific terminal conditions e.g. brain tumour, lung cancer.</td>
</tr>
<tr>
<td></td>
<td>• Case Studies</td>
</tr>
<tr>
<td></td>
<td>• Studies narrating descriptions of ethical, legal or regulatory issues.</td>
</tr>
</tbody>
</table>

3.2 Systematic assessment

Palliative care responds to physical, psychological, social and spiritual needs, and extends to support in bereavement. The need for excellent assessment of patient and family need is emphasized in the definition of palliative care as an approach:

"that improves the quality of life of patients and their families facing the problem associated with life threatening illness...", through “.... the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”

(World Health Organisation, 2002)

However, studies internationally indicate that optimal assessment practices may not always occur in clinical practice as clinicians often underestimate or fail to detect patient’s experience of palliative care symptoms and issues (Strömgren et al., 2001; Petersen et al., 2006; DesHarnais et al., 2007). This has been linked to a variety of
factors that include inadequate staff preparation and education (Narayanasamy and Owens, 2001), lack of confidence and competence (Lawrie et al., 2004; DesHarnais et al., 2007) and time constraints (Velikova et al., 2001). Assessment is crucial to identification of problems, which in turn is key to providing necessary and appropriate interventions, and facilitating access to services for patients (National Institute for Clinical Excellence, 2004). These guidelines recommend that:

“effective assessment hinges on the provision of appropriate education and training for healthcare and social care professionals, feasible and sensitive assessment tools and the availability of skilled personnel.”

Systematic assessment can improve the assessment and aid identification of symptoms requiring intervention (Homsi et al., 2006). There is a significant difference between symptoms reported voluntarily by patients compared with those identified when specifically inquired for (Osse et al., 2004). Therefore, to enquire in a standardised way increases the identification of symptoms (Baile et al., 2011). Use of systematic symptom assessment tools can increase recognition of the need for intervention and reduce symptom burden in palliative care patients (Hockstra et al., 2006). Additionally, patient satisfaction may improve with respect to perception of emotional support received from the physician without increasing time to complete assessments (Detmar et al., 2002). Furthermore, delineation of symptoms relating to psychological distress, emotional needs, fatigue and pain is increased with systematic assessment methods (Crooks et al., 2004).

3.3 Pain

Building on a systematic literature review conducted by a working group from the European Association of Palliative Care (Caraceni et al., 2002), Hølen and colleagues conducted a systematic literature review of pain assessment tools for use in palliative care and consulted a panel of clinical experts to determine the most important factors or domains in pain assessment both in clinical practice and palliative care research (Hølen et al., 2006). The literature search identified eighty tools containing at least one item relating to assessment of pain, 48 tools focusing on pain and 32 emphasising symptom
assessment or health related quality of life. These tools contained a total of 1,011 pain items. From these an expert review panel identified 10 pain domains (See Table 3.3.1), and these were ranked according to importance in the assessment of pain in palliative care.

Table 3.3.1: Pain domains, in order of their importance in respect of the assessment of pain in palliative pain.

<table>
<thead>
<tr>
<th>Pain Domain</th>
<th>Domain Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Intensity*</td>
<td>Measure of the pain strength</td>
</tr>
<tr>
<td>2 Temporal Pattern*</td>
<td>Fluctuations in intensity</td>
</tr>
<tr>
<td>3 Treatment and that which alleviates aggravates the experience of pain*</td>
<td>Both medical and non medical</td>
</tr>
<tr>
<td>4 Location*</td>
<td>Where the pain is</td>
</tr>
<tr>
<td>5 Interference*</td>
<td>Extent to which quality of life or activities of daily living are impacted</td>
</tr>
<tr>
<td>6 Quality</td>
<td>Physical feeling or sensation of the pain</td>
</tr>
<tr>
<td>7 Effect</td>
<td>Psychological or emotional impact of the pain</td>
</tr>
<tr>
<td>8 Duration</td>
<td>Length of time pain is experienced</td>
</tr>
<tr>
<td>9 Beliefs</td>
<td>Perception of origin and result of the pain and resilience or ability to manage the pain experience</td>
</tr>
<tr>
<td>10 History</td>
<td>Pain experience from the past medical history</td>
</tr>
</tbody>
</table>

* The most important domains in a palliative care context.

Pain intensity, temporal pattern (including breakthrough pain/episodic pain), treatment and exacerbating/relieving factors (particularly related to physical activity), location and interference with function were identified as the most important domains when completing an assessment of pain in palliative care patients (Hjermstad et al., 2008). The other domains were rated as less important, particularly when balancing the need for comprehensiveness of assessment with assessment burden in respect of palliative care patients (Hølen et al., 2006).

Only three tools cover all five domains recommended by the expert panel in Hølen et al.’s study: the Aberdeen Low Back Pain Scale (AB) (Ruta et al., 1994), the World Health Organisation Quality of Life Assessment Tool – Pain Module (WHOQOL-Pain) (Meenan et al., 1980), and the Pain Assessment Questionnaire for Patients with
Advanced Disease, 2001 (PAQ) (Perron and Schonwetter, 2001). Hølen et. al. (2006) suggested that the Aberdeen Low Back Pain Scale includes the suggested dimensions, and contains suitable items that may be suitable if the word ‘back’ is removed. The World Health Organisation Quality of Life Assessment Tool – Pain Module includes the essential domains of pain effect, duration of pain and beliefs about the causes and consequences of pain. However, it contains 149 items and so may be considered inappropriate for routine use in palliative care due to its length.

The Pain Assessment Questionnaire (PAQ) for a Patient with Advanced Disease is derived from the Management of Cancer Pain: Clinical Practice Guidelines (Jacox et al., 1995). The PAQ is a set of questioning guidelines rather than a specific measure or tool.

### Table 3.3.2 Illustrating the question areas in the pain assessment questionnaire for a patient with advanced disease (Perron and Schonwetter, 2001)

<table>
<thead>
<tr>
<th>Pain assessment questionnaire includes review of the following</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Onset and temporal pattern</td>
</tr>
<tr>
<td>2</td>
<td>Pain intensity</td>
</tr>
<tr>
<td>3</td>
<td>Location</td>
</tr>
<tr>
<td>4</td>
<td>Aggravating / Relieving Factors</td>
</tr>
<tr>
<td>5</td>
<td>Quality</td>
</tr>
<tr>
<td>6</td>
<td>Radiation</td>
</tr>
<tr>
<td>7</td>
<td>Meaning</td>
</tr>
<tr>
<td>8</td>
<td>Impact</td>
</tr>
<tr>
<td>9</td>
<td>Treatment preferences</td>
</tr>
</tbody>
</table>

In addition to reviewing the areas outlined in Table 3.3.2, the clinician is encouraged to conduct a systems review, neurologic evaluation and physical examination.
Jensen’s review of pain measures in adults with cancer concluded that the Visual Analogue Scale (VAS), the Numerical Rating Scale (NRS), and the Verbal Rating Scale (VRS) are equally acceptable as measures of pain intensity in respect of validity (Paice and Cohen, 1997; Caraceni et al., 2002) and reliability (non completion) (Jensen, 2003). However, Numerical and Verbal Rating Scales show slightly lower rates of non completion than Visual Analogue Scales, particularly if the patient is older. The patient’s capacity to complete Visual Analogue Scales decreases as palliation progresses. Increasing intake of opioids is also associated with higher failure rates when using Visual Analogue Scales and such patients are more likely to prefer Verbal Rating Scales and Numerical Rating Scales (Paice and Cohen, 1997). Numerical rating scales are commonly used in clinical practice (Perron and Schonwetter, 2001) and appropriate for use in palliative care (Costello et al., 2001). However, an expert working group of the European Association of Palliative Care concluded that a simple verbal rating scale was the most common measure of pain intensity in clinical practice, although the increased number of measurement points offered by numerical rating and visual analogue scales increases sensitivity which is desirable in both clinical practice and research. (Caraceni et al., 2002). Cognitive impairment is associated with inability to complete numerical rating scales (Jensen, 2003). Patients who are unable to complete a 0-10 numerical rating scales may be able to complete a four point verbal rating scale. Jensen recommended a 4 point Verbal Rating Scale (e.g., none, mild, moderate, or severe pain) as the preferred method for measuring pain intensity if the study population were expected to include patients with significant cognitive impairment. Jensen highlighted that the 0-10 numerical rating scale was acceptable to the majority of patients and has been found to be as sensitive and as valid as the visual analogue rating scale. The European Palliative Care Research Collaborative (EPCRC) (Hjermstad et al., 2008), surveyed international experts and recommended measurement of pain intensity by a 0–10 numerical rating scale rather than by a 0–5 visual analogue rating scale, although many survey respondents reiterated the concern that a numerical rating scale might be too complicated for the cognitively impaired.

Others have cautioned that using a single rating of current pain intensity may not accurately capture a patient’s experience of pain and recommend asking about pain in the last week or pain in the last twenty four hours. In addition, they suggest using particular terminology to describe pain when interviewing a patient such as worst or
average pain may be more accurate in determining actual pain burden and more effective in making clinical decisions such as judging the effectiveness of treatments. (Hjermstad et al., 2008; Shi et al., 2009).

A European Association Palliative Care expert working group recommended the Brief Pain Inventory – Short Form (BPI-SF) and the Short Form McGill Pain Questionnaire (SFMGPQ) for use in international research as both have been validated in several languages (Caraceni et al., 2002). The group suggested that the BPI – SF was suitable for research involving adults with cognitive impairment and that the SFMGPQ could be used in studies emphasizing pain quality. However, the group cautioned that the tools can be burdensome and may reduce sample sizes due to non-completion (Caraceni et al., 2002; Hølen et al., 2006).

The Abbey Pain Scale and the Pain Assessment in Advanced Dementia (PAINAD), were originally developed as observational pain assessment scales for use with patients with advanced dementia. They were first used in seventeen care homes with palliative care patients who were cognitively impaired, (van Iersel et al., 2006) for the purposes of evaluating their ease of use and the care staff’s perception of their usefulness for evaluating pain in non-verbal patients. The staff scored the Abbey scale slightly higher than PAINAD scale. However, no psychometric information was reported by these authors in respect to either scale.

The literature search identified a number of other tools that have been validated with palliative care patients, (see Table 3.3.3 for a summary of the tools identified and psychometric data collated). The Abbey Pain Scale, the Brief Pain diary (Maunsell et al., 2000) and the Cancer Pain Prognostic score (Hwang et al., 2002) are not included in this table for a variety of reasons. The article describing the Abbey Pain Scale did not report psychometric properties. The Brief Pain Diary has been validated for use with advanced cancer patients over a four week period from the time of initial assessment. Therefore, this tool is not appropriate for use in an initial admission assessment. The Cancer Pain Prognostic Scale was not included as it is a scale to predict the likelihood of reduction in pain intensity in response to treatment.
On the basis of the evidence generated in this literature review, a pain assessment form for the initial admission assessment was developed and included in the MPCAT. The MPCAT pain assessment form included three elements;

i. The questioning guidelines described in the PAQ.

ii. Questions relate to pain intensity at the time of assessment and at its worst over the last twenty fours using a 0 -10 numerical rating scale,

iii. A body map to visually locate pain.

Therefore the MPCAT pain assessment includes the five most important pain domains; intensity, temporal pattern, location, interference and factors which aggravate or relieve the patients experience of pain derived from the PAQ. Two ratings of pain intensity using a numerical rating scale (at the time of assessment and over the previous twenty four hours) were included to gain a more accurate understanding of the patient’s pain burden.
Table 3.3.3 Pain assessment tools validated for use in palliative care settings

<table>
<thead>
<tr>
<th>Tool</th>
<th>Sample Size and Purpose and Population of tool</th>
<th>Items, Domains, and Question Format</th>
<th>Validity</th>
<th>Reliability</th>
<th>Feasibility, e.g. time to implement in practice</th>
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<tbody>
<tr>
<td>McGill Pain Questionnaire (MPQ) (Teno, 2000)*</td>
<td>Palliative patients. Assessment of pain intensity and quality of pain and change in pain that can be attributed to an intervention.</td>
<td>Four parts: 1st part, patients mark the location of pain. 2nd part contains 78 pain word descriptors, 5 subclasses: Sensory, affect, evaluative class, miscellaneous and a total class. 3rd part measures change over time in pain intensity and that which affects it. 4th part is pain intensity. Simple score is the number of words chosen, range of 0-78 and the Present Pain Intensity (PPI) 1-5 verbal rating scale. Rank value of chosen words be added to obtain a Pain Rating Index (PRI) for each category, as well as a total score. The SF-MPQ has 15 items - 11 sensory and 4 affective, rated on a 0-4 verbal intensity scale.</td>
<td>High affective scores on the MPQ have been correlated with increased scores on depression instruments in cancer patients. The sensory, affective, and total scores of the MPQ and SF-MPQ were found to be significantly correlated.</td>
<td>Consistency of word choices by 10 cancer patients over 3 days range from 50 - 100% with a mean of 70.3%. Repeated administrations of the MPQ resulted in a consistency index of 75% (range 35-90%) between the two administrations.</td>
<td>The MPQ takes 5-10 minutes to administer. The SF-MPQ takes 2 - 5 minutes.</td>
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<tr>
<td>McGill Pain Questionnaire (MPQ) (Mystakidou et al., 2002a)</td>
<td>114 Cancer patients before the initiation of palliative treatment, 80 cancer patients during the treatment 7 days later. Advanced cancer patients. Purpose: detect changes in pain intensity over time.</td>
<td></td>
<td>Statistically significant difference (P&lt;0.005) on the G-MPQ scores in patients with different performance status Indicates a convergent construct validity.</td>
<td>Pre treatment cronbach’s alpha was 0.96. Values for cronbach’s alphas for single items ranged from 0.95-0.97.</td>
<td>Test-retest reliability for the PRI, PPI (and NWC at 2 different times assessed by Pearson’s correlation coefficient value range from 0.22 for NWC to 0.43 for PPI. Low to moderate correlation could be explained by the fact that pain decreased as a result of palliative care treatment.</td>
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<tr>
<td>Tool</td>
<td>Sample Size, Population and Purpose</td>
<td>Items, Domains, and Question Format</td>
<td>Validity</td>
<td>Reliability</td>
<td>Feasibility and Notes</td>
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<tr>
<td>Memorial Pain Assessment Card (MPAC)</td>
<td>The MPAC was used in multiple studies of cancer patients, especially as part of quality of life assessments in clinical trials.</td>
<td>MPAC is an 8.5x11 inch card designed to provide a rapid evaluation of pain intensity, pain relief, and psychological distress. 8 pain intensity descriptors and 3 visual analog scales (VAS) to quantify intensity of pain, pain relief and mood.</td>
<td>The McGill pain questionnaire, the Profile of Mood States (PMOS), the Zung anxiety scale and the Hamilton rating scale to quantify intensity of pain, pain relief and mood. Correlations under sub-scales were consistent with expected relationship among pain intensity, pain relief and mood. The visual analog rating of pain and the total word count on the MPQ were strongly correlated.</td>
<td></td>
<td>Completion time of less than 20 seconds if the patient has used it before. Approximately half of advanced cancer patients were able to complete the MPAC if self-administered (Shannon et al., 1995).</td>
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<tr>
<td>Wisconsin Brief Pain Questionnaire</td>
<td>Used in patients with cancer, rheumatoid arthritis and HIV patients.</td>
<td>Self-administered instrument that assesses pain history, worse pain, usual pain and pain now. The BPQ body map to indicate pain location, pain intensity score, relief medication, and ratings of pain interference. A 0 - 4 verbal rating scale (0 = not at all, 4 = extremely).</td>
<td>Pain medication use correlation to overall pain ratings revealed the percentage of patients taking medication increased significantly with higher pain ratings. Correlation between usual pain ratings and ratings of pain interference was high (r = 0.62, p &lt; 0.001).</td>
<td>The consistency of responding to the pain history items was assessed in the long-term follow-up sample. Percentage agreement for initial pain was 76%, 81% for no pain and 67% for pain in the last month.</td>
<td>Test-retest revealed higher reliability when the time interval was short (r = 0.93 for worst pain, r = 0.78 for usual pain, r = 0.59 for pain now) rather than a long interval (r = 0.34 for worse pain, r = 0.24 for usual pain, r = 0.22 for pain now).</td>
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<tr>
<td>Revised Edmonton Staging System (rESS)</td>
<td>Patients with advanced cancer Pain classification system, to improve cancer pain management and as an outcome measure to improve resource allocation.</td>
<td>Five features: mechanism of pain, incidental pain, psychological distress, addictive behaviour, cognitive function.</td>
<td>Experts and a modified delphi survey technique. Two separate panels of experts selected (regional and international). Average ratings of effectiveness in clinical practice ranged from 3.6 to 4.2</td>
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<td>Tool</td>
<td>Sample Size, Population and Purpose</td>
<td>Items, Domains, and Question Format</td>
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<td>Feasibility, and Notes</td>
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<tr>
<td>Revised Edmonton Staging System (rESS) - Canada (Fainsinger et al., 2005)</td>
<td>746 patients with advanced cancer, Classification of pain</td>
<td>4 pain features: Mechanism of Pain (no pain syndrome, visceral, bone or soft tissue, neuropathic, mixed, and unknown pain) Incidental pain, psychological distress and addictive behaviour, (4 cage screening questions for alcoholism included) and cognitive function.</td>
<td>Literature review, extensive clinical use of the tool, expert panel. Piloted with 82 palliative cancer patients to refine definitions and methodology for multicentre study.</td>
<td>Inter-rater reliability, r = 0.68, ICC, r = 0.68 for psychological distress, incidental pain ICC, r = 0.72. Two separate clinical assessments conducted by clinicians blinded to the outcome of the others assessment were conducted within 24 hours.</td>
<td>Clinician administered, one minute to complete, for use in clinical practice.</td>
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<td>PAINAD (Hutchinson et al., 2006)</td>
<td>PAINAD group: 27, Control group: 53. To determine if use of tool improves ability to detect pain in cognitively impaired patients who are unable to self report</td>
<td>5 item observational tool; breathing, negative vocalisation, facial expression, body language and consolability. Potential score from 0 - 10. No pain was 0.</td>
<td>Opioid usage for the purposes of pain relief was significantly higher in the group using the PAINAD rather than the control group, 11.25 mg versus 5.75 mg, p = 0.003</td>
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<td>Neuropathic Pain Impact on Quality of Life Measure (NePIQoL) (Poole et al., 2009)</td>
<td>305 participants, primary diagnosis neuropathic pain. Quality of life measure for neuropathic pain</td>
<td>Six subscales: psychological, physical, symptoms, personal care, relationships and social/work activity. Five point scale ranging from strongly disagree to strongly disagree and always to never.</td>
<td>Patient focus groups and expert panel, initial items pre-tested using cognitive interviewing with patients. 91 item version administered - poorly performing items identified and internal consistencies examined (phase 2). Phase 3 revised NePIQoL was administered to 110 patients on two occasions to examine validity and re-test reliability. Pre-testing led to extensive revision resulting in final measure of 42 items.</td>
<td>Neurpathic Pain Scale (NPS) and the NePIQoL (r = 0.57, p &lt; 0.001). Pain intensity significantly associated with NePIQoL subscales: range 0.24 - 0.35, p &lt; 0.001; Correlation for the Brief Pain Inventory for NePIQoL total scores r = 0.56. HADS Anxiety Scales r = 0.57, HADS Depression Scale r = 0.51 and with numerical scale, r = 0.47. Physical functioning scale of SF-36 r = -0.59, Social functioning r = -0.48; Emotional role limitations of SF-36 = -0.45. Pain in the SF-36 r = -0.45. Mental health of the SF-36, r = -0.31. Energy vitality subscale of the SF-36, r = 0.32.</td>
<td>Cronbach's alpha was above 0.7 for the six subscales; psychological: 0.90; social activity: 0.91; relationships: 0.82; symptoms: 0.87; physical: 0.93; personal care: 0.91.</td>
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<tr>
<td>Tool</td>
<td>Sample Size, Population and Purpose</td>
<td>Items, Domains, and Question Format</td>
<td>Validity</td>
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<td>Feasibility and Notes</td>
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<tr>
<td>Brief Pain Inventory (BPI)</td>
<td>300 patients with malignant disease admitted to hospital, prospective study. Pain assessment tool for advanced cancer patients</td>
<td>BPI is designed to measure subjective intensity of pain and the impairment caused by pain. 4 items address pain severity, 7 items address pain interference on function. Uses numeric rating scales. Patients asked to rate pain now, pain at its worst, least and average for the last 24 hours. A pain severity index is calculated by adding the scores on the pain severity items. Functional interference index calculated by adding the scores on the interference items.</td>
<td>Criteria and validity: correlation between BPI pain severity index and the pain intensity item in the EORTCQLQ-C30 was 0.70, p &lt; 0.001. Correlation between the BPI interference factor and interference from pain on daily function in the EORTCQLQ-C30 was 0.62, p&lt;0.001. 3 factors identified. Pain intensity, interference items describing pain influence on physical functions e.g. General activity, walking ability and normal work and items describing pain influence on psychological related functions is the third factor e.g. mood, relations with other people, enjoyment of life and sleep. Eigenvalues of the 3 factors were 6.9, 1.1 and 0.99. 3 factors explained 82% of the variance.</td>
<td>Cronbach's alpha values for pain severity was 0.87 and was 0.92 for the interference scales. Cronbach's alpha values for the 2 subscales of the interference subscales were identified in the factor analysis as 0.92 and 0.90 for the physical and psychological subscales respectively, therefore good internal consistency.</td>
<td>35% did not complete one or more items in the tool. These patients had lower functional performance scores than patients who fully completed the BPI. The tool may not be feasible in studies involving severely advanced malignant disease or those with severe cognitive impairment.</td>
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</tbody>
</table>

EORTCQLQ-C30: European Organisation for Research and Treatment Core Quality of Life Questionnaire. HADS: Hospital Anxiety and Depression Scale, SF36: Short Form Health Survey. ICC: Intraclass correlation coefficient.

*The psychometric properties of the McGill Pain Questionnaire tools, Memorial pain assessment card and Wisconsin Brief Pain questionnaire were reported in the toolkit of instruments to measure end of life care (Teno, 2000).
3.4 Symptom assessment and symptom clusters

Advanced cancer patients typically have multiple symptoms with studies suggesting a median of 11 (range 1 – 27) symptoms, the most commonly experienced of which were pain, fatigue, weakness, anorexia, reduced energy, dry mouth, constipation, early satiety, shortness of breath and weight loss (Walsh et al., 2000). A variety of studies have identified symptom clusters in palliative patients with advanced cancer, and report that recognition of concurrent symptoms is important since interventions can be targeted to impact more than one symptom at a time. However, there is limited agreement as to the constituents of symptom clusters (See Table 3.4.1).

Table 3.4.1 Studies describing symptoms clusters experienced by palliative care patients with advanced cancer.

<table>
<thead>
<tr>
<th>(Esper and Heidrich, 2005)</th>
<th>(Walsh, 2006)</th>
<th>(Cheung et al., 2009)</th>
<th>(Tsai et al., 2010)</th>
<th>(Jiménez et al., 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edmonton Symptom Assessment Scale*</td>
<td>Symptom list containing 38 items*</td>
<td>Edmonton Symptom Assessment Scale*</td>
<td>Symptom list containing 21 items*</td>
<td>Edmonton Symptom Assessment Scale*</td>
</tr>
<tr>
<td>Pain, constipation, and confusion</td>
<td>Pain and constipation</td>
<td></td>
<td></td>
<td>Cognitive impairment, agitation, urinary incontinence</td>
</tr>
<tr>
<td>Anxiety, agitation, and delirium</td>
<td>Edema and confusion</td>
<td></td>
<td>Restlessness, dizziness, insomnia, and night sweats</td>
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</tr>
<tr>
<td>Nausea, anorexia, and dehydration</td>
<td>Nausea and vomiting</td>
<td>Nausea and vomiting, abdominal fullness, and dyspnea</td>
<td></td>
<td>Nausea and vomiting</td>
</tr>
<tr>
<td>Cough, breathlessness, and fatigue</td>
<td>Easy fatigue, weakness, anorexia, lack of energy, dry mouth, early satiety, weight loss, taste changes</td>
<td>Fatigue, drowsiness, nausea, decreased appetite, and dyspnea</td>
<td>Anorexia, taste alteration, dysphagia, constipation, and dry mouth/thirst;</td>
<td>Anorexia, weight loss, and tiredness</td>
</tr>
<tr>
<td>Sleep problems, depression, anxiety</td>
<td>Anxiety and depression</td>
<td></td>
<td></td>
<td>Anxiety, depression, and insomnia</td>
</tr>
<tr>
<td>Dizzy spells, dyspepsia, belching, bloating;</td>
<td></td>
<td></td>
<td>Fatigue and weakness</td>
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<tr>
<td>Dysphagia, dyspnea, cough, hoarseness</td>
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</table>

*Assessment method/tool used by the authors to identify symptoms

Pain and constipation co–existed in the studies reported by Walsh et al. (2006) and Esper et al. (2005), although the latter also included confusion. Nausea and vomiting were reported by Jiménez et al. (2011), Walsh et al. (2006) and Tsai et al. (2010) who
also included abdominal fullness and dyspnea in the symptom cluster they reported. Anxiety, depression and difficulty sleeping were also reported as a cluster by more than one study.

The identification of symptoms in clusters may be impacted by the tools used to collect data, as comparison between tools is complicated by the difference in parameters of cluster criteria. The study reported by Walsh et al. (2006) used a symptom list of 38 symptoms, Cheung et al. (2009) used the Edmonton Symptom Assessment Scale which does not include constipation, edema, cough or confusion and a number of other symptoms that were investigated by the previous authors. Jiménez et al. (2011) used the ESAS supplemented by thirteen symptoms. However, there is sufficient evidence for concurring symptoms which may impact each other and may be jointly addressed through appropriate intervention. Consequently, assessment of symptoms should be comprehensive and holistic.

In order to aid feasibility of assessment of very ill patients, the MPCAT steering group wished to consider assessment of physical symptoms using symptom assessment tools validated for use with palliative care patients that included the most common physical symptoms experienced. See Table 3.4.2 for the symptom assessment tools validated for use in palliative care conditions that were considered by the steering committee.

The Admission Assessment Tool, developed to facilitate prioritisation of patients being referred for admission to a specialist palliative care in-patient unit, and based on the STAS support team assessment schedule, was not included in the literature review as it has not been validated due to poor inter-rater agreement and high false positive rates (Fergus et al., 2008).

An adapted version of the symptom assessment checklist described by Homsi et al, (2006) was utilised with permission in the MPCAT as it was felt to be optimally detailed – balancing the need for comprehensive coverage of symptoms with patient burden. This tool is used in conjunction with a physical examination. This tool is based on a systems review and the version included in the MPCAT contains a list of 50
symptoms grouped as follows: respiratory system, cardiovascular, central nervous systems and the upper, middle and lower gastrointestinal system and general symptoms (Homsi et al., 2006)
<table>
<thead>
<tr>
<th>Tool</th>
<th>Sample Size, Population and Purpose</th>
<th>Items and Domains Question Format</th>
<th>Content Validity</th>
<th>Construct Validity</th>
<th>Internal Consistency</th>
<th>Reproducibility</th>
<th>Feasibility and Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs Near the End-of-Life Care Screening Tool NEST, (Emanuel et al., 2001)</td>
<td>988 at outset, 650 follow up. Patients at end of life. Developed as screening tool to identify areas for further assessment in clinical practice and possibly assess impact of interventions.</td>
<td>Screening for social needs (4); Existential (4); Symptoms (2), Therapeutic relational(3) - 13 dimensions: financial (1), access to care (1) closeness (1), care-giving needs (1) distress (1), anxiety/depression (1) spirituality / religiousness (1), Settledness/personal acceptance (1), sense of purpose (1), patient / clinician relationship (1), information needs/clinician communication (1) Goals of Care. 0 - 10 point numerical rating scale - screening tool. Additional questions to explore dimension if cut off score is reached or exceeded.</td>
<td>Literature interviews, 15 focus groups, interviews with patients pilot work and expert review.</td>
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<td>Clinician administered. Acceptability: 69.2% patients found interview was helpful. Short form was as reliable as the original version.</td>
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<tr>
<td>Edmonton Symptom Assessment Scale (ESAS), (Nekolaichuk et al., 2008)*</td>
<td>Terminally ill patients in a palliative care setting. - Symptom Assessment and detect change over time</td>
<td>9 symptoms 9 items on 100mm visual analog scale. Pain, activity, nausea, depression, anxiety, drowsiness, appetite, shortness of breath and sensation of well-being. Designed for symptom assessment twice a day. Information is transferred to a graph that can present the ratings of up to 21 days on one page. The revised Edmonton Symptom Assessment Scale, (ESAS R) uses a 11 point numerical rating scale (0 - 10).</td>
<td>Correlation to MSAS, Global Distress $r = 0.73$; TMSAS scale (0.72), GDI (0.73), Physical Symptom sub-scale (0.74), Psychological symptoms subscale (0.56); ESAS Summary distress score to Fact G: Physical well-being subscale (-0.75), QOL (-0.69), Functional well-being (-0.63), emotional well-being (-0.52), social/family wellbeing (-0.25);</td>
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<td>Test-retest reliability $r = 0.86$ at 2 days and 0.45 at one week; all items significantly correlated at two days ($r = 0.43-0.86$). At one week only pain (0.75), activity (0.65), depression (0.54), shortness of breath (0.53) and distress (0.45) were significantly correlated.</td>
<td>Self administered or by proxy e.g. staff member/relative. Tool is brief to complete. A change in person recording the answers over time may bias data. Patients may be impacted by symptoms other than those listed.</td>
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<tr>
<td>Tool</td>
<td>Sample Size, Population and Purpose</td>
<td>Items and Domains Question Format</td>
<td>Validity</td>
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<td>Feasibility and Notes</td>
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<td>Memorial Symptom Assessment Scale (MSAS), (Teno, 2000)</td>
<td>MSAS has been utilised in AIDS patients and cancer patients. The 10 item global distress index (frequency of emotional symptoms and distress items from pain and treatment) was considered to be the most clinically useful subscale as it is easy to interpret and can be used alone. Symptom assessment scale. Section 1 ; 3 items to fast track review by a SPCS. Section 2 assesses patients wellbeing - seven items: physical, changes in functional status, psychological, information, 32 psychological and physical symptoms in terms of the presence, frequency, severity and degree of distress. Verbal rating scale. Subscales: psychological state, (emotional symptom and concentration sub-groups); high frequency physical symptoms which can be divided into (pain and pain treatment and gastrointestinal distress); and low frequency symptoms.</td>
<td>Correlation between mean severity and mean frequency scores across symptoms was ( r = 0.80 ). Correlation between mean severity scores and mean distress scores was ( r = 0.70 ). Correlation between mean frequency scores and mean distress scores was ( r = 0.43 ). Pair wise correlation = average correlations; ( r = 0.65 ) (range 0.25 - 0.80) for severity and frequency; ( r = 0.67 ) (range 0.43 - 0.87) for severity and distress; ( r = 0.50 ) (range 0.21 - 0.77) for frequency and distress.</td>
<td>Hypothesis that in-patients would have higher symptom distress than out-patients was confirmed. Comparison measures; mental health inventory well-being subscale, (RAND), distress subscale, symptom distress scale, functional living index-cancer, and Karnofsky performance scale, memorial symptom assessment card were correlated with total MSAS scores identified Highly significant association between the MSAS and MSAS sub-scales</td>
<td>High for highly prevalent symptoms in psychological state sub-scales (Cronbach’s alpha 0.88 and 0.83). Internal consistency - pain group = high (Cronbach’s alpha of 0.87) and moderate for gastrointestinal distress (Cronbach’s alpha of 0.75). For low prevalence symptoms, (Cronbach’s alpha of 0.58).</td>
<td>Completion rate of the MSAS reported as acceptable. Can be self-administered or clinician administered. The 10 item global distress index can be used alone if global symptom of distress if that is the primary area of interest</td>
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<td>Support team assessment schedule (STAS), (Teno, 2000)</td>
<td>Mixed diseases - hospice patients. To determine effectiveness of palliative care teams. 17 items - 7 items grouped into patient and family items (4) service items and (3) Physical symptoms. Multidimensional measure, 8 domains: Pain / symptom control, insight, psychosocial needs, family needs, home services, affairs in order, support of other professionals, communication.</td>
<td>Validity by type of rater: kappa for patient to staff (N = 62 - 78) Range from 0.12 - 0.78, total score spearman's ( r = 0.66 ); Kappa for family to staff (N = 58 - 67) Range from -0.06 - 0.51, total score, ( r = 0.44 ). Validity by comparison to patient rating: overall ( r = 0.09 ) palliative care and ( r = 0.28 ) oncology (p &gt; 0.05); family rating overall ( r = 0.38 ) palliative care and ( r = 0.37 ) oncology (p &gt; 0.05); item Kappa 0.00 - 0.61.</td>
<td>Inter-observer reliability mostly, ( r = 0.4 - 0.6 ) (range 0.27 - 1.0); intra-observer reliability ( r = 0.33 - 0.88 ). For overall score and range 0.1 - 1.0 for items; test - retest 0.50 for palliative care team and 0.71 for oncology team</td>
<td>Interview administered</td>
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<td>Tool</td>
<td>Sample Size, Population and Purpose</td>
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<td>Palliative Care Needs Assessment Tool (PC-NAT), (Waller et al., 2008)</td>
<td>103 participants viewed 3 ten minute consultations utilising PC-NAT. Patients with advanced cancer Needs assessment tool to identify need for palliative care service</td>
<td>Spiritual / existential, health beliefs / cultural / social and financial / legal domains. Ability of the care givers to provide for patients including physical changes in functional status, psychological, information and family and relationship domains. Care givers wellbeing, including physical and psychological issues and dealing with grief. Referral section. Sections 1 and 5 response options: 'yes' or 'no', sections; sections 2 - 4 assessed according to the level of concern. Prompt questions for each item included on back page to facilitate consistency in how issues were addressed.</td>
<td>National consensus meeting held providing preliminary support for face and content validity. Extensive literature review, expert consensus panel of 66 leaders and key stakeholders in palliative care, service user representatives and health advocates. Consultative process resulted in the formation of a draft PC-NAT, pilot testing.</td>
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<td>5-10 minutes per consultation, familiarity with PC-NAT reducing completion time. Simple language and addition of prompt questions facilitate clarity when using. Will aid care planning information and allocation of resources in a clinical setting</td>
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<td>Needs Assessment Tool: Progressive Disease - Cancer (PC-NAT), (Waller et al., 2010)</td>
<td>50 patients and 11 staff from the palliative care service completed one page of the PC-NAT for each participant, second staff completed second copy of PC-NAT for the same participant on the same day without discussing the patient or comparing responses. Patients with advanced cancer and their care givers. Needs assessment tool to identify need for palliative care service</td>
<td>See Above</td>
<td>See Above</td>
<td>Cohen's Kappa ranged from 0.02 - 0.59. Percentage agreement of inter rater reliability ranged from 48% - 88%.</td>
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<td>Rotterdam Symptom Checklist (Hardy et al., 1999)</td>
<td>Initially 52 patients in palliative care unit Checklist completed at the time of admission and every week for 4 weeks or until discharge/condition deteriorated. Analysis confined to 3 weeks of data due to attrition rate 28 Patients. Symptom assessment scale</td>
<td>Physical and psychological aspects of Quality of Life 30 Items. Psychological domain, and physical domain. Score symptoms from 0 - 3, corresponds to Not at all, a little, somewhat, very much. Best possible score is 29, worst possible score is 116.</td>
<td>Poor correlation between overall QOL score and Eastern Cooperative Oncology Group (ECOG) score ($r = 0.15$) and VAS scores ($r = 0.03$).</td>
<td>Developed by the Royal Marsden Trust. Significantly better QOL scores ($p = 0.05$ by Friedman test, evaluates difference between groups, and $p = 0.023$ by test of trends). Test of week 3 versus baseline week 1 reaches statistical significance ($p = 0.05$). Suggestion of a decline from baseline to week 2 ($p = 0.1$) Evidence of improvement was weak when psychological and physical components RSCL were assessed individually using the Friedman test ($p = 0.28$ and $p = 0.11$). It was stronger but not significant when the test of trends was used ($p = 0.07$ and $p = 0.06$ respectively).</td>
<td>Patients self-administered. Occasionally receive assistance from family or staff.</td>
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<td>Needs Assessment for Advanced Cancer Patients (NA-ACP), (Rainbird et al., 2005)</td>
<td>246, Advanced cancer patients / terminal care patients / life expectancy more than 3 months but not more than 2 years, advanced incurable cancer not currently receiving formal palliative care. 132 items - initial questionnaire. 7 domains: medical communication / information: 25 items, psychological / emotional: 31 items, daily living: 9 items, financial: 9 items, symptoms: 6 items, spiritual: 8 items, social: 7 items. 5 point ordinal rating scale. No &quot;physical&quot; domain emerged further to component analysis. May be attributed to small sample size/physical issues are not highly correlated and rather than belonging to one a physical category each of these items (dealing with pain, nausea and vomiting, coping with shortness of breath) may be assessing an individual area of need rather than one general physical category.</td>
<td>Literature review, expert review, focus groups.</td>
<td>Literature review, health professional’s consultation, focus group with patients with advanced incurable disease. Draft instrument developed further to the above, 6 of the 7 domains reached acceptable level of 0.8. The symptom domain was just below at 0.79. Domain range, Cronbach's Alpha: 0.79 - 0.98. (Symptom domain - 0.98 - medical communication / information domain). Kappa range: $k = 0.18 - 0.83$. Majority of items (78%) displayed a moderate or better level of agreement ($k &gt; 0.4$). Fair level of agreement displayed by 21% ($k = 0.4 - 0.2$). Slight level of agreement found for 1% ($k &lt;0.2$).</td>
<td>Self-administered. Flesch Score, reading ease, was 76.9. Accessibility: 86%, questions clear and understandable. Time to complete was 76 minutes. Majority (93%) did not feel that this was too long.</td>
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<td>Condensed Memorial Symptom Assessment Scale (CMSAS) (Chang et al., 2004)</td>
<td>479 Palliative Care Patients Symptom Assessment Scale</td>
<td>Three sub scales: CMSAS-PHYS, (lack of energy, lack of appetite, pain, dry mouth, weight loss, feeling drowsy, difficulty concentrating, shortness of breath, difficulty sleeping, nausea, constipation,) CMSAS-PSYCH, (worrying, feeling sad, and feeling nervous) and CMSAS SUM contain14 symptoms. Physical symptom distress is scored from 0 - 4 (not at all, a little bit, somewhat, quite a bit, very much). If a physical symptom is present, the weight is 0.8 for each category (0.8 for not at all, 1.6 for a little bit, 2.4 for somewhat, 3.2 for quite a bit, and 4.0 for very much). The PHYS is the average of all the physical symptoms. Psychological symptom frequency is scored from 1 to 4 (rarely, occasionally, frequently, and almost constantly). PSYCH score is the average of all the psychological symptoms.</td>
<td>Derived from MSAS-SF (32 items)</td>
<td>CMSAS correlated against MSAS-SF sub-scale, FACT-G and KPS. CMSAS-SUM and the GDI (MSAS-SF) had the strongest correlation, r = 0.96. All CMSAF subscales showed significant inverse correlation with FACT-G (-0.76 for CMSAS-PHYS and FACT-G Physical Well Being -0.65 for MSAS-PSYCH and FACT-G emotional well being -0.61 for CMSAS-SUM and FACT G Functional well being and -0.70 for CMSAS-SUM and FACT-G SUMQOL. Correlation with CMSAS-PHYS AND MSAS-PHYS, r = 0.933, p &lt; 0.0001; CMSAS-PSYCH with MSAS-PSYCH, r = 0.894, p&lt; 0.0001; CMSAS-SUM and MSAS TMSAS, r = 0.934, p &lt; 0.0001.</td>
<td>Cronbach's alpha of 0.82 for CMSAS-PHYS, 0.72 CMSAS-PSYCH, 0.85 for CMSAS-SUM</td>
<td>Self administered or interviewer administered. Time to complete is 2 - 4 minutes. Choice of symptoms identified in the CMSAS are strengthened by the fact they have been used in clinical symptom assessment instruments such as the Edmonton Symptom Assessment Scale, Rotterdam Symptom Checklist and the Symptom Distress Scale.</td>
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<td>Memorial Symptom Assessment Scale Short Form (MSAS-SF), (Chang, 2000)</td>
<td>299 Cancer patients with advanced disease Symptom Assessment Scale</td>
<td>Assesses distress caused by 26 physical symptoms and frequency of 4 psychological symptoms, over past 7 days. If distressed rated on a 5 point (0 - 4) likert scale . Frequency of psychological symptoms is 1 - 4 rarely - almost constantly. Global Distress (GDI), 4 psychological symptoms: Physical symptom distress score (PHYS) comprises 12 physical symptoms and 6 psychological symptoms.</td>
<td>Iterative process: changed the items from the initial scales by relying on previous work ; then – consulted with oncology health care professionals. List of potential items was modified further to data obtained from patients with cancer related symptoms.</td>
<td>Validated with the FACT-G. Correlation coefficient was -0.74 (p &lt; 0.001) for the PHYS and FACT-G PWB, -0.68 (p &lt; 0.001) for the PSYCH and FACT-G EWB, and -0.70 (p &lt; 0.01) for GDI and FACT-G SUMQOL.</td>
<td>Cronbach's alpha was 0.8 for the GDI, 0.82 for the Physical symptom distress (PHYS), 0.76 for the psychological symptom distress (PSYCH), 0.87 for the TMSAS</td>
<td>Test re-test reliability: one day 0.86 - 0.94. One week test group ranged from 0.40 - 0.84. Authors suggest that the scale should be reset for a time interval of 2 days instead of week.</td>
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<td>M. D. Anderson Symptom Inventory (MDASI) (Kwon et al., 2006)</td>
<td>142 terminal cancer patients. To determine validity of the MDASI. Quantifies severity and impact of symptoms.</td>
<td>Severity is assessed for 13 core MDASI symptom items and 6 interference items. 2 domains: General Symptom Severity Factor, Gastrointestinal factor. 11 point scale (0 - 10) to indicate presence and severity of the symptom, 0 meaning &quot;not present&quot; and 10 meaning &quot;as bad as you can imagine&quot;. Each symptom was rated as its worst in the last 24 hours. Interference measured on a 0 - 10 scale, 0: &quot;did not interfere&quot;, 10 : &quot;interfered completely&quot;.</td>
<td>Tested with the principal component analysis using a varimax rotation to explore underlying structure. Two factor solution for all MDASI items was confirmed in study population. Factor 1 contains 13 symptom items, Factor 2 contains 6 interference items. Eigenvalue of factor 1 was 7.04, Factor 2 was 1.93 explaining 37.1% and 10.2% respectively of the variation. Cronbach's alpha of 0.90 for all 19 items, 0.85 for 13 symptom items, 0.89 – for the 6 interference items, 0.84 for general symptom subscales, Cronbach’s alpha of 0.72 for gastrointestinal symptom subscales, thereby high level of reliability was suggested.</td>
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<td>CAMPAS-R. Cambridge Palliative Assessment Schedule (Ewing et al., 2004b)</td>
<td>109, adults in the palliative phase of progressive illness, being cared for at home and estimated to be in the last year of their life. Measure of severity and impact of 6 prevalent symptoms - pain, nausea, vomiting, constipation, diarrhea, breathlessness and patient and carer anxiety, patient depression / feeling low, carer depression / feeling low. Symptoms scored using a hundred mm visual analog scale on two dimensions. Compared with Brief Pain Inventory, Hospital Anxiety and Depression Scale and EORTC QLQ-C30. Patient and carer interviews, GP's, student nurses and nurses.</td>
<td>CAMPAS-R pain scores and pain scales on the Brief Pain Inventory and the EORTC QLQ-C30 were highly correlated. 2 scales evaluated severity and interference, Cronbach’s alpha for severity of 0.77 (n = 96), for interference of 0.80 (n = 94).</td>
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<td>Self-administered or by family. Approximately 5 minutes to complete.</td>
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<td>The Early Risk and Resilience Inventory (ERRI) (Early et al., 2000)</td>
<td>35 terminally ill patients. An assessment tool developed to measure the dying person’s balance of stress, strength and to assess risk if they remain at home cared for by primary care giver. Measures terminally ill patients, physical, psychological, social and spiritual needs. Determines the coping strategies that modify impact of unmet needs. Determines adequacy of coping or whether additional support is required. Contains 47 items, 3 point scale 0 - 2, 0:areas not currently problematic; 2: serious problem. Second part of each item only relevant if the respondent assess the needs at the problem level, if identified patient is then asked to list sources of resilience.</td>
<td>3 of 4 sub-scales of the instrument - concrete needs, physical and spiritual needs had strong Cronbach’s alpha scores (concrete needs, 0.774; physical needs, 0.899; spiritual needs, 0.829). Fourth subscale, psychosocial needs had low Cronbach’s alpha of 0.312.</td>
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<td>Structured Interview Assessment of Symptoms and Concerns in Palliative Care (SISC) (Wilson et al., 2004)</td>
<td>69 patients receiving palliative care for advanced cancer. Patients reviewing experience over the previous day. Longer time frames utilised to review specific core criteria and symptoms of anxiety and depressive disorders. Symptom assessment.</td>
<td>13 items. Each item includes measurement of severity of the symptom or concern. Seven point ordinal scale (0 = none, 1 = minimal, 2 = large, 3 = moderate, 4 = strong, 5 = severe, 6 = extreme).</td>
<td>Literature review. Autonomy is a sub-domain for the palliative care cancer patients (PNPC), the development of which occurred further to a two stage qualitative study. For use in research and empirical studies.</td>
<td>Participants completed 10cm VAS scale for each SISC item. Symptoms of anxiety and depressive disorders were compared against the Primary Care Evaluation of Mental Disorders (PRIME-MD). SISC items generally had good concordance with VAS counterparts (r = 0.71 - 0.90, all significant, p &lt; 0.001)</td>
<td>Retest reliability: 1st interviews, 68 participants, 2nd interview, 46 participants. (1 - 3 day follow up interval range, r = 0.50 - 0.90). VAS coefficients ranged from r = 0.42 - 0.90, p &lt; 0.006. Inter-rater SISC ranged from r = 0.92 - 0.99, p &lt; 0.001. Clinician administered. Average time for completion was 53.8 minutes. Range of 25 to 145 minutes. Can be broken into shorter sessions when necessary. Second interview, average time for completion of 28.6 minutes, range from 10 to 60 minutes.</td>
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<td>Inter RAI PC version 7 (Steele et al., 2003)</td>
<td>Dual assessments carried out on 144 of the 151 patients derived from 7 sites. Quarter of the sample were people predicted to be in the last week of life. Assessment tool for use with palliative care patients at home, in assisted living facilities, nursing homes, in-patient hospices and other places including a geriatric ward.</td>
<td>Health conditions, nutritional status, psychosocial well-being, physical functioning and cognitive functioning. Has a number of measures included: CPS, ADL-Hierarchy Scale, DRS and a 2 domain pain scale. Verbal rating scales and numerical rating scales</td>
<td>Literature review</td>
<td>Test retest - 2 forms completed within 72 hours. Inter rater reliability: 2 clinicians independently evaluated the same patient. 8 domains: symptoms / conditions (kappa range from 0.77 - 0.95), Majority had a Kappa value of 0.81 or above.</td>
<td>Clinician administered Usually takes 20minutes but may fluctuate depending on how unwell the patient is. States that it is clinician and patient friendly - no data presented from their perspective. If further information is required about a specific symptom or domain, other validated tools should be used, e.g. McGill Pain Questionnaire/ Braden Scale regarding pressure sores</td>
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<td>Inter RAI PC version 7, (Brink and Frise Smith, 2008)</td>
<td>536 home care patient assessments, 450 suffered from cancer. Comprehensive assessment tool for use in homecare, acute care, complex</td>
<td>Health conditions, nutritional status, psychosocial well-being, physical functioning and cognitive functioning. Has a number of measures including: CPS, ADL-Hierarchy Scale, DRS and a 2 domain pain scale. Verbal rating scales and numerical rating scales</td>
<td>Content Validity</td>
<td>Construct Validity</td>
<td>Internal Consistency</td>
<td>Reproducibility</td>
<td>Clinician administered Usually takes 20min to complete may fluctuate depending on how unwell the patient is.</td>
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<td>Problems and needs in palliative care questionnaire (PNPC), (Osse et al., 2004)</td>
<td>64 palliative care patients living at home. Identify prevalence of problems and needs and the patients need for help.</td>
<td>138 items. ADL and IADL (7), physical symptoms (18), role activities (4), financial and administrative issues (5), social issues (15), psychological issues (15), spiritual issues (5), autonomy (9), information needs (9), problems and consultations (3), over-riding problems in consultations (3 item), over-riding problems in quality of care (9), concerning the GP (20), concerning the specialist (19). PNPC asks two questions of each item 1) Is this item a problem? 2)Do you want professional attention for this item?</td>
<td>Item generation after 1) in depth qualitative interviews with 9 patients and their families. 2) Structured interviews with 31 patients after drafting the tool.</td>
<td>Compared against HRQOL tools - EROTC-QLQ C30 and the COOP-WONCA charts. Problem dimension correlation with HRQOL ranged from r = -0.74 – 0.75. Need for support ranged from r = -0.56 – 0.69</td>
<td>Cronbach's alpha range for both domains was 0.67-0.92, Item to total correlations ranged from 0.10 - 0.53 (problem severity of physical symptoms) to 0.64-0.77 (need for support with spiritual issues).</td>
<td>Problem dimension correlation with HRQOL ranged from r = -0.76 – 0.69. Need for support ranged from r = -0.59 – 0.65</td>
<td>Cronbach's alpha range for both domains was 0.61-0.92, Item correlations to PNPC ranged from 0.83 - 0.98 (identification of problems) to 0.88-0.98 (need for support with spiritual issues).</td>
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<td>Problems and needs in palliative care questionnaire short version (PNPC sv), (Osse et al., 2007)</td>
<td>94 palliative care patients at home. Identify the patients problems and need for help with problems identified.</td>
<td>33 items - ADL (3), physical symptoms (5), autonomy (4), financial issues (2), social issues (5), psychological issues (5), spiritual issues (4), information needs (1)</td>
<td>Derived from the PNPC - problems were experienced by at least 20% of patients</td>
<td>Compared against HRQOL tools - EROTC-QLQ C30 and the COOP-WONCA charts. Problem dimension correlation with HRQOL ranged from r = -0.76 – 0.69. Need for support ranged from r = -0.59 – 0.65</td>
<td>Cronbach's alpha range for both dimensions was 0.61-0.92, Item correlations to PNPC ranged from 0.83 - 0.98 (identification of problems) to 0.88-0.98 (need for support with spiritual issues).</td>
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<td>Patient Self Administered</td>
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<td>Sheffield Profile for Assessment and Referral to Care, UK (SPARC) (Ahmed et al., 2008)</td>
<td>Screening tool to assess need for specialist palliative and supportive care.</td>
<td>45 items, 7 domains: communication information (1), physical symptoms (21), psychological concerns (9), religious and spiritual concerns (2), independence in activity (3), family and social issues (4), treatment issues (5). Majority of items: 4 point rating scale 0 - 3 ranging from 'not at all' to 'very much' with exception of communication information which has a yes no format.</td>
<td>Systematic literature review, secondary data analysis, interviews with patients, carers and health care professionals. 53 question measure was piloted and refined to 45 questions.</td>
<td>SPARC compared against the EORTC QLQ-C30, Brief Pain Inventory, Needs Assessment of Neuropathic Symptoms and Signs and Multi-Dimensional Fatigue Inventory in sample of over 100 cancer patients.</td>
<td>Patient administered or family assists. Completion time is 15-25 minutes</td>
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<td>Palliative Care Assessment (PACA) (Ellershaw et al., 1995)</td>
<td>Validity assessed in 91 hospice inpatients. Assesses effectiveness of hospital’s palliative care program</td>
<td>12 items; 3 domains: symptom control (semi-structured interview), patient's awareness of diagnosis and prognosis (observer rated), and future placement (observer rated). Four-point scale, (0-3) Insight: 5 point scale (1-5) Placement: four point scale (1-4)</td>
<td>Correlations between the 5 symptom scores of the PACA and the Mc Corkle symptom distress scale were significant (p&lt;0.001) Cronbach’s alpha scores; pain was 0.58, nausea was 0.80, dyspnoea was 0.70, anorexia was 0.80 and insomnia was 0.80</td>
<td>Kappa values for symptoms ranged from 0.44 - 1.00 insight, k = 0.78, placement, k = 0.44</td>
<td>Clinician administered For use in clinical practice</td>
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<td>Symptom Assessment Scale (SAS) (Aoun et al., 2011)</td>
<td>572 cancer patients from 5 palliative care facilities. Screening tool to identify need for further assessment</td>
<td>Breathing problems, bowel problems, appetite problems, pain, insomnia, nausea and fatigue. 0-10 Numerical rating scale, 7 items</td>
<td>Cronbach's alpha was 0.64–0.92</td>
<td>Pearson's correlation coefficient used to measure test-retest reliability of 0.84–0.92</td>
<td>Can be completed by either the patient family or staff</td>
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*The article reporting the Edmonton symptom assessment scales is a fifteen year retrospective review of validation studies.*
3.5 Prognosis and function

The steering group of the European Association for Palliative Care made recommendations in respect of assessing prognosis and reported that accurate determination of the potential life expectancy of patients with palliative care needs is important to care planning, including the most appropriate place of care for patients. Furthermore, prognosis is an important element in communications with patients and families that can facilitate their decision-making (Maltoni et al., 2005). The group highlighted that aids to assess prognosis include the following:

- The clinical prediction of survival, (the accuracy of which is impacted by the clinician’s experience, its usage in combination with other prognostic tools, and whether or not prediction is short-term).
- Signs and symptoms (such as poor functional status, weight loss, reduced nutritional intake, delirium).
- Biological indicators such as leucocytosis, lymphocytopenia and high C-reactive protein.

Maltoni et al. (2005) cautioned that unless prognostic indicators are regularly reviewed by experienced clinicians and used in the context of an open patient centred palliative care approach they may be damaging to the patient. This group also referenced the Palliative Prognostic Score (PaP) and the Palliative Prognostic Index (PPI) as possible scales that can be used to assess prognosis. Studies of the psychometric properties of both the PaP and the PPI are reported in Table 3.5.1. The PPI was chosen for incorporation in the MPCAT as unlike the PaP it includes delirium. Moreover, the PPI is brief, easy to use, and does not require blood testing which may be unnecessarily invasive for patients. Although the EAPC recommended the PaP score over PPI, this was linked to the observation that the PaP score had been more comprehensively validated at that time (Stone et al., 2008).
Functional status is also associated with prognosis (Lau et al., 2009; Weng et al., 2009). Consequently, a review of measures of functional performance validated in a palliative setting was also conducted and identified measures are included in Table 3.5.1. It should be noted that while the Eastern Cooperative Oncology Group performance status (ECOG) tool was part of the pre-intervention assessment documentation, no specific paper evidencing validation of the tool in a palliative care setting was identified in this review. Researchers have suggested that the ECOG does not sufficiently distinguish between patients with different levels of performance status and that increased levels of categorisation are required in a palliative care setting (Abernethy et al., 2005). These authors recommended that the Australian Karnofsky Performance Score (AKPS) is sensitive to change in performance status for patients with a low performance status in comparison to the Karnofsky Performance Score (KPS) or the Thorne Karnofsky Performance Score (TKPS). Further to comparison of the inter rater reliability of the KPS, the ECOG, the AKPS and the Palliative Performance Scale, (PPS a modification of the KPS) all of the scales were highly and significantly correlated, and reliability of the scales was good (Myers et al., 2010). On the basis that the PPS facilitates 10 levels of categorisation regarding patient performance status and its outcome is required to score the PPI, the PPS was selected for inclusion in the MPCAT.
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<td>Edmonton Functional Assessment Tool (EFAT), (Kaasa et al., 1997)</td>
<td>25 Patients - to test inter rater reliability and concurrent validity. Construct validity was tested in 101 patients to determine change over time and distinguish between groups. For use in inpatient palliative care units. Measure performance status</td>
<td>10 items mainly function, Global performance score (PS)</td>
<td>Consultation with Palliative Care Physiotherapy and Occupational Therapy Staff</td>
<td>Concurrent Validity - Correlated against the KPS - Karnofsky performance status, ( r = -0.79; P &lt; 0.001 ) and the ECOG, ( r = 0.85, p &lt; 0.001 ). Total EFAT correlated with the PS, ( r = 0.89 ). EFAT is able to distinguish between groups e.g. patients who are for end of life care or transfer to another care facility versus patients who are for discharge home.</td>
<td>Inter-rater reliability was 0.88</td>
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<td>Palliative Prognostic Score (PaP) (Maltoni et al., 1999)</td>
<td>451 patients across hospice programmes in 14 palliative care centers. Prognostic indicator</td>
<td>6 predictive factors of death: dyspnea, anorexia, Karnofsky Performance Status score, clinical prediction of survival score, total white blood count and lymphocyte percentage.</td>
<td>Identified significant clinical variables through multivariable analysis and identification of biological parameters. Outcome was used to develop an integrated prognostic score.</td>
<td>Median survival and relative 95% confidence interval were as follows: Group A = 76 days (95% C.I., range = 67-87 days); Group B = 32 days (95% C.I., range = 28 - 39 days) Group C = 14 days (95% C.I.; range = 11 - 18 days).</td>
<td>Tool can categorise patients to 3 specific risk groups in respect of mortality</td>
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<td>Edmonton Functional Assessment Tool (EFAT) (Kaasa and Wessel, 2001)</td>
<td>272 Palliative care patients, further validation. Measure performance status</td>
<td>10 items, Cognitive and affective factors</td>
<td>Derived from the Thorne Karnofsky Performance Scale and the original Karnofsky Performance Status Scale. Face validity confirmed for the AKPS.</td>
<td>Compared against the Karnofsky Performance Status (KPS) and the Thorne Karnofsky Performance Status (TKPS) scales. Kappa coefficient for agreement between all KPS and TKPS was 0.71 (p&lt;0.001) and between all TKPS and KPS = 0.84 (p&lt;0.001) and between AKPS and TKPS = 0.82 (p&lt;0.001)</td>
<td>Cronbach's alpha was 0.86</td>
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<td>Australian - modified Karnofsky performance status (AKPS) (Abernethy et al., 2005)</td>
<td>306 palliative patients randomised controlled trial (1600 time points). To determine most appropriate performance status measure for use in clinical practice and research</td>
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<td>AKPS was the most predictive of the three scales of survival. Authors recommended that the AKPS was a worthwhile revision of the KPS, appropriate for clinical settings. AKPS was superior to KPS and TKPS in the lower range of the scale indicating applicability to patients at end of life. Scale offers more gradations categories than previous versions.</td>
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<td>Name of Tool and Reference</td>
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<td>Palliative Performance Scale (PPS) (Olajide et al., 2007)</td>
<td>261 adult patients with advanced cancer or other life limiting diseases in a hospital based palliative care consultative service. To assess functional status and quantify rate of deterioration.</td>
<td>Ambulation, activity and evidence of disease, self-care, intake and consciousness level</td>
<td>A lower PPS was significantly associated with a higher level of dyspnea (odds ratio 0.72, 95% C.I. 0.60 - 0.86) and agitated delirium (odds ratio 0.72, 95% C.I. 0.57 - 0.90).</td>
<td>Authors were able to categorise sample to 3 groups according to their prognosis. PPS identified as a useful tool to predict risk of mortality across populations but may not be as useful in an individual patient.</td>
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<td>Palliative Prognostic Index (PPI) (Stone et al., 2008)</td>
<td>194 patients. At the time of analysis actual survival data was available for (or 78% of sample, (n = 151). Prediction of survival. The samples was derived from patients in three services including a hospital based palliative care service, a home care service and an in-patient hospice service</td>
<td>Palliative performance scale. Possible score 0 - 4, oral intake (0 - 2.5), odema present or absent (0 - 1), dyspnea at rest present or absent (0 - 3.5) and delirium present or absent (0 - 4). 3 sub groups: (i) PPI ≤ 4, (ii)PPI &gt; 4 and ≤ 6 (iii)PPI &gt; 6</td>
<td>Divides patients into 3 groups: Group 1: PPI ≤ 4, median survival 68 days, 95% C.I. 52, 115 days. Group 2: PPI is &gt; 4 ≤ 6, median survival 21 days, 95% C.I. 13, 33. Group 3: PPI &gt; 6, median survival 5 days, 95% C.I. 3, 11. PPI is quick and easy, not invasive to patients and doesn’t require blood testing. Positive Predictive Value : Survival of less than 3 weeks is 0.86, survival of less than 6 weeks is 0.91. Negative Predictive Value: Survival of less than 4 weeks is 0.64, survival of less than 6 weeks is 0.76. Sensitivity: Survival of less than 3 weeks is 0.56 and survival of less than 6 weeks is 0.63. Specificity: Survival of less than 3 weeks is 0.94.</td>
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<td>Palliative Prognostic Score with Delirium (D-PaP) (Scarpi et al., 2011)</td>
<td>361 Palliative Care Patients Prognostic Indicator</td>
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<td>Overall Performance of D - PaP reported to be better than PaP.</td>
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<td><strong>Palliative Prognostic Score (PaP)</strong>, (Tarumi et al., 2011)</td>
<td>958 palliative care patients. To validate the PaP and determine ability of PaP and routinely collected clinical data (Diagnosis of Delirium, Palliative Performance Score, MMSE) to estimate prognosis</td>
<td>30 day survival rates for 3 different groups: Group A: 78%, Group B: 55%, Group C: 11%. Median survival for groups with delirium was 11 days (95% C.I., 7-15 days), without delirium was 43 days (95% C.I., 38-48 days). Normal MMSE - 14 days (95% C.I., 11-17 days), abnormal MMSE 61 days (95% C.I., 52-70 days)</td>
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<td>Largest sample in which PaP has been validated to date.</td>
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3.6 Cognitive impairment and delirium

Cognitive impairment is one of the most frequent psychiatric problems experienced by patients with advanced cancer. It is a prognostic indicator of the likelihood of discharge, impacts decision making capacity and communication with family members and health care providers (Irwin et al., 2008). Moreover, it can be remediated in a large number of patients (Lawlor et al., 2000; Leonard et al., 2008). Cognitive impairment or neurocognitive disorder (as it has recently been termed in DSM-5), includes delirium, major neurocognitive disorders such as dementia and amnestic disorders and mild neurocognitive disorders that involve impairment of thinking, reasoning, formulating ideas, and concentrating (Henderson and Hotopf, 2007). Prospective studies report an incidence of between 34% - 44% in patients with advanced cancer at the time of admission to palliative care inpatient facilities. (Power et al., 1993; Pereira et al., 1997)

Cognitive failure (or delirium) is one of the most commonly experienced neuropsychiatric symptoms suffered by patients with advanced cancer, especially in the late stages of terminal illness. It is frequently undetected and under treated (Casarett and Inouye, 2001), is distressing to both the patient and family members (Breitbart et al., 2002; Namba et al., 2007; Bruera et al., 2009), reduces opportunities for communication with the patient, (Steinhauser et al., 2000) and significantly complicates patient care and symptom management within healthcare services. Between 80 - 90% of palliative patients may experience delirium or “terminal agitation” prior to death (Fainsinger et al., 2000; Lawlor et al., 2000; Morita et al., 2001). Studies have reported the prevalence of delirium on admission to palliative facilities to range from 19 – 42% (Lawlor et al., 2000; Durkin et al., 2003).

Delirium is typically multi-factorial in etiology with 3-4 significant factors identifiable in any case, while a specific cause cannot be identified in up to half of the patients who experience delirium in the late stages of advanced cancer (Bruera et al., 1992). Delirium can be significantly controlled or reversed in approximately 50% of patients with advanced cancer. This is usually achieved with relatively simple interventions emphasising change or dose reductions of opioids, discontinuation of deliriogenic
medication (e.g. anticholinergic agents, benzodiazepines), hydration and prudent use of antipsychotic treatments (Gagnon et al., 2000; Lawlor et al., 2000). Delirium is less likely to be reversible where it is linked to organ failure, in older patients or those who experience severe cognitive impairment, particularly in respect of attention, vigilance and visuo-spatial ability (Leonard et al., 2008). Given the impact on patient care and outcomes, along with its potential for reversal with timely identification and intervention, delirium has been identified as a key healthcare target, including in palliative care (Meagher, 2009). Table 3.6.1 provides a summary of tools for the assessment of cognitive impairment and delirium that have been validated in a palliative population.
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<th>Tool</th>
<th>Sample size, Population and Purpose</th>
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<td>Memorial Delirium Assessment Scale (MDAS) (Breitbart et al., 1997)</td>
<td>33 hospitalised patients, 30 had cancer. Quantifies delirium symptom severity, for use in clinical intervention trials. Tool was not developed as a diagnostic tool, but the results indicated that it could be used as such.</td>
<td>10 items assess disturbances in arousal, level of consciousness and cognitive function. 4 point clinician rated scale. Possible range 0-30. Integrates behavioural observations and objective cognitive testing. Cut off scores of 13 or above indicate presence of delirium</td>
<td>Can be administered repeatedly within the same day. Allow 10 minutes to administer. Can be pro-rated.</td>
<td>Simultaneous evaluation by 2 psychiatrists using DSM III-R. Comparison with MMSE and DRS, clinicians global rating of delirium severity and type. For DRS, r = 0.88, p &lt; 0.001; MMSE r = -0.91, p &lt; 0.001; global rating of delirium severity, r = 0.89, p &lt; 0.001</td>
<td>Cronbach’s alpha: 0.91. Item to total correlations for the 10 items range from 0.31 to 0.91 with only items 7 and 8 having item total correlations</td>
<td>Inter rater reliability: r = 0.92 (range = 0.64 - 0.99). 8 items above 0.70 and 5 were above 0.80 indicating substantial agreement</td>
<td>70</td>
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<td>Blessed Orientation-Memory-Concentration (BOMC) (Arsène 2000) *</td>
<td>25 patients with advanced cancer, Validation of the BOMC as a tool to screen for delirium in patients with advanced cancer who were taking opioids.</td>
<td>Cut off score: 6, 6 items</td>
<td>100% of patients completed the BOMC. 76% completed it in full. 4 minutes 12 seconds less than the MMSE to complete. Age or educational level did not affect ability to complete the BOMC.</td>
<td>Compared against diagnosis of delirium according to the DSM IV criteria and completion of the MMSE – all completed by the same examiner.</td>
<td>0.83 PPV reported as 0.91</td>
<td>0.95 NPV reported as 0.91</td>
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<td>Bedside Confusion Scale (Stillman and Rybicki, 2000)</td>
<td>31 consecutive admissions to an inpatient palliative care facility. Screening test for confusion, developed for cancer patients in palliative care</td>
<td>Assesses level of alertness (normal = 0, hyperactive = 1, hypoactive = 1) plus test for attention, timed recitation of each month of the year in reverse order, scores range from 1-4, 0 = Normal. 1 = border line confusion, 2 -5 = abnormal, diagnostic of confusion</td>
<td>Less than 2 minutes Observational tool and timed attention task- Easily integrated to routine clinical practice</td>
<td>Derived from a neurologist screening evaluation of attention and consciousness</td>
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<td>Score ≥1:0.54, Score ≥2: 0.85</td>
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<td><strong>Memorial Delirium Assessment Scale (MDAS)</strong> (Lawlor, 2000)**</td>
<td>104 patients, consecutive admissions to a specialist palliative care unit. Severity rating of delirium in patients with advanced cancer</td>
<td>Rate severity of impairment in 10 domains: 2 Factor Structure identified; Factor 1: global cognitive, Factor 2: neurobehavioural. Items: rated on a four point scale, 0 (none) to 3 (severe). Maximum score is 30. Cut off score of 7: best results for incidence of delirium.</td>
<td>Physician rated instrument. Requires patient participation, incorporated as part of a semi structured interview.</td>
<td>MMSE and standardised semi-structured interview derived from DSM-IV criteria for delirium. Correlations among scale items range from low to moderate correlation (r = 0.02 - 0.68.) Moderate correlation between MMSE and MDAS (r = 0.55, moderate correlation</td>
<td>Cronbach's alpha for factor 1 of 0.80 and for factor 2 of 0.66. Cronbach's alpha for all 10 items: 0.78</td>
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<td><strong>Agitation Distress Scale, ADS</strong> (Morita et al., 2001)</td>
<td>30 consecutive terminally ill cancer patients admitted to a palliative care unit. Evaluation of delirium in the terminal stage of end of life, severity of patients agitated behaviour</td>
<td>6 items, 4 point observer rating scale. Each question is scored 0-4. Items: Frequency, extent and content of physical restlessness, psychological instability, hallucinations and delusions, and sleep disturbance. Total score = 0 – 18; Clinicians rate scores based on the most severe symptoms during observational period</td>
<td>Allows repeated measurement and doesn't require patient engagement.</td>
<td>Spearman’s correlations: modified MDAS w as 0.24., Delirium scale 0.61, P&lt;0.01 and 0.14 with the sedation scale (Combined score of CCS and ADS was highly correlated with Modified MDAS and DRS score, r = 0.83 and 0.83 respectively, p &lt; 0.01. Principle component analysis (PCA) identified a single factor. Cronbach’s alpha: 0.91 Item total correlations ranged from 0.42 - 0.83.</td>
<td>Cronbach’s alpha: 0.91 Item total correlations ranged from 0.42 - 0.83.</td>
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<td><strong>Communication Capacity Scale</strong> (Morita et al., 2001)</td>
<td>30 consecutive terminally ill cancer patients admitted to a palliative care unit. Quantification of communication capacity and delirium in terminal cancer patients with delirium. Estimates cognitive capacity</td>
<td>5 items, Conscious level, answers to open ended questions, answers to closed questions, voluntary communication, voluntary movement, Score = 0-3/0-5. Total score = 0- 17</td>
<td>Principle component analysis (PCA) identified a single factor.</td>
<td>Spearman’s correlations: modified MDAS Scale was 0.780, p&lt;0.01. Delirium scale was 0.44, p&lt;0.05 and sedation scale was 0.86, p&lt;0.01 . Combined score CCS and ADS was highly correlated with modified MDAS and DRS score, r = 0.83 and 0.83 respectively, p &lt; 0.01.</td>
<td>Cronbach’s alpha: 0.96 Item total correlations ranged from 0.80 - 0.94.</td>
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**Note:** Inter-rater reliability: Cohen's kappa range from 0.72 - 1.00 Indicating substantial agreement
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<td>Memorial Delirium Assessment Scale (Grassi et al., 2001)</td>
<td>105 patients with advanced cancer. Assessing delirium among patients with advanced cancer. Specifically designed to quantify severity of delirium symptoms. To validate the tool in an Italian population of patients with advanced cancer.</td>
<td>Includes items for level of consciousness, disorientation, short term memory, digit span, attention, disorganized thinking, perceptual disturbances, delusions, psychomotor activity, and sleep-wake cycle disturbances. 10 four point observer rated items. Integrates objective cognitive testing and evaluation of behavioural symptoms. Yields a global score ranging from 0 - 30. Cut off score ≥13 for delirium.</td>
<td>Developed to be consistent with DSM-IV diagnostic criteria for delirium. Compared against clinician evaluation using the DSM-III-R criteria for delirium. DRS and MDAS, r = 0.76, p = 0.001. MMSE - r = -0.88, p = 0.001. Individual MDAS scores were highly correlated with MMSE total score, range -0.03 to -0.82. Cronbach’s Alpha: 0.89. Item total correlation for 10 items range from 0.03 to 0.82.</td>
<td>Cronbach’s Alpha: 0.89. MMSE - r = -0.88, p = 0.001. Item total correlation for 10 items range from 0.03 to 0.82.</td>
<td>0.68 NPV = 0.63 PPV = 0.95</td>
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<td>Delirium Rating Scale (Grassi et al., 2001)</td>
<td>105 patients with advanced cancer. Assessing delirium among patients with advanced cancer. Originally developed to identify delirium in medically ill and to measure severity. Study carried out across 6 centres including 2 palliative care units. To validate the tool in an Italian population of patients with advanced cancer.</td>
<td>Three factor structure; factor 1; vigilance and attention disturbances, factor 2: psychotic symptoms, factor 3: time, course and cause, 10 item. Scored from 0 - 3 or 0 - 4. Total DRS scores obtained by summing from the 10 items (range = 0 - 32). Cut off scores of 10 and 12 have been suggested to distinguish patients with delirium from patients with other neuro-psychiatric conditions.</td>
<td>Clinician rated, DRS score is derived from patient interview, mental status examination, nursing observation over a 24 hour period and family reports. Items were derived from DSM-III criteria.</td>
<td>Compared against clinicians evaluation using the DSM-III-R criteria for delirium and against Confusion Assessment Method scores. Significant association between the DRS and the MDAS total score, r = 0.76, p = 0.001. DRS significantly associated with MMSE r = -0.67, p = 0.001</td>
<td>Cronbach’s alpha: 0.70. Item total correlation for 10 items range from 0.09 to 0.56. Cut off of ≥10 = 0.95, NPV 0.89 Cut off of ≥12 = 0.80, Negative predictive value 0.69 Cut off of ≥10 = 0.61, PPV 0.80 Cut off of ≥12 = 0.76, Positive predictive value 0.85</td>
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<td><strong>Delirium Rating Scale - Revised - 98 (DRS-R-98)</strong> (Trzepacz et al., 2001)</td>
<td>68 subjects evaluated from five diagnostic groups. Subjects recruited from psychiatric units, nursing home or rehabilitation units</td>
<td>16 items. 13 severity items and 3 diagnostic items. Maximum total scale score of 46 points. Includes 3 diagnostic items and maximum severity score of 39 points. Cut off score of 17.75</td>
<td>Clinician rating scale</td>
<td>DRS correlation with DRS-R-98, $r = 0.83$, $p &lt; 0.001$. DRS-R-98 Severity, $r = 0.80$, $p &lt; 0.001$. DRS-R-98 correlation with the CTD, $r = -0.41$, $p &lt; 0.005$ for the DRS; $r = -0.62$, $p = 0.001$ for the DRS-R-98 total and $r = -0.63$, $p &lt; 0.001$ for the DRS-R-98 Severity.</td>
<td>Cronbach's alpha = 0.90 = total score. Cronbach's alpha for severity scale = 0.87.</td>
<td>0.92</td>
<td>0.95</td>
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<td><strong>Mini Mental State Exam, MMSE (4 Items)</strong> (Fayers et al., 2005)</td>
<td>217 cancer patients. Determine the effectiveness of the MMSE items in predicting delirium in palliative patients and to identify if a shortened version could be used as screening tool for cognitive impairment.</td>
<td>4 item version: year, date, backward spelling, and copy a design. 6 item version; year, date, backward spelling, copying a design, orientation to time and recall.</td>
<td>Copying a design – is problematic in a palliative population due to patients lying in bed, complication of treatment such as IV lines, fatigue, decreased strength and difficulty holding a pen.</td>
<td>Applied logistic regression and item response theory to data obtained from completion of the MMSE.</td>
<td>AMTS, 3 item recall test from the MMSE. Attention tests = Digit Span and reciting months of the year backwards.</td>
<td>0.96</td>
<td>0.91</td>
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<td><strong>Clock Drawing Test</strong> (Henderson and Hotopf, 2007)</td>
<td>81 hospice patients. To review the effectiveness of the test in a hospice population as a screening tool and to determine if the test was distinguishing between confusion</td>
<td>10 Point scoring system Cut off score of 7/8</td>
<td>No patient who consented to take part in the study declined to complete the clock drawing test.</td>
<td>0.92 (0.86 – 0.98) PPV - 0.61</td>
<td>0.73 (0.64 – 0.83) NPV - 0.95</td>
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<td>Confusion Assessment Method (CAM) (Ryan et al., 2009)</td>
<td>52 patients, derived from consecutive admissions to SPCU. To determine sensitivity and specificity of the CAM in diagnosing delirium when used by NCHD's working in the specialist palliative care unit.</td>
<td>4 item algorithm - diagnosis of delirium requires acute onset of altered mental status, inattention and either evidence of disorganised thinking or altered consciousness. The CAM is based on operationalised criteria from the Diagnostic and Statistical Manual of Mental Disorders – III R</td>
<td>Clinician Rating Scale</td>
<td>Compared against psychiatrists assessments, (blinded to the CAM assessment) patient and family interview, chart review and DRS-R-98, CTD, and MDAS.</td>
<td>0.88 (0.62 - 0.98)</td>
<td>1.0 (0.88 - 1.0)</td>
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<td>Delirium Observation Screening (DOS) (Detroyer et al., 2010)</td>
<td>48 Patients admitted to a palliative care unit. To detect and measure delirium severity. The scale can be completed by nurses further to observation of the patient during routine care.</td>
<td>13 item scales, derived from the DSM-IV criteria. Assessments are conducted 3 times a day at the end of each 8 hour shift. Each item / behavioural observation can be scored as absent, present or unable to rate. Scores range from 0-13. The score for the day is the average of the score from each of the 3 shifts. Cut off score = greater than or equal to 33</td>
<td>Scoring requires no extensive training – scoring can be completed in approximately one minute</td>
<td>Compared against CAM and by correlating against the Delirium Index. Paired DOS shift scores with total DI scores ($r = 0.53$; (p&lt;0.001) Delirious patients (13 observations) DOS and DI = 0.73 (p&lt;0.01)</td>
<td>Cronbach's alpha: 0.772. Item total correlation were moderate (Pearson correlation coefficient: 0.566-.401) for 9 items; fair for 3 items (Pearson correlation coefficient = .390-.254) and weak for one item – 0.177</td>
<td>0.81 (95% C.I. = 52-95), NPV: 0.98</td>
<td>0.96 (95% C.I.: 90-98) PPV: 0.69</td>
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**MM DAS: Modified Memorial Delirium Assessment Scale, CAM: Confusion Assessment method; DI: Delirium Index; CTD: Cognitive Tests for Delirium; MDAS: Memorial Delirium Assessment ; AMTS: Abbreviated mental status questionnaire; NPV: Negative predictive value. PPV: Positive predictive value.**

* Authors reported the time it took to complete the Blessed Orientation and Memory Concentration test was correlated with the score (0.6). A time to complete, of 3 min 20 sec had 0.91 sensitivity and specificity for delirium diagnosis.

**Both the Agitation and Distress Scale and the Communication Capacity Scale were originally written in Japanese, and then underwent a double back-translation process to develop an English Version**
3.7 Spirituality

Spirituality is a generic characteristic of human beings that reveals itself in the search for meaning, relationships, purpose and hope (Association of Hospice & Palliative Care Chaplains, 2006). It has been defined as a belief system focusing on intangible elements that impart vitality and meaning to life events (Maugans, 1996). It is a subjective experience that exists both within and outside traditional religious systems (Mitchell, 2003), and relates to the way in which people understand and live their lives in view of their core beliefs and values (Puchalski et al., 2009).

World Health Organisation guidelines (The WHOQOL Group, 1995) consider spirituality an important dimension of quality of life. Spiritual distress and existential suffering can be expressed as physical pain or even be the primary cause of severe analgesic resistant pain (Strang and Strang, 2002), can affect quality of life (Hampton et al., 2007) and influence treatment choices.

Spiritual assessment and assessment of spiritual need or distress is a core element of palliative care assessment (World Health Organisation, 2002; Okon, 2005). As such it should form part of the admission assessment to a palliative care service to identify which patients will benefit from a more in depth spiritual assessment (including spiritual distress or spiritual resources of strength) (Ruder, 2008; Puchalski et al., 2009) (Dahlin, 2009) and lead to appropriate referrals for specialist care which will include taking a spiritual history (Lo et al., 2002). At the time of admission, clinicians ideally make a distinction between spiritual and psychosocial issues and identify the appropriate professionals to provide specialist care.

Steinhauser et. al., (2006) suggested that a practical evidence based approach to discussing spiritual concerns in a scope suitable to a physician-patient relationship may improve the quality of the clinical encounter (Steinhauser et al., 2006b). Many patients would like their clinicians to consider their spiritual needs (Hart et al., 2003; Okon, 2005) and the inquiry or evaluation itself may be therapeutic.
3.7.1 The spiritual assessment process

“Spiritual care should be seen as a responsibility of the whole team, while recognising that an individual may hold specific responsibility for ensuring its provision, as patients may express their needs (spiritual needs) only once, it is important for those assessing needs to be highly attuned to the spiritual dimension of patient care”.

(National Institute for Clinical Excellence, 2004)

According to the NICE guidance assessment of spiritual needs does not have to be structured, but should include core elements such as exploring how people make sense of what happens to them, what sources of strength they can draw upon, and whether these are felt to be helpful to them at this point in their life. However, the Clinical Practice Guidelines for Quality Palliative Care, (2009) from the National Consensus project recommends using a structured instrument for spiritual assessment. They suggest that the regular assessment of spiritual needs and distress should be documented, including but not limited to, review of life experiences, meaning and values attributed to life experiences, existential fears and distress, fears relating to dying and the afterlife and that wherever possible a standardised instrument should be used. Periodic reassessment of the impact of spiritual and existential interventions and preferences of the patient and their families should occur. Spiritual assessment is a far reaching process of active listening to the patient, conducted by a specialist in spiritual care that clarifies the needs and resources during the process of assessment. The assessment should result in a spiritual care plan that is then documented and communicated to the rest of the clinical team (Dahlin, 2009).

In accordance with the Marie Curie Spiritual and Religious Care Competencies model (which is also recommended in the NICE guidance document), there are four levels of competency proposed in assessing and responding to spiritual needs (Marie Curie Cancer Care, 2003). Staff operating at level one with occasional contact with patients, understand the importance of spiritual need and have elementary skills in responding to patient need and an awareness of when to refer to a more appropriate professional. Staff operating at level two, whose role requires them to work directly with patients, have a more enhanced awareness of spiritual need. These staff should be able to actively listen
and empathetically communicate with patients and identify when it is necessary to refer a patient.

Members of the multidisciplinary team operating at level 3 should be able to conduct an assessment of spiritual and religious need. They will be able to identify interventions in response to the detection of difficult spiritual, religious and ethical concerns and be able to document their assessment in a sensitive manner which respects the confidentiality of patients and carers. Staff operating at level 4 will be able to care for patients, families/carers and staff with complex spiritual and religious needs. In particular they will deal with the existential and practical needs arising from the impact on individuals and families from illness, life, dying and death. They will document and provide feedback to individual staff members. They will have a clear understanding of their own personal beliefs and be able to journey with others focused on other people’s needs and agenda.

3.7.2 Identifying spiritual issues as part of the initial assessment: questioning guidelines identified

The guidance document ‘Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer’ (Cancer Action Team, 2007) suggests that it is important to have a ‘lead in’ to the spiritual domain, meaning a couple of preparatory sentences that mark a shift to questions of a quite different nature from those related to ‘clinical’ needs. Clinicians engaging in discourse about spiritual existential issues with patients have several objectives (Lo et al., 2002; Okon, 2005; Dahlin, 2009):

- Identifying of the patient’s perspective, attitudes and beliefs relating to the meaning of and value of their lives, including both religious and non-religious elements.
- Offering support through the techniques of active listening and empathetic communication.
- Collaboration with the patient to plan care and the goals of care that are respectful of the patient’s beliefs.
• Activation of support for the patient to aid coping and resilience.

Several authors have suggested questioning guidelines to aid clinicians when screening for spiritual needs and distress. A common theme among the questioning guidelines relates to the patient’s attribution of meaning to their lives, and their sources of support and their current effectiveness to aid resilience.

Clinical Practice Guidelines for Quality Palliative Care suggest that good models of spiritual screening use a few simple questions that can be asked in the course of an overall patient and family screening and requires little training (Dahlin, 2009). Examples of such questions include:

• “Are spirituality or religion important in your life?”
• “How well are those resources working for you at this time?”

Similar example questions which avoid specific reference to religion include:

• “What nourishes you?”
• “What feeds your spirit?”
• “Where do you find strength in difficult times?”
(Hegarty, 2007):

The Mount Vernon Cancer Network (MVCN) (2008), developed a spiritual care assessment tool for patients with cancer and other long-term conditions in line with the Nice Guidelines and the Marie Curie Competencies document. The assessment tool is part of the holistic assessment aide memoir tool that has been adapted from the PEPSI-COLA tool (NHS, 2009).

The tool is based on three core questions as follows:

• “How do you make sense of what is happening to you?
• “What sources of strength do you look to when life is difficult?”
• “Would you find it helpful to talk to someone who could help you explore the issues of spirituality/faith?”
(Mount Vernon Cancer Network, 2008)
The questions are intended as a guideline or trigger to open a conversation about spirituality and can be supplemented with additional questions. The St Michael’s Hospice spiritual needs assessment tool for people nearing the end of their life covers three main areas utilising open questions – issues of sense, meaning and purpose; individual practice; and spiritual or religious connections.

They include questions such as:

- “When life is hard how have you kept going?”
- “Is there anyone or anything that has helped you keep going?”
- “How are you coping with what’s happening to you?”

(Okon, 2005)

Okon provides questions in an open-ended format to facilitate the taking of a spiritual history, e.g.

- “Is faith important in your life?”
- “What roles does spirituality or religion play in your life?”
- “Does life feel like a gift or like a burden as you go through this illness?”
- “What brings meaning and purpose to your life?”

(Okon, 2005)

The single question ‘Are you at peace?’ can be used as an initiator for further conversation, orientated towards the patient’s values, preferences and life experiences (Steinhauser et al., 2006b).

3.7.3 Taking a spiritual history

Clinical Practice Guidelines for Quality Palliative Care suggests that spiritual history taking uses a broader set of questions to gather important information about the patient’s perception and current views of the life they have led, fears, hopes, values, needs, views on the afterlife and sources of support using a structured instrument. The taking of a spiritual history can be in the context of a comprehensive assessment by the clinician (doctor, nurse, pastoral care worker or social worker) who is responsible for providing direct care or through referral to specialists. The information from the history
permits the clinician to understand how spiritual concerns could either complement or complicate the patient’s overall care. It also allows the clinician to incorporate spiritual care into the patient’s overall care plan and should be reviewed periodically and in response to interventions. Spiritual assessment is a more extensive process of active listening to the patient’s story, conducted by a specialist in spiritual care that summarises the needs and resources during the process of assessment.

The assessment should result in a spiritual care plan that is then communicated to the rest of the clinical team (Dahlin, 2009). The formal process of obtaining a spiritual history can be structured by utilising either the HOPE, FICA or SPIRIT tools (see Table 3.7.3.1) (Okon, 2005; Dahlin, 2009). These authors recommend that clinicians taking a spiritual history should have relevant training in and be confident to deal with issues that may emerge. Furthermore, clinicians should have knowledge of how to engage patients comfortably in this discussion. Other tools identified through the literature review relative to spiritual history-taking are summarised in Table 3.7.3.2.
<table>
<thead>
<tr>
<th>Tool</th>
<th>Domains</th>
<th>Examples of Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>HOPE</td>
<td>H: Sources of hope</td>
<td>H: What gives you hope (or strength or comfort or peace) in the time of illness?</td>
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<tr>
<td></td>
<td>O: Organised religion</td>
<td>O: Are you part / member of religious or spiritual community? Does it help you? How?</td>
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<td></td>
<td>P: Personal spirituality and practices</td>
<td>P: What aspects of your spiritual beliefs do you find most helpful and meaningful personally?</td>
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<td></td>
<td>E: Effect on medical care and end of life issues</td>
<td>E: How do your beliefs affect the kind of medical care you would like me to provide over the next few days /weeks /months?</td>
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</table>

**Additional question:** Would you like to speak to pastoral care/How can we help in the provision of spiritual care?

(Anadarajah and Hight, 2001)
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<thead>
<tr>
<th>Tool</th>
<th>Domains</th>
<th>Examples of Content</th>
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<tbody>
<tr>
<td>FICA:</td>
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<tr>
<td></td>
<td>Spiritual History</td>
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<td>F: Faith</td>
<td>What is your faith? Do you consider yourself spiritual or religious?</td>
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<tr>
<td>I: Importance</td>
<td>What importance does your faith or belief have in your life?</td>
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<td>C: Community</td>
<td>Are you part of a religious community?</td>
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<td>A: Address / apply</td>
<td>How would you like me as your care provider to address these issues in your care?</td>
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(Puchalski and Romer, 2000)
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<th>Tool</th>
<th>Domains</th>
<th>Examples of Content</th>
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<tbody>
<tr>
<td>3. Spirit</td>
<td>S: Spiritual belief system</td>
<td>S: Do you have a formal religious affiliation? Do you have a spiritual life that is important to you?</td>
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<td>P: Personal Spirituality</td>
<td>P: In what ways is your spirituality important to you?</td>
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<td>I: Integration with a spiritual</td>
<td>I: Do you belong to any religious or spiritual groups / communities</td>
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<td>R: Ritualised practices and restriction</td>
<td>R: What specific practices do you carry out as part of religious or spiritual life?</td>
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<td></td>
<td>I: Implications for medical care</td>
<td>I: Would you like to discuss religious or spiritual implications of health care?</td>
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<td></td>
<td>T: Terminal Events</td>
<td>T: Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion / spirituality?</td>
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</table>

(Maugans, 1996)
Table 3.7.3.2 Spirituality assessment tools validated in a palliative care population

<table>
<thead>
<tr>
<th>Tool</th>
<th>Sample Size, Population and Purpose</th>
<th>Format, Items and Domains</th>
<th>Validity</th>
<th>Reliability</th>
<th>Feasibility and Notes</th>
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</thead>
<tbody>
<tr>
<td>Herth Hope Scale, (Herth, 1991)</td>
<td>Designed to gather data concerning hopefulness from patients.</td>
<td>12 item scale, composed of 3 dimensions, 4 items per domain: temporality and future, positive reasoning expectancy, and interconnectedness. Tool is scored on a 1 - 4 Likert scale creating a score range from 12 - 48.</td>
<td>Hope scores produced negative correlation with depression and positive relationship to self-esteem, both were significant, p = 0.001</td>
<td>Cronbach's alpha was 0.88</td>
<td>Clinician administered, useful in palliative care and with chronically and terminally ill. Short and easy to administer.</td>
</tr>
<tr>
<td>Functional Assessment of Chronic Illness Therapy-Spiritual FACIT-Sp, (Peterman et al., 2002)</td>
<td>1617, (most had cancer), To aid assessment of spiritual dimension of quality of life with persons with chronic or life threatening illness.</td>
<td>12 items, 2 factors: factor 1: Role of faith in providing support during illness 4 items, factor 2; Sense of meaning/peace 8 items.</td>
<td>Compared to Fact - G (Positively associated: Spearman’s r = .58) and Profile and Mood states (Spearman’s r = -0.54)</td>
<td>Range from 0.81-0.88, total scale and two sub scales. Correlation between the two factors, r = 0.54, p = .0001</td>
<td>Does not assume a belief of God. The meaning/peace factor had strong associations with psychological adjustment. Made for research</td>
</tr>
<tr>
<td>Systems of Belief Inventory (SBI-15R), (Holland et al., 1998)</td>
<td>69 religious persons and 228 lay persons. A measure of religious involvement and spirituality for patients with chronic illness. Subscale measures derived from contact with religious community.</td>
<td>15 items, 4 point scale: (none of the time to all of the time. Spirituality in Cancer Care 2 subscales 1) beliefs and practices, 10 items 2) social support, 5 items</td>
<td>Expert Consensus</td>
<td>Cronbach’s alpha for the total scale: 0.93. Religious beliefs: 0.92, social support: 0.89</td>
<td>Self report, examined support from a religious/spiritual community and presence and importance of religious and spiritual beliefs and practices, made for research.</td>
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<tr>
<td>Brief R-COPE (Pargament et al., 1998)</td>
<td>551 participants with medical illness. To measure spiritual adjustment.</td>
<td>21 items, 2 dimensions: 12 items - positive religious coping, 9 items - negative coping</td>
<td>Positive religious coping Cronbach’s alpha: 0.87, negative coping Cronbach’s alpha: 0.69</td>
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<td>Identifies spiritual adjustment i.e. the degree to which conflict, self-blame or anger at God is present.</td>
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<td>Tool</td>
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<td>Content Validity</td>
<td>Construct Validity</td>
<td>Internal Consistency</td>
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<td>SWB scales appears to have sufficient validity for use as a QOL indicator. SWB scores correlated with other scales. The SWB, RWB and EWB all correlated positively with the purpose in life test.</td>
<td>Cronbach's alpha coefficients reflecting internal consistency were 0.89 (SWB), 0.87 (RWB), 0.78 (EWB).</td>
<td>Test retest reliability coefficients were 0.93 (SWB), 0.96 (RWB) and 0.86 (EWB).</td>
</tr>
<tr>
<td>Spiritual Well being (Teno, 2000)</td>
<td>Chronically ill patients. Designed to measure spiritual well being.</td>
<td>20 items - 2 domains, religious and existential. 2 sub scales are included: 1. religious well-being (RWB), 10 religious items; 2. existential well-being (EWB), 10 items with no reference to God. Half the items from each sub scale are worded in positive and negative directions. 3 scores: 1 total SWB score, 2. sum score for RWB 3. sum score for EWB.</td>
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<tr>
<td>Death transcendence scale (DTS) (Teno, 2000)</td>
<td>Designed to test what ways respondents use to transcend death, been used in a diverse population of adults including hospitalised patients but not the terminally ill.</td>
<td>25 item self-administered questionnaire - 5 subscales: religious, mystical, biosocial, creative and nature. Items are answered on a Likert scale (1 = strongly disagree, 4 = strongly agree).</td>
<td>Religious scores were correlated with depression, self-esteem and hope, most strongly with hope (r = 0.43). Nature sub-scale scores were lower in the urban population as compared to the rural.</td>
<td>Cronbach's alpha was 0.74 ranging from 0.79 for the religious sub-scale to 0.51 for the nature items.</td>
<td>Self administered. Scales suggest people seek to transcend death through the relationship and influences, applied in adult in and out patients. Indicate need for pastoral intervention in patient care and their families.</td>
</tr>
<tr>
<td>Meaning of Life Scale, (ML) (Teno, 2000)</td>
<td>224 chronically ill residents of, 61 patients with terminal illness and 59 patients with other conditions, and relatives and health professionals. Measure patient’s perception of the worth of their life.</td>
<td>15 item administered by interview. Scale includes positive and negatively worded items (require recoding when analysing). Scores range from 1 = low negative - 5 = high positive. Scale includes evaluation of respondents satisfaction with life, work etc.</td>
<td>Development of the scale was a 4 phase project, Tested in a group of</td>
<td>Cronbach's alpha: 0.78 (indicates high internal consistency).</td>
<td>Test retest correlations ranged from 0.27 - 0.58: 5 of the 15 items had correlations of 0.40 or less.</td>
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<tr>
<td>Tool</td>
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<td>Content Validity</td>
<td>Construct Validity</td>
<td>Internal Consistency</td>
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<tr>
<td>Spiritual Involvement and Belief Scale (SIBS) (Mistakidou, 2007)</td>
<td>82 advanced cancer patients in a palliative care unit in Greece. Designed to assess needs and outcomes of spiritual care</td>
<td>4 domains - internal beliefs, external practices; personal application such as practising humility and forgiveness towards other people; and existential and meditative beliefs. 26 questions, 5 point ordinal scale</td>
<td>Compared with G-SIBS and G-HADS. Factor one items: correlation with external / ritual subscale, range of 0.47 - 0.84, p &lt; 0.0005. Significant correlation between factor two items with the internal / beliefs subscale, range of 0.24 - 0.84; p &lt; 0.0005. Factor 3 items correlated with existential / meditative subscale, range of 0.58 - 0.77; p &lt; 0.001. Factor four items correlated with humility / personal forgiveness subscale, range of 0.51 - 0.80; p &lt; 0.0005. Subscales correlated significantly with each other, range of 0.63 - 0.83; p &lt; 0.0005.</td>
<td>Cronbach's alpha: 0.89 for the total scale, all items had correlation of 0.8 with both the total SIBS and the Cronbach’s adjusted total score. Cronbach’s alpha for the subscales = 0.91 for the external / ritual, 0.78 for the internal / belief, 0.80 for existential / meditative and 0.58 for the humility / personal.</td>
<td>Test retest reliability: patient responses tested on two occasions, three days apart. Pearson Correlation Coefficient ranged from r = 0.81 - 0.98. (p &lt; 0.0005)</td>
</tr>
<tr>
<td>Spiritual Involvement and Belief Scale (SIBS) (Hatch, 1998)</td>
<td>See above</td>
<td>Concurrent validity correlated SIBS subscales with indicators of psychological distress. Scored the measurement using the Greek version of the HADS. Correlation between SIBS subscales and HAD - Anxiety = 0.30 - 0.49. Between SIBS subscales and HAD depression = 0.20 - 0.54 (p &lt; 0.05).</td>
<td>Cronbach's alpha for subscales = 0.92 - external/ritual, 0.78 - internal/fluid, 0.80 - existential/meditative, 0.58 - humility/personal</td>
<td>Test retest reliability evaluated for 3 days apart. correlation: external/ritual = 0.35, internal/fluid = 0.81, existential/ = 0.98, humility /personal application = 0.96</td>
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<tr>
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<td>Are you at peace? (Steinhaus er et al., 2006b)</td>
<td>248 patients with advanced serious illness. Examined correlations with other assessments of spirituality and quality of life to identify constructs as associated with experience of being at peace.</td>
<td>One item</td>
<td>Factors considered important at the end of life analysed through sponsors in a national representative samples of these family members and patients with advanced serious illness.</td>
<td>Peacefulness more strongly associated with emotional and spiritual well-being of the FACT-G. QOL subscales (r = 0.52 and 0.60 respectively). Small to moderately relationships with other dimensions of QOL, r = 0.28 - physical well-being, r = 0.35 - functional well-being, r = 0.41 - social well-being. No significant association with either instrumental or effective support given by patients (r = 0.06 and r = -0.08 respectively). Correlations between peacefulness and the two dimensions in the spirituality subscale demonstrated significant associations, purpose: r = 0.47, p &lt; 0.001; faith: r = 0.51, p &lt; 0.001 - suggests similar construct resonance for religious and mean-making components of spirituality. Relationship between SIBS subscales and HAD anxiety, r = 0.30 - 0.49. Correlation between SIBS subscales and HAD - depression = 0.20 - 0.54 (p &lt; .005)</td>
<td></td>
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<tr>
<td>Tool</td>
<td>Sample Size, Population and Purpose</td>
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<tr>
<td>Spiritual Needs Inventory (SNI) (Hermann, 2006)</td>
<td>100 hospice patient. To measure the extent to which spiritual needs of patients at end of life are met.</td>
<td>17 items, Likert Scale of 1 (never) - 5 (always)</td>
<td>Literature review and qualitative interviews with patients to identify spiritual needs as they were experienced near the end of life.</td>
<td>Item to total correlations ranged from 0.07 - 0.65. Therefore final 17 item spiritual needs inventory emerged, that explained 63.7% of variance.</td>
<td>Cronbach’s alpha for a 17 item scale is 0.85. Item to total correlations range: 0.33 - 0.67.</td>
</tr>
<tr>
<td>Jarel Spiritual Well Being Scale (Hungelm ann et al., 1996)</td>
<td>Screening/ assessment tool for clinicians to identify spiritual distress</td>
<td>21 items, 6 response options (strongly agree - strongly disagree)</td>
<td>Literature review and 31 qualitative interviews and observations</td>
<td>3 Factors: factor 1: Faith/ beliefs (7 items), factor 2: Life/ Self Responsibility (7 items reverse scored), factor 3: Life-satisfaction/ self-actualization (7 items)</td>
<td>For use in clinical practice</td>
</tr>
<tr>
<td>Peace (Mack et al., 2008)</td>
<td>160, terminally ill patients with advanced cancer - to determine emotional acceptance of end of life</td>
<td>12 items: 2 subscales. Struggle With Illness subscale (7 items). Peaceful Acceptance subscale (5 items); 4 Response options, (1 not at all, 2 : to a slight extent 3 : to some extent, 4 : to a large extent)</td>
<td>Literature review, interviews with terminally ill patients</td>
<td>Correlated against patient's self rated peacefullness, ( r = 0.66; p &lt;.0001 ) and inversely correlated with Struggle With Illness score, ( r =0.54; p &lt;.0001 )</td>
<td>Struggle With Illness subscale: cronbach’s alpha: 0.81, Peaceful Acceptance cronbach’s alpha: 0.78. Item to total correlations for the Struggle With Illness subscale ranged from 0.33 to 0.69. Item to total correlations for the Peaceful Acceptance subscale ranged from 0.33 to 0.66</td>
</tr>
</tbody>
</table>

G-SIBS: Greek version of the Spiritual Involvement and Belief Scale, G-HADS: Greek version of Hospital Anxiety and Depression Scale, FACT – G: Functional Assessment of Cancer Therapy – General. QOL: Quality of Life, HADS: Hospital Anxiety and Depression Scale
3.8 Psychosocial needs

Understanding a patient’s psychosocial needs and sources of emotional distress and their interaction with the patient’s experience of physical symptoms and physical distress is an important element of end of life care. Psychological distress has been defined as:

“a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature.”

(Thekkumpurath et al., 2008)

Effective management of physical symptoms and pain are an essential prerequisite to addressing psychosocial needs (Steinhauser et al., 2000; Steinhauser et al., 2006a). Conversely, undetected and unaddressed psychological distress can impact on a patient’s quality of life, alleviation of physical symptoms such as pain, physical functioning, role and social functioning, impact on relationships, adversely affect compliance with treatment and prolong stays in medical facilities (Breitbart et al., 1995). Distress is associated with a patient’s perception of themselves as a burden to others, that their life has no value and be linked to feelings of depression, hopelessness and desire for a hastened death (Chochinov et al., 2002; Chochinov et al., 2007).

Importantly, psychosocial distress can be remediated through intervention (Breitbart et al., 1995; Thekkumpurath et al., 2008; Breitbart et al., 2010; Breitbart, 2012; Lloyd-Williams et al., 2013). Effective interventions in the management of psychosocial distress have included the provision of opportunities to tell their life story, legacy generation, exploration of the patient’s interpretation of the meaning of the illness. (Chochinov et al., 2005; Lloyd-Williams et al., 2013).

Good communication between patients and clinicians about death and dying can result in improved patient outcomes, such as fewer aggressive interventions e.g. medical care (ventilation, resuscitation earlier initiation of hospice care), better patient mental health and decreased likelihood that care givers will experience complicated grief. Conversely, overly aggressive care is associated with decreased patient quality of life and poor bereavement adjustment (Wright et al., 2008).
Psychosocial distress in palliative care patients may be considered on a continuum of severity that ranges from normal adaptive grief and sadness to much broader and mixed forms of psychiatric morbidity, such as depression and adjustment disorders in the terminally ill (Kelly et al., 2006; Thekkumpurath et al., 2009b; Ziegler et al., 2011). Approximately 50% of patients with advanced cancer meet criteria for psychiatric disorder. The most common are adjustment disorders (11-35%), and major depression (5-26%) (Hotopf et al., 2002; Miovic and Block, 2007). The prevalence of psychological morbidity is between 20% and 30% (Wilson et al., 2007). A systematic review reported a prevalence of 29% - 32% for all depressive disorders and highlighted that depression is one of the top ten symptoms within palliative care (Hotopf et al., 2002).

Unfortunately, psychological distress and its sources are frequently undetected (Ziegler et al., 2011). Normalising of distress by patients and clinicians, difficulties in assessment (Lawrie et al., 2004), underreporting (Wen and Gustafson, 2004), lack of confidence (Block, 2000), and lack of education and clinical experience can result in limited management options and contribute to under detection (Thekkumpurath et al., 2009b). For example, many of the somatic symptoms normally used to diagnose depression, such as difficulty sleeping, difficulty concentrating or lack of appetite, occur as a consequence of terminal illnesses or occur as side effects of treatment, making it difficult to diagnose depression in palliative care patients (Lloyd-Williams et al., 1999; Irving and Lloyd-Williams, 2010).

Important considerations when assessing psychosocial needs and sources of psychological distress at the time of initial assessment include:

- Awareness of diagnosis and prognosis (International Association of Hospice and Palliative Care, 2012),
- Willingness to discuss psychosocial issues (National Institute for Clinical Excellence, 2004; International Association of Hospice and Palliative Care, 2012).
- Assessment of the patient’s coping style, sources of support, aids to resilience and impact of the illness on their ability to cope (National Institute for Clinical Excellence, 2004; Cancer Action Team, 2007).
• Determination of whether there is a family member that a patient may be concerned about; sources of support derived from family and friends; important relationships and ability of the patient and family to discuss the illness. (National Institute for Clinical Excellence, 2004; King and Quill, 2006; The Irish Hospice Foundation, 2010)

• Previous history of mental illness and indicators of the presence of depression and anxiety (National Institute for Clinical Excellence, 2004; Cancer Action Team, 2007; Claessen et al., 2011; International Association of Hospice and Palliative Care, 2012). Depression at end of life is associated with desire for death, inadequate pain control, (Emanuel and Emanuel, 1998) lack of social support, (Chochinov, 2000) poor quality of life, poor performance status and presence of immobility, tiredness and fatigue (Jefford et al., 2004b) (Jefford et al., 2004a; Lloyd-Williams et al., 2004b). A history of depression of two or more episodes during their lifetime or familial history indicates a higher risk of developing subsequent depressive episodes. (Chochinov, 2001).

• Potential contributory causes of anxiety such as fears related to death and the dying process, untreated side effects of medication or medication withdrawal, existential distress, underlying personality traits and delirium should be investigated when a patient exhibits anxiety. (Chochinov, 2000)

• Hopelessness, guilt (Block, 2000) and poor sleep quality correlate with a desire for hastened death and contribute to poor quality of life for patients at end of life (Breitbart et al., 2000). These symptoms should be considered during assessment in order to provide the appropriate treatment. (Mystakidou et al., 2007a)

• Identifying patients at risk of substance abuse will lead to increased awareness of the potential risks associated with opioid prescribing. (Parsons et al., 2008)

• Financial or legal issues that the patient may need assistance with. (National Institute for Clinical Excellence, 2004; Cancer Action Team, 2007; Department of Health, 2008)
The literature was reviewed for evidence based tools that would facilitate assessment of psychosocial distress or components of psychosocial distress such as depression, anxiety, alcoholism, or substance abuse (see table 3.8.1 for a summary of the tools identified). The search did not identify any evidence based tool that was considered appropriate for the purposes of screening for psychosocial distress as part of the initial admission assessment. Therefore, a graduated interview with example open questions, to screen for the priority issues relevant to psychosocial need was developed by the researcher instead. The steering group was consulted in respect of the exact wording of the open questions.

In order to identify a suitable process to assess for possible depression the two item interview in respect of depression which includes the questions “Are you depressed?” and “Have you lost interest in activities you would normally enjoy?” was included as part of the interview to screen for depression. (Akechi et al., 2006). The guidelines of the admission assessment require that if a patient answers yes to either of these questions, the Brief Edinburgh Depression Scale will be utilised to further investigate for the presence of depression.

In comparing the Single item interview, the two item interview, the Visual Analog Scale for Depression and the Beck Depression Inventory – Short Form, the two item interview was found to have a slightly high rate of false positive identifications when compared with diagnosis based on the diagnostic interview (adapted for the Schedule of Affective Disorders and Schizophrenia, SADS). However, its performance was reported as considerably superior to the Beck Depression Inventory - Short Form and Visual Analogue Scale Measures (Chochinov et al., 1997). The Brief Edinburgh Depression Scale has been identified as the most appropriate tool for use when screening for depression with palliative care patients in systematic reviews (Thekkumpurath et al., 2008; Ziegler et al., 2011).
<table>
<thead>
<tr>
<th>Tool</th>
<th>Sample size, Population and Purpose</th>
<th>Items and Domains, Format and Optimal Cut off Score</th>
<th>Sensitivity</th>
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<th>Positive Predictive Value</th>
<th>Negative Predictive Value</th>
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<td></td>
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<td></td>
<td>Content Validity</td>
<td>Construct Validity</td>
<td>Internal Consistency</td>
<td>Reproducibility</td>
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<tr>
<td>Single item interview screening (Are you depressed?) (Chochinov et al., 1997)</td>
<td>197 Palliative Inpatients, with advanced cancer. Major and minor depressive episodes</td>
<td>Single item question: Are you depressed?</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>Single item interview was compared against diagnostic interview adapted from the schedule for effective disorders and schizophrenia (SADS). Only items pertaining to the diagnosis major and minor depressive episodes occurs in research and diagnostic criteria were included.</td>
<td>Very brief, Correctly identified the eventual diagnostic outcome of every patient in the study</td>
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<tr>
<td>Beck Depression Inventory (BDI) (Chochinov et al., 1997)</td>
<td>See Above</td>
<td>13 items, cut off &gt; 8</td>
<td>0.79</td>
<td>0.71</td>
<td>0.27</td>
<td>0.96</td>
<td>Compared against diagnostic interview adapted from the schedule for effective disorders and schizophrenia (SADS). 13 item version correlated to 21 item version (r = 0.96).</td>
<td>Self administered, most patients in the study required it to be presented orally by the interviewer</td>
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<tr>
<td>Two item interview screening (Evidence of a depressed mood and a loss of interest in everyday) (Chochinov et al., 1997)</td>
<td>See Above</td>
<td>2 item interview Evidence of a depressed mood and a loss of interest in everyday activities?</td>
<td>1</td>
<td>0.98</td>
<td>0.86</td>
<td>1</td>
<td>See Above</td>
<td>Very brief, inclusive of the core criteria in symptoms of depression and therefore reduces the possibility of false/negative results.</td>
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<td>Visual Analogue Scale (Chochinov et al., 1997)</td>
<td>See Above</td>
<td>100mm line anchored at the ends with verbal descriptors: &quot;worst possible mood&quot; and &quot;best possible mood&quot;, cut off point is less than 55mm</td>
<td>0.72</td>
<td>0.5</td>
<td>0.17</td>
<td>0.92</td>
<td>See Above</td>
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<tr>
<td><strong>Hospital Anxiety and Depression Scale (HADS)</strong> (Le Fevre et al., 1999)</td>
<td>79 palliative care inpatients. To detect moderate and severe depression.</td>
<td>Two subscales - anxiety and depression: 14 questions, each question scored 0 to 3. The maximum possible score is 42. Suggested cut off point of 20</td>
<td>0.77</td>
<td>0.85</td>
<td>0.48</td>
<td></td>
<td>Semi-structured psychiatric interview, the revised clinical interview schedule (CIS-R) to provide diagnosis according to ICD 10 criteria</td>
<td></td>
<td>When the HADS is used in its combined form to identify depression according to Endicott’s criteria with a cut-off level of greater than or equal to 20 the HADS was superior to GHQ-12 to diagnose depression. Likelihood ratio positive (of a positive result being from an actual case/noncase) was 5.13</td>
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<tr>
<td><strong>General Health Questionnaire (GHQ-12)</strong> (Le Fevre et al., 1999)</td>
<td>79 palliative care inpatients. Designed to indicate the possibility of psychiatric “caseness” rather than a specific diagnosis, although if depressed will score highly.</td>
<td>The original 60 item version was too lengthy so the shorter versions (GHQ-28, GHQ-12) are commonly used.</td>
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<td>The result from GHQ-12 are compared to the revised clinical interview schedule, CIS-R, (Psychiatric interview), a gold standard diagnosis.</td>
<td></td>
<td>The GHQ contains “somatic” related symptoms and may therefore be expected to produce some false positives in palliative care patients. Quick and can be either self administered or by proxy, different raters may impact outcome.</td>
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<tr>
<td><strong>Hospital Anxiety and Depression Scale HADS</strong> (Lloyd-Williams et al., 2001)</td>
<td>100 palliative care inpatients with advanced metastatic cancer. To test the validity of the tool to detect depression in palliative care patients</td>
<td>Cut of 14</td>
<td>0.77</td>
<td>0.37</td>
<td>0.25</td>
<td>0.85</td>
<td></td>
<td>Cronbach’s alpha for total scale was 0.85, for the depression subscale was 0.75 and for the anxiety subscale was 0.80</td>
<td>Positive likelihood ratio: (likelihood of correctly identifying cases) 2.44, Negative likelihood ratio: (likelihood of identifying non cases) 0.29</td>
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<td>CAGE Questionnaire (Chow et al., 2001)</td>
<td>128 Patients in an inpatient palliative radiotherapy clinic. To determine prevalence of problem drinking utilising CAGE questionnaire</td>
<td>Four questions cut off score of 2 or more indicated positive test result.</td>
<td>0.75 - 0.91</td>
<td>0.77 – 0.96</td>
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<td>The Life Closure Scale, (Dobratz, 2004)</td>
<td>113 Hospice patients. Tool used to quantify psychological adjustment at end of life</td>
<td>20 items, 2 sub scales 1) self-reconciled 2) self-restructuring. LCS has 2 independent sub scales, Positive Affect scale (PAS) and the Negative affect scale (NAS)</td>
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<td>Problems and need in palliative care questionnaire (PNPC), (Osse et al., 2004)</td>
<td>64 palliative care cancer patients living at home. To identify palliative care needs</td>
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<td>Two step qualitative study: 1) In depth interviews with 9 cancer patients and partners; 2) Structured interviews with 31 patients post administration of draft tool; 3) Interviews held with clinicians, members of home care organisations, pain teams and specialist oncology nursing teams.</td>
</tr>
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<tr>
<td>Brief Case Find for Depression (BCD)</td>
<td>100 Medical oncology and palliative care patients. BCD designed to recognise both major and minor depression.</td>
<td>4 questions, response format: yes or no answers. Patients are disposed to probable case of depression if they answer yes to at least one of the questions a and b and yes to one of the questions c and d</td>
<td>0.67</td>
<td>0.75</td>
<td>0.41</td>
<td>0.89</td>
<td>Based on the General Health Questionnaire (GHQ).</td>
<td>Kappa values are calculated to determine the correlation between the BCD, PRIME-MD, BDI and HADS. Agreement with the PRIME-MD Kappa = 0.21. BDI, Kappa = 0.43 and was fair for the Depression Sub-scale of the HADS. Kappa = 0.27. Only slight agreement reported between positive cases of BCD and positive cases on the anxiety scale of the HADS, Kappa = 0.19. Patients with probable depression on BCD had significantly higher BDI scores and HADS Depression scores than patients without probable depression on BCD (p &lt; 0.001 for all comparisons).</td>
<td>Interviewer / clinician administered instrument. Approximately one minute to complete.</td>
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<tr>
<td>Verbal Rating Scale</td>
<td>74 patients attending a palliative care day unit. Purpose was to detect depressed mood.</td>
<td>Verbal Rating Scale 0 - 10, cut off point equal to 3</td>
<td>0.80</td>
<td>0.43</td>
<td>0.34</td>
<td>0.85</td>
<td>Compared against a semi-structured clinical psychiatric interview according to DSM-IV Criteria</td>
<td>Majority of patients understood how to rate their mood on a scale of 0 - 10, but repeated ratings did not agree with clinician assessment in a number of cases. Likelihood ratio of correctly identifying cases/patients who are depressed of 1.4</td>
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<tr>
<td>&quot;Are You Depressed?&quot;</td>
<td>74 patients attending a palliative care day unit. Purpose was to detect depressed mood.</td>
<td>Single Item Question &quot;Are You Depressed?&quot;</td>
<td>0.55</td>
<td>0.74</td>
<td>0.44</td>
<td>0.82</td>
<td>Question was taken from the schedule of effective disorders and schizophrenia diagnostic criteria</td>
<td>Likelihood ratio of correctly identifying cases/patients who are depressed of 2.1</td>
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<td>Edinburgh Post-Natal Depression Score (Lloyd-Williams et al., 2004a)</td>
<td>74 patients attending a palliative care day unit To detect depressed mood. 10 items, each response is rated on a 4 point scale ranging from 0 - 3 in severity, maximum score 30. Cut off point ≥ 13 Tool includes non somatic symptoms of depression including subjective sadness, hopelessness, guilt and thoughts of deliberate self-harm</td>
<td>Self-report questionnaire, 14 items, 4 point likert scale. Anxiety and Depression subscale (0 - 21points each), total scores range from 0 - 42. Subjects rate how they felt during the previous week.</td>
<td>0.70 (95% C.I.: 48.1 - 85.5)</td>
<td>0.80 (95% C.I.: 67.1 - 88.2)</td>
<td>0.56 (95% C.I.: 37.1 - 73.3)</td>
<td>0.88 (95% C.I.: 75.8 - 94.3)</td>
<td>Cronbach’s alpha was 0.83, split half reliability was 0.63 for division one, 0.80 for division two with a correlation of 0.76. Average item total correlation computed to be 0.61 (Standard Deviation – 0.16)</td>
<td>Sensitivity and specificity values identified in the Lloyd-Williams 2004 study were lower than those identified an earlier study by the same author (Lloyd-Williams et al., 2000). However the studies used different diagnostic interviews as comparators. Likelihood ratio of correctly identifying cases/patients who are depressed of 3.5,</td>
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<td>Hospital Anxiety and Depression Scale (HADS), (Akechi et al., 2006)</td>
<td>209 palliative care patients. To screen for adjustment disorders and or major depression. Self-report questionnaire, 14 items, 4 point likert scale. Anxiety and Depression subscale (0 - 21points each), total scores range from 0 - 42. Subjects rate how they felt during the previous week.</td>
<td>Total score greater than or equal to 17.</td>
<td>0.8</td>
<td>0.67</td>
<td>0.41</td>
<td>0.92</td>
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<tr>
<td>Hospital Anxiety and Depression Scale (HADS) (Akechi et al., 2006)</td>
<td>209 palliative care patients. To screen for major depression. Total score greater than or equal to 17.</td>
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<tr>
<td>Are you Depressed? (Akechi et al., 2006)</td>
<td>209 palliative care patients. Screening for adjustment disorders and or major depression. Single item question</td>
<td></td>
<td>0.47</td>
<td>0.97</td>
<td>0.81</td>
<td>0.86</td>
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<tr>
<td>Have you lost interest?</td>
<td>(Akechi et al., 2006) 209 palliative care patients. Screening for adjustment disorders and major depression</td>
<td>Single item question</td>
<td>0.47</td>
<td>0.96</td>
<td>0.76</td>
<td>0.86</td>
<td></td>
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<td>Likelihood ratio positive: 10.86, Likelihood ratio negative: 0.56</td>
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<tr>
<td>Are you depressed or have you lost interest?</td>
<td>(Akechi et al., 2006) 209 palliative care patients. Screening for adjustment disorders and major depression</td>
<td>2 questions</td>
<td>0.68</td>
<td>0.94</td>
<td>0.76</td>
<td>0.91</td>
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<td>Likelihood ratio positive: 11.03, Likelihood ratio negative: 0.34</td>
</tr>
<tr>
<td>Are you Depressed?</td>
<td>(Akechi et al., 2006) 209 palliative care patients. Screening for major depression</td>
<td>See above</td>
<td>0.79</td>
<td>0.92</td>
<td>0.41</td>
<td>0.98</td>
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<td>Likelihood ratio positive: 9.58, likelihood ratio negative: 0.23</td>
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<tr>
<td>Have you lost interest?</td>
<td>(Akechi et al., 2006) 209 palliative care patients. Screening for major depression</td>
<td>See above</td>
<td>0.93</td>
<td>0.92</td>
<td>0.45</td>
<td>0.99</td>
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<td>Likelihood ratio positive: 11.32, Likelihood ratio negative: 0.08</td>
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<tr>
<td>Are you depressed or have you lost interest?</td>
<td>(Akechi et al., 2006) 209 palliative care patients. Screening for major depression</td>
<td>See above</td>
<td>1</td>
<td>0.86</td>
<td>0.23</td>
<td>1</td>
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<td>Likelihood ratio positive: 6.96, Likelihood ratio negative: 0.04</td>
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<tr>
<td>Edinburgh Depression Scale</td>
<td>(Lloyd-Williams et al., 2007) 246, Palliative Day Care Unit Patients To detect depression</td>
<td>Cut off point of 13</td>
<td>0.51 (95% C.I.: 40.0 - 63.9)</td>
<td>0.85 (95% C.I.: 78.5 - 90.0)</td>
<td>0.60 (95% C.I.: 47.2 - 72.4)</td>
<td>0.80 (95% C.I.: 73.3 - 85.7)</td>
<td></td>
<td>C Statistic was 0.78</td>
<td>Prevalence of depression was 26.3% at a cut off of greater than 13 Prevalence of depression is 40% at a cut off of 11 or greater. Positive likelihood ratio when using cut off of 13 is 3.40 (95% C.I.: 2.3 - 5.2). Positive likelihood ratio when using cut off of 11 or greater = 2.76 (95% C.I.: 2.1 - 3.7)</td>
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Content Validity: Cronbach’s alpha was 0.78
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<tbody>
<tr>
<td>Brief Edinburgh Depression Scale (Lloyd-Williams et al., 2007)</td>
<td>246 Palliative Day Care Unit Patients - to detect depression</td>
<td>Cut off score ≥ 6 0.72 (95% C.I.: 0.61 – 0.82) 0.83 (95% C.I.: 0.76 – 0.88) 0.85 (95% C.I.: 0.53 – 0.75) 0.87</td>
<td>Compared against Public State Examination (PSE)</td>
<td>Cronbach's alpha was 0.78</td>
<td>Prevalence of depression of 34%. ROC analysis: (area under the curve) = 0.85 (95% C.I.: 0.80 - 0.91) Positive likelihood ration = 4.24 (95% C.I.: 3.0 - 6.1)</td>
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<td>Patient Dignity Inventory (PDI) (Chochinov et al., 2008)</td>
<td>251 palliative care patients. Designed to measure various sources of dignity-related distress among patients nearing the end of life. Symptom distress, existential distress, dependency, peace of mind and social support.</td>
<td>25 items: Respondent confirms degree to which items impact their perception of dignity. 5 point verbal rating scale, from &quot;Not a problem&quot; to &quot;Overwhelming problem&quot;.</td>
<td>Instrument was developed by researchers and vetted by 18 end of life care patients to clarify the exact wording of each item and confirm the content validity of the emerging instrument. A 22 item prototype was then administered to 211 patients who were asked to indicate the degree that each item related to their sense of dignity. Several revisions made thereafter.</td>
<td>Significant associations between PDI factors and factors included in the ESAS, Beck Depression Inventory (BDI), the Structured Interview Assessment of Symptoms and Concerns in Palliative Care (SISC) and the National Centre General Well-Being Schedule.</td>
<td>Cronbach's alpha was 0.83. Researchers correlated the initial PDI self-report with the PDI self-report of 24 hours later. Test retest reliability for full PDI was r = 0.85 (individual variables test retest reliabilities ranging from r = 0.37 to r = 0.76). Patient completing by themselves takes one or two minutes. If patient requires assistance it can take longer (about 10 - 15minutes).</td>
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<tr>
<td>Distress Thermometer (DT) (Gessler et al., 2008)</td>
<td>171 consenting patients from oncology and palliative care patient clinics. Patients completed all data collection points. Screening tool used to determine need for further assessment re mood disorder</td>
<td>39 items, 11 point scale (0 - 10) to describe how much distress patient has being experiencing in the past week including today. Domains include practical problems, family problems, emotional problems, spiritual and religious concerns and physical problems. Cut off point of 4 versus 5 for the DT against the HADS. 0.79, 95% C.I.: 0.72 - 0.86. DT against GHQ-12, cut off point 3 versus 4. 0.68, 95% C.I. = 0.61 - 0.75</td>
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| **Brief Symptom Inventory - BDI 18** (Thekkumpur ath et al., 2009b)  | See above                                                                                           | 18 items, 3 dimensions: depression, anxiety, and somatoform Total score equates to a global severity index, via touch screen computer | Cut-off ≥ 61 0.78  
Cut-off ≥ 62 0.78  
Cut-off ≥ 63 0.77 | 0.50         | 0.45         | 0.82         | See above                 |                       |            |             | Median time to complete is 3 minutes; range is 2 to 11 minutes. Administered using a touch screen computer at the patient’s bedside. |
| **Distress Thermometer (DT)** (Thekkumpur ath et al., 2009b)        | 150 inpatients and out patients with advanced cancer. Purpose is to identify distress and utility of touch screen computers | Single item visual analogue scale, via touch screen computer | Cut-off ≥ 4 0.8  
Cut-off ≥ 5 0.77  
Cut-off ≥ 6 0.65 | 0.50         | 0.45         | 0.82         | Compared against the a semi-structured psychiatric interview, Schedules for Clinical Assessment in Neuropsychiatry (SCAN). |                       |            |             | Median time to complete 1 minute, range from 1 to 5 minutes. Administered using a touch screen computer at the patient’s bedside. |
| **General Health Questionnaire (GHQ 12)** (Thekkumpur ath et al., 2009b) | See above                                                                                           | 12 items – to identify general psychological morbidity and distress. Each item is scored on a scale of increasing severity (0-4). | Cut-off ≥ 4 0.8  
Cut-off ≥ 5 0.77  
Cut-off ≥ 6 0.71 | 0.53         | 0.47         | 0.85         | See Above                 |                       |            |             | Median time to complete is 3 minutes, range from 1to 8 minutes. Administered using a touch screen computer at the patient’s bedside. |

PRIME-MD: Primary Care Evaluation of Mental Disorders, BDI: Beck Depression Inventory, ESAS: Edmonton Symptom Assessment Scale
3.9 Assessment of carer needs

Careful attention should be paid to the psychological and social needs of carers (National Institute for Clinical Excellence, 2004; Harding and Leam, 2005). Carer’s experience significant psychological distress and it is important to ensure that their need for support and information, which increase as the patient approaches end of life, are assessed separately to that of patients.

Risk factors associated with distress or burden among family caregivers include being female, marital relationship, being of a younger age, loss of income, financial burden and lack of emotional support (Haley et al., 2003; Given et al., 2004; Rossi Ferrario et al., 2004; Dumont et al., 2006; Grov et al., 2006; Tomarken et al., 2008). Caregivers, are at increased risk of developing a psychiatric disorder (Bambauer et al., 2006; Kris et al., 2006; Mystakidou et al., 2007b). Assessment in respect of risk of complicated grief should be initiated at point of referral and should continue to specialist palliative care services and into early bereavement, as palliative care services are ideally placed to offer interventions that will remediate the potential for complicated grief (Aranda and Milne, 2000). An integrated approach to assessment that examines sources of resilience and coping as well as risk factors is necessary (Agnew et al., 2010), particularly as the provision of unnecessary bereavement support can be harmful (Jordan and Neimeyer, 2003).

When assessing the risk of complicated grief the availability of social support and social circumstances are important considerations, as is family style of coping. Concurrent stressors such as social deprivation, poor housing, limited financial resources can increase vulnerability and should be explored (Relf et al., 2010).

Caregiver’s who are unprepared for death or less accepting of the death may suffer from greater risk of depression, anxiety and complicated grief during bereavement (Hebert et al., 2009). Hebert et. al. (2009) reported that the duration of care giving, patient’s illness, previous planning regarding death, advanced directives, previous experiences with care giving or death and medical sophistication all impact a caregivers preparedness. However, there is ample evidence that communication around prognosis and end of life issues does not always meet the needs of care givers (Clayton et al., 2005; Hancock et al., 2007). Improved symptom management which promoted higher
patient quality of life was associated with better care giver outcomes, including overall quality of life; self-reported health, physical functioning and mental well-being. Care givers of patients with good quality of life are more prepared for the death and experience less regret in bereavement (Wright et al., 2008).

Care givers who feel confident in their ability to look after a patient in the palliative phase are more protected from feelings of burden associated with caring and psychological distress. The provision of support, targeted psychosocial and educational interventions derived from the anticipated needs of patients as the illness progresses can equip care givers and develop their sense of self competence and confidence, which ultimately aids patient care (Dumont et al., 2006). Another important intervention to reduce distress in care givers can be to facilitate their participation in valued activities and interests (Cameron et al., 2002).

Areas highlighted by the literature review regarding screening for carer need include:

- Carer’s awareness of diagnosis and prognosis (International Association of Hospice and Palliative Care, 2012).
- Assessment of sources of support and their effectiveness in facilitating the carer’s resilience, and the need for additional support (National Institute for Clinical Excellence, 2004; Department of Health, 2008; Relf et al., 2010).
- Consideration of the impact of culture and ethnic diversity when considering needs (National Institute for Clinical Excellence, 2004).
- Addressing the need for additional information about the illness, end of life issues, symptoms or prognosis (National Institute for Clinical Excellence, 2004; Department of Health, 2008).
- Ability of the family to communicate about the illness or the family member the carer may be concerned about (Aranda and Milne, 2000).
- Identifying training needs in respect of issues such as manual handling, managing distressing symptoms (e.g. incontinence) (Department of Health, 2008).
- Identifying the need for assistance in respect of managing finances, the home and caring for other dependents (Department of Health, 2008; Relf et al., 2010).
Many tools have been identified to assess carer’s needs within the palliative care context. Table 3.9.1 provides a summary of tools identified in this review. Due to the importance of assessing for complicated grief, tools to assess bereavement risk were also included in the review. However, a tool which adequately facilitated the assessment of carer’s needs was not identified at the time of this review as many of the tools were either too lengthy or did not directly assess needs of carers concurrent to the provision of care to patients. Consequently, a graduated interview using open questions by the researcher and in consultation with the steering group was developed. The interview facilitates assessment of the key components of carer’s needs and was to be completed by nursing staff with the patient’s identified next of kin. It should be noted that the paper reporting the validation Carer Support Needs Assessment, a fourteen item screening tool was published after this review (Ewing et al., 2013).
Table 3.9.1 Summary of tools which assess needs of caregivers of palliative care patients

<table>
<thead>
<tr>
<th>Tool</th>
<th>Sample Size, Purpose and Population</th>
<th>Items and Domains, and Question Format</th>
<th>Validity</th>
<th>Reliability</th>
<th>Feasibility, e.g. time to implement in practice</th>
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<tr>
<td>Caregiver Quality of Life Index (CQLI) (McMillan and Mahon, 1994)</td>
<td>68 caregivers of patients in hospice. To assess caregivers quality of life</td>
<td>4 items. Domains: physical, psychological, social and financial quality of life. Visual analog score 0 - 100</td>
<td>Expert panel</td>
<td>Cronbach's alpha was 0.76. 4 weeks later, Cronbach's alpha was 0.88</td>
<td>Test retest reliability: no difference identified when given four weeks apart. May not be sensitive to change as there was no significant difference found four weeks later</td>
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<tr>
<td>Family Inventory of Needs (FIN) (Kristjanson et al., 1995)</td>
<td>109 family members of advanced cancer patients in three hospice programmes Care give needs identification</td>
<td>One domain: importance and fulfillment of care needs of patient’s family. 20 items. Two sub-scales: importance of family care needs scored 0 - 10 (0 = not important, 10 = very important) Fulfillment of care needs scores 0-1 (1 = needs met, 0 = needs not met)</td>
<td>Based on Critical Care Family of Needs Inventory (CCFNI).</td>
<td>Cronbach's Alpha was 0.83</td>
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<tr>
<td>Caregiver Quality of Life Index - Cancer (CQOLC) (Weitzner and McMillan, 1999)</td>
<td>239 caregivers of hospice patients. To determine impact of caregiving on caregivers quality of life</td>
<td>35 item, 5 point likert scale, 'not at all' (0) to 'not at all' (4). 4 subscales: burden, disruption, positive adaptation and positive concerns.</td>
<td>Correlated with mostly distressed measures - Medical Outcome Study Short Form (SF-36), Beck Depression Inventory and State Trait Anxiety Inventory, r = 0.50 - 0.65.</td>
<td>Cronbach's Alpha was 0.9</td>
<td>Test retest reliability over two weeks: 0.95 CQOLC has been translated to Korean.</td>
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<tr>
<td>Caregiving Impact Scale (Cameron et al., 2002)</td>
<td>44 Family caregivers with advanced cancer patients. Impact on caregiver’s lifestyle.</td>
<td>14 domains of caregivers lifestyle, 7 point likert scales measuring degree of interference, (1 = not very much 7 = very much.)</td>
<td>Cronbach's alpha was 0.87</td>
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<td>Is a modification of the illness intrusiveness rating scale</td>
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<tr>
<td>Families evaluation of management, care and disclosure for terminal stage cancer patients (Mystakidou et al., 2002b)</td>
<td>146 family members of patients with advanced cancer Perceptions of carers regarding palliative care provided to their relative</td>
<td>21 items, 5 multi-item and 5 single-item scales</td>
<td>Systematic literature review</td>
<td>Cronbach's alpha was 0.66, range was 0.50-0.70</td>
<td>Can be completed in 8 - 10 minutes</td>
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<td>Tool</td>
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<td>Family APGAR Scale (Powazki and Walsh, 2002)</td>
<td>15 patient participants and 10 primary care givers, pilot study. Family Functioning regarding patients in an acute care palliative medicine unit</td>
<td>Family functioning in five areas: adaptation, partnership, growth, affection and resolve. Each of the five items is scored on a 3 point scale: Sum of the five items is the total score ranging from 0 - 10. Scores less than 3 indicate severe dysfunction, scores of 4 - 6 indicate moderate dysfunction, scores of 7 - 10 suggest well functioning family unit.</td>
<td>Content Validity</td>
<td>Construct Validity</td>
<td>Internal Consistency</td>
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<tr>
<td>Family Inventory of Needs (FIN) (Hwang et al., 2003)</td>
<td>100 caregivers of patients with advanced cancer. To assess caregivers needs</td>
<td>See above</td>
<td>Correlated with the Famcare; ( r = 0.48 ) and ( -0.46, p &lt; 0.0001 ) and ( p = 0.003 ) respectively.</td>
<td>Cronbach’s alpha was 0.92</td>
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<td>Caregiver Burden (Redinbaugh et al., 2003)</td>
<td>31 caregivers of terminally ill Hospice at Home patients To measure caregiver burden</td>
<td>Rotated factor analysis identified 5 indices; general strain (8 items), isolation (3 items), disappointment (5 items), emotional involvement (3 items) and environment (3 items)</td>
<td>Cronbach's alpha was 0.92</td>
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<td>The Stressful Care giving Adult Reactions to Experiences of Dying scale (SCARED) (Prigerson et al., 2003)</td>
<td>76 hospice patient caregivers; To assess caregiver reaction to patients distress and the fear and helplessness evoked</td>
<td>Respondent’s review 10 items and uses likert scales to identify frequency of occurrences, and fear and helplessness invoked.</td>
<td>Measured depressive disorder (MDD) diagnosed with a structured clinical interview for the DSM-IV; complicated grief (CG) care assessors diagnosed with the inventory of complicated grief caregiver items. Quality of life domains assessed with the medical outcome survey short form-36.</td>
<td>Cronbach's alpha was 0.77</td>
<td>Authors suggest it could be a clinically useful tool for identifying caregivers at risk of major depressive disorder and identifying aspects of care giving which may require intervention. Self administered or proxy</td>
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<tr>
<td>Family strain questionnaire, (Rossi Ferrario et al., 2004)</td>
<td>111 caregivers of patients with advanced cancer To measure caregiver burden</td>
<td>Semi structured interview regarding nature of disease, how it is managed and financial problems relating to use of health and social care services, 35 items (response: yes/no); 5 factors: emotional burden, problems of social involvement, need for knowledge of the disease, quality of family relationships and thoughts about death. 9 non-factorial items regarding care perception of problems relating to social stigma and emotional issue</td>
<td>Emotional burden; Pearson correlation of 0.74 with State Trait Anxiety Inventory XI (STAI XI). Patient correlation coefficient was 0.79 with depression questionnaire (DQ)</td>
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<td>Average time to complete is 20 minutes</td>
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<td>Caregiving at end of life's end (Salmon et al., 2005)</td>
<td>51 caregivers, 34 current and 17 bereaved caregivers. To assess end of life caregiver needs and evaluate how aspects of caregiver closure affect their experience</td>
<td>3 domains: self acceptance, meaning and closure and caregiver comfort regarding information about patient care and how to communicate with professionals; 5 point scale: (Strongly disagree - strongly agree)</td>
<td>Pearson correlation, range from 0.29 - 0.54.</td>
<td>Literature review and adaptation of existing scales. Derived from the Finding Meaning through Caregiving questionnaire, revised Caregiving Appraisal Scale, Life Attitude Profile, Personal Goal Subscale of Hogan Grief Reaction Checklist plus 12 bespoke questions and Care Giver Comfort Scale.</td>
<td>Cronbach's alpha was 0.67 - 0.90</td>
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<td>Bereavement Risk Index (modified) (Kristjanson et al., 2005)</td>
<td>138 family members of patients who had received care in a hospice. To assess grief reactions of bereft family members in a home hospice care setting. To identify which types of family members are most likely to experience a more difficult grief reaction.</td>
<td>Background information is collated. 8 items, scoring option 0 - 5 per item, risk index: high (19 or higher), moderate (13-19), low (12 or lower). Possible total scores range from 6 - 14.</td>
<td>Compared against the Core Bereavement Items (CBI), the SF36 and the Family Assessment Device (FAD).</td>
<td>Cronbach's alpha was 0.64. Four items, D (clinging or pining, resistance to reality of patients death), E (anger), F (self-reproach, self-blame/guilt and or responsible for something), H (current relationships).</td>
<td>Abbreviated version of tool utilising items D, E, F and H was used for subsequent analysis to determine how a briefer instrument would predict outcomes.</td>
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<td>Brief Assessment Scale for Caregivers (BASC) (Glajchen et al., 2005)</td>
<td>102 Caregivers of patients with chronic illness, including cancer.</td>
<td>14 items. Domains: An 8 item subscale = negative personal impact (NPI). 5 factors: negative personal impact (5 items), positive personal impact (3 items), other family members (2 items), medical issues (3 items), concern about love one (2 items). 4 point likert scale (not at all, a little, some, a lot).</td>
<td>Literature review and 3 focus groups for caregivers and 1 with professionals involved in palliative care.</td>
<td>Validated the BASC by comparing it with the BAS, CHQ, Objective Caregiver Burden, Spiritual Well-Being was assessed by FACIT-SP, MOSSS, Consumer Satisfaction Survey for Caregivers, Caregivers Unmet Needs, MHI-5 introduced half way through the study. Results available for 49 caregivers regarding overall impact on QOL. BASC - r = 0.54, p &lt; 0.001; NPI r = 0.64, p &lt; 0.001. Unmet Needs Scale BASC r = 0.40, p &lt; 0.001; NPI r = 0.39, p &lt; 0.001. Negative correlations with measures of caregiver quality of life, the overall impact on QOL scale = BASC r = -0.42, P &lt; 0.001; NPI r = -0.29, p = 0.003 and the MHI-5 BASC r = -0.42, p = 0.002; NPI r = -0.39, p = 0.006.</td>
<td>Cronbach's alpha was 0.70 for the BASC and 0.80 for the NPI.</td>
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<td>Quality of Life Scale (QOLS) (Grover et al., 2006)</td>
<td>71 patients and their primary caregivers, patients with advanced cancer being care for at home</td>
<td>16 items, Domains: 3 factor structure relationship and material well-being, health and functioning, personal social and community commitment. Level of satisfaction as reported on 7 point scale, (7 = most satisfied state and 1 = least satisfied) Scale is scored by adding up the items and dividing the total providing a total QOLS score which results in the total mean QOLS ranging from 1 (worst) to 7 (best) when divided by 16.</td>
<td>Content Validity</td>
<td>Construct Validity</td>
<td>Internal Consistency</td>
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<td>Caregiver Competence Scale (Hudson and Hayman-White, 2006)</td>
<td>106 caregivers, Competence/Preparedness of family caregivers of patients with advanced cancer receiving home based community palliative care in Australia</td>
<td>4 items. 4 point likert-type scale (0 - 3)</td>
<td>Kaisers criteria indicated single component, this component accounted for 70.9% of variance in the data.</td>
<td>Cronbach's alpha was 0.86</td>
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<tr>
<td>Caregiving Mastery (Hudson and Hayman-White, 2006)</td>
<td>106 caregivers, Competence/Preparedness of family caregivers of patients with advanced cancer receiving home based community palliative care in Australia</td>
<td>6 items. Principal component extraction and rotation indicated 2 components. However, 2 items had relatively high loadings on both components and therefore this item was discarded. 1st = role appraisal, 3 items, 2nd = role proficiency, 2 items. 5 point likert-type scale (0 = strongly disagree and 4 = strongly agree)</td>
<td>Kaisers criterion indicated two components.</td>
<td>Role appraisal Cronbach's alpha was 0.70 and for role proficiency alpha was 0.56.</td>
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<td>Preparedness for caregiving scale (Hudson and Hayman-White, 2006)</td>
<td>106 caregivers, Competence/Preparedness of family caregivers of patients with advanced cancer receiving home based community palliative care in Australia</td>
<td>8 items - single component. Component accounted for 66.7% variance of data. Component preparedness. 5 point likert scale (0 = not at all prepared, 4 = very well prepared)</td>
<td>Construct validity confirmed by Kaisers Criterion.</td>
<td>Cronbach's alpha was 0.93</td>
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<td>Family appraisal of care giving questionnaire for palliative care (FACQ-PC, Australia) (Cooper et al., 2006)</td>
<td>160 adult primary caregivers to people receiving home-based palliative care. All care recipients were diagnosed with advanced incurable cancer</td>
<td>25 items, rated on a 5 point scale ranging from 1 (strongly disagree) to 5 (strongly agree). Evaluation of care giving. 4 domains: caregiver strain, positive appraisals, caregiver distress, family well-being</td>
<td>Literature review, pilot scale, expert review, based on research on a model of the stress process.</td>
<td>Caregiving strain subscale most strongly correlated with subjective burden ($r = 0.83$), family well-being subscale most strongly correlated with the Family Relationships index, FRI ($r = 0.65$), caregiver distress subscale most strongly related to negative effect ($r = 0.56$), positive care giving appraisal subscale correlated with positive effect ($r = 0.30$). Slightly higher correlation found with the FRI ($r = 0.35$).</td>
<td>Correlation ranged from 0.28 - 0.78. Caregiver strain range: 0.41 - 0.69. Positive care giving appraisal range Cronbach’s alpha: range 0.28 - 0.63. Re care distress subscale Cronbach’s alpha range: 0.28 - 0.65 (item total correlations). Family well-being subscale Cronbach’s alpha was 0.84, range 0.37 - 0.78 (item total correlations). Cronbach’s alpha was 0.86 for caregiver strain subscale. Positive care giving appraisal subscale Cronbach’s alpha of 0.73.</td>
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<td>Quality of Life in Life Threatening Illness - Family Carer Version (QOLLTI-F, Cohen et al., 2006)</td>
<td>149 completed questionnaires on three occasions Family caregivers of palliative care populations, Canada</td>
<td>16 items. 0 - 10 (11 point) scale that best represents how respondents feel. Respondents consider previous 2 days. Reviews carer and patient well-being, quality of care, outlook, environment, finances and relationships.</td>
<td>Three phases of questionnaire development.</td>
<td>Qualitative study where carers identified what was important to the quality of their life</td>
<td>Cronbach’s alpha = 0.86</td>
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<td>Tool</td>
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<td>Problems and Needs in Palliative Care Questionnaire - Care Giver Form (PNPC-C) (Osse et al., 2006)</td>
<td>76 carers of patients with advanced cancer who were being cared for at home. Measure of caregiver needs</td>
<td>67 items. Care givers indicate if they felt the issue to be a problem. Response format = yes / somewhat / no. Professional Attention / Support, e.g. yes, more / as much as until now / no. Additional 9 items concerning informational needs phrased as: do you need information about. yes / no.</td>
<td>Based on interviews with patients and their care givers.</td>
<td>Cronbach's alpha was 0.95 (English Version). Cronbach's Alpha : 0.91 for the phenomenological experience and 0.89 for the demand appraisal component</td>
<td>Authors state that validity and reliability was confirmed in use of checklist in a sample of caregivers.</td>
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<tr>
<td>Care Givers Burden Scale in End of Life Care, (Dumont et al., 2008)</td>
<td>167 Family Care Givers for patients with terminal cancer. Measure of caregiver burden</td>
<td>16 items questionnaire, Two dimensions, current appraisal situation and phenomenological experience</td>
<td>Seven researchers, (group 1), 15 professional clinicians working in palliative care (group 2), group of six carers (group 3). Principal component analysis identified two components, Kaiser-Meyer-Olkin coefficient, r = 0.93.</td>
<td>Qualitative data analysis. Correlated against the Zarit Burden Inventory r = 0.72 (p &lt; 0.01); HADS for Depression, Profile for Mood Sates (POMS) for Fatigue, = 0.69 (p &lt; 0.01); d) POMS (vigor) = -0.27 (p &lt; 0.05). Social desirability Cowne and Marlowe questionnaire (r = - 0.24).</td>
<td>Self report French and English versions. Clinical sensitivity identified by comparison by correlation to needs dissatisfaction in a sample of 102 family care givers, r = 0.4, p = 0.01 between high burden and presence of several unmet needs.</td>
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<tr>
<td>Pre Death Inventory of Complicated Grief - Caregiver Version (Pre-ICG), (Tomarken et al., 2008)</td>
<td>248 Caregivers of terminally ill cancer patients. To identify grief as a result of the anticipation of loss.</td>
<td>4 items. Refined versions of the ICG were used with the palliative care population in determining the psychometric properties; therefore only four questions were included.</td>
<td>Cronbach's alpha was 0.76</td>
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<td>The Checklist of Family Relational Abilities (Wilkins et al., 2009)</td>
<td>13 families, families of patients receiving inpatient care at a palliative care service. To assess family functioning and strength of family attachments. Pilot Study.</td>
<td>4 point ranking of overall functioning: attachment bonds, openness of communication regarding the current illness, collaborative decision making re illness, overall level of family relational abilities.</td>
<td>Wynne's epigenetic model of family relational functioning used to create tool.</td>
<td>Compared against Family Relationships Index (FRI), a short form of the Family Environment Scale (FES). Significant correlation of checklists overall functioning with total FRI, $r = 0.64, p &lt; 0.05$ and FRI conflict resolution, $r = 0.69, p &lt; 0.05$. Checklist attachments significantly associated with total FRI, $r = 0.61, p &lt; 0.05$ and indicated a significant association with FRI expressiveness, $r = 0.60, p = 0.05$.</td>
<td>Inter-rater reliability: inter-class correlation coefficient calculated for attachment, communication, decision making and overall functioning was 0.96, $p &lt; 0.001$; 0.52, $p = 0.08$; 0.44, $p = 0.14$; 0.91 $p &lt; 0.001$ respectively.</td>
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<td>Hospital Anxiety And Depression Scale (HADS) (Gough and Hudson, 2009)</td>
<td>106 caregivers of patients dying with cancer in Australia. To identify depression in caregivers</td>
<td>14 items, domains: Depression, anxiety and general distress.</td>
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<td>Psychological Wellbeing Scale for Caregivers (PWS-C) (Wu et al., 2010)</td>
<td>132 family caregivers in palliative care unit. Psychological Wellbeing Scale for caregivers to screen for psychological distress. Could be used to measure outcome of psychological intervention for psychological wellbeing.</td>
<td>5 Sub-scales. 4 factors e.g. 1) Life meaning and social support subscale 2) emotional distress, 3) care giving inadequacy 4) hospital care. 11 item, 0-10 scale, (0 = totally disagree, 10 = totally agree with the statements)</td>
<td>Literature review</td>
<td>Subscale scores of PWS-C were moderately correlated with HADS scores. Corrected item total correlation coefficient $r = 0.53$ for social support, $r = 0.43 - 0.54$ for life meaning, $r = 0.51$ for emotional distress, $r = 0.47$ for care giving inadequacy, $r = 0.76$ for hospital care.</td>
<td>Reliability of subscales was acceptable; Cronbach's alpha was 0.69 for social support, 0.68 for life meaning, 0.68 for emotional distress, 0.63 for care giver inadequacy and 0.86 for hospital care.</td>
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</tbody>
</table>

FACIT –SP: Functional Assessment of Chronic Illness Therapy-Spiritual, BAS: Burden Assessment Scale, CHQ: Caregiver Health Questionnaire, MOSSSS: Medical Outcome Study Social Support Survey, MHI-5: Mental Health Index 5
3.10 Development of the MPCAT

On the basis of this literature review a novel assessment tool was developed which comprises;

a) Pain assessment based upon:
   i. The questioning guidelines described in the Pain Assessment Questionnaire for a Patient with Advanced Disease (Jacox et al., 1995)
   ii. Questions relate to pain intensity at the time of assessment and at its worst over the last twenty fours using a 0-10 numerical rating scale (Hjermstad et al., 2008; Shi et al., 2009)
   iii. A body map to visually locate pain.

b) General symptoms assessed with an adapted version of the symptom assessment checklist (Homsi et al., 2006) was utilised with permission in the MPCAT as it was felt to be optimally detailed – balancing the need for comprehensive coverage of symptoms with minimisation of patient burden. This tool is used in conjunction with a physical examination.

c) The Palliative Performance Scale (PPS) (Olajide et al., 2007) and the Palliative Performance Index (PPI) (Stone et al., 2008) to assess function and prognosis. The PPS facilitates 10 levels of categorisation regarding patient performance status (Abernethy et al., 2005) and its outcome is required to score the PPI. The PPI was chosen for incorporation in the MPCAT as unlike the Palliative Prognostic Score (PaP) it includes delirium. Moreover the PPI is brief, easy to use, and does not require blood testing.

d) Cognitive function assessed with
   i. The Blessed Orientation-Memory-Concentration (BOMC) (Arsène and Lassaunière, 2000) was chosen to screen for cognitive impairment as it is brief, does not require the patient to write, and unlike the Mini Mental State Exam is not affected by age or educational level. Questions answered in the BOMC can be used
when using the Confusion Assessment Method (CAM) to screen for delirium.

ii. The CAM was chosen to screen for delirium and further to a review of tools to screen for delirium was identified as the current gold standard tool to identify DSM-IV delirium (Ryan et al., 2009). The CAM is brief, thereby reducing burden to the patient. The CAM has been recommended by the NICE Guidelines recommend the CAM as an appropriate tool to use when diagnosing delirium (National Institute for Clinical Excellence, 2010).

e) With regard to Spiritual Distress the tools chosen for inclusion in the admission assessment proforma included the FICA (Puchalski and Romer, 2000; Okon, 2005; Dahlin, 2009) and the questioning guidelines from the Mount Vernon Cancer Network (MVCN) (Mount Vernon Cancer Network, 2008). The FICA was to be used by the admitting doctor as a screening tool for spiritual distress. The questioning guidelines from the MVCN were chosen for use by the pastoral care professionals for the purposes of spiritual assessment.

f) The literature search did not identify an evidence based tool that was felt to be appropriate for the purposes of screening for psychosocial distress as part of the initial admission assessment. Therefore, a graduated interview was developed with example open questions, to screen for the priority issues relevant to psychosocial need identified in the literature. The areas prioritised for screening were as follows:

- Awareness of diagnosis and prognosis, and willingness to discuss psychosocial issues (National Institute for Clinical Excellence, 2004; International Association of Hospice and Palliative Care, 2012).
- Assessment of the patient’s coping style, sources of support, aids to resilience and impact of the illness on their ability to cope (National Institute for Clinical Excellence, 2004; Cancer Action Team, 2007).
- Determination of whether there is a family member that a patient may be concerned about, sources of support derived from family and friends and
important relationships and ability of the patient and family to discuss the illness (National Institute for Clinical Excellence, 2004; King and Quill, 2006; The Irish Hospice Foundation, 2010).

- Identification of previous history of mental illness, indicators of depression and anxiety (National Institute for Clinical Excellence, 2004; Cancer Action Team, 2007; Claessen et al., 2011; International Association of Hospice and Palliative Care, 2012). The two item interview in respect of depression which includes the questions “Are you depressed?” and “Have you lost interest in activities you would normally enjoy?” were included as part of the interview to screen for depression (Akechi et al., 2006). The guidelines of the admission assessment require that if a patient answers yes to either of these questions, the Brief Edinburgh Depression Scale (Thekkumpurath et al., 2008; Ziegler et al., 2011), will be utilised to further investigate the presence of depression.

- Identification of potential contributory causes of anxiety such as fears related to death and the dying process, untreated side effects of medication or medication withdrawal, existential distress, underlying personality traits and delirium should be investigated when a patient exhibits anxiety (Chochinov, 2000).

- Hopelessness, guilt (Block, 2000) and poor sleep quality correlate with a desire for hastened death and contribute to poor quality of life for patients at end of life (Breitbart et al., 2000). These symptoms should be considered during assessment in order to provide the appropriate treatment. (Mystakidou et al., 2007a)

- Determination of patients at risk of substance abuse will lead to increased awareness of the potential risks associated with opioid prescribing. (Parsons et al., 2008)

- Financial or legal issues with which the patient may need assistance. (National Institute for Clinical Excellence, 2004; Cancer Action Team, 2007; Department of Health, 2008).

g) A tool which adequately facilitated the assessment of carer’s needs was not identified at the time the admission assessment protocol was being developed as many of the tools were either too lengthy or did not directly assess needs. Consequently, a graduated interview using open questions by the researcher
and in consultation with the steering group was developed. The interview facilitates assessment of the key components of carer’s needs and was to be completed by nursing staff with the patients identified next of kin.

3.11 Conclusion

This chapter has explained the process undertaken to systematically review literature in order that evidence-based tools might be identified for inclusion in the MPCAT. The results of the review are illustrated per domain of palliative care need. The choice of tools included in the MPCAT are justified.
Chapter 4 Results

This chapter describes both the quantitative and qualitative data collected during phases 2, 4 and 5. The data was derived from interviews of patients at two time points and the audits of patient’s charts at three time points. Pre-intervention relates to patient interviews and audits of charts conducted prior to any change to the admission assessment process at Milford Care Centre (MCC). Post-intervention time 1 (Time 1) relates to 6 months post introduction of the Milford Palliative Care Assessment Tool (MPCAT). Post-intervention time 2 (Time 2) relates to 12 months post introduction of the MPCAT. The charts of 35 patients were reviewed in the pre-intervention stage, and 46 charts were reviewed in the post-intervention stage, Time 1 and 42 charts at post-intervention stage, Time 2. The quantitative analyses are as follows:

(i) The MPCAT is compared with multidisciplinary documentation systems used for initial patient assessment used in hospices in Ireland and the UK

(ii) An audit of the admission assessment at three time points, the pre-intervention baseline (phase 2), post-intervention time 1 (phase 4), and post-intervention time 2 (phase 5).

(iii) Referral rates and referral patterns amongst interdisciplinary team members as a result of the admission assessment process were monitored at the three time points.

(iv) Patients self rated their symptoms and needs using validated tools at two time points, the pre-intervention baseline (phase 2), and the post-intervention time 1 (phase 4).

(v) The clinician’s assessment and the patient’s self-rating of symptoms and issues were compared at two time points, the pre-intervention baseline (phase 2), and the post-intervention time 1 (phase 4). This comparison identified if the clinical assessment process identified the same symptoms and issues as were identified by the patient.

(vi) Carers completed a validated tool to evaluate the quality of care received and to identify if their needs were met at two time points.

(vii) Change in confidence and competence of non consultant hospital doctors to conduct the psychosocial assessment is evaluated post-intervention to investigate the effectiveness of the training programme for the MPCAT.
(viii) A survey of staff perspectives of the admission assessment process and its documentation at two time points, pre-intervention baseline (phase 2), post-intervention Time 1 (phase 4).

In addition, the qualitative review of staff views of the assessment process through semi-structured interview at two time points, pre-intervention baseline (phase 2), post-intervention Time 1 (phase 4) is also described.

4.1 Patient Characteristics

The demographic and basic clinical data for patients assessed at each of the three time points shown on Table 4.1.1

Table 4.1.1 Demographics of patients who agreed to be interviewed and whose charts were audited.

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention (n=35)</th>
<th>Post-intervention Time 1 (n=46)</th>
<th>Post-intervention Time 2 (n=42)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age, Standard Deviation (SD)</td>
<td>67 (12.5)</td>
<td>69 (13.1)</td>
<td>68 (14.7)</td>
</tr>
<tr>
<td>Male Gender</td>
<td>54%</td>
<td>47%</td>
<td>57%</td>
</tr>
<tr>
<td>Female Gender</td>
<td>46%</td>
<td>52%</td>
<td>43%</td>
</tr>
<tr>
<td>Malignant Diagnosis</td>
<td>86%</td>
<td>96%</td>
<td>95%</td>
</tr>
<tr>
<td>Non Malignant Diagnosis</td>
<td>14%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>Patients with an ECOG Score of 2 or less</td>
<td>50%</td>
<td>68%</td>
<td>*</td>
</tr>
<tr>
<td>First Time Admission</td>
<td>74%</td>
<td>87%</td>
<td>81%</td>
</tr>
<tr>
<td>Repeat Admission</td>
<td>26%</td>
<td>13%</td>
<td>26%</td>
</tr>
</tbody>
</table>

* The ECOG was included in the inclusion form as part of the patient interview selection process and was not collected at this time.
At pre-intervention the most common malignancies were prostate, 15%, (n=5) followed by breast 12%, (n=4). Pre-intervention, 50% of patients had a European Cooperative Oncology Group (ECOG) performance status score of 2 or less. At post-intervention stage Time 1, the most common malignancies were lung, 16% (n=7), followed by breast 14% (n=6). At post-intervention stage Time 1, 68% (n=30) of patients had an ECOG Performance status score of 2 or less. At 12 months post-intervention stage Time 2, the most common malignancy was lung, 26%, (n=11). There was no statistical difference in respect of gender (p = 0.36), age, (p = 0.19), and diagnosis (p = 0.12) or admission stage (p = 0.12) in patients who were interviewed over the three time points.

4.2 Rate of assessment evidenced though audit of charts

When auditing post-intervention Time 1, two audit criteria were checked for each symptom or issue, 1) determining if there was clear documented evidence of assessment 2) did the outcome of the assessment suggest that the patient was experiencing the symptom or issue. At 12 months post-intervention Time 2, the audit criteria focussed on whether there was documented evidence of assessment only. The first set of results will focus on documented evidence of assessment pre and post-intervention Time 1 and 2.

The documented rate of assessment was either maintained or improved in all areas post-intervention Time 1, with the exception of risk of falling and measures taken in response to oral care issues.

4.3 Pain

Pre-intervention, there was clear documented evidence of assessment of pain in 72% (n=25) of charts, some evidence of documentation regarding pain but the outcome of assessment was unclear in 14%, (n=5) charts and no evidence of assessment in 14% (n=5). Post-intervention Time 1 and 2 there was significantly greater evidence of assessment of pain; 100% of charts at Time 1, (n=46) 100% of charts (n=42) at Time 2 (p = 0.005).
Both the pre-existing admission proforma and the MPCAT require that a pain assessment form was completed for any patient that reported pain. The MPCAT pain assessment requires that the patient rate the intensity of their pain on a numerical rating scale of 0-10. Any pain assessment that did not include at least one numerical rating of pain as a measure of baseline intensity, was rated as partially completed post-intervention, despite detail in all other sections of the pain assessment. Twenty-nine patients had pain pre-intervention and post-intervention. The pain assessment form was more likely to be completed in full post-intervention Time 1 ($p = 0.023$). Pre-intervention there was full completion in 9% ($n=3$) charts. At post-intervention, Time 1 and 2 respectively, there was full completion in 44% ($n=20$) charts and 43% ($n=18$) charts. (See Figure 4.3.1 below). Not applicable refers to those patients who reported they had no pain and therefore the full pain assessment form was not completed.

**Figure 4.3.1  Evidence of completion of the pain assessment tool pre and post-intervention.**

<table>
<thead>
<tr>
<th></th>
<th>Completed in full</th>
<th>Partial Completion</th>
<th>Not Completed</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre Intervention</td>
<td>9</td>
<td>17</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Post Intervention, Time 1</td>
<td>44</td>
<td>15</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Post Intervention, Time 2</td>
<td>43</td>
<td>10</td>
<td>4</td>
<td>43</td>
</tr>
</tbody>
</table>

Not applicable refers to those patients who reported they had no pain and therefore the full pain assessment form was not completed.
4.4 Assessment of physical symptoms

The most prevalent physical symptoms experienced by palliative patients include pain, fatigue, lack of energy, weakness, appetite loss, weight loss, dry mouth, constipation, insomnia, dyspnea, nausea, vomiting, coughing, sweating, drowsiness and diarrhoea (Cancer Action Team, 2007; Teunissen et al., 2007; International Association of Hospice and Palliative Care, 2012). Table 4.4.1 illustrates the frequency assessment of these important physical symptoms at the different time points. The rate of assessment was significantly higher post-intervention for all symptoms except lack of appetite which approached statistical significance at p=0.054 (see table 4.4.1).

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Pre-intervention (n=35)</th>
<th>Post-intervention Time 1 (n=46)</th>
<th>Post-intervention Time 2 (n=42)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>69</td>
<td>91</td>
<td>100</td>
<td>0.0005</td>
</tr>
<tr>
<td>Nausea</td>
<td>57</td>
<td>96</td>
<td>98</td>
<td>0.0005</td>
</tr>
<tr>
<td>Vomiting</td>
<td>51</td>
<td>96</td>
<td>98</td>
<td>0.0005</td>
</tr>
<tr>
<td>Disturbed Sleep</td>
<td>66</td>
<td>98</td>
<td>100</td>
<td>0.0005</td>
</tr>
<tr>
<td>Shortness of Breath</td>
<td>71</td>
<td>96</td>
<td>100</td>
<td>0.0005</td>
</tr>
<tr>
<td>Cough</td>
<td>66</td>
<td>91</td>
<td>100</td>
<td>0.0005</td>
</tr>
<tr>
<td>Constipation</td>
<td>66</td>
<td>96</td>
<td>97</td>
<td>0.0005</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>43</td>
<td>93</td>
<td>97</td>
<td>0.0005</td>
</tr>
<tr>
<td>Lack of appetite</td>
<td>91</td>
<td>100</td>
<td>100</td>
<td>0.054</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>74</td>
<td>98</td>
<td>100</td>
<td>0.012</td>
</tr>
<tr>
<td>Ulcers</td>
<td>69</td>
<td>100</td>
<td>100</td>
<td>0.0005</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>86</td>
<td>98</td>
<td>98</td>
<td>0.005</td>
</tr>
<tr>
<td>Sweating</td>
<td>40</td>
<td>83</td>
<td>100</td>
<td>0.0005</td>
</tr>
</tbody>
</table>

4.5 Cognition

Pre-intervention, cognitive impairment was screened for using the abbreviated mental test score. Post-intervention the Blessed Short Orientation Memory Test
(SOMCT) was utilised. Although the rate of assessment of cognitive impairment significantly improved at Time 1 (p = 0.05), the rate of assessment dropped slightly lower than the pre-intervention rate at Time 2 (see table 4.5.1). Delirium was not included in the assessment proforma prior to the intervention. The rate of assessment of delirium increased at Time 1 but reduced at Time 2.

Table 4.5.1 The frequency percentage of documented evidence of cognition and delirium

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Pre-intervention (n=35)</th>
<th>Post-intervention Time 1 (n=46)</th>
<th>Post-intervention Time 2 (n=42)</th>
<th>P*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognition</td>
<td>69</td>
<td>87</td>
<td>62</td>
<td>0.54</td>
</tr>
<tr>
<td>Delirium</td>
<td>0</td>
<td>87</td>
<td>68</td>
<td>0.0005</td>
</tr>
</tbody>
</table>

* The significance value refers to pre-intervention values versus post-intervention Time 1 and 2

4.6 Resuscitation

Documentation regarding resuscitation status had not been included in the pre-intervention proforma. This was added to the MPCAT, along with specific documentation denotation regarding the resuscitation status including a decision making algorithm. At time 1 resuscitation status was documented in 91% (n=42) of charts, with the resuscitation form countersigned by a senior clinician in 11% (n=5). Twelve months post-intervention, the resuscitation form was completed in 93% (n=39) of charts, and countersigned by a senior clinician in 29% (n=12) of charts.

There were no criteria included in the post-intervention Time 1 audit about whether or not the patient was consulted (if appropriate) regarding their resuscitation status or the reasons that a patient was identified as not being appropriate for resuscitation. This data was included in the post-intervention audit 2, see figure 4.6.1.
4.7 Psychological needs

There was clear evidence of improved screening for depression, with 67% (n=31) of cases post-intervention, Time 1 and 79% (n=30) 12 months post-intervention Time 2 (assessment was inappropriate for four patients as they were delirious or unconscious), in comparison to 21 % (n=7) of cases pre-intervention, (p < 0.001).

There was a significantly higher rate of assessment of anxiety in post-intervention, Time 1, in 59% (n=27) in comparison to 31% of patients (n=11) of cases pre-intervention, (p < 0.001). This improvement was maintained post-intervention Time 2, with 82%, (n=32) of patients assessed for anxiety.

At the pre-intervention stage, questions relating to anxiety and depression were on the same page as questions relating to existential pain and suffering and the patient’s acceptance of their illness in the medical proforma. Frequently there was no evidence of assessment of these issues in the medical proforma; the average rate of non-completion of these questions was 92%. See Figure 4.7. 1
Figure 4.7.1  Documentation of psychological impact of the disease in the notes completed by doctors prior to the intervention

![Bar chart showing percentages of psychological impact assessments](chart.png)

There was clear evidence that psychological impact was assessed in the nursing notes in 11% (n=4) of charts and the outcome of assessment was unclear in 9% (n=3) of charts pre-intervention. There was no evidence of assessment of psychological issues in 80% (n=28) of nursing notes. In order to examine this in closer detail the nursing notes of a subsection of these patients (n=5/28) were reviewed for three days post admission to determine if the assessment of psychological impact occurred after the first day. The documentation under the section entitled “psychological issues” in nursing notes was either “nil raised/ nil expressed” in four of the charts and there was notation in the fifth chart on the second day that the patient was distressed due to pain. There was no reference to psychological distress.

With regard to the psychosocial assessment, the most commonly assessed issues at Time 1 and 2 were; impact of the illness, identification of additional needs for support and the patient’s view of how well the family were coping (see table 4.7.2). The most common issue not assessed at Time 1 and Time 2 related to determining if there were legal or financial issues that the patient wanted
assistance with during the admission. However, evidence of assessment of financial issues increased from 37%, at Time 1 to 62% at Time 2, p < 0.001.

Table 4.7.2 Assessment of psychosocial needs

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Pre-intervention, (n=35)</th>
<th>Post-intervention Time 1 (n=46)</th>
<th>Post-intervention Time 2 (n=42)</th>
<th>P**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>20</td>
<td>67</td>
<td>79</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Anxiety</td>
<td>31</td>
<td>59</td>
<td>82</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Impact of the Illness</td>
<td>14</td>
<td>91</td>
<td>95</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Support Needs determined</td>
<td>11</td>
<td>85</td>
<td>93</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Family communication</td>
<td>6</td>
<td>59</td>
<td>*</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Patients view of family coping</td>
<td>3</td>
<td>52</td>
<td>79</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Family member that the patient is worried about</td>
<td>6</td>
<td>52</td>
<td>75</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Financial worries screened for</td>
<td>0</td>
<td>37</td>
<td>62</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>

*Not included in the 12 months post-intervention audit criteria Time 2.

** The significance value refers to pre-intervention values versus post-intervention Time 1 and 2 with the exception of family communication which refers to pre-intervention values versus post-intervention Time 1.

The psychosocial aspect of the admission assessment proforma was amended between Time 1 and 2 post-intervention audits. Prior to the amendment, clinicians had been asked to document the patient’s narrative as a result of conducting the guided interview. Post the amendment, more explicit questions were asked of the clinician when documenting the outcome of their psychosocial assessment in that they were additionally requested to circle the appropriate yes or no response to a list of questions. This amendment may have been responsible in part for improvement in the audit outcome in that the outcome of the assessment was more specific.

In keeping with the MPCAT guidelines, where it was deemed inappropriate to complete aspects of the admission assessment on the first day of the admission, these can be completed on subsequent days, depending on the patient’s symptom burden.
The social workers screened the chart to determine if the psychosocial assessment or the assessment of carer's needs or aspects of these assessments were not completed on day one and completed the assessment as appropriate thereafter. In one case, there was no evidence of assessment of the psychosocial needs of a patient who was a repeat admission, and who did not have an assessment of their psychosocial needs in the initial admission assessment.

At post-intervention Time 1, at least one aspect of the psychosocial assessment was completed by the following disciplines: Doctor 74% (n=34), nurses 4% (n=2), both doctors and nurses 2% (n=1), social worker 7% (n=3), doctor and social worker 9%, (n=4) and not completed 4% (n=2). Post-intervention, Time 2, the psychosocial assessment was completed by the following: Doctor 88% (n=37), nurses 2% (n=1). The psychosocial assessment could not be completed with 4 patients as they were deemed too unwell.

4.8 Spiritual Needs

Pre-intervention, the patients religious preference was specified in 91% (n=32) of charts and in 98% (n=45) and 100% (n=42) post intervention Time 1 and 2 respectively. Pre-intervention there were sections in the medical and nursing assessment forms with regard to assessment of spiritual needs. With regard to the medical assessment, there was evidence of assessment of existential pain and suffering for 6% (n=2) and of existential fear and whether or not the patient had accepted their illness in one chart (3%) pre-intervention (see table 4.8.1).
Figure 4.8.1 Documentation of spiritual needs in the medical notes pre-intervention

In the nursing assessment notes, there was no evidence of spiritual needs assessment in 46% (n=16) charts. The outcome of assessment was unclear in 31% (n=11) and there was clear assessment of spiritual needs in 23% (n=8) charts, (see figure 4.8.2). Post-intervention the percentage of documented evidence of screening for spiritual need increased to 70% and 82% at Time 1 and Time 2 respectively (p <0.001).

Figure 4.8.2 Documentation of spiritual issues by nurses pre-intervention
4.9 Assessment of carer’s needs

The only question relating to assessment of carer’s needs in the pre-intervention stage was labelled “Family Issues” in the nursing documentation. There was clear evidence of assessment of this issue, typically relating to impact of the illness on a family member in 27% (n=9) of charts. There was no family present during admission in 6% of charts (n=2) and there was some documentation relating to this issue but the outcome of the assessment was unclear in 21% (n=7) of charts. For example, in respect of one patient, the family’s aims for the admission were documented, but there was no documentation relating to their understanding of the illness, the impact of the illness on them, aspects of the caring role that may have been difficult for them, needs related to additional information or determination if they required advice on seeking allowances or additional support in the community (See table 4.9.1).

Table 4.9.1 Documentation of assessment of carer needs

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention (n=35)</th>
<th>Post-intervention, Time 1 (n=46)</th>
<th>Post-intervention, Time 2 (n=38*)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact of illness on the carer determined?</td>
<td>14</td>
<td>30</td>
<td>68</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Carer's view of family coping determined?</td>
<td>3</td>
<td>27</td>
<td>76</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Carer's view of family communication about the illness determined?</td>
<td>0</td>
<td>26</td>
<td>70</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Determination of a family member that the carer is concerned about?</td>
<td>3</td>
<td>24</td>
<td>70</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Carer's aims for the admission determined</td>
<td>6</td>
<td>30</td>
<td>69</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Preferred place of care at end of life as specified by the carer</td>
<td>0</td>
<td>4</td>
<td>18</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>

* Four Patients did not have carers
For another patient, who died within three weeks of admission and who functioned as the main carer for a person with a disability, there was notation as to the knowledge of diagnosis by the person with a disability. Four days post admission a family member requested input from the social work team. In respect of a third patient, the nursing notes document that the patient was “very worried” about their spouse. This patient’s notes post admission were reviewed, notation in the nursing notes under family issues related to which family member visited. A member of the social work team visited the patient seven days (five working days) post admission.

There was no evidence of assessment of families needs in 46% of charts (n=15). A subsection of these charts (n=7), were reviewed with regard to assessment of families needs for a number of days post admission. The only notation in five charts of the family issues section related to either which family member visited or “nil raised”. Awareness by the family of diagnosis was documented in the sixth chart and there was notation that family members were ‘happy’ with the input of the multidisciplinary team in the seventh chart.

Assessment of carer’s needs was the domain that was least assessed in the MPCAT, post-intervention Time 1, with an average completion rate of 23% across this cohort of scores. If determination of carer’s understanding of diagnosis and prognosis is excluded, there was no documented evidence of assessment of carer’s needs in 59% (n= 26) of charts at Time 1. After the post-intervention Time 1 audit was completed, the Meitheal form (a record of multidisciplinary meeting to review care) was revised. Part of the aim of the revision was to ensure an action plan was devised to assure that any outstanding area of assessment was completed, including identification of the responsible discipline. Post-intervention, Time 2 there was an average completion rate of 62% across the cohort of scores relating to assessment of carer’s needs. Post-intervention Time 2 the assessment of carer’s need was completed by the following: Nursing staff 63% (n=24), social worker 3% (n=1), nurse and doctor 3% (n=1), by a doctor alone on 8% (n=3) and not completed 24% (n=9) of occasions. Four patients did not have a carer.
4.10 Referral to the other members of the Multidisciplinary team

The speed of referral (number of referrals made to Physiotherapy, Occupational Therapy, Social Worker, Pastoral Care and Complimentary Therapy in the first 24 hours) and number of referrals to other members of the multidisciplinary team (dietitian, Art Therapy, Music Therapy and Horticulture) increased post-intervention (See graph 4.10.1).

Figure 4.10.1 Percentage referrals to members of the multidisciplinary team occurring in the first 24 hours of admission

The numbers of referrals made within the first 24 hours at Time 1 was significantly greater than the pre-intervention baseline for all disciplines. This increase in referrals slightly increased at Time 2 for all disciplines except complementary therapy (See table 4.10.1).
Table 4.10.1  Frequency of referrals to members of the multidisciplinary team within the first twenty four hours of admission

<table>
<thead>
<tr>
<th>Referrals within the first 24 hours of admission</th>
<th>Pre-intervention (n=35)</th>
<th>Post-intervention Time 1 (n=46)</th>
<th>Post-intervention Time 2 (n=42)</th>
<th>p*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiotherapy</td>
<td>41</td>
<td>80</td>
<td>81</td>
<td>0.001</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>37</td>
<td>76</td>
<td>79</td>
<td>0.001</td>
</tr>
<tr>
<td>Social Worker</td>
<td>20</td>
<td>67</td>
<td>79</td>
<td>0.0005</td>
</tr>
<tr>
<td>Pastoral Care</td>
<td>11</td>
<td>70</td>
<td>73</td>
<td>0.0005</td>
</tr>
<tr>
<td>Complementary Therapy</td>
<td>11</td>
<td>41</td>
<td>19</td>
<td>0.016</td>
</tr>
</tbody>
</table>

*Refers to pre-intervention versus post-intervention Time 1 and Time 2

The median number of referrals to other disciplines (including dietitian, art therapy, music therapy and horticulture) was significantly higher post-intervention (Median = 1.00; n=46) in comparison to pre-intervention (Median = 0.00; n = 35, p = 0.002).

Figure 4.10.2  Frequency of referrals to other members of the Multidisciplinary team, before and after the intervention
4.11 Genogram and access issues

The rate of completion of the genogram (family tree) improved post-intervention in comparison to pre-intervention as did issues relating to patients access to bathroom, bedroom, equipment already in the home and support for completion of self-care and household duties (see figure 4.11.1). Identification of equipment at home, needs relating to household duties and self care increased the most at Time 2 in comparison to the pre-intervention baseline. It is important to be aware of these issues as early in the admission as possible to facilitate planning for discharge.

**Figure 4.11.1** Documented evidence of the completion of a genogram and assessment of other practical domestic issues

![Graph showing improvements in genogram and access issues](image)

4.12 Nursing assessment of physical symptoms

Documentation relating to nursing assessment of physical symptoms was very similar in the MPCAT to that of the pre-intervention documentation with the exception of the addition of a moving and handling risk assessment. Although documentation relating to the presence of a known infection on admission improved at Time 1, there is still considerable room for improvement in that there was no documentation relating to infection status in 57% (n=25) of charts. This figure
decreased slightly to 45% (n=19) at Time 2. Documentation of the risk of falls (documentation pre-intervention = 100%, post-intervention = 80% (n=37) and Time 1 and was 95% (n=40) at Time 2 (see table 4.12.1). Documentation of measures in response to assessment of oral care needs had decreased post-intervention Time 1, at 48% (n= 22) in comparison to pre-intervention 63% (n=22), but increased considerably at Time 2, 91% (n=32). The wording and format of both falls risk and of measures in response to oral care need was reviewed between Time 1 and 2 audits in addition to the provision of audit feedback.

Table 4.12.1 Percentage of documented evidence assessment of activities of daily living

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention (n=35)</th>
<th>6 Months Post-intervention (n=46)</th>
<th>12 Months Post-intervention (n=42)</th>
<th>P Values *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manual Handling aids required</td>
<td>43</td>
<td>65</td>
<td>78</td>
<td>0.010</td>
</tr>
<tr>
<td>Risk of Falls</td>
<td>100</td>
<td>80</td>
<td>95</td>
<td>0.004</td>
</tr>
<tr>
<td>Risk of pressure ulcers</td>
<td>97</td>
<td>100</td>
<td>98</td>
<td>NS*</td>
</tr>
<tr>
<td>If at risk of pressure sores, controls documented</td>
<td>62</td>
<td>61</td>
<td>83</td>
<td>0.004</td>
</tr>
<tr>
<td>Nutritional Assessment completed</td>
<td>94</td>
<td>98</td>
<td>93</td>
<td>NS</td>
</tr>
<tr>
<td>Spoken to regarding dietary requirements?</td>
<td>60</td>
<td>96</td>
<td>98</td>
<td>0.001</td>
</tr>
<tr>
<td>Notifiable infection Identified</td>
<td>0</td>
<td>43</td>
<td>55</td>
<td>0.001</td>
</tr>
<tr>
<td>Oral Care Assessment scored</td>
<td>100</td>
<td>100</td>
<td>95</td>
<td>NS</td>
</tr>
<tr>
<td>If indicated by oral care assessment measures in response documented</td>
<td>63</td>
<td>48</td>
<td>91</td>
<td>0.052</td>
</tr>
</tbody>
</table>

*The significance value relates to comparison between pre-intervention versus post-intervention Time 1 and 2.
4.13 Falls

Although documentation of the risk of falls decreased post-intervention, the number of interventions documented to mitigate risk of falls increased considerably post-intervention (see figure 4.13.1).

**Figure 4.13.1 Frequency of falls prevention procedures documented to reduce risk of falls when a patient was at risk of falls**

![Graph showing frequency of falls prevention procedures](image)

Pre-intervention, 57% (n=20) of patients were at risk of falls. Post-intervention Time 1, 73% (n=34) of patients were at risk of falls and 76% (n=32) of patients were at risk of falls at Time 2. There are a significantly greater number of controls to prevent reoccurrence of falls post-intervention Time 1 (n=34; Median (Md) = 5, interquartile range (IQR) = 3) than pre-intervention (n =20; Md = 1.00, IQR = 0, U = 78.5; p = 0.0005). The median number of interventions to reduce risk of falls post-intervention Time 2 was 5 (IQR= 4), indicating that the improvement in documentation of controls was maintained 12 months post-intervention.

4.14 Diagnosis and prognosis

Identification of the patient’s and family member’s knowledge of prognosis was not included as a prompt in pre-intervention documentation. However, there was some documentation of these issues in the pre-intervention admission assessment
documentation. Documentation increased considerably when formal prompts were included in the MPCAT both Time 1 (65%, n = 30) and Time 2 (95%, n = 40) indicating that this improvement was maintained 12 months post-intervention (see figure 4.14.1).

**Figure 4.14.1 Percentage of documented evidence of patient’s and families’ awareness of diagnosis and prognosis**

<table>
<thead>
<tr>
<th></th>
<th>Pre Intervention</th>
<th>Post Intervention</th>
<th>12 Months Post Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pt awareness of</td>
<td>100</td>
<td>95</td>
<td>95</td>
</tr>
<tr>
<td>diagnosis assessed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pt awareness of</td>
<td>100</td>
<td>65</td>
<td>64</td>
</tr>
<tr>
<td>prognosis assessed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer/Family aware</td>
<td>100</td>
<td>58</td>
<td>9</td>
</tr>
<tr>
<td>of diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer/Family is</td>
<td>100</td>
<td>90</td>
<td>54</td>
</tr>
<tr>
<td>aware of prognosis</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**4.15 Preferred place of care at end of life**

Post-intervention Time 1, 33% (n=15) of patients specified their preferred place of care on admission in comparison to 24% (n=9) at Time 2, 12 months post-intervention. Post-intervention Time 1, 4% (n=2) of patients were undecided as to their preferred place of care at end of life. A prompt was included to indicate if it was the clinician’s view that it was appropriate to engage a patient in a discussion regarding preferred place of care – this was not responded to in 50% (n=23) of charts. It was documented as being inappropriate to discuss on admission in 13% (n=6) of charts at Time 1 and in 31% (n=9) at Time 2. This reflected a variety of reasons including that the patient too unwell or fatigued, patient had limited knowledge of diagnosis and prognosis or that “it was not an issue at the moment”.

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4.16 Results of patient interviews

The majority of patients answered all questions in the patient interviews (see table 4.16.1).

Table 4.16.1  The completion, median severity and interquartile range of patient ratings

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>% Completed</th>
<th>Median</th>
<th>Interquartile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>81</td>
<td>100</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Fatigue</td>
<td>80</td>
<td>99</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Nausea</td>
<td>81</td>
<td>100</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Disturbed Sleep</td>
<td>81</td>
<td>100</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Distressed Feelings</td>
<td>79</td>
<td>98</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Shortness of Breath</td>
<td>81</td>
<td>100</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Difficulty remembering</td>
<td>79</td>
<td>97</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Lack of appetite</td>
<td>80</td>
<td>98</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Feeling drowsy</td>
<td>80</td>
<td>98</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>81</td>
<td>100</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Feeling Sad</td>
<td>79</td>
<td>97</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Vomiting</td>
<td>81</td>
<td>100</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Numbness or tingling</td>
<td>81</td>
<td>100</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>General Activity</td>
<td>79</td>
<td>98</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Mood</td>
<td>79</td>
<td>98</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Work*</td>
<td>28</td>
<td>35</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Relations with other people</td>
<td>79</td>
<td>98</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Walking</td>
<td>73</td>
<td>90</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Enjoyment</td>
<td>75</td>
<td>93</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Appearance</td>
<td>75</td>
<td>93</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Financial Hardship</td>
<td>75</td>
<td>93</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Senseless and meaningless</td>
<td>67</td>
<td>83</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Family Communication about Illness**</td>
<td>78</td>
<td>96</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Shared Worries**</td>
<td>72</td>
<td>89</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Quality of life**</td>
<td>75</td>
<td>93</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Someone to confide in</td>
<td>78</td>
<td>96</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Religious belief or spiritual life</td>
<td>75</td>
<td>93</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Settled relationships</td>
<td>72</td>
<td>89</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Sense of purpose</td>
<td>61</td>
<td>75</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Clear information at admission</td>
<td>68</td>
<td>84</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Care fits with goals</td>
<td>71</td>
<td>88</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*If the patient had been transferred from hospital or was interview on the 3rd day of admission, the question relating to work was not applicable. **These items were reverse scored e.g. The parameters of the question related to satisfaction with family communication about illness, 0 – Not Satisfied, 10 = completely satisfied.

A comparison of severity ratings pre and post-intervention did not reveal differences with the exception of patient severity ratings of nausea pre (Md = 3, n=35) and post (Md = 0.00, n=46; p = 0.02)
4.17 Time to complete the admission assessment

The mean time to complete the MPCAT admission assessment (including its documentation) was sixty five minutes post-intervention, (n=10, standard deviation =18.39). Feedback from staff suggested that complex admissions can take up to ninety minutes. The time to complete the pre-intervention assessment process was not captured formally.

4.18 Patients perspectives regarding participating in research

At the end of each interview, patients were asked to describe their experience of participation in the research project. This question was a check to determine if any patient found the interview difficult or distressing in any way. Responses from patients to participation in the study were documented by the researcher, themed and can be characterised as follows:

Patients have a desire to and benefit from telling their story:

“I didn’t know palliative care covered all that, it was wonderful... really questions like that should be asked more often”.

Pre 109

“That helped me – It’s funny - you might be thinking things but it is good to say them out.”

Post 0223

“...The more you know about a person with a terminal illness the better for a patient.”

Post 0243

“It gives an opportunity to think about things”

Pre 114

Some patients are motivated to participate for altruistic reasons:
“That was fine, very straight forward, I am supportive of research.”

Pre 134

It should not be presumed that Palliative Care Patients will be distressed by participation in research:

“Excellent interview, very thorough. I have no problem answering those questions”

Post 0221

“That was grand, it is only when you ask the hard questions that you get an honest answer.”

Post 0244

4.19 Comparison of results of clinician’s admission assessment with patient’s self-rating of symptoms and issues.

The relationship between symptoms and issues as identified through assessment by a clinician and those rated by patient’s symptoms and issues as measured by the MD Anderson Symptom Inventory (MDASI) and the Needs Near the End of Life Screening Tool (NEST) were investigated. The investigation focussed on concordance between the clinician assessment and the patient’s ratings pre and post intervention.

The Mann Whitney U Test was used to determine if those patients who were identified as experiencing a symptom or issue by clinicians, rated the severity of the symptom/issue higher than those patients who were assessed as not experiencing the symptom/issue. With regard to pain, pre-intervention there was no documented evidence of assessment of pain or the outcome of the assessment was unclear in 29% (n=10) of patient charts. There was no significant difference between patient self reported severity ratings and the clinician’s assessment of whether or not the patient had pain (see pre-intervention figure 4.19.1).
Self-reported pain severity ratings in patients who were assessed as experiencing pain by clinicians (Md = 6.00, n=20, IQR = 9; p = 0.24) were not significantly different when compared to those patients that clinicians assessed as not experiencing pain (Md = 1.00, n=5, IQR = 7). Post-intervention there was a significant difference between the self-reported severity ratings of those patients who were assessed as experiencing pain by clinicians (Md= 6.00, n=30, IQR = 6) in comparison to those who clinicians assessed as not experiencing pain (Md = 0.00, n= 16, IQR = 2; p = 0.0005).

With regard to fatigue, pre-intervention 32% of patients (n=11) were either not assessed or the outcome of assessment was unclear in respect of fatigue. Only one patient was assessed as not experiencing fatigue by clinicians, this person rated their fatigue as 6 out of 10 (10 being the worst fatigue they could imagine). Due to the small sample size in the group that was assessed as not experiencing fatigue; we did not test for significance pre-intervention. Post-intervention there was no significant
difference in medians scores of patient severity ratings between severity ratings who were assessed as having fatigue (Md = 6.00, n=33, IQR = 5) and those who assessed as not having fatigue, (Md = 8.00, n=8, IQR = 5; p = 0.25).

**Figure 4.19.2 Patient self-rating and clinician assessment of fatigue**

Cough, fatigue, sweating numbness and tingling were the physical symptoms with the lowest documented evidence of assessment post-intervention Time 1, having rates of no evidence of assessment of 9%, 9 % 15% and 23% respectively.
Pre-intervention, 43% (n=15) of patients were not assessed in respect of nausea or the outcome of assessment was unclear. Post-intervention this percentage was 4% (n=2). In respect of nausea, pre-intervention, there was a significant difference in severity ratings between patients who were assessed as not experiencing nausea (all seven patients rated nausea as 0/10, indicating no nausea) and those patients who were assessed by clinicians as having nausea, (Md = 6.00, n=13, IQR = 4; p = 0.001) indicating a significant difference. Post-intervention severity ratings in patients who were assessed as not experiencing nausea by clinicians, (Md = 0.00, n= 31, IQR = 0) were significantly lower when compared to those patients that clinicians assessed as experiencing nausea (Md = 3.00, n= 13, IQR = 7, p = 0.0005).
Pre-intervention, 29% of patients were either not assessed in respect of shortness of breath (23%; n=8) or the outcome of assessment was unclear (6%; n=2). In respect of patients who were assessed, there was a significant difference in severity ratings of those patients who were assessed as not experiencing shortness of breath (Md = 0.00, n= 9, IQR = 2) and those patients who were assessed as experiencing shortness of breath (Md = 6.5, n= 16, IQR = 7); p =0.006).

Post-intervention, 5% of patients were either not assessed in respect of shortness of breath (2%; n=1) or the outcome of assessment was unclear (2%; n=1). The difference in patient severity ratings was greater post–intervention (p < 0.001). In that severity ratings of patients who were assessed as not experiencing shortness of breath were lower (Md = 0.00, n= 22, IQR =2) than for those who were assessed as experiencing shortness of breath (Md = 6.00, n= 22, IQR = 7).
Regarding disturbed sleep, pre-intervention, it was either not assessed (29%; n=10), or the outcome of assessment was unclear (9%; n=3). There was no significant difference between severity ratings of those patients who were assessed as not experiencing disturbed sleep (Md = 0.00, n= 14, IQR = 5) and those patients who were assessed as experiencing disturbed sleep (Md = 1, n= 8, IQR = 7; p = 0.34). Post-intervention, there was no significant difference between those patients who were assessed as not experiencing disturbed sleep (Md = 0.0, n= 30, IQR = 7) and those patients who were assessed as experiencing disturbed sleep, (Md = 3, n= 15, IQR = 6; p = 0.55).
Figure 4.19.6  Patient self-rating and clinician assessment of lack of appetite

Pre-intervention, 6% (n=2) were not assessed in respect of lack of appetite and the outcome of assessment was unclear in 3% of patients, (n=1). There was no significant difference in severity ratings of those patients who were assessed as not experiencing lack of appetite, Md = 2.00, (n=20) and those patients who were assessed as experiencing appetite, Md = 2, (n=12). Post-intervention, there was no significant difference but there was a trend towards significance (p=0.16), between severity ratings of patients who were assessed as not experiencing lack of appetite (Md = 0.00, n= 21, IQR = 6) and those who were assessed as experiencing lack of appetite (Md = 2.00, n = 25, IQR = 5).
In respect of experience of dry mouth, pre-intervention 6% (n = 2) were not assessed and the outcome of assessment was unclear in 9% of patients, (n = 3). There was a significant difference between patients who were assessed as not experiencing dry mouth (n=19, p = 0.047, Md = 5.00, IQR = 6) and those who were assessed as experiencing dry mouth (n=11, Md = 6.00, IQR = 5; p = 0.047). Post-intervention, the outcome of assessment was unclear in 2%, (n=1) patients. There was a significant difference in severity of dry mouth experienced between patients who were assessed as having dry mouth (Md =7, n = 23, IQR =8) and those who were not assessed as experiencing dry mouth (Md = 3, n = 22, IQR = 6, p = 0.027).
4.20 Psychosocial issues

There was no evidence of assessment of need in respect of financial issues pre-intervention, even though 37% (n=13) of patients rated the severity of financial impact of their illness as 3 or more (10 being the worst they could imagine). Three or more is the cut off score at which authors of the Nest recommend that there should be further assessment with the patient regarding financial issues. Of these 13 patients, no referral to social work occurred in 69% (n = 9), 2 patients were referred within 24 hours, 1 within 48 hours and 1 within 72 hours. Impact on finances due to the illness was rated as 10 (the worst they could imagine) by 14% (n = 5) patients, 80% (n = 4) of these patients were not referred to Social Work pre-intervention.

Post-intervention, 9% (n=4) of patients did not rate financial hardship when interviewed. There is no evidence of assessment regarding impact of the illness on patient finances in 50% (n=23) of patients. Two of this group of patients did not rate financial hardship, resulting in a subgroup total of 21 patients. 76% (n=16) reported they were not experiencing financial hardship. In respect of those patients who were assessed by the admitting doctor (n=23); the outcome of assessment is unclear for 14% (n= 6/23), 69.5% of patients were assessed as not experiencing financial hardship (Md = 0, n = 16, IQR = 3) and one patient was assessed as experiencing financial hardship. Financial hardship was not rated by two of this group of patients, resulting in a subgroup total of 21 patients. Two thirds (n=14/21) of the patients who were assessed as not experiencing financial hardship reported that they were not experiencing financial hardship when they self rated. However, the remaining patients did indicate that they were experiencing financial hardship, of whom the majority ( n= 6/21) rated severity of financial impact as 3 or more. Of this group, 50% (n=3/6) rated financial impact as the worst they could imagine and were referred to social work within 24 hours of admission post-intervention.

Pre-intervention, there was clear documented evidence of assessment of psychological distress or impact of the illness on the patient in 14% (n=5) of the charts reviewed, characterised as low mood, fear, anxiety and worry in respect of how family members will cope. All five patients self-reported that they were not
experiencing feelings of distress when completing the MDASI. One of these patients was referred to Social Work, none were referred to pastoral care. Post-intervention, there was a significant difference between patient experience of distress in respect of patients who were assessed as not experiencing psychological distress (n=23; median 0.00; IQR = 3) and those who were assessed as experiencing, psychological distress (n=18) (median score of 4.00; IQR = 8) (p = 0.044). The majority of these patients (n=14) were referred to Social Work and pastoral care post-intervention.

According to the authors of the NEST, the question “How much does this illness seem senseless and meaningless to you” (scored out of 10, 0 = Not at all, 10 = A great deal/completely) relates to psychological distress. Although a significant difference was not noted post-intervention between those who were assessed as psychological distressed (n=15; median score of 8.00), and those who were assessed as not experiencing psychological distress (n=16; median score of 0.0), there was a strong trend towards significance (p = 0.08). Pre-intervention, the severity ratings of those who were assessed as experiencing distress were (n=4; median 8) and the severity rating of the person who was assessed as not experiencing distress was 0/10 (p = 0.147).

Patients were asked to rate impact of their illness on mood as part of the MDASI. Pre-intervention, the numbers (n=3) evaluated were too small to compare. Post-intervention, median patient severity ratings of impact on mood in those who were assessed as not depressed (n =27; median 0.00) were similar to those who were assessed as depressed (n = 4; median 0.00).

Patients were asked to rate their feelings of sadness (10 being the worst sadness they could imagine) as part of the MDASI. Pre-intervention, there was no significant difference between patients who were assessed as not experiencing depression (n = 4; median 0.00) and those who were assessed as experiencing depression (n=3; median 0.00; p = 1.0). Post-intervention, there is no significant difference between patient experience of sadness in respect of patients who were assessed as not experiencing depression (n = 27; median 1.00) and those who were assessed as experiencing depression (n = 4; median 2.00; p = 0.58).
With regard to communication within the family, the cut off score to warrant further assessment is 6 or more in response to the availability of someone to confide in (10 being there was never someone to confide in). Pre-intervention, 2 patients scored 7 out of 10. Neither of these patients were identified as experiencing difficulty in respect of family communication on assessment. There was no evidence of assessment of family communication of the patient being able to discuss the illness within the family in 93% (n= 33) of the patients sampled, pre-intervention, therefore no test of difference in severity ratings was conducted.

Post-intervention, no patient scored 6 or higher in response to the question “how often is there someone to confide in. Four patients were assessed as potentially experiencing difficulties in respect of family communication (Md = 0.00, IQR = 2) there was no significant difference in severity ratings for these patients in comparison to patients who were assessed as not experiencing difficulties in respect of family communication, (Md = 0.00, n = 22, IQR = 0).

4.21 Spiritual Issues

In respect of spiritual distress, pre-intervention there is no significant difference in patient severity ratings of spiritual impact for those patients who were assessed as experiencing spiritual distress (Md = 2.5, n=6) and those who were assessed as not experiencing spiritual distress (Md = 2, n=2) (p = 0.59). Pre-intervention, 23% (n= 8) of patients indicated that they may be experiencing spiritual distress in that they scored 6 or more in response to the question “How much does religious belief or your spiritual life contribute to your sense of purpose?”. A score of 6 is the cut off score in the Nest interview which indicates the requirement for further assessment regarding spiritual distress. None of these patients were referred to Pastoral care.

Post-intervention, only 2 patients were assessed as potentially experiencing spiritual distress, there is no significant difference in severity ratings, for those patients in comparison to patients who were assessed as not experiencing spiritual distress, (Md = 0.00, n = 28) ( p = 0.29). Post-intervention, 19% (n=9) of patients in the post-intervention group indicated that they may be experiencing spiritual distress. 55%
(n=5) of these patients were referred to Pastoral care. There was evidence of a spiritual assessment in the admission assessment in 44% (n=4) of this group, two of the 4 spiritual assessments were conducted by pastoral care clinicians. It was documented that it was not appropriate to conduct a spiritual assessment with 4 of these 9 patients.

**Figure 4.21.1 Patient self-rating and clinician assessment of spirituality**

![Graph showing patient self-rating and clinician assessment of spirituality](image)

**4.22 Patient priority issues**

Each patient was asked to identify the symptoms or issues that they most wanted help with from the team. The symptoms or issues documented in the care plan summary for each patient was compared against that which the patient identified. Although there was an increase in the number of care plans which clearly identified the symptoms and issues identified by the patient at post-intervention Time 1, the increase was not significant (See figure 14.22.1).
4.23 Assessment of carer’s perception of the quality of care pre and post-intervention

The FAMCARE 2 is scored out of 85 and contains four factors; patients physical symptoms and comfort, provision of information, family support and patient psychological care (Aoun et al., 2010). Total scores and factors scores were calculated in accordance with the methodology used within the validation paper. Missing data was replaced with the mean scores of the pooled responses. Although this reduces the variability in responses, it was necessary as the sample size was small and this methodology is in accordance with the Famcare 2 validation paper. The respondents answers were coded using numerical scores from 1 (very dissatisfied) to 5 (very satisfied). A “0” was assigned if the respondent identified the item as not relevant to their situation. Results indicated a high degree of satisfaction which was largely similar at the pre and post stages of intervention.
Table 4.23.1  Total score and median factor scores of the FAMCARE 2 pre and post-intervention

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention, n = 25 (IQR)</th>
<th>Post-intervention, Time 1 (IQR)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Score</td>
<td>76 (17)</td>
<td>81 (11)</td>
<td>0.41</td>
</tr>
<tr>
<td>Patients Physical Symptoms and Comfort</td>
<td>25 (3)</td>
<td>25 (2)</td>
<td>0.71</td>
</tr>
<tr>
<td>Provision of Information</td>
<td>18 (5)</td>
<td>18 (3)</td>
<td>0.57</td>
</tr>
<tr>
<td>Family Support</td>
<td>17 (6)</td>
<td>19 (4)</td>
<td>0.28</td>
</tr>
<tr>
<td>Patient Psychological Care</td>
<td>20 (3)</td>
<td>19 (3)</td>
<td>0.28</td>
</tr>
</tbody>
</table>

However, there were significantly higher respondents ratings of management of patients physical symptoms and comfort, in comparison to the respondents ratings of the three other factors both pre and post-intervention (p<0.001), see table 4.23.2. Some additional bespoke questions were asked at the end of the Famcare 2, see table 4.23.3.

Table 4.23.2  Median scores of additional questions asked of carers

<table>
<thead>
<tr>
<th></th>
<th>Pre-intervention Median (IQR)</th>
<th>Post-intervention Median (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with Financial concerns</td>
<td>3 (4)</td>
<td>3 (4)</td>
</tr>
<tr>
<td>Advise about additional supports</td>
<td>4 (2)</td>
<td>4 (4)</td>
</tr>
<tr>
<td>Clear explanation of services provided at the time of admission</td>
<td>4.5 (1)</td>
<td>5 (1)</td>
</tr>
<tr>
<td>First meeting with the doctor and nurse was manageable and acceptable</td>
<td>5 (1)</td>
<td>5 (0)</td>
</tr>
</tbody>
</table>

There was no significant difference in respondent’s ratings pre and post-intervention in respect of these questions.

4.24 Confidence and competence of Non Consultant Hospital Doctors to conduct psychosocial Assessment

Twenty non consultant hospital doctors (NCHDs) completed a rotation in the inpatient unit during the data collection time period. Two doctors rotated for a second time and two doctors did not complete the initial questionnaire resulting in a
sample size of sixteen doctors. Data was not collected with regard to NCHD confidence and competence pre-intervention. The data was collected at three time points; prior to receipt of training (Time 1), after receipt of training (Time 2), and three months post receipt of training (Time 3). The results suggest that the provision of training and evidence-based guidance increased the confidence of NCHDs in discussing psychological needs with patients when providing support and communicating around death and dying. Experience further increased confidence and sense of competence in these areas.

Table 4.24.1  Change in confidence and competence (median scores) of NCHD’s to conduct psychosocial assessment

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Time 1 (n=16)</th>
<th>Time 2 (n=10)</th>
<th>Time 3 (n=10)</th>
<th>P Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussing psychological problems</td>
<td>5.5</td>
<td>7.5</td>
<td>8</td>
<td>0.005</td>
</tr>
<tr>
<td>Discussing body image</td>
<td>5</td>
<td>6.5</td>
<td>8</td>
<td>0.02</td>
</tr>
<tr>
<td>Discussing sex</td>
<td>4</td>
<td>4</td>
<td>7</td>
<td>0.02</td>
</tr>
<tr>
<td>Information re efficacy of treatments</td>
<td>5</td>
<td>7</td>
<td>8</td>
<td>0.06</td>
</tr>
<tr>
<td>Providing complex information to highly intelligent</td>
<td>5</td>
<td>6.5</td>
<td>7.5</td>
<td>0.04</td>
</tr>
<tr>
<td>Communicating with emotionally withdrawn patients</td>
<td>4</td>
<td>5</td>
<td>8</td>
<td>0.03</td>
</tr>
<tr>
<td>Giving complex information to patients with limited ability to understand</td>
<td>5</td>
<td>5</td>
<td>8</td>
<td>0.08</td>
</tr>
<tr>
<td>Communicating with somebody the same age as you</td>
<td>5</td>
<td>5</td>
<td>8</td>
<td>0.05</td>
</tr>
<tr>
<td>Communicating with either doctor or nurse</td>
<td>4</td>
<td>6</td>
<td>7</td>
<td>0.03</td>
</tr>
<tr>
<td>Discussing prognosis</td>
<td>4</td>
<td>6</td>
<td>9</td>
<td>0.02</td>
</tr>
<tr>
<td>Discussing death and dying</td>
<td>5</td>
<td>7</td>
<td>8</td>
<td>0.02</td>
</tr>
<tr>
<td>Informing relatives death is imminent</td>
<td>5</td>
<td>8</td>
<td>9</td>
<td>0.01</td>
</tr>
<tr>
<td>Providing support to relatives of patients who have died</td>
<td>4</td>
<td>7</td>
<td>9</td>
<td>0.02</td>
</tr>
<tr>
<td>Providing support to distressed junior health professionals</td>
<td>4</td>
<td>7</td>
<td>8</td>
<td>0.11</td>
</tr>
</tbody>
</table>

*The p value refers to comparison between time 1, 2 and 3

Between Time 1 and Time 2 the provision of training and evidence-based guidance resulted in significant change in confidence levels with regard to all areas except communicating with emotionally with drawn patients, with patients of similar age to the NCHDs and communicating with other doctors and nurses.
Table 4.24.2  Change in confidence and competence (median scores) of non consultant hospital doctor’s to conduct psychosocial assessment between Time 1 and Time 2.

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Time 1 (n=16)</th>
<th>Time 2 (n=10)</th>
<th>P Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussing psychological problems</td>
<td>6</td>
<td>8</td>
<td>0.011</td>
</tr>
<tr>
<td>Discussing body image</td>
<td>5</td>
<td>7</td>
<td>0.024</td>
</tr>
<tr>
<td>Discussing sex</td>
<td>3.5</td>
<td>4</td>
<td>0.023</td>
</tr>
<tr>
<td>Information re efficacy of treatments</td>
<td>5.5</td>
<td>7</td>
<td>0.025</td>
</tr>
<tr>
<td>Providing complex information to highly intelligent patients</td>
<td>6</td>
<td>7</td>
<td>0.011</td>
</tr>
<tr>
<td>Communicating with emotionally withdrawn patients</td>
<td>5</td>
<td>6</td>
<td>0.102</td>
</tr>
<tr>
<td>Giving complex information to patients with limited ability to understand</td>
<td>6</td>
<td>6</td>
<td>0.076</td>
</tr>
<tr>
<td>Communicating with somebody the same age as you</td>
<td>6</td>
<td>6</td>
<td>0.518</td>
</tr>
<tr>
<td>Communicating with either doctor or nurse</td>
<td>6</td>
<td>7</td>
<td>0.336</td>
</tr>
<tr>
<td>Discussing prognosis</td>
<td>4</td>
<td>7</td>
<td>0.054</td>
</tr>
<tr>
<td>Discussing death and dying</td>
<td>4.5</td>
<td>7</td>
<td>0.026</td>
</tr>
<tr>
<td>Informing relatives death is imminent</td>
<td>5.5</td>
<td>8</td>
<td>0.026</td>
</tr>
<tr>
<td>Providing support to relatives of pts who have died</td>
<td>5</td>
<td>6.5</td>
<td>0.025</td>
</tr>
<tr>
<td>Providing support to distressed junior health professionals</td>
<td>5.5</td>
<td>7</td>
<td>0.045</td>
</tr>
</tbody>
</table>

Analysis of data between Time 2 and Time 3 indicates that experience and time in the inpatient unit resulted in a change in confidence levels with regard to a number of issues. These included communication with patients of a similar age to the NCHDs and with other doctors and nurses, in addition to discussing psychological problems and provision of information with regard to efficacy of treatments.
Table 4.24.3  Change in confidence and competence (median scores) of non consultant hospital doctor’s to conduct psychosocial Assessment between Time 2 and Time 3.

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Time 2 (n=10)</th>
<th>Time 3 (n=10)</th>
<th>P Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussing psychological problems</td>
<td>8</td>
<td>8</td>
<td>0.038</td>
</tr>
<tr>
<td>Discussing body image</td>
<td>7</td>
<td>8</td>
<td>0.084</td>
</tr>
<tr>
<td>Discussing sex</td>
<td>4</td>
<td>6.5</td>
<td>0.071</td>
</tr>
<tr>
<td>Information re efficacy of treatments</td>
<td>7</td>
<td>8</td>
<td>0.041</td>
</tr>
<tr>
<td>Providing complex information to highly intelligent patients</td>
<td>7</td>
<td>7.5</td>
<td>0.071</td>
</tr>
<tr>
<td>Communicating with emotionally withdrawn patients</td>
<td>6</td>
<td>7</td>
<td>0.111</td>
</tr>
<tr>
<td>Giving complex information to patients with limited ability to understand</td>
<td>6</td>
<td>7</td>
<td>0.078</td>
</tr>
<tr>
<td>Communicating with somebody the same age as you</td>
<td>6</td>
<td>7.5</td>
<td>0.041</td>
</tr>
<tr>
<td>Communicating with either doctor or nurse</td>
<td>7</td>
<td>8</td>
<td>0.024</td>
</tr>
<tr>
<td>Discussing prognosis</td>
<td>7</td>
<td>8.5</td>
<td>0.114</td>
</tr>
<tr>
<td>Discussing death and dying</td>
<td>7</td>
<td>8</td>
<td>0.112</td>
</tr>
<tr>
<td>Informing relatives death is imminent</td>
<td>8</td>
<td>9</td>
<td>0.131</td>
</tr>
<tr>
<td>Providing support to relatives of pts who have died</td>
<td>6.5</td>
<td>9</td>
<td>0.058</td>
</tr>
<tr>
<td>Providing support to distressed junior health professionals</td>
<td>7</td>
<td>7</td>
<td>0.461</td>
</tr>
</tbody>
</table>

4.25 Comparison of the MCC pre-intervention admission assessment tool with other specialist palliative care units palliative care inpatient admission assessment tools, nationally and internationally

Hospices in Ireland and the United Kingdom (n= 268) were contacted. Ten hospices who returned information were exclusively day services or hospice at home services based in the community. Sixteen hospices made contact but did not return documentation. The response rate was 22%, as 58 hospices returned initial assessment documentation for inpatient services.

Table 4.25.1 illustrates the sections or assessment domains included in the returned assessment documents form national and international hospices in percentages. The table further illustrates if the assessment sections were included in the admission assessment document pre-intervention and if the assessment was included in the MPCAT post-intervention.
## Table 4.25.1 Comparison of the pre-intervention and the MPCAT with other inpatient admission assessments

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
<th>Included Pre-intervention</th>
<th>Included Post-intervention MPCAT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinician’s Signature Sheet</td>
<td>21</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Thromboprophylaxis assess.</td>
<td>5</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Demographic and Diagnostic/ Medical Background</td>
<td>100</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Pain</td>
<td>98</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Uses pain assessment tool/form</td>
<td>76</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Physical Examination</td>
<td>55</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Nausea and Vomiting</td>
<td>78</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Appetite/Weight/Diet/ Eating and Drinking</td>
<td>83</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Nutrition Assessment Tool</td>
<td>17</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Mouth Care/ Oral Comfort</td>
<td>83</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Mouth Care/Oral Assessment form</td>
<td>31</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Respiratory/ Breathing /Cough</td>
<td>76</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Physical Activity/ Mobility</td>
<td>54</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Fatigue/Weakness</td>
<td>45</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sleep</td>
<td>78</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sweating/Controlling body Temperature</td>
<td>16</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Elimination</td>
<td>97</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Bowel Assessment Chart</td>
<td>21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive Function</td>
<td>71</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Cognitive Assessment Tool</td>
<td>24</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Delirium</td>
<td>9</td>
<td>No</td>
<td>Yes</td>
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<tr>
<td>Function assessment tools</td>
<td>17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wound Assessment/Pressure Ulcers/Skin Condition</td>
<td>66</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Oedema</td>
<td>33</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Falls Risk</td>
<td>43</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Moving and Handling Risk Assessment</td>
<td>62</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Cot side/Bed rail assessment</td>
<td>14</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Falls Assessment Form</td>
<td>27</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Personal Care</td>
<td>64</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Maintaining /Safe Environment</td>
<td>24</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Work/ Hobbies/Interests</td>
<td>41</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>Communication</td>
<td>77</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Waterlow Assessment Tool</td>
<td>28</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Family/Significant Others</td>
<td>86</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Uses Genogram</td>
<td>79</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Social Situation/Home/ House Details</td>
<td>90</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Social Issues/Support Network/ Systems</td>
<td>83</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>Patient/Carer Awareness/ Insight</td>
<td>86</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Financial Status/ Allowances or assistance required</td>
<td>67</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Difficulties experienced/ Worries/Previous/ Current stressors</td>
<td>69</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Psychological Issues or distress/ Emotion/Mood</td>
<td>67</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Patients ability to cope/What aids coping/Resilience</td>
<td>55</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Family issues/ Relationship /Patients perspective of impact on the family</td>
<td>71</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Depression and Anxiety</td>
<td>55</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Previous mental health history</td>
<td>26</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Risk of self harm</td>
<td>14</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sexuality</td>
<td>57</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Body Image</td>
<td>48</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Ethnic Monitoring/ Cultural Issues/ Rituals to be observed</td>
<td>66</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Spirituality Assessment/Faith Needs</td>
<td>93</td>
<td>Yes</td>
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<td>Carer Assessment</td>
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<td>Bereavement Risk Assessment</td>
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<td>CPR/ Resuscitation Status</td>
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<td>Patient Goals/ Aims</td>
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<td>Consent to share information</td>
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<td>Included Post-intervention MPCAT</td>
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<td>Mood and Symptom Questionnaire</td>
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A pain assessment form was included in 76% of the admission assessment forms. Two of the pain assessment forms returned were the Edmonton classification system of pain. A nutrition assessment form was included in 17% (n=10) of the assessments. This figure does not include those charts that contained the Must tool (nutrition assessment tool) as part of the Waterlow (pressure ulcer risk assessment tool), although 5% (n=7) of admission assessments reviewed had highlighted the Must tool as a separate assessment tool. A prompt regarding elimination including micturition or bowel function was included in 97% of the admission assessment documentation systems. A separate bowel assessment chart was included in 21% (n=12) and 3% (n=2) had a continence assessment chart.

Cognition or confusion was a prompt in 71% (n=41) of the admission assessments. Of these, the Abbreviated Mental Test, Short Orientation Memory and Concentration Test and the Mini Mental State Exam were used to assess cognitive function in 14% (n=8), 7% (n=4) and 3% (n=2) respectively. Delirium was assessed in 7% (n=4) of the admission assessments. Three used the clock drawing test and one used the Confusion Assessment Method. Validated tools used to assess function included the
Palliative Performance Scale in 5% (n=3), and the ECOG in 10% (n=6). One admission assessment used the Palliative Prognostic Index to assess prognosis with the Palliative Performance Scale.

Condition of the skin, wounds, or risk of pressure sore was used as a prompt in 95% (n=55) of admissions. This included utilization of the Waterlow scale in 28% (n=16) the Braden scales in 9% (n=5), and the EPUAP (European Pressure Ulcer Advisory Panel) in 5% (n=3) of admissions. The Hunters Hill (a variation of the Braden pressure sore tool) and the Medley tool were each used in one assessment. Moving and handling needs were included in 62% (n=36) of the admission assessments. A specific moving and handling assessment form was included in 50% (n=29) of the admission assessments. Falls risk assessment was included in 43% (n=25). Of these, 3% (n=2) used the stratify falls risk assessment tool, 3% (n=2) used the Morse fall risk assessment scale.

There was a prompt regarding assessment of carer’s needs in 53% (n=31) of admission assessments. A specific form guiding assessment of carer’s needs was included in 36% (n=21) of these. A prompt to identify the need for bereavement support or risk factors relating to complicated grief was included in 22% (n=13) of the admission assessments and 14% (n=8) had a specific form regarding assessment of potential for need for bereavement support.

4.26 Quantitative results of clinicians views of the admission assessment process and its documentation

The number of health care professionals who responded to the survey to elicit their views of the admission assessment pre-intervention was 40; 27 nurses, 9 therapy and social care staff and 4 doctors. Post-intervention 37 responded, 23 nurses, 9 therapy and social care staff and 5 doctors.

There was no significant difference between respondent’s pre and post-intervention in role, years of palliative care experience, or years at Milford Care Centre. The majority of respondents had between 3 and 10 years experience.
Post-intervention, 77% (n=24) of clinicians felt the admission assessment could be improved in comparison to 82% (n=28) pre-intervention. This difference was not significant. There were numerous suggestions for improvement pre-intervention in respect of the domains to be assessed, the timing, formatting and the disciplines to be involved in the assessment process;

“It is important to commence a plan of care/aim for home and discharge from admission involving all MDT.”

Pre Nurse 0137

“The assessment should be carried out over the first 48 hours of the admission when rapport is developed. Patients are very distressed on admission by very invasive questions. Family members have stated they have already gave all the information to the previous hospital.”

Pre Nurse 0109

Post-intervention, although some respondents felt the admission assessment was improved,

“It’s wonderful! Small bit of rejigging - DNACPR bit, VTE bit to add. Better font, better paper - looking forward to these”.

Post Doctor 0263
There was more emphasis on the length of the admission assessment proforma, the need for more training and the need to differentiate between types of admission, post-intervention.

“I certainly think it is very comprehensive, more so than anywhere else I have worked. I think the main challenge is to keep rotating clinicians of doctors every three months, trained up in completing the documentation.”

Post Doctor 0257

“I find the documentation very long and it is difficult to find specific information as a result.”

Post Therapy and Social 0264

There was a slight decrease in the percentage of respondents who felt there was continued need to improve the documentation of the admission assessment post-intervention at 78% (n=25) in comparison to pre-intervention of 80% (n=25). One fifth of clinicians (n=8) pre-intervention and 16% (n=6) post-intervention were undecided about the need to improve documentation of the admission assessment.

Pre-intervention training was an important theme in feedback from clinicians;

“More SENIOR staff nurses to carry out admissions with doctors during the period of Pall Medical Team rotations. Admission assessments can be a hugely difficult time for patient families/carers - the decision made to come to Milford, the progress of their disease, children perhaps at home - I think perhaps on a "busy" day it is all too easy to forget the "journey" some patients have made to enter the hospice and a good nurse/doctor "introductory mix" is vital to "relay clearly" relevant/accurate details/information of a delivery package of care.”

Pre Nurse 0105

“Clinicians require more training to ensure uniformity no matter what members of the team do the assessment. More training demonstration for doctors new to the area....”

Pre Nurse 0126
There was a significant difference in views in respect of the need for additional training post-intervention in comparison to the pre-intervention. Significantly more health care professionals agreed or strongly agreed that there was “no need for additional training” post-intervention at 52% of respondents (n=14), in comparison to 18% (n=6) pre-intervention (n= 61) (p = 0.006) (see figure 4.26.3). Six clinicians pre-intervention and ten post-intervention were undecided about the need for additional training.

**Figure 4.26.2 Respondents views of need for additional training***

*Respondents were responding to the statement: “there is no need for additional training”

Pre-intervention, clinicians recommended incorporation of symptom assessment tools and more detailed assessment of the spiritual and psychological domains;

“…*Patient symptoms should be assessed on initial assessment and reviewed on an ongoing basis via standardised symptom assessment tool. e.g. ESAS or another relevant tool.*”

Pre Therapy and Social 0108

“…*Better documentation of readmissions required, old and new problems. Somehow encompassing scores such as Waterlow, oral assessment, moving and handling assessments into the document.*”

Pre Nurse 0127
“The admission documentation appears to have all the necessary domains, i.e. symptom control, physical, psychological, social and spiritual. Often, however, there is limited information recorded on the psychological and spiritual. Might be important to have a more in depth measure for depression and quality of life.”

Pre Nurse 0123

However, there was concern from clinicians concerning appropriateness of timing to conduct assessment and the requirement to give patients and carers time to become familiar with the hospice and the need to be sensitive to distress;

“A more in depth assessment of spiritual needs and psychological needs. However timeframe for assessment of same could be expanded to give patient and family time to get to know us and feel more relaxed with us (maybe assess over a 3-4 day period than a 24hr period....”

Pre Nurse 0110

Pre-intervention, the need to focus more on the assessment of spiritual and psychological needs was a recurrent theme in feedback from clinicians;

“Large sections of the admission assessment form are regularly left incomplete. Generally the section regarding spiritual and psychosocial domain.”

Pre Therapy and Social 0125

There was a significant difference in clinicians’ views in respect of the comprehensiveness of assessment of all domains post-intervention in comparison to the pre-intervention. More health care professionals agreed or strongly agreed that “The current admission assessment documentation comprehensively assesses all domains of need (symptom control, psychological, spiritual and social support)” post-intervention at 88% of respondents (n=30), rather than 59% (n=19) pre-intervention (n = 66) (p = 0.01). One fifth of clinicians (n =8) pre-intervention and 8% (n=3) post-intervention were undecided about the need to improve documentation of the admission assessment.
Although significantly more staff agreed that the MPCAT facilitated comprehensive assessment of all domains, some staff continued to express concern regarding the assessment of the patient’s psychosocial and spiritual needs. Post-intervention concern was expressed concerning competency of clinicians completing assessments;

“The psychosocial and spiritual domains are rarely filled in adequately and the responsibility for this needs to be with social work and pastoral care. Not nurses/doctors. Discomfort with difficult conversations is obviously an impediment to the completion of the form for many practitioners. Only those who have completed the advanced communication skills should be filling in the form...the absence of these skills is all too obvious when reading assessment forms”

Post Therapy and Social 0265

Significantly more health care professionals agreed or strongly agreed that there was need for additional evidence-based assessment tools pre-intervention at 73% of respondents (n=24), rather than 19% (n=5) post-intervention (n= 59) (p<0.001). One
fifth of clinicians (n=8) pre-intervention and 18% (n=7) post-intervention were undecided about the need to incorporate additional evidence-based assessment tools.

**Figure 4.26.4 Respondents’ views of the need to incorporate additional evidence-based assessment tools**

![Bar chart showing respondents' views](chart.png)

Additionally, some staff suggested that it would be beneficial if the assessment were reevaluated at a later period in the admission;

“*Assessment of psychological needs/spiritual needs might need to be repeated towards end of admission period or one week after admission, when patient knows staff better and has more confidence in them. Assessment of depression and its implications from therapeutic point of view of patients survival months time might need to be discussed and probably audited as rarely used*”

Post Medical 0256

Pre-intervention the lack of assessment of needs of carers was identified as an area for improvement several times;

“*Current admission does not explore needs of carers*”

Pre Nurse 0136

“A portion should be assigned to check the carer’s needs”

Pre Nurse 0116
There was a significant difference in clinician’s views of assessment of carer’s needs post-intervention in comparison to the pre-intervention. Significantly more health care professionals agreed or strongly agreed that “The current assessment document supports the documentation of carer’s needs.” post-intervention at 87 % of respondents (n=28), rather than 30% (n=10) pre-intervention (n=65) (p < 0.001). A small number of clinicians (n=4) pre-intervention and 14% (n=5) clinicians post-intervention were undecided as to whether or not the admission assessment supported the documentation of carer’s needs.

**Figure 4.26.5 Clinicians’ perspectives concerning assessment of carer’s need***

![Bar chart showing the percentage of clinicians agreeing or disagreeing with the statement “The current assessment document supports the documentation of carer’s needs.”](image)

*Respondents were responding to the statement “The current assessment document supports the documentation of carer’s needs.”

Despite significantly more clinicians reporting that the admission assessment facilitates assessment of carer’s need post-intervention, clinicians continued to identify areas for improvement in respect of assessment of carer’s needs;

“All benefit of getting carer information in such a formal manner when "off the cuff" informal conversations obtain same information. Psychological or spiritual information often not obtained on the day of admission and with nurse off duty, paperwork often not completed although relevant information is collected in 48 hours.”

Post Nurse 0274
4.27 Qualitative results of clinicians views of the admission assessment process and its documentation.

4.27.1 Thematic Analysis

The data from 20 interviews, conducted prior to the redevelopment of the admission assessment was compared to data from 16 interviews conducted post development of the MPCAT admission assessment. As outlined in the methodology chapter, the interviews were analysed using thematic analysis (Braun and Clarke, 2006) facilitated by N-Vivo software.

4.27.2 Profile of Interviewees

Pre-intervention interviewees included 2 doctors, 11 nurses and 7 therapy and social care staff. Post-intervention interviewees included 3 doctors, 8 nurses and 5 therapy and social care staff. Although there were less staff interviewed post-intervention, the years of palliative care experience were similar in terms of mean years of experience and the percentage representation of disciplines within groups.

4.27.3 Thematic Results: Medical and nursing joint admission assessments are beneficial

A major theme from pre and post interviews related to a positive view of the multidisciplinary nature of the joint assessment conducted by nurses and doctors on the first day of admission. Such a process was felt to improve the outcome, allow more efficient use of time and was less burdensome to the patient. Twenty seven members of staff reported that they felt the joint medical and nursing assessment was beneficial and appropriate within the palliative care setting;

“It provides a welcome to the patient as they get the attention of two members of staff for however long it takes and that could be forty five minutes or an hour and it’s a very strong message to a patient, we are listening to you and you really matter”

Pre Nurse 002

The commitment to the assessment process was supported by the management team within the inpatient unit and staff were clear that it was an integral part of their role;
“I know that the CNM’s will say if you are gone for an hour and a half doing an admission you know that would be normal they wouldn’t question any if that or your other colleagues that you could be working with that day wouldn’t take any notice if an admission took that length of time they would have no issue with that”

Pre Nurse 010

Facilitating two disciplines to conduct a joint interview was viewed as a means of simultaneous gathering of information, increased efficiency, reduced repetition of questions to the patient and therefore reduced burden to the patient;

“It works very well as the assessment is with the medical personnel as well so it’s more beneficial for the patient as it’s less time consuming with the two people assessing you at two people at one time as well so you get to know people very quickly.”

Pre Nurse 003

The inpatient unit is a teaching facility which rotates non consultant hospital doctors every three to six months. The data suggested that the quality of the assessment process and its outcome are facilitated and promoted by pairing less experienced staff with more experienced staff to aid learning in how questions can be phrased, responsiveness to cues from the patient and the pacing of the interview;

“The nurses definitely add to I suppose you learn, they ask questions at the start anyway and you take things from how they ask the difficult questions.”

Post doctor 0201

“One of the younger doctors, having a nurse there is a big asset and it is important that it is an interdisciplinary assessment so with that duo agree on what referrals need to be made as a team.”

Pre Doctor 001

One staff member felt that a more appropriate composition for conducting the initial admission assessment might include a doctor or nurse and a member of the therapy and social care staff. A second member of staff suggested that for a small number of admissions, the assessment might be more appropriately conducted by a doctor and a
social worker if the reason for admission related to psychosocial issues.

4.27.4 Time frame of the admission assessment

The majority of staff held the view that the admission assessment should continue beyond the first day for many patients. This view was common to pre and post interviews. Across the disciplines, many staff felt that only part of the assessment should be conducted on the first day. Reasons cited for the extension of the admission assessment were that the patient was often too symptomatic on initial admission, fear of admission to the inpatient unit precluded a full assessment and that a comprehensive assessment of all domains would be too exhausting for patients. Acute and severe pain, nausea, fatigue and breathlessness were cited as common symptoms which required intervention prior to further assessment;

“Sometimes also they might come in a pain crisis we get on top of their pain quickly and not bombard them with questions. They are usually exhausted and we go back to it that may be twenty four hours later.”

Pre Nurse 001

“I mean there is no point in asking someone about their psychosocial or spiritual needs if they are in pain and distressed and uncomfortable. Comfort comes first basically.”

Post Nurse 0206

Many staff across the disciplines felt that patients needed an opportunity to process and recover due to the psychological implications of the admission to the inpatient unit;

“most of our patients don’t even want to come in here, they fear coming in here and then they come in and we are bombarding them with all these questions, you know I think we need to go in a bit more gently with them and assess them on that level first I suppose”

Pre nurse 005
“I think it works very well albeit I would have reservations about the length of it. I would prefer if it could be broken down into maybe the spiritual assessment and carer’s assessment and the personal things would be done after a good night’s sleep when people have settled in and they are not traumatised about coming in here”

Post therapy and social care Staff 0204

As a consequence of the patient’s experience of anxiety and fear associated with the admission, many staff felt that for some patients it was inappropriate to conduct an assessment of psychosocial or spiritual distress until a patient has time to adjust. Whilst there was considerable concern that it was important to offer appropriate support to patients at the time of the admission due the fear expressed by patients, it was also suggested that the assessment is more effective if the patient has an opportunity to reconcile the fear experienced in anticipation of admission and their experience after admission;

“Often their fears are highest on the day they come in as opposed to the next morning”

Post Doctor 0202

“I also don’t think that the initial assessment is the time really to assess psychosocial and spiritual and existential issues unless they are actually volunteered by the patient. Am I don’t think the initial assessment form should be completed on a once of basis I think it should be added to as new information comes forward”

Pre doctor 002

4.27.5 Assessment of psychosocial and spiritual needs are particular areas that require further attention

Pre-intervention the majority of staff (16 of the 20) reported that while there was a comprehensive assessment of physical symptoms, there was considerable room for improvement in assessment of psychosocial and spiritual needs. There was a consensus amongst many of the staff across the disciplines that the assessment of psychosocial distress and spiritual needs was not equivalent to the assessment of the
pain and physical symptoms. Many staff reported that these areas of the assessment were not completed at all as part of the admission assessment;

“The section on exploring existential domain is very open to interpretation and if I am to perfectly honest is always incompletely filled in”

Pre doctor 002

“I wouldn’t say they are equally assessed. I think if a patient comes in with pain then pain will be assessed in every shape and form and less attention will be given to the emotional side of the problem which may be completely significant.”

Pre nurse 002

“I suppose psychologically we touch on but we don’t delve into that either and that could be important as with some people their pain can be more psychological thinking of kids at home or different worries they have financial or something, we don’t look into the financial on admission and that can be one of the bigger worries for social worker input then we would have picked up from the assessment.”

Pre nurse 003

“I think that there is maybe more emphasis on the physical side like the symptom management than there would be on the other factors like the holistic approach.”

Pre nurse 005

“Psychosocial and spiritual and I notice this is something that is often left blank”

Pre therapy and social care staff 006

“The psychosocial can be left blank, there is one section on body image say and the majority of the time this isn’t completed, in the spiritual area they are often blank also so although the documentation is there they are often not completed.”

Pre therapy and social care staff 007

Reasons for non completion of assessment of psychosocial and spiritual needs included a lack of confidence, lack of clarity of areas to be assessed, disagreement of
role responsibility and concern regarding appropriateness of timing and potential to cause the patient distress;

“I think the physical is definitely concentrated on probably because of the training of the people assessing would be more focused on the physical rather than the psychosocial and the spiritual and emotional needs of patients and carers.”

Pre therapy and social care staff 006

Staff suggested that while the outcome of the assessment was prompted in the pre-intervention admission assessment, the documentation did not support or facilitate a standardised assessment;

“in the sense of it doesn’t really guide you as to what questions or areas to probe and that and that some of the headings then can be interpreted quite differently by various different people, the headings that I mean would be spiritual, existential domain.”

Pre Doctor 002

A view was shared that lack of comprehensiveness of assessment may relate to a lack of training or competency and confidence to conduct assessments. It was suggested that it may be more appropriate for disciplines such as social work and pastoral care to conduct the assessment of psychological and spiritual need;

“So from that point of view I think it’s insufficient (referring to assessment of psychological and spiritual needs) as I wouldn’t expect from a doctor and a nurse to have those competencies or chaplaincy competencies”

Pre therapy and social care staff 002

Staff reported they found assessment of psychosocial and spiritual needs difficult to conduct. Staff were of the view that it was necessary to afford the patient time to get to know and trust staff and that assessments more appropriate 2 or 3 days after admission;
“I suppose the psychological is much more abstract, it can be harder to quantify it or tie it down for its assessment management you know”

Post Nurse 006

“I think like I say it’s very hard to go in there initially and just ask all the questions about everything (referring to assessment of psychosocial and spiritual needs)”

Pre Nurse 005

“but I do think sometimes more information could be gleaned (referring to assessment of psychosocial and spiritual needs) and if not there, the day after or two days after by somebody else by someone who approaches it in maybe a slightly different manner….I think it’s easier for someone to assess something out of ten than assess something not touchable”

Pre Nurse 002

“it’s not always possible now in fairness because if for instance say patients have difficulties or family issues at home say you know if there’s any cracks in the family network at all they will widen when there’s strain on them but they won’t know us well enough to say this so it will be four or five days when you have built up a rapport with them and it’ll come out I’m not talking to my sister or whatever and we can then refer them on to social work or pastoral care or whatever so it’s not always possible to do it all the very first time you meet them you have to build up a relationship with them really.”

Pre Nurse 009

Post-intervention many staff reported that assessment of all domains of need including assessment of psychosocial and spiritual needs were increasingly facilitated and supported through the assessment process and assessment proforma;

“I think it’s very holistic and that’s what I like about it”

Post doctor 0202
“It’s much clearer now that each domain of the patient is assessed so before I think the assessment documentation mainly, people were documenting the physical elements of care of the assessment process whereas now you can clearly identify if their psychosocial and spiritual issues as well as physical issues, and I just think it’s very clear the assessment that has been done”

Post therapy and social care staff 0203

“I think it’s better than what we had, so I do believe it’s more holistic”

Post nurse 0208

However, despite the provision of evidence-based guidance on the assessment of psychosocial and spiritual distress and assessment of carer’s needs, some participants held a view that the social work and pastoral care staff should have responsibility for assessment of these domains. There was a view that conduction of assessment of these domains by social work and pastoral care would be a safer from the perspective of the patient and a more effective process in respect of outcome of the assessment;

“if the pastoral care or social work who ever might have more time that might be more appropriate or might be able to provide a safer setting or you know

Post nurse 0202

“we do leave it more to the pastoral care team and the social worker but then they have time to go in and just sit down whereas we know you can get into a conversation and you have to leave in the middle of it”

Post nurse 0203

“I found those a bit for the (referring to assessment of carer’s needs), certainly for an initial assessment I think that to me would be more appropriate if a social worker came to, came and spoke to them, if we felt absolutely they need to be referred to social work then the social worker would ask those questions more so than a nurse on admission, you see on admission as well an awful lot, from my point of view”

Post nurse 0204
Additionally, concern was expressed that if an assessment was initiated but not comprehensively and appropriately completed it may make it more difficult for other staff to investigate issues with patients;

“That leaves it more difficult to go back and ask those questions or get that information because it’s been touched on in the initial assessment if you understand what I’m saying and then for me it’s ‘well I’ve been asked those questions’ then for me it’s saying they’ve been touched on but haven’t been answered adequately they haven’t been gone into in depth so it takes a bit more time to get to where they want to be whereas if it wasn’t addressed then it would be fine I could go and say listen how are you, as part of the assessment process there was a section I thought it would be better to have a chat and go through it then but if it’s been opened it starts to go
damp and stale and it’s hard to go there again. That’s my sense.”

Post therapy and social care staff 0204

Staff shared a view that assessment of psychosocial, spiritual distress and carer’s needs as suggested by the guided interviews was difficult. It was felt the guided interviews were too formal, that asking questions was too direct an approach on the first day of the admission, particularly if the patient was distressed on admission. Concern was expressed that if on assessment a patient became distressed, they may not be able to adequately support patients within the time allotted to the admission assessment;

“I suppose sometimes a psychological assessment isn’t easy to do when you’ve just met somebody and they can be quiet emotional and then you’ve mightn’t have the time to give them as much support as you feel that they need when you’ve opened up these kind of areas”

Post Nurse 0205

“I still feel having done several admissions I still feel the carer’s assessment and the spiritual and psychological assessment is a little bit too intrusive particularly for the first at least 24 hours of assessment I don’t believe it’s appropriate I understand the rational but while it’s very good to get an assessment of their spiritual feelings of the patient and carer’s perspective that I just feel it’s a little bit intrusive having asked a
lot of physical questions about their physical wellbeing….I think for me personally it’s easier to ask questions about peoples physical health”…..I would have never asked them (referring to guided interviews of psychosocial needs), I would never ask a patient”

Post Nurse 0202

“the nursing staff but we would certainly have a more I think a more basic or general assessment of the carers in the sense of we would ask them like “what help do you have at home what help do you feel you need” I think a bit of the carer’s questions goes into the psychology kind of and I wouldn’t personally be asking them those kind of in depth questions, certainly at the admission”

Post Nurse 0204

“the carer’s assessment and the psychological seems to be not being filled in till last day I suppose, maybe it’s just that, is there a fear element there with people as well that you have it down in black and white and I don’t know ….I don’t know why I said fear now, but I suppose it’s maybe that you’re not writing it clearly that its, don’t know, and all these questions prompt you and then they mightn’t, that mightn’t be what they want to talk about”

Post Nurse 0205

“when it’s psychological and social issues it’s actually harder to write your admission because there’s nothing concrete that you can say”

Post Nurse 0203

4.27.6 Changing practice takes time

Implementing changes within clinical practice is an iterative process that staff must feel involved in and have ownership of. Significant consultation and discussion is required to identify changes to clinical practice that are feasible and effective. Effective changes to practice require a process of trial, review implementation of changes further to feedback and retrial;

“I think it’s good that you have consulted with colleagues who are filling it out and experiencing it because there is a sense of being listened to so that’s good. When
“you assess the document the tendency to say what you feel should be changed so what I’m not saying is I don’t think this is a bad document I think it’s effective, I think it’s been improved as it’s been listened to and I think probably over the next six months it will be good to continue to look at peoples suggestions for the document and changing what is appropriate because I think it is improving with those alterations but I think that’s been very useful.””

Post Doctor 0203

Additionally staff require time to adjust to changes to clinical practice before their effectiveness can be fully evaluated. Initial negative reactions to change will not necessarily be retained or used to evaluate the appropriateness of a change to practice;

“Just it wasn’t as daunting as I think we expected once we got into it”

Post Nurse 0203

“It looks daunting with all the questions and that but it’s not really when you get used to it you can go through it and you know how to either ask or not ask them if they are able for it or not.”

Post Nurse 0206

Staff felt pressure to complete the full assessment on the first day as that had been the practice prior to the intervention. A tension was created when this was not appropriate with an individual patient despite guidelines which encouraged the appropriate phasing of assessment of domains over the first 48 – 72 hours in accordance with the presenting condition of the patient;

“I think people still, I suppose from my perspective I don’t feel that we need to get it all done on the first day, a lot of people feel very stressed about that. I don’t because I believe assessment is ongoing anyway…I think the element of change is very hard for the nurses and I’m still not too sure about that because a lot of their documentation didn’t really change that much and it was the doctors that really changed more. I think everyone just got a little caught up in the carer’s section and feelings that they had to do it on the day of admission but then it’s quite interesting
now that some people now see it because we have been talking about being involved in research and that, that it’s important that we contribute to patient care and now some people see it as contributing to patient care and that we are involved in a piece of live research which I think is really good.”

Post Nurse 0208

“Well to be honest I think it’s working better now and mainly because maybe I’m working better with it because do you remember previously we thought we had to get everything done on the first day, that doesn’t work. So now that we know that other people can come along the following day you don’t have to have everything filled in because it’s not possible”

Post Nurse 0206

“there are bound to be teething problems and a bit of ironing out the creases and I suppose what we have to realise is that admission is an ongoing process and we are still getting bogged down with saying everything has to be done on day one”

Post Nurse 0207

Introducing change to clinical practice requires careful consideration of the processes and structures that support the clinical practice also and how they might be adjusted in order to support the changes to practice. Introducing changes to the assessment process, required careful consideration of the content; determination of the most appropriate disciplines to conduct the assessment, timing of the assessment and a comprehensive training plan. The change process requires ongoing assessment of and reflection on practice and review of audit results in consultation with staff;

“I just think overall it’s a valuable tool and even though I had very great doubts initially that this may be a paper exercise I find the assessment form combined with the new Meitheal process it’s clearer, it’s more concise and easily accessible. It makes the work and the access to support patients more possible.”

Post Therapy and social care 0205

I just think there are still practice issues around the documentation and I do think we have gotten very caught up in the documentation and filling it out as opposed to a
practice of re-checking in with the patient and the families so I think that’s what we need to work on next. We will always be tweaking the documentation and that’s fine but it’s now more around a practice issue and us as practitioners all checking in that we have done everything and who’s checking what and building that into our practice.

Post Nurse 0208

4.27.7 The changes that have occurred: Care planning and communication is facilitated

There were several staff who felt that there were positive outcomes as a result of the redevelopment of the admission assessment process and its associated documentation. These changes included increased comprehensiveness of assessment, assessment that is more guided by the documentation, improved communication between disciplines, earlier referrals to members of the multidisciplinary team, and improved care plans which were responsive to patient need;

“I think initially you are going oh my God it’s so long to fill out but if you didn’t have it in the beginning and we are only doing this three months (referring to length of rotation in the inpatient unit), I’ve never had the background of palliative care, it’s perfect. I’ve never worked in palliative care apart from patients in the hospital obviously but in terms of the detail in here about their needs, the dietician, the complementary stuff, the social needs, spiritual or financial or whatever that type of stuff we don’t really get involved in so it’s really well broken down from that point of view…. I like the last page (referring to the care plan summary) I think the referral system, that’s great cos you just tick dietician and everyone goes to the last page, you have your care plan and you know who needs to get involved the next day. That works really well”

Post Doctor 0203

“I think it’s quite exciting, I think it does have a positive impact on patient and family care”

Post Nurse 0208
“I feel quiet informed before I’d ever met the patient so that if there’s anything that I feel I need more detail on I can kind of go straight to that if that makes sense

Post therapy and social care staff 0202

“I remember of the old section the referral, the referral was at the very front of the chart and they were often not filled in so I think because of after the plan I presume its easier for the doctors because it’s part of the plan to see the therapies straight away so they can tick I think it’s easier more often than not the referrals were not filled in before …. I had to find out through other means if they were for physio or not the other way (referring to the pre-intervention admission assessment documentation) so it was a little bit it wasn’t very clear”

Post therapy and social care staff 0201

Pre-intervention, a view was shared that discharge planning should be initiated earlier in the admission assessment process for the purposes of a shared understanding among the multidisciplinary team, of the purpose and probable outcome of the admission;

“That needs to be clarified is discharge planning not necessarily straight away in that assessment but certainly within twenty four hours as to not do that just leads to ambiguity and confusion and it’s very important that the plan of care is understood by everybody.”

Pre Nurse 006

Staff expressed a view that the care plan was communicated more clearly as a result of the revision of the assessment process and associated this with an increase in comprehensiveness of domains of palliative care assessment.

““I think it’s a lot clearer from reading through the patient’s chart that a comprehensive assessment has been done …I think it’s just you’re not going through lots of notes to try and find the information that you want it’s all in one place and it just I just think it’s very comprehensive it assesses all the domains of care but also
then like there’s very clear plan of care following it so it give a really good page that summarises like the issues that have been identified and then what the plan of care is following identification of them issues and then if you, which members of the team then are referred onto so it’s all in one place and it’s easy to access and then it’s very comprehensive and there’s a clear plan of care following the assessment”

Post therapy and social care staff 0203

“The home circumstances do you know that seems to be looked at now sooner do you know”

Post Nurse 0205

Pre-intervention an assessment of carer’s needs was identified as a domain which should be included as part of the initial admission assessment by many staff;

“The carer’s needs aren’t really documented anywhere in the documentation.”

Pre therapy and social care staff 007

An assessment of carer’s needs was included in the revised admission assessment process and this was welcomed by staff as appropriate and an important component of an assessment within a palliative care context within a palliative care context;

“It involves family and that is an area that is more looked at in comparison to the old admission……the carer’s needs okay and their aims more suppose documentation about the carer rather than our opinions okay. You know they are getting to have their say”

Post Nurse 0201

“I really like the carer’s assessment as well I think it’s really important to try and capture the carer’s perspective because looking after them this is important”.

Post Nurse 0208
4.27.8 Areas for improvement and further review

In addition to issues relating to confidence and competence, and the integration of the process changes relating to the admission assessment already discussed, there was concern expressed in both pre and post-interviews regarding the length of the assessment process and associated documentation. Concerns were expressed almost equally in that eleven staff made references that the assessment process was lengthy or long pre-intervention and ten post-intervention.
Chapter 5 Discussion

5.1 Conducting the research

This chapter considers the key findings of the research and outlines implications for policy and practice in the area of palliative care. In addition, the chapter provides a synthesis, analysis of results, critical reflection of and contextualisation of the study’s findings with regard to the published literature. The strengths and limitations of the research are considered and contextualised in the context of palliative care. Finally, recommendations for future research in the area are proposed with rationalisation for the same relative to current policy.

Within Palliative Care, effective treatment of a patient’s symptoms and subsequent needs are predicated upon comprehensive and accurate assessment. Central to this is the quality of patient-physician communication in facilitating the prioritisation of goals of treatment based upon a comprehensive assessment (Heavan and Maguire, 1996; Stajduhar et al., 2010). This study set out to contribute to the knowledge-base relating to the admission assessment within specialist palliative care settings. The study is unique in both its approach and breadth and has significant implications for the work practices of specialist palliative care services within Ireland and internationally. Further, this research set out to inform the area of patient care through comprehensive evaluation of a contemporary admission assessment, comparison of the outcome of evaluation with the literature and the existing knowledge base. The need for further guidance to facilitate comprehensive holistic assessment of palliative care patients is evidenced by the work of other authors both in United Kingdom and in Ireland (Cancer Action Team, 2007; McIlfatrick, 2014).

A mixed methods approach with five phases was applied. These included;
(a) A systematic literature review to identify evidence-based assessment tools and assessment guidelines appropriate for use in a specialist palliative care inpatient unit. Coupled with this was the collation of admission assessment documentation systems in Ireland and Britain which were compared and contrasted.
(b) Quantitative interviews of patients to facilitate patient reporting of the severity of symptoms and audit of the clinician’s initial admission assessment. The audit of the
outcome of assessment was compared with the patient’s self-rating. The methodologies were employed pre-intervention to capture a baseline measure of the effectiveness of the admission assessment.

(c) A comprehensive systematic literature review coupled with an extensive consultation process with expert clinicians informed the revision and redevelopment of the initial admission assessment process and documentation (the intervention). Central to this was the incorporation of evidence-based assessment tools, screening tools and interview guidelines. In determining tools for inclusion to the admission assessment, priority selection criteria included; validation of tools within a palliative care population; minimisation of burden to the patient and feasibility of the tools within clinical practice.

(d) The same techniques as had been employed pre-intervention were employed post-intervention to determine effectiveness of the admission assessment process. This process facilitated comparison of results.

(e) The admission assessment documentation was re audited a further six months later to determine the integration of the Milford Palliative Care Assessment Tool (MPCAT) to practice.

The views of Staff as to the effectiveness and appropriateness of the admission assessment were sought pre and post-intervention. This took the structure of questionnaires (quantitative) and interviews (qualitative) regarding the admission assessment process pre and post-intervention (MPCAT).

5.2 Conducting research with palliative care patients and their families, ethical considerations

Of the 587 patients who were admitted during the time frame of the study, the total number of patients who agreed to participate was 83 or 45% of those patients who were well enough to be approached. Consequently, only 14% of patients of consecutively admitted patients participated. This is not dissimilar to the inclusion rate in other studies involving interviews with palliative care inpatients (Reeve et al., 2008; Arnold, 2011) and higher than some (Kelly et al., 2004; Wilson et al., 2007). Engaging patients and family members in research in a palliative care setting can be challenging due to high attrition rates, rapid changes in the patient’s condition and
problems in engaging patients due to ‘gate keeping’ by health professionals (Rinck et al., 1997; Ewing et al., 2004a; Ryan et al., 2012).

Numerous strategies were considered at the design stage of the study to facilitate the collection of a reasonable sample size in accordance with recommendations within the literature (Harris et al., 2008b; Duke and Bennett, 2010). These strategies included consideration of the research design to minimize burden to the patient and impact on the clinical environment. Clinicians were also provided with explanations of the research design and potential value of the outcome of the work. Additionally, the use of an exclusion form was suggested as a useful strategy to minimise ‘gate keeping’ by clinicians as they are encouraged to be objective in their decision making (Cassarett and Karlawish, 2000; Gysels et al., 2012). The researcher asserts that the inclusion rate of palliative care patients is attributable to the implementation of the aforementioned strategies.

A further ethical consideration is that the high numbers of patients who are too unwell to participate and/or who choose not to participate negatively impacts the representativeness of the sample and thus reduces the value of conducting research (Addington-Hall, 2002; Duke and Bennett, 2010). There is concern that to engage palliative care patients in research potentially adds further burden to patients who are already unwell, may add to distress as well as detract from time with family and friends (De Raeve, 1994; Janssens and Gordijn, 2000). Conversely, others suggest that it is unethical to exclude patients at end of life on the basis of their illness (Seymour and Skilbeck, 2002; Harris et al., 2008b). These authors and others suggest that patients as autonomous individuals have the right to make an informed choice (Berry, 2004). The findings of this study supports the work of other authors that research with palliative care patients is valuable and feasible but requires careful consideration at all stages of the process (Cassarett and Karlawish, 2000; Pessin et al., 2008).

Thematic analysis of participant’s views of this research did not suggest that participation was burdensome or distressing. Considerable time was given to providing the patients with a verbal explanation of the research, the nature of the questions that would be asked and checking their understanding of the process. It is
essential that palliative care patients engaging in research do so voluntarily (Sweet et al., 2014). The principles of process consent were employed when engaging with potential participants (Munhall, 1991; Usher and Arthur, 1998; Addington-Hall, 2002; Seymour and Skilbeck, 2002; Harris et al., 2008a). Process consent requires collaboration with the research participant during the course of the study. This includes the provision of detailed information about the study and periodic rechecking of consent to continue. Consequently, the participants may have been empowered to be open with the researcher as they felt secure that their participation was 'safe' and within their control.

The participants may have benefited from the opportunity to reflect on and describe their experience of illness and to have their story heard (Jordhøy et al., 1999; Pessin et al., 2008). Similar to reports in the literature, some of the patients in this study were altruistically motivated and appreciated the opportunity to give back and help to improve health care organisations (Williams et al., 2006; Gysels et al., 2008). Indeed, the opportunity to find meaning in illness and consider their legacy have been reported as significant factors in the acceptance of illness and an effective intervention in alleviating psychosocial distress at end of life (Chochinov et al., 2005; Lloyd-Williams et al., 2013).

Naturally, it is of fundamental importance to consider the research process carefully when engaging palliative care patients (or their families) in research. Seeking ethical approval with the consequent requirement to critically appraise the application of the research methodology is an important component in a process that seeks to avoid harm. As part of this process, thought should be given to sources of potential harm to participants including burden and distress. Issues of confidentiality and privacy and how these issues should be managed or remediated in line with the principles of the Declaration of Helsinki (World Medical Association, 2008) must also be considered. It is important that clinicians providing care determine if patients are well enough to be approached to participate in research. However, this should not be confused with clinicians making a decision on behalf of patients about participation. Rather, it is a safety mechanism to avoid disturbing very unwell patients or causing harm to patients. The decision to participate in research, further to provision of information of the risks, benefits and constituent components of the research, should
always rest with the participant. Patients have a fundamental right to choose to participate if that is their wish.

Many authors have experienced difficulty seeking ethical approval from research committees to engage persons at end of life in research (Cassarett and Karlawish, 2000; Ewing et al., 2004a; Mc Loughlin, 2010). Presentation to the ethics committee and further explanation of controls to be employed was required when seeking ethical approval for this study. No element of the study was objected to or denied ethical approval. Comprehensive attention to ethical issues may have highlighted that there was sufficient sources of support, on site governance and also of the bona fides of the researcher (Seymour and Skilbeck, 2002; Seymour et al., 2005). Authors have highlighted the necessity of specific end of life training for palliative care researchers in order that they may be appropriately cognisant of the needs of palliative care patients (Clark et al., 2000; Agrawal and Danis, 2002). The researcher would certainly concur with this, and was very aware of the importance of using effective communication (as described in section 5.3).

5.3 Completion rate of the patient interviews

The interviews conducted with patients included assessment of issues related to identification of physical symptoms, social needs, existential distress, depression, issues related to personal acceptance, relationships and finances. The interview tools employed were carefully chosen as they facilitated enquiry to empirically identified palliative care specific domains of need (Emanuel et al., 2001; Kwon et al., 2006; Cleeland, 2009). The high response rate to questions (see Table 4.12.1) demonstrates that patients are willing to consider and discuss these issues early in their admission. These narratives provided rich information as to the patient’s acceptance of their illness, their sources of support and their fears for the future.

The interviews were carefully conducted at a location, time and place of the patients choosing. The researcher was cognisant of the significance of communication during interviews with patients. The interviews were conducted using a patient-centred approach including sensitive empathetic communication skills which sought to avoid normalising patients emotions or blocking a patients expression of emotion.
(Wilkinson, 1991; Mead and Bower, 2000; Stajduhar et al., 2010). The factors critical to successful interviewing were carefully considered and employed. Micro skills such as active listening, open body posture, silence, the use of touch when appropriate, assisted the researcher to be truly present with the patient as he/she told their story. The researcher was aware that she was meeting the patient on several levels- a person to person connection and she was privileged to be invited to listen to their story, but also as a researcher. The researcher was comfortable with meeting the person on these planes; partly because of her considerable clinical experience in palliative care.

Using these skills, in combination with tools which comprehensively enquired about palliative care specific domains of need, patients were willing to be open about the impact of the illness and share their experience. There were occasions when the researcher asked had the patient discussed with a clinician an issue the patient had raised during the course of the interview. If the patient answered that they had not, their permission was sought to report it to the appropriate member of the team. It is important to ensure that any information relevant to the care needs of patients is communicated to the clinical team with the consent of the patient (Duke and Bennett, 2010). It may be that in certain instances patients gave information that had not been divulged to the clinical staff as they perceived the researcher to have more time than clinical staff and were therefore more open with the researcher (Seymour et al., 2005). Other authors have reported that one of the motivations for patients to participate in research is an opportunity to tell their story to a person they perceive as having time to listen (Barnett, 2001; Gysels et al., 2008). However, these results may also challenge suggestions from some staff that assessment of all domains of need, including psychosocial and spiritual distress, is inappropriate early in the admission. The results suggest that utilisation of empirically derived tools which comprehensively assess palliative care domains enables communication with patients. A systematic focussed assessment aids identification of need which can then be responded to (Osse et al., 2004; Scandrett et al., 2010).

No patient reported that they found the questions distressing. Patients frequently reported that they found the interview helpful. Understanding a patient’s psychological and spiritual response to their terminal illness is an essential
component of end of life care (Rosenblatt and Meyer, 2012). The results indicate that patients are willing to engage in discussions about their dying experience and some described the discussion itself as beneficial. Patient’s motivations to participate in research also include, altruism, a desire to share their story and wish to give back to, or impact the service. Furthermore, the concept that participation itself as being perceived as therapeutic to the patient has been widely reported in the literature (Gysels et al., 2008; Pessin et al., 2008; Gysels et al., 2012).

5.4 Conducting research with staff

Mixed methods research provides a rich opportunity to illuminate the perspectives of staff and to compliment the numerical representation of views gathered through quantitative research. The response rates of 62% (Pre) and 55% (Post) intervention in respect of returned qualitative questionnaires from staff were somewhat lower than in other studies, despite explanatory sessions prior to initiation of research and reminders. Some surveys of doctors and nurses in palliative care have reported response rates of 70% and 76% (Addington-Hall and Karisen, 2005; Vejlgaard and Addington-Hall, 2005). However, there have been lower response rates reported by other authors of studies involving hospice staff (e.g. 52%) (Kirsh et al., 2004). Reasons for non-participation may include that some disciplines are not directly involved in the admission assessment process and therefore may not have prioritised participating in research to evaluate the admission assessment. Equally, the clinical environment in which this research was set is busy and clinicians may have felt that their clinical workload had to take precedence and therefore that participation in research was of less importance (Casarett et al., 2002; Seymour et al., 2005).

5.5 Reflexivity

Reflexivity was an important tool in the conduction of this research. Used effectively reflexivity facilitates minimisation of bias and increases the validity of results of research (Finlay, 2002). Aids to reflexivity incorporated in this research included consultation with the steering group, utilisation of a reflexive journal and multiple rounds of coding and refinement of resultant themes and sub themes from the qualitative data. These tools and processes were vital to the conduction of this
research, in that they supported the researcher to critically examine what they were doing and why (Mason, 2002). As a long standing employee of the organisation in which this research was situated and given that the intervention that was being evaluated was developed by the researcher, investment in processes which supported continuous evaluation and critical reflection were essential. It was vital that the research design and planned methodology were critically appraised in consultation with the steering group prior to implementation in order that they might be as comprehensive and as robust as possible (Symon et al., 2001; Finlay 2002). The journal was necessary to monitor reactions to interviews, impact of the research and effect on the researcher’s feelings and emotions (Ahern, 1999). By investing time in considering feelings, opinions, values and perspective to encounters with both patients and staff the researcher is enabled to illuminate potential biases in the conduction of research (Cassell and Cymon, 2004). This became particularly important at the time of qualitative data collection, analysis and presentation of qualitative results. By considering the beliefs and assumptions that the researcher was bringing to the research process the researcher was cautioned to carefully examine whether the data supported the codes being generated from the qualitative data. The researcher was conscious of the potential of confirmation bias in that more attention might be paid to the data that supported the views of the researcher (Soeken and Sripusanapan, 2003). Through cautious examination and re-examination of codes, some themes were abandoned as the data to support them was insufficient. By considering alternative interpretations and being suspicious of whether the researcher’s own beliefs and opinions are impacting the analysis process, afforded increased vigour to the analysis process and increased the validity of findings.

The conduction of the research was a significant undertaking which was particularly challenging for the researcher. Despite years of clinical experience it had been a number of years since the researcher had routine daily contact with patients or families. The initial nervousness experienced when conducting interviews with patients was unexpected and thankfully short lived. The generosity and openness of patients and their families was inspirational and ensured that data collection was a particularly enjoyable and thought provoking phase of the research. There were many moments that will always remain with the researcher including the patient who when asked “How much does religious belief or your spiritual life contribute to your sense
of purpose?” replied “It’s just me and the worms my girl just me and the worms”. In reply to the same question another patient paused, looked out the window and then replied “I know he (referring to God) will look after me”. Both patients were absolutely confident in their beliefs. It was the strength of their conviction and apparent associated peacefulness which was most thought provoking to the researcher. The researcher was saddened by the number of patients who reported that the child abuse scandals in the Catholic Church had impacted their religious beliefs. These patients appeared to have less access to the spiritual comfort that may have been afforded to them, if their trust in the church had not been so damaged.

There were many times particularly in the data analysis, results generation and write up phases that the researcher felt almost overwhelmed and had recurrent thoughts of “I can’t do this”. It was not any one individual task that was particularly problematic. However the breadth and volume of the work to be completed and associated impact on free time and personal life was particularly challenging. Having multiple sources of support including the steering group, staff on the ward who were supportive of the intervention, access to a statistician and supervisors all offered different types of support at various stages. Having multiple and varied sources of support were essential. Conduction of research of this type, which is of significant breadth and which challenges the practise of others is arduous and at times potentially isolating. Possibly the staff on the ward and the steering group members were the most important in supporting the researcher to implement the change process. They were the closest to the conflict being generated by the change process and their belief and faith in the intervention sustained the researcher. The words of one staff member resonated with the researcher and were of particular sustenance: “Faith or fear, choose!” These words will persist with the researcher into the future.

5.6 Effectiveness of the new admission assessment

Post-intervention results indicated significant improvement in documented evidence of assessment of key symptoms and issues relevant to the key domains of palliative care. These results indicate that the MPCAT facilitates more reliable and consistent assessment of patient need. Consistent, coordinated and comprehensive assessment of patients needs are likely to result in improved outcomes for patients and carers.
(Ferris et al., 2002; Weissman and Meier, 2011). Significantly, increased concordance of outcome of clinical assessment with the patients self-rating of symptoms was evident. The increased likelihood of symptom recognition as a result of implementation of the MPCAT enables increased opportunity for appropriate intervention and consequent improvement in care provided. Tools included in the admission assessment are evidence-based and facilitate a more comprehensive assessment of the most common symptoms experienced and key domains relevant to palliative care. Authors have reported that standardised systematic assessment is a critical component of a comprehensive admission assessment (Walsh et al., 2000; Strömgren et al., 2002; Homsi et al., 2006). The findings of this study support this and the increased evidence of documented assessment, which was maintained at the second audit phase, indicates that the MPCAT is clinically feasible and relevant to daily practice.

The redevelopment of the admission assessment was grounded in empirical evidence within the published literature but carefully crafted further to extensive consultation with senior clinical decision makers within the specialist palliative care inpatient unit. The combination of evidence, time, critical reflection and consultation with expert clinicians and practitioners bridged the divide between the ward and the classroom (Kenny, 2003; Curry et al., 2009). Comparison with the literature and standards relevant to palliative care identified gaps in the assessment process including lack of assessment relating to delirium (International Association of Hospice and Palliative Care, 2012), prognosis (Maltoni et al., 2005), resuscitation status (Department of Health, 2008) and preferred place of care at end of life (National Institute for Clinical Excellence, 2004; Department of Health, 2008). The review of assessment documentation returned by other Irish specialist palliative care providers indicated that similar gaps were evident. Only one other Irish inpatient unit was formally assessing for delirium at the time of data collection. None of the other services were documenting whether a patient was for resuscitation or investigated their preferred place of care at the time of admission to service.

One of the key elements of success was that the assessment process in its totality was considered in partnership with the personnel who would be implementing the assessment. This meant that evidence-based tools were chosen which overlapped or
were mutually beneficial and allowed for greater efficiency in assessment procedures. For example, some of the questions in the cognitive tool Blessed Short Orientation Memory Test (SOMCT) (Arsène and Lassaunière, 2000) which is used primarily as a measure of general cognition can also be used to assess attention as part of the assessment of delirium in Confusion Assessment Method (Ryan et al., 2009). The score of the Palliative Prognostic Score (Stone et al., 2008) is calculated by using the results of the Palliative Performance Scale (Olajide et al., 2007). Similar questions were asked in the assessment of carers needs as had been asked in the assessment of the patient’s psychosocial needs. This facilitates checking of the congruence between perception of the patient and carer in respect of a number of issues as shall be explored further (see section 5.7.7). By considering all elements of the admission assessment process at the same time there is an increased interconnectedness between the constituent parts that significantly adds to the effectiveness of the process. The feasibility of completion of a comprehensive assessment is increased as a result of this interconnectedness which reduces the number of questions to be asked and consequent burden to the patient.

The time to complete the admission assessment (including its documentation) was averaged over ten assessments, at sixty five minutes post-intervention. More complex admissions have taken up to ninety minutes. An admission assessment of this duration is felt to be appropriate further to consultation with senior clinical decision makers on the inpatient unit. It is thought to be an increase in time required to complete in comparison to the pre-intervention admission assessment process. Although the average time to complete the pre-intervention assessment process was not captured formally, it was anecdotally reported to be 45 minutes to one hour, depending on the complexity of the patient. However, pre-intervention the qualitative interviews make reference to the interviews of 1.5 hours for patients with complex needs. There was almost the same number of references of concern by staff with regard to the length of the admission assessment pre-intervention as there was post-intervention. There is a requirement for a shortened admission assessment focussed on responsiveness to the patients’ needs in the dying phase for patients who are imminently dying. It is important to balance comprehensiveness and quality of assessment against burden to both patient and staff (Bruera, 1996; Arseven et al., 2005).
The number of referrals to members of the multidisciplinary team within the first twenty hours of admission to service increased significantly further to introducing the MPCAT. Qualitative interviews with staff post introduction of the MPCAT suggested that the assessment was more comprehensive than previous admission documentation. Furthermore, the outcome of assessment was clearer and the rationale behind the care plan developed in response to the assessment was obvious. Although, not significantly different, there was an increase in patient priority issues identified in the care plan post-intervention in comparison to pre-intervention. Therapy and social care staff reported that the reason for referral was more explicit and associated this increase in clarity with the comprehensiveness of the assessment and that there was improved communication of the outcome of assessment and improved communication between multidisciplinary team members.

A factor in the improvement of documented evidence of assessment may relate to the development of readmission proforma (adaptation of the MPCAT) in addition to the initial admission assessment proforma. Although, there is no statistically significant difference, there were a higher percentage of the admissions pre intervention related to patients who were being admitted for the 2\textsuperscript{nd} or 3\textsuperscript{rd} time in comparison to post intervention time 1. It is possible that a comprehensive assessment was routinely conducted during repeat admissions pre-intervention and that only symptoms that were relevant to the patient were documented. However, it is important to screen for all symptoms and issues. Assessment documentation should provide evidence of a comprehensive systematic baseline assessment which indicates symptoms that were identified as not relevant to the patient in addition to those that are experienced by the patient. Assessments of this nature will facilitate determination of an increase in symptoms and changes in the patient’s condition.

5.7 Introducing change to clinical practice: an iterative process that requires commitment and cooperation.

In addition to the assessment tools that are used; the process, timing, the discipline of completing the tool, formatting of the documentation coupled with the experience/expertise of the team are all important elements in assuring the quality and outcome of the assessment process (Strömgren et al., 2002; Radbruch et al.,
The researcher has a background in quality within health care services and was therefore aware of the gap that can exist between required standards and that which actually happens in clinical practice, particularly in respect of evidence of documentation (Rafferty et al., 1996; Emanuel, 2008; Wilson, 2008). Much of what occurs in practice is not documented and unfortunately optimal investigation of patient’s needs and preferences at end of life does not always occur (Strömgren et al., 2001; Velikova et al., 2001; DesHarnais et al., 2007; Wright et al., 2008).

The pre-intervention results indicated that there was considerable room for improvement in documenting evidence of assessment of psychosocial needs and preferences at end of life. The introduction of change to clinical practice is difficult, requiring careful consideration, planning and resources (Mount et al., 2009; Booth et al., 2014). Purely didactic sessions with staff are generally ineffective in altering practice (Kanouse and Jacoby, 1988; Davis et al., 1999). Additionally, the requirements of patient care, time constraints and workload make it difficult to release staff to engage in educational opportunities (Dowell, 2002). However, this study included extensive engagement with clinical staff at all levels of seniority. This was possible in part because senior clinical decision makers were members of the research steering committee.

The senior staff were deeply embedded in the process of research, committed to the project and therefore worked extensively to release staff to engage with the researcher. Garnering support and building relationships with clinicians is critical to the success of any study and the integration of an intervention to practice (Grande and Todd, 2000). Engagement with staff included interactive workshops and feedback sessions in respect of individual evidence-based tools and the assessment process as a whole. The interactive process focussed on alteration of practice, critical reflection and discussion of outcome. This process was repeated and continued over an extended period of time in line with the principles of adult education (Monaghan, 2006). The ‘in process’ feedback on the redeveloped admission assessment procedure informed the researcher in real time and was pivotal to the success of the research (Weissman and Meier, 2011). This process of continuous and prolonged engagement with staff allowed for optimal integration of the MPCAT into practice.
The principles of quality improvement including an iterative process of cycles of audit, feedback and discussion with staff have been reported to be effective mechanisms to improve clinical practice (Hanson et al., 2005; Dudgeon et al., 2008; Ivers et al., 2012). These principles were used with effect in this study as is apparent from the increase in evidence of assessment across the palliative care domains and in particular relating to assessment of patient psychosocial distress and assessment of carer’s need. Additionally, clinicians were more likely to detect particular symptoms, including the patient’s experiencing psychosocial distress, using the MPCAT.

The iterative process of audit and feedback also highlighted areas for adjustment to the formatting and presentation of the admission assessment process. The value of considering the presentation, formatting and response options in health care documentation systems should not be underestimated. The researcher used the literature review, knowledge of the clinical experts and the outcome of the review of international admission assessment documentation systems to aid the development of checklists, and tick box response options whenever possible.

Systematic comprehensive assessment can be burdensome to document, with reports that clinicians can spend between 15-25% of their time on documentation of care (Korst et al., 2003). The burden of documentation and its detraction from time available for patient care is a source of particular concern for clinicians (Gugerty et al., 2007). Time required to document assessment can be decreased by tick box response options rather than a narrative entry of assessment. This methodology decreases the time needed to document findings, aids standardisation of documentation, offers a consistent location for information and can act as an aide memoire to staff in the assessment process. Additionally, simple formatting tools such as increases to font size, indentation and bolding of information are useful tools for highlighting sections that need particular attention. Additionally, such techniques can aid the communication of the outcome of assessment to other members of the multidisciplinary team as the information is highlighted.

Two further changes aimed at implementing the MPCAT were introduced as a result of the significant interaction with clinical staff during feedback sessions. These changes included the integration of the multidisciplinary charts to a single unified
chart and the altering of the Meitheal form (record of the weekly multidisciplinary care plan review meeting) to facilitate tracking of the completion of the assessment of psychological, spiritual issues and carers needs. The willingness of the clinical team to introduce significant changes to practice in addition to the MPCAT is further evidence of the commitment of the senior clinical decision makers to the MPCAT’s integration to clinical practice. Consideration of processes and practices in the clinical setting are as important as the assessment tool when aiming to improve the patient symptom assessment (Howel et al., 2009; Gilbert et al., 2012).

5.8 Assessment domains

5.8.1 Pain

There was a significant increase in the documented evidence of assessment of both the patient’s pain, and an increase in the full completion of the pain assessment tool post-intervention. Additionally, the clinician is more likely to accurately document the patient’s experience of pain using the MPCAT since the results indicated that clinician and patient severity ratings of pain were more likely to be concordant after the introduction of the MPCAT.

Although pain was identified in 71% of charts reviewed pre-intervention, the pain assessment chart focussing on the exploration of the patient’s pain was not completed in over half of charts and partially completed in 17% of charts. The pain assessment chart used in the MPCAT is informed by the Pain Assessment Questionnaire for a Patient With Advanced Disease (PAQ) (Perron and Schonwetter, 2001) and measures pain intensity using numerical rating scales, temporal pattern, treatment and exacerbating/relieving factors, pain location and pain interference. Assessment of the multi-dimensional nature of pain is in accordance with the recommendations in the review Hølen and colleagues (2006) in addition to a systems review, neurologic evaluation and physical examination (Hølen et al., 2006). Rates of full completion of the pain assessment chart increased from 9% pre-intervention to 43% at 12 months post introduction of the MPCAT. The MPCAT pain assessment chart included more prompts for staff when questioning patients about the factors associated with pain. This may have acted as an aide memoire for staff and increased
the understanding of less experienced medical staff of the more important aspects of pain in palliative care patients. Additionally, patients are asked to rate their pain intensity at two time points, at the time of the admission assessment and pain at its worst over the last 24 hours on a 0–10 numerical rating scale in the MPCAT. This allows for a fuller understanding of the impact of pain, in accordance with recommendations from the literature (Hjermstad et al., 2008; Shi et al., 2009).

The more comprehensive assessment of patient’s pain associated with the completion of pain assessment in the MPCAT may explain the increase in concordance of physician assessment to the patients self-rating of pain when using this tool. Pre-intervention, there was low concordance between patients self-reported severity ratings of pain and distress (0-10, numerical rating scale) and clinician assessment. Post-intervention there was significant agreement between patient self-assessment and clinician assessment. There were significant differences in self-assessed pain severity ratings in patients who were assessed as experiencing pain by clinicians, when compared to those patients that clinicians assessed as not.

Interestingly, the use of a numerical rating scale to measure intensity of pain in the MPCAT has been included as one of three Key Performance Indicators (KPI) being piloted by the National Palliative Care Programme in 2014. This KPI uses the measure of pain intensity as part assessment and response to pain. Jensen (2003) reviewed pain measures in adults with cancer and concluded that the Visual Analogue Scale (VAS), the Numerical Rating Scale, (NRS), and the Verbal Rating Scale (VRS) are equally acceptable as measures of pain intensity in respect of validity (Paice and Cohen, 1997; Caraceni et al., 2002) and reliability (Jensen, 2003). However, numerical and verbal rating scales show slightly less failure rates than visual analogue scales, particularly if the patient is older. In addition, the ability to complete visual analogue scales decreases as palliative conditions progress. Further to a survey of international experts, the European Palliative Care Research Collaborative (EPCRC) (Hjermstad et al., 2008), recommended the measurement of pain intensity by a NRS with a range of 0–10 rather than 0–5 VRS. Use of numerical rating scales in the clinical environment is supported by the results of this work.
5.8.2 Physical symptom assessment

Patients often fail to volunteer symptoms and even pain of moderate and severe intensity is more likely to be identified through systematic assessment using specific questions (Hoekstra et al., 2006; Homsi et al., 2006). The symptom assessment in the post-intervention proforma was adapted with permission from the author of the Palliative Medicine Symptom Assessment (Homsi et al., 2006). The symptom list included is very similar in content to the pre-intervention list. However, the assessment rate of physical symptoms improved significantly post-intervention in comparison to pre-intervention rates of completion, with the exception of weight loss. This improvement was maintained 12 months post implementation of the MPCAT, indicating integration to practice.

In addition to pain, the symptoms audited included fatigue, nausea, vomiting, shortness of breath, dry mouth, sleep disturbance, constipation, diahorrea, lack of appetite, and weight loss. With the exception of nausea, vomiting and diahorrea, these symptoms have been documented as the most prevalent in palliative care (Donnelly et al., 1995; Walsh et al., 2000). Re-formatting and grouping of symptoms according to general, respiratory, cardiovascular, central nervous system, upper, middle and lower gastrointestinal and genitourinary symptoms to aid recollection may be partly responsible for the increased completion rate.

In addition to the increase in frequency of documented evidence of assessment of physical symptoms using the MPCAT, the level of concordance between clinician assessment and patient self-assessment also improved. Post-intervention, the level of concordance between patient self-rating of severity of symptoms and clinician assessment also increased in respect of nausea, shortness of breath, lack of appetite and dry mouth.

Significant concordance was not apparent in respect of disturbed sleep pre or post-intervention. It should be noted that the MD Symptom Assessment Inventory (MDSAI) asks the patient to rate their experience of symptoms at their worst over the previous 24 hours. The majority of the patient interviews were conducted on the
second day of admission or the morning after the patient’s first night in the inpatient unit. The fact of the admission and its associated emotional impact may have contributed to some patient’s experience of disturbed sleep.

5.8.3 Cognition and delirium

The cognitive assessment tool was changed from the abbreviated mental test (10 items) to the Blessed Short Orientation Memory Concentration Test (SOMCT). The tool was chosen as it is a short validated tool of cognitive impairment, containing six verbal questions that takes less than three and a half minutes to complete (Arsène and Lassaunière, 2000). The scores from each of the six items are multiplied to yield a weighted score. Two of the questions in the SOMCT include asking the patient to count backwards from 20 – 1 and to say the months of the year in reverse order. The response to these questions can also be used by clinicians to rate inattention as part of the Confusion Assessment Method, a screening assessment for delirium. The brevity of the SOMCT, the fact that all questions are verbal and that some of the questions facilitate completion of another screening tool are in line with the overall objectives of the research which include minimization of repetition and burden to the patient.

The SOMCT was reported to be as sensitive, specific and reliable as the Mental Status Questionnaire (MST) and the Mini Mental State Examination (MMSE) in a study involving a mixed population of patients including those with dementia, Alzheimer’s, neurological and psychiatric conditions (Morita et al., 2001). It has been recommended as an appropriate tool for use in hospice care (Lawlor and Bush, 2014) and reported to be one of the most commonly used cognitive screening tools in palliative care (Leonard et al., 2014). The MMSE was used in 13 of 22 studies included in a systematic review examining methods of assessment of cognitive failure in palliative care (Hjermstad et al., 2004). However, the MMSE was viewed as cumbersome in clinical practice by clinicians and some items are unsuited to testing of highly frail patients. The MMSE involves asking the patient to copy a drawing which can be difficult for some palliative care patients as it requires fine motor skills and involves sitting up and having the strength to use a pen (Fayers et al., 2005).
However, despite being completed in 87% of charts reviewed post-intervention, the weighted score of the SOMCT was not always calculated. This makes it more difficult for clinicians reviewing the chart after the assessment to quickly determine if cognitive impairment is an issue for the patient. This may in part be due to confusion over which scores require rating (the initial request to the patient to repeat a name and address after the clinician is not scored). The SOMCT was reformatted to highlight this issue and to prompt a calculation of the weighted score after data collection. In the subsequent audit, the reformating was as effective and the total score was completed in 95% of occasions that the SOMCT was completed. However, the use of the SOMCT reduced to 62% at 12 months post implementation of the MPCAT. On the majority of the occasions of non-completion, the admitting doctor documented that the tool was not applicable as the patient evidenced normal cognition. However, it is essential to conduct formal monitoring since routine clinical observation can miss cognitive impairment (Irwin et al., 2008; Burton et al., 2012). A baseline at the time of admission is a prerequisite to being able to identify and quantify change in cognitive function in response to illness, disease activity or interventions. The requirement to complete a baseline assessment of cognitive functioning has been emphasised in the admission assessment documentation, and will be communicated at the time of induction and audited in the future for effectiveness.

A screen for delirium was not included in the pre-intervention proforma. However, up to 90% of palliative patients may experience delirium prior to death (Morita et al., 2001). Prospective studies report prevalence of between 34% - 44% of patients with advanced cancer at the time of admission to palliative care inpatient facilities (Power et al., 1993; Pereira et al., 1997). Delirium is reversible in 30-50 % of cases (Lawlor et al., 2006; Leonard et al., 2009). Screening for delirium is included in the International Association for Hospice and Palliative Care, (IAHPC) list of Essential Practices in Palliative Care (International Association of Hospice and Palliative Care, 2012) and given its prevalence and potential for remediation, is an important element of an admission to a specialist palliative care service.

The Confusion Assessment Method was chosen because it is brief, validated in a palliative care population (Ryan et al., 2009), and can be completed with minimal
effort from the patient. The rate of completion of the assessment of delirium, using the CAM was 87% further to initial introduction of the MPCAT. This rate dropped to 68% at 12 months post implementation of the MPCAT. Non-completion was more common in patients who were identified as having normal cognition. The requirement to complete a baseline evaluation of cognition and delirium should be emphasised in future training.

5.8.4 Function and Prognosis

The Palliative Performance Scale (PPS) was chosen to evaluate functional status and replaced the Eastern Cooperative Oncology Group Performance Status (ECOG). The PPS is highly correlated with the ECOG (Myers et al., 2010) but offers greater categorisation levels in comparison to the ECOG and can be used as part completion of the prognostic tool utilised in the MPCAT. The initial rate of completion was 92% at six months and 79% at twelve months after implementation of MPCAT.

The European Association for Palliative Care research network recommended that clinicians should incorporate prognostic indicators based on clinical signs and symptoms as an aid to development of care plans and patient management. Establishment and communication of a patient’s prognosis can aid care planning and decision making by clinicians, patients and their families (Maltoni et al., 2005). The Palliative Prognostic Score (PPS) was recommended as the tool of choice. However, the Palliative Prognostic Index (PPI) has been subsequently validated in an inpatient palliative care population (Stone et al., 2008) and was chosen to be incorporated in the MPCAT as, unlike the PPS, it does not require invasive procedures such as the taking of blood samples or rely on clinical prediction of survival, the accuracy of which is considerably affected by clinician’s experience (Maltoni et al., 2005). This is an important consideration in the context of the variability in experience of clinicians completing the admission assessment.
5.8.5 Psychological and spiritual issues

The audit of admission assessments indicated that psychological and spiritual needs of patients were the domains of need that were least assessed pre-intervention. These audit findings were confirmed further to consultation with staff, which suggested that the lack of completion of assessments of psychosocial and spiritual needs of patients was a common concern across the disciplines working in the SPCU. Other studies also indicate that psychosocial and spiritual needs are often not assessed (Whelan et al., 1997; Morize et al., 1999; Strömgren et al., 2001; Johnston and Smith, 2006; Gunhardsson et al., 2008) and consequently not addressed (National Institute for Clinical Excellence, 2004; Thekkumpurath et al., 2008). Conversely, the factors associated with the illness experience such as impact of the illness on the family, psychological distress, changes in role, fears related to increasing dependency, financial pressure, and spiritual issues are as important and sometimes the dominant concerns for the patient (Kutner et al., 1999; Arnold, 2011). Furthermore “care of the whole person” and “quality of life” were reported to be amongst the most important aspects of care by hospice staff (Addington-Hall and Karisen, 2005). Despite a palliative care clinician’s aspiration to treat the whole person, it cannot be presumed that such holistic care occurs in practice (Strömgren, 2001; Strömgren et al., 2001; McIlfatrick, 2014). It is important that audit of the assessment process occurs within the clinical environment to assure that comprehensive assessment of all palliative care domains is occurring (Health Information and Quality Authority, 2012; Palliative Care Competence Framework Steering Group, 2014). Where audit results indicate a lack of optimal assessment, it is essential that engagement with staff occurs to ascertain possible causes and that staff are consulted to identify suggestions for improvement that are appropriate, practical and feasible.

As highlighted pre-intervention, there was frequently no evidence of assessment of psychosocial issues in the medical proforma. The average rate of non-completion of these questions was 92% and there was no evidence of assessment of psychological issues in nursing documentation in 80% of patient’s charts. These findings are of particular concern given that the study was situated in a specialist palliative care inpatient unit and highlights how the development of nationally agreed competency
frameworks for all disciplines is timely and necessary (Palliative Care Competence Framework Steering Group, 2014).

Reasons for non-completion of these assessments are suggested in the qualitative interviews with staff. Staff in the SPCU expressed concern regarding appropriateness of timing and time available on admission to facilitate the assessment of spiritual need and psychosocial distress. Pre-intervention staff suggested that it was inappropriate to initiate assessment of psychosocial and spiritual needs on the day of admission if the patient was experiencing severe physical symptoms or was distressed by the admission to the inpatient unit. It was suggested that many patients need a number of days to become sufficiently familiar with staff and to develop a bond with staff in order that they would feel comfortable to bring up sensitive issues. The appropriate timing of a holistic assessment is an important consideration (Richardson et al., 2005; Cancer Action Team, 2007).

However, reports of the effectiveness of short psychological interventions in reducing distress suggest that time to develop a relationship is not essential (McClement et al., 2007; Chochinov et al., 2011; Hudson et al., 2013). Equally, the high response rate to interview questions completed as part of the research with patients appears to contradict the qualitative and quantitative feedback from some staff. These had suggested that many patients required a number of days to develop a bond with staff prior to investigation of psychosocial and spiritual needs. Utilisation of questions such as “How much does this illness seem senseless and meaningless?” and “How often is there someone to confide in?” were often a catalyst for the patient to tell the story of their illness experience and how they have interpreted the experience of dying. These narratives provided rich information as to the patient’s acceptance of their illness, their sources of support and their fears for their future and that of their families.

Interviews were most frequently conducted the day after admission and always within the first seventy two hours of admission. Although, patients were given information as to the nature of the questions and time to reflect as to whether or not they wished to participate, there was no opportunity to develop a therapeutic bond. These results and the high rate of question completion, may add weight to the
suggestion that psychosocial and spiritual needs should be discussed with some patients the day after the initial admission to the inpatient unit.

It was also suggested that the prompts in the pre-intervention proforma were confusing and were open to different interpretations. Thus engagement with staff indicated that the assessment process needed to be flexible in order that it be appropriately responsive to the presenting condition of the patient. Furthermore, the provision of further guidance and assessment tools for staff in the assessment of psychosocial and spiritual domains was indicated. Utilisation of validated assessment tools facilitates communication of needs by patients and can guide clinicians in care planning (Ferris et al., 2002; Richardson et al., 2005; Weissman and Meier, 2011).

Post-intervention, an assessment framework for psychosocial and spiritual need was provided. These areas of focus were derived from the clinical experience of members of the steering group and literature review of the important domains at end of life (Mularski et al., 2007). In particular the IAHPC list of Essential Practices in Palliative Care (International Association of Hospice and Palliative Care, 2012), Holistic Common Assessment of supportive and Palliative Care needs for adults requiring end of life care (Cancer Action Team, 2007) and the Nice guidelines on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer (National Institute for Clinical Excellence, 2004) were reviewed.

The inclusion of an evidence-based guided interview may have contributed to the improvement in the rate of assessment and concordance with patients self-assessed distress (i.e. questions relating to patients feelings of being distressed from the MDSAI). Additionally, the MPCAT guidelines suggested that assessment could be completed over 72 hours in order to provide adequate time for patients to settle in to the inpatient unit and to have acute symptoms treated.

The lengthened timeframe for admission and assessment resulted in significant improvement in evidence of assessment. However there are further areas for improvement with regard to assessment of psychosocial and spiritual needs. Post-intervention qualitative analysis suggests that not all staff were comfortable or
sufficiently confident to conduct assessments of psychosocial and spiritual needs. Nurses, therapy and social care staff suggested that the psychosocial and spiritual assessments should be completed by social workers and pastoral care staff. It is clear that assessment of psychosocial, emotional and spiritual needs of palliative patients is complex and warrants detailed consideration. The rate of assessment remained lower than that for physical symptoms and may be attributable to staff’s willingness, confidence and competence to engage in investigation of these needs. Previous work suggests that clinicians feel least prepared to provide emotional care to patients, to talk with patients about dying, to provide psychological and spiritual support (Ferrell et al., 2000; White et al., 2001; Williams et al., 2008; Jones and Cutcliffe, 2009; Griffiths et al., 2010). Clinician anxiety and desire to avoid situations where patients will exhibit strong emotions may be the root cause of lack of assessment (Copp, 1994; Jones, 2006). Consequently patients concerns are frequently undetected (Heaven and Maguire, 1996; Farrell et al., 2005).

Given that the illness experience and its impact upon the patient’s quality of life are as important to the patient as symptom management and are sometimes the dominant concern (Kutner et al., 1999; Arnold, 2011), it is vital that these needs are addressed. Open communication in the context of a trusted therapeutic relationship conducted by competent empathic health care professionals will aid in the total care of a patient (Rosenblatt and Meyer, 2012). It is only through screening for need at a level appropriate to the patient’s needs and desire for direct and detailed communication, that clinicians will effectively prioritise issues for intervention, anticipate needs and be ready to respond effectively to suffering of both the patient and family members. Given the results of this study, which indicate that this does not always occur in practice, further research to explore the assessment of psychosocial, emotional and spiritual needs at the time of admission to specialist services is warranted.

The clinician/patient discourse must facilitate patient-directed engagement and exploration to elicit the impact of the illness on the patient as an individual and the patient as a family member (Kutner et al., 1999). It is through such patient-orientated discourse, focusing on factors contributing to quality of life, that effective palliative care occurs. In the UK and in Ireland, communication skills have been recognised as a core competency for palliative care professionals and must be maintained as part
of continuous professional development (Department of Health, 2004; Palliative Care Competence Framework Steering Group, 2014). A mandatory advance communication skills training course “Connected” has been initiated in the UK to assure clinicians competency with regard to communication (Department of Health, 2007). However, the fact that it is mandatory is a source of contention for some clinicians and may adversely impact the success of this training (Turner et al., 2011). The results of this study suggest that it may be timely to develop a methodology for the assessment of competencies, including those relating to the assessment of need and communication in the clinical environment. The implementation of such a process may facilitate the targeting of additional advanced communication skills for those that require same.

Additionally, the inclusion of palliative care training at undergraduate level may require review as studies indicate that undergraduate training in palliative care is often considerably less than that which is recommended (Dowell, 2002; Field and Wee, 2002; Jones and Cutcliffe, 2009; EAPC, 2013). A recent review by the European Association of Palliative Care’s steering group on medical education and training suggested a programme, facilitated over a minimum of forty hours. It was recommended that six sections should be included in as part of a syllabus aimed at appropriately equipping medical students with the required skills, knowledge and attitudes to care for patients with life limiting illnesses (EAPC, 2013). The recommended syllabus includes the following:

- Basics of palliative care
- Pain and symptom management
- Psychosocial and spiritual aspects
- Ethical and legal issues
- Team work
- Self-reflection
The results indicate that pre-intervention documentation of assessment of spiritual distress was limited, often focusing on identifying the patient’s religion. Spiritual care is not just the facilitation of an appropriate ritual, but engaging with an individual’s search for existential meaning (Speck et al., 2004). Addressing spiritual needs and existential questions among the dying should be a priority as patients at end of life particularly value freedom from pain and existential contentment (Greisinger et al., 1997; Steinhauser et al., 2006b). Consequently, palliative care providers must prioritise the assessment and response to patient’s spiritual need in equal measure to that of pain and physical symptoms. Neglecting to do so is a lost opportunity to intervene at a critical point in the patient’s illness journey. There is “strong evidence that if the human elements of compassion and hope, understanding and relationship between carer and cared for are ignored, then we are forgetting and losing a crucial element of the healing process” (Scotland. NHS, 2009). Patients with high levels of existential/spiritual well-being are less likely to be anxious or depressed (Mako et al., 2006; McCoubrie and Davies, 2006), experience suicidal ideation, hopelessness or to have a desire for a hastened death (McClain et al., 2003).

Despite its importance within a clinical assessment, clinicians may find it difficult to initiate a spiritual discussion with patients as they believe patients may find it intrusive, believe that it is not their role, or feel it is inappropriate to initiate as part of the initial assessment (Puchalski et al., 2013). Similarly, clinicians may be concerned that they have inadequate knowledge and skill in this area (Kuuppermäki, 2001; Narayanasammy and Owens, 2001) and lack time (Sinclair, 2009). The facility in which this research is based is a teaching facility and therefore the staff involved in the admission assessment, have varying levels of expertise as is evident in the outcome of the qualitative and quantitative enquiry with staff. Palliative Care is unique in its attention to the spiritual needs of patients and if prior to working within this SPCU staff have had limited or no experience of palliative care it becomes all the more important to offer training and guidance in the conduct of spiritual care needs. The rate of assessment improved post-intervention and this improvement was maintained twelve months following the introduction of the MPCAT.

If illness is a barrier to the patient’s ability to access resources that normally aid coping, part of the function of an assessment is to determine alternative or substitute
aids to coping and resilience (Holloway et al., 2010). If the assessment is not conducted an opportunity to respond to need is lost.

5.8.6 Psychiatric illness

Psychiatric illness that is not identified can impact effectiveness of interventions aimed at management of pain, physical functioning, quality of life, compliance with treatment and impact on communication within families (Breitbart et al., 2000). Studies indicate an increasing prevalence of co-existing psychiatric illness in palliative care patients (Thekkumpurath et al., 2009b); the most common are adjustment disorders (11-35%) followed by major depression (5-26%) (Hotopf et al., 2002; Miovic and Block, 2007) A systematic review of prevalence studies of across the spectrum of depressive illnesses indicated a prevalence of 29% - 32% (Hotopf et al., 2002) suggesting that depression is one of the ten most commonly occurring symptoms within palliative care. It is essential that depression is specifically inquired about in a similar way to the other highly prevalent palliative care symptoms.

Inappropriate normalising of psychological suffering by patients and health care professionals, difficulties in assessment (Lawrie et al., 2004), underreporting (Davies and Shah, 2001; Hotopf et al., 2002; Wen and Gustafson, 2004) lack of confidence (Block, 2000), poor education, and difficulties in detecting and differentiating distress form appropriate sadness can result in failure to identify and treat (Thekkumpurath et al., 2009b). Detection of depression is further complicated because many of the symptoms that might normally be considered as indicators of depression, such as difficulty sleeping, fatigue, weight loss and impaired concentration, are common symptoms experienced by patients with advanced cancer occurring as a result of their illness or side effects from their treatment. It is therefore important to utilise criteria which focus on non-somatic symptoms of illness (such as anhedonia) in a palliative care setting (Lloyd-Williams et al., 1999).

The (two item interview) comprising the questions “Are you depressed?” and “Have you experienced loss of interest in things or activities that you would normally enjoy?” two item interview) were included in both the MPCAT and pre-intervention proforma as a screen for depression. This has been compared with other
questionnaires, including the Hospital Anxiety and Depression Scale (Akechi et al., 2006) and the Beck Depression Inventory Short Form and a Visual Analogue scale (Chochinov et al., 1997), and found to be an effective and sensitive tool when screening for depression in patients with advanced cancer. It has also been validated as a sensitive tool in an Irish inpatient palliative population (Payne et al., 2007). This study identified that the two item interview did not require specialist training and had a high sensitivity for identifying depression. However, pre-intervention, there was either no evidence of assessment of depression or outcome of assessment was unclear pre-intervention in 80% of charts. Post-intervention there was clear evidence of screening for depression in two thirds of cases post-intervention, time 1. The improvement in evidence of assessment significantly increased at 12 months post-intervention, time 2.

The Brief Edinburgh Depression Scale (BEDS) was included in the MPCAT as a diagnostic aid for depression, if a patient answered yes to either question in the two item interview. The Brief Edinburgh Depression Scale was identified as the most appropriate self-report measure to identify depression in the palliative phase (Ziegler et al., 2011). There was clear documentation that depression was an issue for 9% of patients. There were no audit criteria included in the post-intervention audit (time 1) as to whether patients were requested to complete the BEDS or referred for psychiatric consultation. These criteria were included in 12 month post-intervention audit; the two item interview indicated that 11% of patients may be depressed; but none of these patients completed the BEDS depression scale. The inclusion of both the two item interview and the BEDS in the admission assessment should be reviewed as both are screening tools. The results indicate that the two item interview was more likely to used by clinicians in this setting. It is important to ensure that depression, which is treatable in a palliative population, is appropriately identified and managed (Maguire, 2000; Thekkumpurath et al., 2009a). Further monitoring should occur to ensure that screening for depression continues to occur and that appropriate clinical assessment occurs when depression is suspected (Rayner et al., 2010).
5.8.7 Assessment of carers needs

Greater attention should be paid to the psychological and social needs of carers (National Institute for Clinical Excellence, 2004; Harding and Leam, 2005). It is important to ensure that carers needs for support and information, which increases as the patient approaches end of life should be assessed separately to that of patients (Dumont et al., 2006). Investigation of and responsiveness to carers needs is critical given the importance of the carers role in the provision of care to the patient (Bernard, 2005; Currow et al., 2011), carers potential for psychological morbidity (Dumont et al., 2006; Hudson et al., 2011) and the potential for relatively short term interventions to be effective in reducing distress associated with the provision of care of the terminally ill patient (Hudson et al., 2013).

The steering group considered a number of measures aimed at identification of carers needs. However a tool which was sufficiently comprehensive and of an appropriate length was not identified. Ultimately the steering group chose to utilise a semi-structured interview, the questions in which facilitated a cross check with the outcome of the assessment of the patients psychosocial needs with regard to a number of issues. The issues included; communication within the family about the illness, sources of resilience, family members who were struggling to cope and financial distress. The questions developed for the semi-structured interview were in accordance with the recommendations of the Nice guidelines (National Institute for Clinical Excellence, 2004). The interview was carefully crafted further to consultation with the steering group members. The concept of supporting the family as a whole is validated by evidence that demonstrates linkages between patient and family distress and psychiatric morbidity and that cohesiveness within the family impacts patient welfare and vice versa (Kurtz et al., 1995; Hodgson et al., 1997; Bambauer et al., 2006; Kris et al., 2006). Lack of cohesiveness between family members in responding to the illness is associated with increased risk of complicated grief among caregivers (Kissane and Bloch, 2002; Kissane et al., 2003).

Assessment of carers needs was to be assessed by the nursing staff on the day of admission or the social workers thereafter if this was not feasible, according to the guidelines for completion of the MPCAT. Assessment of carers needs was the
domain that was least assessed in the MPCAT post-intervention time 1. This was concerning and is an aspect of assessment that warranted further review.

The median length of stay in the specialist palliative care inpatient unit in 2012 was 9.7 days and of similar length in 2013. If assessment of carers needs did not occur within the first three days of an admission, there was the potential for inadequate time to implement necessary interventions. After the post-intervention time 1 audit was completed, the Meitheal form (record of multidisciplinary meeting to review care) was revised as previously discussed. Part of the aim of the revision was to ensure an action plan was devised to assure that any outstanding area of assessment was completed, including identification of the responsible discipline. Twelve months post-intervention, time 2 there was a significant increase in assessment of carers needs. Despite the considerable improvement in results 12 months post-intervention, it is a domain of need which requires further consideration.

The FAMCARE 2 was collected pre-intervention and post-intervention time 1 to evaluate carer’s perspectives of quality of care provided and to measure to what extent their perceived needs were met. The FAMCARE 2 contains four factors; management of patients physical symptoms and comfort, provision of information, family support and patient psychological care. The results of the FAMCARE 2 indicated that carers were highly satisfied with the quality of care provided both pre-intervention, and post-intervention. Although median ratings were higher post-intervention, there was no significant difference in ratings between pre and post-intervention ratings. However, it should be noted that the results of Famcare 2 completed both pre and post intervention by carers indicated significantly higher respondent ratings of management of patients physical symptoms and comfort, in comparison to the respondents ratings of the three other factors. Future studies should determine if the increased levels of assessment of patient’s psychological needs and assessment of carer’s needs, result in comparable factor ratings.
5.8.8 Preferred place of care at end of life

Prompts about the patient’s preferred place of care at end of life and their carer’s knowledge of, and attitude towards, the patients preferred place of care at end of life were included in the MPCAT. It has been suggested that the experience of dying would be more likely to be perceived to be of a higher quality if the death occurs at home or in the patients preferred location (Curtis et al., 2002). In a study involving a representative sample of Irish people, it was reported that the majority of Irish persons wish to be involved in such decision making (McCarthy et al., 2010). Outcomes are likely to be improved for both patient and the carer (Seamark et al., 2004). End of life discussions are associated with patients experiencing fewer aggressive interventions, improved quality of life and improved care givers’ bereavement adjustment at follow-up (Wright et al., 2008). Additionally, Wright et al (2008) highlighted that patients who reported engaging in end of life conversations were significantly more likely to accept that their illness was terminal, prefer medical treatment focusing on relieving pain and discomfort over life extending therapies and to have completed a ‘Do Not Resuscitate’ order.

Stating a preference for place of death has been associated with an increased likelihood of dying in the preferred place of care (Karlsen and Addington Hall, 1998; Davison, 2011). An evaluation of an Irish hospice at home service suggested a relationship between whether or not discussion had taken place with family in respect of patients preferred place of death and where the patient actually died (McKay et al., 2011). Preferred place of death had been discussed with families/carers for the two thirds of patients who died at home in the hospice at home evaluation. Only 23% of the patients who died in places other than their own home had a discussion with the hospice at home team in respect of preferred place of death of the patient. It should be noted that this evaluation cautions that there is no evidence of a causal relationship between discussions of preferred place of death and the location of the patient’s death.
Engagement with a patient in respect of their preferred place of care at end of life can be a difficult conversation to initiate and a careful judgment has to be made in respect of preparedness and desire of the patient or carer to engage in such a conversation (International Association of Hospice and Palliative Care, 2012). Coordinated advanced care planning interventions which included trained facilitators, inclusion of the family in the discussion, documentation of the patient’s wishes and systematic education for medical personnel have resulted in a significant increase in respect for patients wishes at end of life. This also has lead to higher ratings of patient and family satisfaction of information and care provided and decreased anxiety, stress and depression in bereaved relatives at follow up (Detering et al., 2010). Given the low rates of documentation of the patient’s preferred location of care at end of life evidenced in this work, further review should occur with regard to the need for additional training and targeted interventions.

A patient’s preferred location for care at end of life may change as their illness progresses or as they become more familiar with care provided in the specialist palliative care unit. The Meitheal form (record of the multidisciplinary team’s weekly review of the patients care) now contains a prompt to identify if the patient’s preferred location of care has been specified in the preceding days. Recording of this information and matching it against the patients location at the time of their death is potentially a useful indicator of the quality of care provided to the patient (Department of Health, 2008). Further exploration should occur to determine concordance between the patient’s stated preferred place of care and the actual place of care at end of life in an Irish context. Additionally, exploration should include the impact of discussions to determine the patient’s preferred place of care on the actual location of care at end of life and impact on patient and carer outcomes.

5.9 Strengths and limitations of the research

As with all research there were strengths and limitations to this work. A particular strength was that the choice of tools for inclusion in the assessment proforma was based on a systematic literature review, consideration of assessment processes in
Ireland and the United Kingdom and significant consultation with local clinical experts. In this way tools chosen were current, derived from empirical knowledge, feasible within clinical practice and acceptable to clinicians. Detailed consideration of each domain of palliative care and of the assessment process as a whole occurred. Requiring clinicians to rate tools that were for consideration against specific criteria increased the objectivity of the selection process of tools for each domain.

The pre and post design and sample size is a limitation of this study. It is not possible to control factors that may have influenced the admission assessment process over the period of implementation of the intervention and the immediate aftermath. Undoubtedly, there were other changes occurring on the ward such as changes of staff and rotation of doctors with potentially variable levels of experience. The introduction of a unified chart as a result of the implementation of the admission assessment and other changes that occurred may have had significant impact. Therefore factors other than the intervention may have impacted upon outcomes at the different stages. It is particularly difficult to control for confounding variables when situating research in the clinical environment, particularly in a palliative care context where sample sizes tend to be small. The lack of control group of patients who did not receive the intervention (admission assessment utilising the MPCAT) for comparison purposes is a limitation of this study. If it had been possible to compare the results of the admission assessment of a control group of patients who were matched to the patients who had received the intervention, it would have been possible to truly investigate the impact of the MPCAT.

The increase in percentage of assessments with regard to some domains diminished at one year follow up compared to the 6 month review. In particular cognitive impairment, delirium and socio adaptive function was not maintained at 12 months. The researcher had a greater presence on the wards at 6 months in comparison to 12 months. This may be an indication that the attention and focus generated by the research itself had an impact on the results. It is possible that staff were more mindful of full completion of assessments due to the presence of the researcher and associated awareness of the audit process. However, if this were the case, it would have also impacted the pre-intervention baseline. Maintaining improvements to practice requires effective education, leadership, opportunities for critical reflection,
promotion of a culture of continuous quality improvement and engagement with practitioners in the clinical setting (Lawlor and Bush, 2014).

This is a single site study with small sample sizes leading to difficulties in the generalisability of results. Larger sample sizes would have facilitated testing for significance in respect of all symptoms and issues. However, sample sizes in palliative care research are often small due to difficulties associated with gatekeeping, recruitment and attrition (Ewing et al., 2004a; Zimmermann et al., 2008). A key strength of the study was the breadth of data collected and the engagement with clinicians over an extended period of time. Data was collected with regard to patients, carers, staff and from the patient chart at multiple time points. This breadth of data collection offered unique insights to the assessment process and an opportunity to analyse data from a wide range of perspectives. A sample size of 81 palliative patients in an inpatient setting which required collection of data directly from patients is high when compared to other similar studies (Hardy et al., 1999; Early et al., 2000; Wilson et al., 2004; Waller et al., 2010). In addition, the recruitment process of patients included consideration of all consecutive inpatients. Patients were approached unless specific exclusion criteria were met. This process increased the objectivity of the recruitment process. The majority of patients reported that participation in interviews with the researcher was a positive experience, which for some was therapeutic. Feedback of this nature from patients is consistent with other reports (Pessin et al., 2008; Gysels et al., 2012). To prevent palliative care patients from participation in research without consultation deprives them of a valuable opportunity to tell their story and to impact upon care provided to others (Gysels et al., 2008).

The researcher is a member of staff in the centre in which the study was located and was responsible for the development and evaluation of the intervention. This degree of involvement may lead to bias and negatively impact objectivity. However, the extensive involvement of the steering group members and engagement with staff included wide-ranging opportunities for critical reflection of the assessment process, thereby increasing objectivity. In addition, the cross correlation of qualitative and quantitative data authenticated conclusions drawn from the results.
The concordance between clinician assessments and patient self-ratings was evaluated by auditing the documentation reporting the clinicians assessment and comparing that to the patients self-ratings. The clinician assessments were completed on a different day to the patient self-ratings, usually the day after. The experience of palliative care symptoms can change rapidly and the difference of a day in assessment may have contributed to lack of concordance. Additionally the actual clinical assessment was not observed and there may be variability between that which was assessed and that which was assessed and documented. However these conditions were present both pre and post-intervention and therefore could have impacted both pre and post-intervention outcomes.

5.10 Recommendations

Ideally a randomised controlled study in multiple centres should be conducted to determine if these results can be replicated. The researchers should be blinded to assignment of staff and patients to the intervention or control arm of the studies. Additionally, further studies which include examining the effect of the intervention over a longer time period and with larger sample sizes should be conducted. Additionally, there is a need to explore the impact of the tool on a range of outcomes. Future research should determine if use of the tool increases the detection of symptoms, increases interventions offered by the clinical team, or impacts the patients or carers experience of care.

This research evidenced an increase in the rate of assessment across the domains of palliative care and increased concordance with patient reported experience of symptoms. Results indicate that reasons for improvement included the application of an evidence-based suite of assessment tools and associated education and training. The National Palliative Care Program (NPCP) has already recognised the importance of the provision of guidance regarding assessment to clinicians operating at levels 1 and 2 of palliative care specialisation. The results of this work suggest that consideration should also be given to the development of a nationally agreed assessment framework for admission to a specialist palliative care service.

An extensive number of validated palliative care assessment tools to enable comprehensive assessment of all domains of palliative care assessment were
identified through this work. The appraisal process included prolonged consideration by a steering group of palliative care experts to choose the most appropriate, sensitive and clinically feasible assessment tools in consultation with the researcher. This work could form the basis for a suite of assessment tools for use by specialist palliative care service providers. The usage of common assessment tools amongst service providers could aid comparison between service providers which would have considerable implications for both clinical practice and research. For example comparison of prevalence and severity of symptoms experienced as well as monitoring the effectiveness of interventions across services would be enabled.

A core objective of the work plan of the NPCP is the further development of specialist palliative care services to improve quality of care delivered to the patient and their carers. One of the consequent work streams is the “collection of evidence-based performance measures that support the quality improvement cycle.” As part of the testing of the MPCAT, an extensive evidence-based audit tool to facilitate evaluation of a multi-domain initial admission assessment to a specialist palliative care unit was developed, piloted in consultation with palliative care experts and implemented on three occasions. This tool could be used to facilitate benchmarking and assessment of the quality of assessment practice amongst service providers.

This study was based in a specialist palliative care inpatient unit. An adapted version of the MPCAT should be developed for use across specialist settings including home-care, day-care and outpatient settings. Implementation of a common assessment framework between teams within palliative care services would enhance communication and care delivery across disciplines and likely to result in improved outcomes for patients and their carers. A common assessment framework between inpatient units, home care and day care services would reduce repetition of some assessments, thereby decreasing patient burden and utilisation of staff resources. Equally, re-evaluation of domains utilising similar assessment tools will aid determination of changes in the patient’s condition and therefore aid care planning.

Palliative care service providers are required to justify their use of resources, evidence the quality of care provided and prove that the quality of care is the best
possible in the context of available resources (McPherson, 2003; Bausewin et al., 2011). Nationally, there is an emphasis within the National Palliative Care Program (NPCP) on the collection of evidence-based measures of performance which will inform continuous quality improvement and facilitate benchmarking between service providers. Three performance measures were trialled in early 2014 for the purposes of assessment of quality and comparison between service providers. The MPCAT facilitated the collection of the indicator, relating to assessment practice, with minimal adaptation. Further review should occur to determine if additional performance measures can be collected from the MPCAT with regard to the processes of assessment and care planning that could be used to benchmark performance. Possible quality indicators may include comprehensive assessment of domains and referrals to members of the multidisciplinary team as a consequence of assessment.

Results indicated that staff felt there was less need for further training post-intervention with regard to assessment of palliative care need than pre-intervention. However, the qualitative data suggested that staff found assessment of psychosocial and spiritual needs difficult and required further guidance on how to assess these aspects of the patient profile. The provision of an evidence-based tool is only one element in the assurance of the quality of an assessment process. The expertise, experience and profession of the clinician are also important factors when considering the effectiveness of the process. Empirical evidence has shown that communication skills training increases the confidence and competence of clinicians (Heavan and Maguire, 1996; Moore et al., 2004; Wilkinson et al., 2008). Further research to investigate the impact of the intervention with regard to patient’s symptom experience would be valuable. Additionally, the intervention in combination with the provision of communication skills and the consequent impact on rate of psychosocial and spiritual assessment should be investigated.

The results of the FAMCARE 2 indicate that carers rated the quality of care for physical symptoms higher than the provision of information, psychological care to the patient and support to the family. This was evident both pre and post-intervention. It would be useful to conduct a qualitative study with carers to investigate the reasons for this and to identify additional supports or interventions...
that could be offered. With regard to ratings of patient psychological care, it should be remembered that the validity of carer’s ratings of patient’s symptom experience have been questioned (McPherson et al., 2008; Jones et al., 2011). Evaluation of the quality and impact of care provided should ideally be measured from the patient’s perspective using a validated patient reported outcome measure (Rhodes and Nocon, 1998; Mularski et al., 2007; Bausewin et al., 2011). Patient reported outcome measures which are feasible and measure the multidimensional aspects of palliative care should be in this inpatient unit to determine the patient’s view of physical and psychological care.

Supporting carers of palliative patients is a key domain of palliative care. However, despite considerable improvement from the baseline, the assessment rates for this domain remained lower than the other domains. Further exploration of the reasons for this should occur with staff. Similarly, further research is warranted to determine if increased rates of assessment of carer’s needs have an impact of carer’s ratings of support to the family as measured by the FAMCARE 2.

Additionally, the study showed that referrals to other disciplines occurred earlier in the admission as a result of the intervention. However, no data was collected with regard to the impact of the intervention on patient symptom experience. It would be valuable to determine whether the increased rate of assessment and increased concordance with patient self-rating of symptoms result in alteration to interventions offered to the patient. Additionally, an evaluation of symptom severity at different time points could determine if there is an alteration to severity of symptoms experienced. However, due to difficulties in recruitment and attrition, conducting randomised control studies have proven difficult with palliative care populations (Zimmermann et al., 2008).

5.11 Conclusions

This study extends our knowledge relating to the admission assessment within specialist palliative care settings by investigating the effectiveness of a palliative care assessment process with palliative care inpatients. This mixed methods research evaluated the pre-intervention admission assessment and investigated the effect of
the implementation of a novel evidence-based multidisciplinary admission assessment protocol, ‘The Milford Palliative Care Assessment Tool’ MPCAT post-intervention.

The study facilitated the development of a systematic evidence-based assessment process and proforma that comprehensively assesses palliative care domains of need. The tools included in the admission assessment were chosen further to an extensive literature review. Tools which were sensitive, specific and as brief as possible were included in order to minimise burden to the patient. The effectiveness, feasibility and acceptability of the MPCAT were then tested in a busy clinical environment.

The results of follow up assessments demonstrated an increase in evidence of assessment across Palliative Care domains and in particular in relation to patient’s psychosocial distress and assessment of carer’s need. Delirium, the patient’s prognosis, and their need for resuscitation are now routinely assessed as a result the MPCAT. Additionally, and importantly in respect of patient outcomes, increased concordance of clinical assessment with the patients self-rating of pain, nausea, breathlessness and distress is evident. The results indicated that the MPCAT facilitates more reliable and consistent assessment of patient need. The increased evidence of documented assessment, which was maintained at the second audit phase, indicates that the MPCAT is clinically feasible and acceptable in daily practice. Furthermore, the intervention increased the rate of multidisciplinary referrals within the first twenty four hours of admission to service.

Staff reported that there was an increase in the assessment of palliative care domains, less need for training and an increased likelihood of assessment of carers needs. The guidance offered by the MPCAT and associated training package has enabled staff to investigate sensitive issues at the time of admission with patients. Furthermore, staff reported that the care plan was communicated more clearly as a result of the MPCAT and associated this with an increase in comprehensiveness of assessment of domains of palliative care. Additionally, discharge planning was facilitated earlier in the admission.
The value of a standardised systematic approach to the conduction of and documentation of a palliative care admission assessment should not be underestimated. Feedback from staff confirms that the proforma provides guidance to clinicians with little palliative care experience. Less experienced staff are supported in the conduction of a comprehensive and palliative care specific assessment with a consequent increased standardisation of the breath and quality of the assessment. In addition, the systematic proforma acts as an aide memoire to more experienced clinicians and facilitates communication and clarity of the outcome of assessment. Not only is this a prerequisite to the development of a patient-centred care plan, it also facilitates clinicians to account for their practice. The clinician is supported in their practice by being able to efficiently evidence the breadth and depth of the assessment process. Modern clinicians must not only be able provide excellent patient care, they must also be able to prove the provision of excellent care through documentation. In addition, the monitoring of assessment processes and adherence to quality standards is enabled.

Healthcare organisations are required to assure implementation of clinical guidelines and evidence-based practice through processes of audit and continuous quality improvement. The development of the MPCAT has invigorated the monitoring of the assessment process and has resulted in ongoing audit of admissions assessments and further refinement of the admission assessment process with regard to depression, and resuscitation. The nursing department have initiated a review to create a standardised daily documentation proforma to assure that symptoms and interventions are evaluated systematically. These quality improvement initiatives are not only essential to improving patient care and the creation of culture in which clinicians are routinely evaluating their practice. Furthermore, the MPCAT has facilitated the collection of pilot national key performance indicators. Within the current healthcare environment there is an increasing onus on providers to monitor and improve their performance and evidence that their practice is safe and effective.

The outcome of the work and its continued relevance and importance in the clinical environment is an endorsement of the value of situating research within the clinical environment. The combination of evidence-base, time, critical reflection and extensive consultation with expert clinicians and practitioners aided the bridging of
the divide between theory and practice (Kenny, 2003; Curry et al., 2009). Other specialist palliative care providers have sought access to the MPCAT further to feedback from clinicians who have used it, emphasising its relevance and importance to the clinical environment. The MPCAT should be tested in other clinical environments to determine if these results can be replicated. An adapted version of the MPCAT should also be developed for the home care and day care services. The development of a common assessment process would ensure the provision of a systematic standardised assessment irrespective of which aspect of a specialist palliative care service a patient is first admitted to. However it should always be remembered the MPCAT is merely a tool to support the interaction between the clinician and the patient at the time of admission. It is only one element in a complex interaction and will only be effective in the hands of a skilled professional practicing patient-centred care.
References


randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer', Journal of Clinical Oncology., 30(12), 1304-1309.


Casarett, D. J. and Inouye, S. K. (2001) 'Diagnosis and management of delirium near the end of life', Annals Of Internal Medicine, 135(1), 32-40.


Clark, D., Ingleton, C. and Seymour, J. (2000) 'Support and supervision in palliative care research', Palliative Medicine, 14(5), 441-446.


Davies, A. N. and Shah, S. (2001) 'A comparison of the Memorial Symptom Assessment Scale and conventional medical and nursing symptom assessments.', Proceedings of the 7th Congress of the European Association for Palliative Care;.


De Raeve, L. (1994) 'Ethical issues in palliative care research.', Palliative Medicine, 8, 298-305.


EAPC (2013) *Recommendations for the European Association of Palliative Care for the Development of undergraduate Curricula in Palliative Medicine in European Medical Schools*, European Association of Palliative Care.


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Gessler, S., Low, J., Daniells, E., Williams, R., Brough, V., Tookman, A. and Jones, L. (2008) 'Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study', *Psycho-Oncology*, 17(6), 538-547.


Gysels, M. H., Evans, C. and Higginson, I. J. (2012) 'Patient, caregiver, health professional and researcher views and experiences of participating in research at the end of life: a critical interpretive synthesis of the literature', *BMC Medical Research Methodology*, 12, 123-123.


Health Services Executive (2009) *Palliative Care Services - five Year/Medium Term Development Framework*, Dublin: Health Services Executive.

Health Services Executive National Programme for Palliative Care Palliative Care Needs Assessment Guidance (2014) Dublin: Health Service Executive; retrieved from [www.hse.ie/palliativecareprogramme/resources/](http://www.hse.ie/palliativecareprogramme/resources/) on 27 January 2014


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International Association of Hospice and Palliative Care (2012) *IAHPC List of Essential Practices in Palliative Care*, Houston: International Association for Hospice and Palliative Care.


Mystakidou, K., Parpa, E., Tsilika, E., Kalaidopoulou, O. and Vlahos, L. (2002b) 'The families evaluation on management, care and disclosure for terminal stage cancer patients', *BMC Palliative Care*, 1(3).


Power, D., Kelly, S., Gilsenan, J., Kearney, M., O'Mahony, D., Walsh, J. B. and Coakley, D. (1993) 'Suitable screening tests for cognitive impairment and
depression in the terminally ill--a prospective prevalence study', Palliative Medicine, 7(3), 213-218.


Puchalski, C. M., Dorff, R. E., Hebbar, B. N. and Hendi, Y. (2013) 'Religion, spirituality and End of Life Care'.


Sinclair, J. (2009) 'Is it appropriate for doctors to take a spiritual history?', European Journal of Palliative Care, 16(4), 174-177.


Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L. and Tulsky, J. A. (2000) 'Factors considered important at the end of life by patients, family, physicians, and other care providers', JAMA: Journal of the American Medical Association, 284(19), 2476-2482.

Steinhauser, K. E., Voils, C. I., Clipp, E. C., Bosworth, H. B., Christakis, N. A. and Tulsky, J. A. (2006b) "Are you at peace?: one item to probe spiritual concerns at the end of life', Archives Of Internal Medicine, 166(1), 101-105.


The Irish Hospice Foundation (2008) *Palliative care for all Integrating Palliative Care into Disease Management Frameworks*, Dublin: The Irish Hospice Foundation.


Appendix A: Admission Assessment Steering Committee Terms of Reference

- To oversee and support the design and implementation of the Milford Care Centre Assessment Documentation evaluation conducted by the researcher
- To receive progress updates from the researcher and communicate same within Milford Care Centre and the Irish Hospice Foundation as necessary
- To oversee the development of key dissemination outputs
- To monitor adherence to timelines

Mode of Working:

The maximum length of the meeting will be one hour, unless it is agreed in advance that more time will be required.

The Head of Therapies and Social Care will Chair the committee. The Head of Education, Research and Professional Development will deputise.

The agenda will be coordinated by the Chairperson and he will forward notes and action points with agenda papers to the Steering Group at least one week in advance of the meetings by email. Group members will send apologies in advance if they cannot attend.

The Steering Group will meet in accordance with the schedule below (which may be revised by the Chairperson) and will receive reports from the researcher (through the Chairperson) demonstrating progress against the project plan. Such reports will be sent by to the Chairperson at least one week in advance of the meetings.

The researcher will attend the Committee meetings.

Membership

The Steering Group’s membership is as follows:

Head of Therapies and Social Care (Chairperson)
Head of Education, Research and Professional Development (Vice-Chairperson)
Head of Non Clinical Support Services
Physiotherapy Manager
Consultant in Palliative Medicine
Representative of Pastoral Care
Principal Social Worker
Three (3) representatives of nursing (2 from the Inpatient Unit and one representing Hospice at Home/Day Care
Appendix B: Search strategy

Medline (EBSCO)

Mesh Headings:
1. AB palliative care or TI palliative care or AB life N4 threatening N4 illness or TI life N4 threatening N4 illness or AB end N3 life TI end N3 life or AB (dying OR hospice * OR terminal * OR palliative) TI (dying OR hospice * OR terminal * OR palliative) MH palliative care or MH Terminal CARE. Total = 26,620

2. AB “symptom control” or AB (functional OR physical OR psychological OR social OR psychosocial OR spiritual OR carer OR pain OR family OR bereavement) or AB family N5 carer N5 support or TI “symptom control” or TI (functional OR physical OR psychological OR social OR psychosocial OR spiritual OR carer OR pain OR family OR bereavement) or TI family N5 carer N5 support or MH spirituality or MH Pastoral Care or MH caregivers or MH Needs Assessment. Total = 337,417

3. AB (evaluate* OR assess* OR histor* OR document* OR valid* OR reliabil* OR instrument OR tools* OR screens* OR scale* OR examination*) or TI (evaluate* OR assess* OR histor* OR document* OR valid* OR reliabil* OR instrument OR tool* OR screen* OR scale* OR examination*) or MH reproducibility of results Total = 871,419

#1 and #2 and #3 Total = 3,992.

Search Strategy for Psych Info (EBSCO)

Mesh Headings: Palliative Care; Terminal Cancer; terminally ill patients; caregivers; caregiver burden; psychological needs; psychological assessment; spirituality; statistical validity; statistical reliability

1. AB Palliative care or TI Palliative care or AB life N6 threatening N6 illness or TI life N6 threatening N6 illness or AB end N4 life or TI end N4 life or AB (dying OR hospice* OR terminal* OR palliative ) or TI ( dying OR hospice* OR terminal* OR palliative ) or MH palliative care or MH Terminal Cancer/ or MH terminally ill patients Total = 5579

2. TI “symptom control” or AB “symptom control” or TI (functional OR physical OR psychological OR social OR psychosocial OR spiritual OR carer OR pain OR family OR bereavement ) or AB ( functional OR physical OR psychological OR social OR psychosocial OR spiritual OR carer OR pain OR family OR bereavement ) or TI family N5 carer N5 support or AB family N5 carer N5 support or MH psychological assessment, or MH psychological needs or MH spirituality  MH caregivers or MH caregiver burden Total = 173798
3. AB (evaluat* OR assess* OR histor* OR document* OR valid* OR reliabil* OR measure* OR instrument* OR tool OR screen* OR scale OR examination* ) or TI ( evaluat* OR assess* OR histor* OR document* OR valid* OR reliabil* OR measure* OR instrument* OR tool OR screen* OR scale OR examination* ) or MH statistical reliability MH statistical validity Total = 271,825

#1 and #2 and #3 Total = 1776.

**Database searched Cinahl (EBSCO).**

1. AB Palliative care or TI Palliative care or AB life N6 threatening N6 illness or TI life N6 threatening N6 illness or AB end N4 life or TI end N4 life or AB (dying OR hospice* OR terminal* OR palliative ) or TI (dying OR hospice* OR terminal* OR palliative ) or MH palliative care or MH terminal care/ or MH patient care/ or MH management/ Total = 44,718

2. TI “symptom control” or AB “symptom control” or TI (functional OR physical OR psychological OR social OR psychosocial OR spiritual OR carer OR pain OR family OR bereavement ) or AB (functional OR physical OR psychological OR social OR psychosocial OR spiritual OR carer OR pain OR family OR bereavement ) or TI family N5 carer N5 support or AB family N5 carer N5 support or MH culture/ or MH psychology, social/ or MH (psychological processes and principles/ ) or MH caregivers or MH stress, psychological/ Total = 297,553.

3. AB (evaluat* OR assess* OR histor* OR document* OR valid* OR reliabil* OR measure* OR instrument* OR tool OR screen* OR scale OR examination* ) or TI (evaluat* OR assess* OR histor* OR document* OR valid* OR reliabil* OR measure* OR instrument* OR tool OR screen* OR scale OR examination* ) or MH clinical assessment tools/ or MH (measurement issues and assessments/ ) or MH functional assessment or MH Professional practise, evidence-based/

Total = 511,620

#1 and #2 and #3 Total = 1,711.
# Appendix C: Data extraction template for the literature review

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<th>Sample Size and Purpose and Population of tool</th>
<th>Items, Domains, and Question Format</th>
<th>Sensitivity</th>
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<th>Positive Predictive Value</th>
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<th>Feasibility e.g. time to implement in practice and Notes</th>
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- **Validity**
- **Reliability**
- **Feasibility** e.g. time to implement in practice and Notes

**Notes:**
- **Content Validity**
- **Construct Validity**
- **Internal Consistency**
- **Reproducibility**
Appendix D: Letter to specialist palliative care providers to request their admission assessments

Re: Initial assessment for Specialist Palliative Care Services

Dear Sir or Madam,

I am writing to request a copy of the initial assessment documentation utilised within your specialist palliative care service. I have been funded by the Irish Hospice Foundation, to complete an evaluation of the initial assessment utilised within the specialist palliative care services provided by Milford Care Centre, including the specialist palliative care in-patient unit, community based homecare service and the day care service. Please see the education research and professional development page of Milford Care Centre at www.milfordcarecentre.ie

As part of the evaluation, I am required to compare and contrast multi-disciplinary documentation systems utilised in other hospices, both in Ireland and internationally.

I would greatly appreciate if I could have a copy of your documentation, including all applicable assessment tools and care pathways/clinical protocols as appropriate. Please see attached the addressed envelope to facilitate return of this information. Should you wish to receive a final copy of the evaluation for your information please let me know. Any assistance that you might be in a position to offer would be very helpful.

Should you require any additional information or wish to discuss this matter with me further, please contact me at your convenience. Thanking you for your time and in anticipation of your cooperation.

Yours Sincerely,

__________________
Martina O’Reilly
Researcher
Email: m.oreilly@milfordcarecentre.ie
Tel. No.: 00353 61 201767
Appendix E: Template for evaluation of pilot patient interviews.

Introduction: I am enquiring re your experience of the process of completion of the interview we have just done.

Having completed the interview how was it for you?

Was completion of the interview particularly upsetting, burdensome, difficult or unacceptable in any way?

Were the questions worded appropriately?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Were the questions asked in an appropriate and sensitive way?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Were there too many questions?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Were there any questions you would prefer we would leave out of future interviews?

Are there any additional questions that you would put in to the interview?

Have you any other comments?

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Have you found completion of the interview upsetting or if you are distressed at this time and wish to access support from the staff in the Social Work Department, Pastoral Care Department or any other member of the team please let me know.

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Appendix F: Inclusion/Exclusion form

Research Title: Evaluation of the Initial Admission Assessment in the Specialist Palliative Care Unit.

All persons admitted to the Specialist Palliative Care will be screened as to whether or not it is appropriate to approach them and to ascertain if they wish to consent to participate in this research.

Patient Name ______________________________________________

Diagnosis _________________________________________________

DOB        __________________________________________________

ICare No __________________________________________________

ECOG Score ________________________________________________

Exclusion criteria includes:-
Persons aged under 18 years. □

There is an identifiable known severe mental health issue(s) which means participation in research could impact upon wellbeing of the patient. (based on clinical judgement). □
The patient is too unwell to participate (based on clinical judgement). □
The patient is ‘actively dying’ (based on clinical judgment) □
There is an unrelated family crisis at the time which means participation in research could impact upon wellbeing of the patient or family. (based on clinical judgement). Participant has experienced bereavement within the last 3 months. □
Patients who do not understand English. □

Is it appropriate for this person to participate in the research? Yes □   No  □

Signature____________________________ Title_________________

Date____________________
Appendix G: M.D. Anderson Symptom Inventory (MDASI)

Date:___________________  Institution:_______________________
Subject Initials:____________  Patient Chart #:___________________
Study Subject #:____________

Part I. How severe are your symptoms?

People with advanced illness frequently have symptoms that are caused by their disease or by their treatment. We ask you to rate how severe the following symptoms have been in the last 24 hours. Please fill in the box below from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be) for each item.

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<th>Not Present</th>
<th>As Bad As You Can Imagine</th>
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1. Your pain at its WORST?

2. Your fatigue (tiredness) at its WORST?

3. Your nausea at its WORST?

4. Your disturbed sleep at its WORST?

5. Your feelings of being distressed (upset) at its WORST?

6. Your shortness of breath at its WORST?

7. Your problem with remembering things?

8. Your problem with lack of appetite at its WORST?

9. Your feeling drowsy (sleepy) at its WORST?
10. Your having a dry mouth at its WORST?  

11. Your feeling sad at its WORST?  

12. Your vomiting at its WORST?  

13. Your numbness or tingling at its WORST?  

**Part II. How have your symptoms interfered with your life?** Symptoms frequently interfere with how we feel and function. How much have your symptoms interfered with the following items in the last 24 hours:

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<tr>
<th>Item</th>
<th>Did Not Interfered</th>
<th>Interfered Completely</th>
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<tr>
<td>14. General activity?</td>
<td>□ □ □ □ □ □ □ □ □ □</td>
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<td>15. Mood?</td>
<td>□ □ □ □ □ □ □ □ □ □</td>
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<td>16. Work (including work around the house)?</td>
<td>□ □ □ □ □ □ □ □ □ □</td>
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<td>17. Relations with other people?</td>
<td>□ □ □ □ □ □ □ □ □ □</td>
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<td>18. Walking?</td>
<td>□ □ □ □ □ □ □ □ □ □</td>
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<td>19. Enjoyment of life?</td>
<td>□ □ □ □ □ □ □ □ □ □</td>
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Appendix H: Adapted Needs near the End of life Care Screening Tool (NEST)

**Interviewer:** I would like to ask you about how you are, using scripted questions. I will ask you a series of 12 questions. The questions are really brief. At the end of each question, I will give you a scale of zero to 10. In the first group of questions, zero indicates .none., nothing .not at all. or .never.. Ten is …Very much, a great deal,.everything, completely, or best possible. Please give the number that best describes how you are feeling. After I ask each question, I will state what these numbers mean again.

**Researcher addition:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
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<tbody>
<tr>
<td>21. How much of a financial hardship is your illness for you or your family?</td>
<td>None - A great deal</td>
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<tr>
<td>22. How much does this illness seem senseless and meaningless?</td>
<td>Not at (completely) - A great deal</td>
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<tr>
<td>23. How satisfied are you with family communication about your Illness?</td>
<td>Very Dissatisfied - Completely Satisfied</td>
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<td>24. How much of your worries have you shared with any member of your family?</td>
<td>Not at All - Very Much</td>
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<tr>
<td>25. How do you rate the quality of your life?</td>
<td>Very Poor - Best Possible</td>
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</table>

**Interviewer:** In the second group of questions, zero indicates .anytime I want., a great deal. or completely. Ten for these questions is .never. or .not at all.. So, the scale is almost the opposite of the questions that you just answered. Please give the number that best describes how you are feeling. After I ask each question, I will state what these numbers mean again.

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<thead>
<tr>
<th>Question</th>
<th>Scale</th>
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<tr>
<td>26. How often is there someone to confide in?</td>
<td>Anytime - Never</td>
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<td>27. How much does religious belief or your spiritual life contribute to your sense of purpose?</td>
<td>A great deal (Completely)</td>
<td>Not at all</td>
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<td>28. How much have you settled your relationships with the people close to you?</td>
<td>Completely</td>
<td>Not at all</td>
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<td>29. Since your illness, how much do you live life with a special sense of purpose?</td>
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<td>30. On admission how clear was the information given to you, about what to expect, regarding your condition?</td>
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<td>31. How much do you feel that the care you are getting fits with your goals?</td>
<td>Completely</td>
<td>Not at all</td>
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<td>32. What are the symptoms and concerns that you would most like help with:</td>
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Appendix I: Qualitative Interviews: Form to record consent to participate

Name ...........................................................................................................

Profession .................................................................................................

Grade.........................................................................................................

How long have you working in Milford Hospice? ..............................

How many years Palliative care experience have you? (Please include Milford based
Palliative experience and experience of working in Palliative Care in other
organisations)

Email .........................................................................................................

Telephone Number...................................................................................

Please tick as appropriate and sign and date:

I am willing to take part in the qualitative interview. I agree to participate in the
interview and to maintain confidentiality following the interview. I am aware that all
sessions will be audio recorded. ☐

Or

I am not able/do not wish to take part. ☐

Signature..................................................Date.......................  

Office Use only: Research Number  

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Appendix J: Protocol for qualitative interviews

Exploring staff perspectives of the multidisciplinary admission assessment:

INTRODUCTION TO SESSION  (pre-recording)

1. Introductions
   - Thanks for attendance and welcome
   - Outline of the session – how the session will be organised, interview will be taped and transcribed, notes will be taken for summary and qualification of points
   - Timing of the session (30 mins)
   - Confidentiality
   - Right to withdraw up to time of publication

2. Why invited:
   - Health professionals who conduct the initial admission assessment on behalf of the multidisciplinary team or who receive referral post the admission assessment
   - To explore the perspectives of staff of the initial admission assessment: are there aspects of the assessment process or documentation of the assessment that could be improved? If so, what are they?
   - To explore and provide an opportunity for qualification of views and the perspectives of staff working in this service.

3. Explanation re accessing the transcript of the interview.
4. Invite questions from the interviewee.

Start of Recording

CONCLUSION TO THE SESSION

Thanks to each interviewee. Acknowledgement of contribution.
Appendix K: Semi structured staff qualitative interview guide

Doctors & Nurses Interview:

Q1 Can you tell me what your understanding is of the purpose of the initial admission assessment process in a palliative care setting?

Q2 What is your experience of how the assessment process works in the inpatient unit?

Possible Prompts:

What do you think about the documentation of the initial admission assessment?

Does the documentation reflect the actual assessment process?

Does the documentation aid the assessment process?

Are the right people involved in the admission assessment and at the right times?

Q3 In your experience are all domains comprehensively assessed? By domains I mean pain and other symptoms, spiritual domains, psychological domains and need for social support domain.

Q4 What works well about the initial admission assessment in the inpatient unit?

Q5 What doesn’t work so well?

Q6 How do you communicate the results of the initial admission assessment to other disciplines?

Therapy and Social Care Staff

Q1 Can you tell me what your understanding is of the purpose of the initial admission assessment process in a palliative care setting?

Q2 What is your experience of how the assessment process works in the inpatient unit?

Possible Prompts:

What do you think about the documentation of the initial admission assessment?

Does the documentation reflect the actual assessment process?

Does the documentation aid the assessment process?

Are the right people involved in the admission assessment and at the right times?
Q3 In your experience are all domains comprehensively assessed? By domains I mean pain and other symptoms, spiritual domains, psychological domains and need for social support domain.

Q4 What works well about the initial admission assessment in the inpatient unit?

Q5 What doesn’t work so well?

Q6 How do you find out about the results of the initial admission assessment of a patient admitted to the inpatient unit?

**Ending questions**

Researcher to provide a summary of the interview followed by: Was this an adequate review of the interview?

What would you like to add?

In thinking about everything we have talked about what for you was the most important?

**Conclusion to the interview**

Express thanks to each interviewee.

Describe the next stage.

Re-stress anonymity.
### Appendix L Standards from which audit criteria were developed

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<td>Cough</td>
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<td>Page 179, A3</td>
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<td>Disturbed sleep/ Insomnia</td>
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<td>Lack of appetite/ Anorexia</td>
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<td>Page 16, 2.17</td>
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<td>3.16 Page 50, 3.37 Page 57</td>
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### Appendix M Admission Assessment Audit Criteria

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<td>Main Problems</td>
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<td>How previous problems were tx.</td>
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<td>Drugs and dosages were recorded</td>
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| A Pain                                        | A: 1 = Clear documentation that this symptom/issue was assessed in respect of this patient  
                                              | 2 = Some documentation relating to assessment of this symptom/issue  
                                              | 3 = No evidence that symptom was assessed                              |
| B Pain                                        | B: 4 = Some documentation, outcome of assessment is unclear,          
                                              | 5 = Clearly documented as being assessed and identified as relevant or problematic for this patient,  
                                              | 6 = Clearly documented that this symptom/issue was not problematic/relevant to this patient  
<pre><code>                                          | 7 = Not Assessed                                                       |
</code></pre>
<p>| 3. If previous column score = 5, Is the Pain Chart completed | (1)in full / (2)Partially / (3)Not completed                         |
| Genogram                                      | 1= Yes, 2 = Not documented                                            |
| Bathroom access                               | 1= Yes, 2 = Not documented                                            |
| Bedroom access                                | 1= Yes, 2 = Not documented                                            |
| Equipment at home                             | 1= Yes, 2 = Not documented                                            |
| Household Duties                              | 1= Yes, 2 = Not documented                                            |
| Selfcare                                      | 1= Yes, 2 = Not documented                                            |
| A. Fatigue                                    |                                                                       |
| B. Fatigue                                    |                                                                       |
| A. Nausea                                     |                                                                       |
| B. Nausea                                     |                                                                       |
| A. Disturbed sleep                            |                                                                       |
| B Disturbed sleep                             |                                                                       |
| A Shortness of breath                         |                                                                       |
| B Shortness of breath                         |                                                                       |
| A Cough                                       |                                                                       |
| B Cough                                       |                                                                       |
| A Problem with remembering things?           |                                                                       |
| B Problem with remembering things?           |                                                                       |
| A Constipation                                |                                                                       |
| B Constipation                                |                                                                       |
| A Diarrhoea                                   |                                                                       |
| B Diarrhoea                                   |                                                                       |
| A Weight Loss                                 |                                                                       |
| B Weight Loss                                 |                                                                       |</p>
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<tr>
<td>B Drowsy (sleepy)</td>
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<tr>
<td>A Dry mouth</td>
<td></td>
</tr>
<tr>
<td>B Dry mouth</td>
<td></td>
</tr>
<tr>
<td>A Sweating</td>
<td></td>
</tr>
<tr>
<td>B Sweating Outcome</td>
<td></td>
</tr>
<tr>
<td>Palliative performance scale</td>
<td>1= Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Palliative prognostic index</td>
<td>1= Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Cognition</td>
<td>1= Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Delirium</td>
<td>1= Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>1= Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Resuscitation status countered</td>
<td>1= Yes, 2 = Not documented</td>
</tr>
<tr>
<td>by the Senior Clinician</td>
<td></td>
</tr>
<tr>
<td>A Walking</td>
<td></td>
</tr>
<tr>
<td>B Walking</td>
<td></td>
</tr>
<tr>
<td>A Vomiting</td>
<td></td>
</tr>
<tr>
<td>B Vomiting</td>
<td></td>
</tr>
<tr>
<td>A Numbness or tingling</td>
<td></td>
</tr>
<tr>
<td>B Numbness or tingling</td>
<td></td>
</tr>
<tr>
<td>A General activity/ Function</td>
<td></td>
</tr>
<tr>
<td>B General activity/ Function</td>
<td></td>
</tr>
<tr>
<td>A Existential Pain</td>
<td></td>
</tr>
<tr>
<td>B Existential Pain</td>
<td></td>
</tr>
<tr>
<td>A Suffering</td>
<td></td>
</tr>
<tr>
<td>B Suffering</td>
<td></td>
</tr>
<tr>
<td>A Anguish</td>
<td></td>
</tr>
<tr>
<td>B Anguish</td>
<td></td>
</tr>
<tr>
<td>A Fear</td>
<td></td>
</tr>
<tr>
<td>B Fear</td>
<td></td>
</tr>
<tr>
<td>A Acceptance</td>
<td></td>
</tr>
<tr>
<td>B Acceptance</td>
<td></td>
</tr>
<tr>
<td>A Peace</td>
<td></td>
</tr>
<tr>
<td>B Peace</td>
<td></td>
</tr>
<tr>
<td>A. Those people who are important?</td>
<td></td>
</tr>
<tr>
<td>B. Those people who are important?</td>
<td></td>
</tr>
<tr>
<td>A. To whom you feel close</td>
<td></td>
</tr>
<tr>
<td>B To whom you feel close</td>
<td></td>
</tr>
<tr>
<td>A Intimacy</td>
<td></td>
</tr>
<tr>
<td>B Intimacy</td>
<td></td>
</tr>
<tr>
<td>Criteria</td>
<td>Codes</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>A Depressed</td>
<td></td>
</tr>
<tr>
<td>B Depressed</td>
<td></td>
</tr>
<tr>
<td>A. Have you experienced loss of interest in things or activities that you would normally enjoy/ Enjoyment of life</td>
<td></td>
</tr>
<tr>
<td>B. Have you experienced loss of interest in things or activities that you would normally enjoy/ Enjoyment of life</td>
<td></td>
</tr>
<tr>
<td>A Anxiety</td>
<td></td>
</tr>
<tr>
<td>B Anxiety</td>
<td></td>
</tr>
<tr>
<td>A. Financial issues/ hardship</td>
<td></td>
</tr>
<tr>
<td>B. Financial issues/ hardship</td>
<td></td>
</tr>
<tr>
<td>A. Family Support - Refers to completeness of family support section in nursing notes</td>
<td></td>
</tr>
<tr>
<td>B. Family Support</td>
<td></td>
</tr>
<tr>
<td>Was there documented evidence of the drugs and dosages the patient was taking on admission?  Yes/No</td>
<td></td>
</tr>
<tr>
<td>Was there documented evidence of the patient being asked if their prognosis, treatment &amp; care could be discussed with the family/ carer Yes/No</td>
<td></td>
</tr>
<tr>
<td>Was there documented evidence of the patient being asked if their prognosis, treatment &amp; care could be discussed with other health care professionals Yes/No</td>
<td></td>
</tr>
<tr>
<td>A. Family Issues/ Concerns</td>
<td></td>
</tr>
<tr>
<td>B. Family Issues/ Concerns</td>
<td></td>
</tr>
<tr>
<td>A Psychological issues - Refers to completeness of Psychological issues section in nursing notes</td>
<td></td>
</tr>
<tr>
<td>B Psychological issues</td>
<td></td>
</tr>
<tr>
<td>A What Religion</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>A Spiritual Issues - Refers to completeness of Spiritual issues section in nursing notes</td>
<td></td>
</tr>
<tr>
<td>B Spiritual Issues</td>
<td></td>
</tr>
<tr>
<td>Spiritual Screen Completed By</td>
<td>Who Completed Carers Assessment : 1 = Nurse, 2 = Doctor, 3 = Pastoral Care 4 = Pastoral Care &amp; Nurse, 5 = No Signature, 6 = Not documented</td>
</tr>
<tr>
<td>Patient aware of diagnosis</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Aware of diagnosis Outcome</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Criteria</td>
<td>Codes</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Patient aware of prognosis</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Aware of prognosis Outcome</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>A Impact of the Illness</td>
<td></td>
</tr>
<tr>
<td>B Impact of the Illness Outcome</td>
<td></td>
</tr>
<tr>
<td>A Support Needs determined</td>
<td></td>
</tr>
<tr>
<td>B Support Needs determined Outcome</td>
<td></td>
</tr>
<tr>
<td>A Pts view Family Coping</td>
<td></td>
</tr>
<tr>
<td>B Pts View family</td>
<td></td>
</tr>
<tr>
<td>A Family Communication about the Illness</td>
<td></td>
</tr>
<tr>
<td>B Family Communication about the Illness Outcome</td>
<td></td>
</tr>
<tr>
<td>A Family member that the patient is worried about</td>
<td></td>
</tr>
<tr>
<td>B Family member that the patient is worried about outcome</td>
<td></td>
</tr>
<tr>
<td>A That the patient had been given the opportunity to have any financial issues assessed?</td>
<td></td>
</tr>
<tr>
<td>B Financial issues</td>
<td></td>
</tr>
<tr>
<td>A Family Support</td>
<td></td>
</tr>
<tr>
<td>A Families Issues Outcome</td>
<td></td>
</tr>
<tr>
<td>B Families Issues/Concerns Outcome</td>
<td></td>
</tr>
<tr>
<td>A Psychological Issues</td>
<td></td>
</tr>
<tr>
<td>B Psychological Issues Outcome</td>
<td></td>
</tr>
<tr>
<td>Determination if it is appropriate to discuss preferred place of care at end of life with the patient</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>If not determined why not</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Preferred place of care at end of life as specified by the patient</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Psychosocial Assessment Completed by</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Summary of patients main problems identified as a result of the admission</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Action per issue Documented</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Pts goals for the future documented</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Patient’s aims for the admission documented</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Care plan communicated to the patient</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Care plan communicated to the carer</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Likely outcome of the admission</td>
<td>1 = Yes, 2 = Not documented</td>
</tr>
<tr>
<td>Referrals to physio documented within 48/72 hours of admission</td>
<td>1 = No Referrals, 2 = 24hours, 3 = 48, 4 = 72, 5 = 96hrs or longer, 6 = died/discharge within 48/72 hours, 99 = N/A</td>
</tr>
<tr>
<td>Criteria</td>
<td>Codes</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Referrals to OT documented within 48/72 hours of admission</td>
<td>1= No Referrals, 2 = 24hours, 3= 48, 4 = 72, 5 = 96hrs or longer, 6 - died/discharge within 48/72 hours, 99 = N/A</td>
</tr>
<tr>
<td>Referrals to SW documented within 48/72 hours of admission</td>
<td>1= No Referrals, 2 = 24hours, 3= 48, 4 = 72, 5 = 96hrs or longer, 6 - died/discharge within 48/72 hours, 99 = N/A</td>
</tr>
<tr>
<td>Referrals to PC documented within 48/72 hours of admission</td>
<td>1= No Referrals, 2 = 24hours, 3= 48, 4 = 72, 5 = 96hrs or longer, 6 - died/discharge within 48/72 hours, 99 = N/A</td>
</tr>
<tr>
<td>Referrals to CT documented within 48/72 hours of admission</td>
<td>1= No Referrals, 2 = 24hours, 3= 48, 4 = 72, 5 = 96hrs or longer, 6 - died/discharge within 48/72 hours, 99 = N/A</td>
</tr>
<tr>
<td>No. of other referrals made within 48/72hours</td>
<td>1= 1, 2 = 2, 3=3, 4 = 4, 5 = 5, 6 = No referrals, 99 = N/A</td>
</tr>
<tr>
<td>Level of Mobility/Moving and Handling</td>
<td>1= yes, 2 = No, 99 = N/A</td>
</tr>
<tr>
<td>Aids to be used documented</td>
<td>1= yes, 2 = No, 99 = N/A</td>
</tr>
<tr>
<td>Patient at risk of Falls</td>
<td>1= Yes, 2 = No, 3 = No Assessed</td>
</tr>
<tr>
<td>If at risk, Falls controls documented</td>
<td>1= 1, 2 = 2, 3 = 3, 4 =4 or more, 5 = No, 6 = Risk Not Assessed 99 = N/A</td>
</tr>
<tr>
<td>At risk of pressure ulcers</td>
<td>1= Yes, 2 = No, 3 = No Assessed, 99 = N/A</td>
</tr>
<tr>
<td>If at risk of pressure sores were controls documented</td>
<td>1= Yes, 2 = No, 3 = No Assessed, 99 = N/A</td>
</tr>
<tr>
<td>Nutritional Assessment completed?</td>
<td>1= Yes, 2 = No, 3 = No Assessed, 99 = N/A</td>
</tr>
<tr>
<td>The patient had been spoken to regarding any specific dietary requirements/preferences?</td>
<td>1= Yes, 2 = No Evidence, 99 = N/A</td>
</tr>
<tr>
<td>Notifiable infection Identified</td>
<td>1= Yes, 2 = No documentation, 99 = N/A</td>
</tr>
<tr>
<td>Oral Care Assessment scored</td>
<td>1= Yes, 2 = No Evidence, 99 = N/A</td>
</tr>
<tr>
<td>If indicated by oral care assessment measures in response documented</td>
<td>1= Yes, 2 = No, 3 = No Assessed, 99 = N/A</td>
</tr>
<tr>
<td>The patient had been asked how they would like to be addressed?</td>
<td>1= Yes, 2 = Not documented 99 = N/A</td>
</tr>
<tr>
<td>The patient had been familiarised with their surroundings as part of the admission process?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Daily routines had been discussed with the patient?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Was there documented evidence of the patient being asked if their prognosis, treatment &amp; care could be discussed with the family/ carer Yes/No</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Was there documented evidence of the patient being asked if their prognosis, treatment &amp; care could be discussed with other health care professionals Yes/No</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Criteria</td>
<td>Codes</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Has the patient had been advised on how to communicate their needs?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Have the family/carer had been familiarised with their surroundings as part of the admission process?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Of who the hospice should contact in the event of an emergency?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Family members have been advised who to contact for help or information while the patient is an inpatient</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Carer aware of diagnosis</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Carer aware of prognosis</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Of the family/carer's aims and expectations for this admission?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>That the family/carer's needs had been assessed?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>That the family/carer had been advised on how to communicate their needs?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Impact of illness on the carer determined?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Carer's view of family coping determined?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Carer's view of family communication about the illness determined?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Determination of a family member that the carer is concerned about?</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Carer's concern re financial/legal matters determined</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Carer's aims for the admission determined</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
<tr>
<td>Preferred place of care at end of life as specified by the carer</td>
<td>1= Yes, 2 = Not documented, 99 = N/A</td>
</tr>
</tbody>
</table>
Appendix N Patient Information Leaflet

Milford Care Centre: Evaluation of the multidisciplinary admission assessment

We would like to invite you to take part in research to evaluate the multidisciplinary admission assessment conducted at Milford’s Hospice, also known as the Specialist Palliative Care In-patient Unit. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take a few minutes to read through the following information and to discuss it with others if you wish.

Please contact Martina O Reilly (details below) if there is anything that is not clear, or if you would like more information.

What is the purpose of the research?

The purpose of the research is to evaluate the initial admission assessment, conducted by the doctor and the nurse at the time a patient is admitted to the Hospice. In particular, we wish to review the admission assessment from the patient’s viewpoint. The information from the research will be used to help us make the multidisciplinary admission assessment better.

What will I be asked to do?

If you decide to take part you will be asked to complete a questionnaire and a short interview which will ask you about the symptoms you are experiencing and how the symptoms are affecting you. The questionnaire should take no more than 10 minutes to complete. The interview will take approximately 10 to 15 minutes. One of the staff from the ward will interview you. They will be a different staff member from those that met you on admission.

Why have I been asked to take part?

We are trying to determine the patient’s view of the symptoms most troublesome to them and the impact of symptoms on the patient’s quality of life. You are the best placed to provide this valuable information. Staff complete the multidisciplinary admission assessment at the time of your admission to the Hospice and we will compare the symptoms you describe with that which is documented in the multidisciplinary admission assessment contained within your patient chart. The researcher will be auditing multidisciplinary admission assessment contained within your patient chart as part of the research.

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research and it is entirely up to you to decide whether or not you would like to take part. However, we hope that you will agree to participate as you have a unique perspective that is important to capture. You are still free to withdraw (and withdraw your information) at any time up to the date of publication of results without giving a reason.
Please be assured that if you decide not to take part or withdraw at any time, this will not affect the standard of care that you receive or access to services provided by Milford Care Centre that you might wish to receive in the future.

What will happen to the data contained within the questionnaire?

The completed questionnaires will be filed as part of your patient chart in order that the Hospice team might use the information contained within when developing and evaluating your plan of care.

The data from the questionnaires will be used as part of research to evaluate the effectiveness of the multidisciplinary admission assessment. The results of the evaluation will identify if any changes or improvements are required of the multidisciplinary admission assessment. Findings, including suggestions for improvement will be fed back to Milford Care Centre’s Senior Management Team and staff of the Hospice. Suggestions for improvement will be reviewed and any recommendations for changes will be acted on as quickly as possible. The results of the evaluation will be written up in a report and may be published in journals or presented at conferences. A copy of the report will be made available once the research is completed.

Who is funding the study?

This study is being funded by the Irish Hospice Foundation.

Who has approved this study?

The Ethics Committee of the Health Service Executive Midwest Regional Hospital approved this study in July 2010.

Whom do I contact if I have a question?

Please feel free to address any questions to Martina O Reilly, who the researcher and who is available by telephone to discuss the survey with you on telephone number 061 201767 or by email at m.oreilly@milfordcarecentre.ie.

Complaints procedures

If you wish to make a complaint about any aspect of this study you may contact the person in charge of the unit or contact Martina O Reilly on telephone number 061 201767 or by email at m.oreilly@milfordcarecentre.ie.

Thank you for taking the time to read this.
Appendix O Carer Information Leaflet

Milford Care Centre: Evaluation of the multidisciplinary admission assessment
We would like to invite you to take part in an evaluation of the care provided by Milford Care Centre to you as a carer. Before you decide whether or not you would like to take part, it is important for you to understand why the survey is being done and what it will involve. Please take a few minutes to read carefully through the following information and discuss it with others if you wish. Also, please ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of this evaluation?
The purpose of this evaluation is to determine if carers feel that needs are being comprehensively identified early in the admission of patients to the Hospice at Milford Care Centre. It is hoped that the staff at Milford Care Centre will learn from any suggestions for improvement and be able to implement changes in order to improve the service and care that is provided to patients and to their families in the Mid West.

Why have I been asked to take part?
You were identified by your family member/friend as their main carer.

Who is funding the evaluation?
This evaluation is being funded by a development grant from The Irish Hospice Foundation.

Who has approved this evaluation?
The ethics committee of the Health Service Executive Midwest Regional Hospital approved this survey.

Do I have to take part?
No, you are under no obligation whatsoever to take part in the evaluation. However, we hope that you will agree to take part and give us your views on care provided at Milford Care Centre. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be provided with a consent form and a questionnaire.

If you decide to take part, you are still free to withdraw at any time (and withdraw your information) without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect current or access to future services provided by Milford Care Centre that you might wish to receive or the standard of care that you or your family member (or friend) receive.

What will happen if I take part?
Further to reading the questionnaire you can decide to complete the questionnaire and return it in the addressed envelope provided. Alternatively you can specify that you
would prefer a staff member to interview you at a time convenient to you in order that they can fill out the questionnaire on your behalf.

**How long will the whole process take?**

Completion of the questionnaire will take approximately 10 – 15 minutes. Completion of the interview may take a little longer. You only need to do one or the other.

**Will my taking part in this survey be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any identifying information shall be removed from returned surveys. All information will be held securely and will be accessed by authorised personnel for the purposes of analysis only and will not be distributed to any other unauthorised individual.

**What will happen to the results of the survey?**

Data collected and suggestions for improvement shall be fed back to the Senior Management Team and staff of Milford Care Centre. Suggestions for improvement shall be reviewed and any recommendations for changes shall be actioned as quickly as possible. The results of the questionnaire will be written up in report format and may be published in journals or presented at conferences. A copy of the report will be available in approximately two years’ time.

**Who do I contact if I have a question?**

Please feel free to address any questions to Martina O’Reilly, who is available on the telephone to discuss the survey with you on 061 201767 or via email m.oreilly@milfordcarecentre.ie

**Who do I contact if I have a complaint?**

In accordance with Milford Care Centre’s complaints policy please address complaints to Martina O’Reilly, Researcher/Quality & Safety Coordinator/Complaints Officer, on 061 485870/201767 or via email m.oreilly@milfordcarecentre.ie

**Thank you for taking the time to read this.**
Appendix P Staff Survey Information Leaflet

Milford Care Centre:
We would like to invite you to take part in a short quantitative survey to explore the multidisciplinary admission assessment process in the Hospice. As you may know already there are qualitative interviews (qualitative research) being conducted with staff on this issue. Before you decide whether or not you would like to take part in the survey in addition to, or instead of the qualitative interviews, it is important for you to understand why the quantitative research is being done and what it will involve. Please take a few minutes to read through the following information and discuss it with others if you wish. Please ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of the quantitative research?

The purpose of conducting the survey in addition to the qualitative interviews is to explore the perspectives of key health professionals conducting the multidisciplinary admission assessment or who receive referrals post the multidisciplinary admission assessment, in as comprehensive a way as possible. A sample of staff, but not all staff will be able to participate in the qualitative interviews. Utilisation of a quantitative survey affords all staff an opportunity to express their opinion. It is hoped that the findings will give direction to future development of the multidisciplinary admission assessment process, with the ultimate aim of improving the service and care that is provided to patients and to their families in the Mid West.

Why have I been asked to take part?

You have been identified as a staff member who conducts the multidisciplinary admission assessment or who receives referrals post the multidisciplinary admission assessment and therefore you have a unique perspective on how the assessment process is working and may be improved.

Who is funding the research?

This study is being funded by the Irish Hospice Foundation.

Who has approved this study?

The Ethics Committee of the Health Service Executive Midwest Regional Hospital approved this evaluation in July 2010.

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research. However, we hope that you will agree to take part and give us your views on the admission assessment process. If you are happy to participate, please see the attached survey and addressed envelope. Please return the survey within three weeks of receipt of this information letter if at all possible. We will send all staff reminders within two weeks of issue of this documentation. You are still free to withdraw (and withdraw your information) at any time up to the date of publication of results without giving a reason.
A decision to withdraw at any time, or a decision not to take part, will not in any way impact your work at Milford Care Centre.

How long will the whole process take?

Completion of the survey will take approximately 5-10 minutes.

Will my taking part in this research be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential. Any identifying information will be removed. All electronic data will be password protected. All information will be held securely and will be accessed by authorised personnel for the purposes of analysis only and will not be distributed to any other unauthorised individual.

What will happen to the results of the surveys?

Data collected and suggestions for improvement will be fed back to Milford Care Centre’s steering group for the research, the Palliative Care Self-Assessment Team, to staff working in the Hospice and to Milford Care Centre’s Senior Management Team. Suggestions for improvement will be reviewed and shall inform the redevelopment of the multidisciplinary admission assessment. The results of the evaluation will be written up in a report and may be published in journals or presented at conferences. A copy of the report will be made available once the evaluation is completed.

Who do I contact if I have a question?

Please feel free to address any questions to Martina O Reilly, who is available on the telephone to discuss the survey with you at 061 485870 or by email at m.oreilly@milfordcarecentre.ie Additionally any member of the steering committee can be contacted with queries. The chair of the steering group is Jim Rhatigan, Head of Therapy and Social Care Staff.

Complaints procedures

If you wish to make a complaint about any aspect of this study you may contact your line manager or contact Martina O Reilly, at 061 485870 or by email at m.oreilly@milfordcarecentre.ie

Thank you for taking the time to read this.
Appendix Q Patient Consent Form

I agree that I have read and understood the Patient Information Leaflet. ☐

I understand that my participation in this research is completely voluntary. ☐

I understand that my completed questionnaires will be included in my chart. ☐

I understand that my patient chart will be audited by the researcher. ☐

I understand that I am free to withdraw at any time. ☐

On this basis, I have agreed to partake in this research.

I declare that I have given consent to Milford Care Centre to use the information gathered for an evaluation of Milford Care Centre’s multidisciplinary admission assessment.

I am aware that the results of the research will be written up in report format and may be published in journals/books and/or presented at conferences.

I understand that this information will only be used for the purposes stated above, and that all reporting will be done so that no individual responses will be identified. All of the information I provide will be held securely and always treated with strict confidentiality.

Signed ___________________________ Date _______________________

Person taking consent Signature __________________ Date ___________________
Appendix R Carer Consent Form

I agree that I have read and understood the Carer Information Leaflet. ☐

I understand that my participation in this evaluation is completely voluntary. ☐

I understand that some of the information contained in my completed questionnaires may be communicated to the relevant clinicians, if appropriate, in order that my needs, as well as the needs of the patient, can be addressed. ☐

I understand that the patient chart will be audited by the researcher. ☐

I understand that I am free to withdraw at any time. ☐

On this basis, I have agreed to partake in this evaluation.

I declare that I have given consent to Milford Care Centre to use the information gathered for an evaluation of Milford Care Centre’s multidisciplinary admission assessment.

I am aware that the results of the evaluation will be written up in report format and may be published in journals/books and/or presented at conferences.

I understand that this information will only be used for the purposes stated above, and that all reporting will be done so that no individual responses will be identified. All of the information I provide will be held securely and always treated with strict confidentiality.

Signed______________________________ Date __________________________

Witness Signature _____________________ Date __________________________
Appendix S Admission Assessment Induction Hand-outs

Slide 1

Initial Admission Assessment
Specialist Palliative Care Inpatient Unit
Martina O’Reilly
Quality & Research Coordinator

Slide 2

Guidelines
- 24/48 hr - Multidisciplinary
  - Doctor, Nurse, pastoral care +/- others
- Ascertain patients
  - Reason for admission
- Understanding of purpose of the admission
- Match against what can be provided
- Build confidence in their sense of control
- Outline areas of assessment
- Check understanding and willingness to participate – recheck periodically

Slide 3

Medical Details
- Principal Diagnosis
  - Stage, histology, date of dx
- Previous Treatments
- Scheduled Appointments
- Co morbid Conditions
- Alcohol/drugs/other substance
- Occupational Exposure
- Infection status
- Presenting complaint
  - What is the most troublesome symptom/issue
Slide 4

**Pain**
- /10 at its worst right now
- /10 at its worst in the last 24 hours
- Does it radiate

1. **History**
   - How long
   - How often
   - Is it constant?

2. **Quality/Type**
3. **Aggravating factors**
4. **Relieving factors**
5. **Impact/Effect**


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Slide 5

**Family & Social History**
- Use a genogram
- Give each generation its own line. Include people who are important other than family.
- Include children’s date of birth or age.
- Denote deaths
- Support sources – family and friends/PHN, Home help etc. Are they enough?
- Planning for discharge
  - Bed/Bathroom
  - Stairs

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Slide 6

**Cognitive Assessment Blessed Short Orientation Memory Test (SOMCT) 0-28**

- Weighted score - Marking Errors on 6 questions
  1. Month (Numerical response is acceptable)
  2. Year
  3. Time within an hour
  4. 20 – 1 backwards (max 2 errors)
  5. Months backwards (max 2 errors)
  6. Recall (max 5 errors)

- Subject starts counting forward or repeats the task, repeated instructions and score one error
- Patient needs to prompt with the last name of the month of the year, one error should be scored

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Slide 7

**Confusion Assessment Method**

- Acute onset and fluctuating course
- Collateral history
- Come or go during the day, increase/decrease in severity
- Inattention (months of the year in reverse/ counting backwards from 20)
- Disorganised thinking - Interpret proverbs
- Altered Level of Consciousness - hypo/hyper
- If you cannot assess because the patient is not rousable, do not assume delirium

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Slide 8

**Symptom Assessment - Today**

- Mild, moderate, Severe, Not Present
- General – fatigue, skin, itch sweating, sleep disturbance
- Respiratory - Short of Breath, Cough
- CVS – Jerking, hallucinations, bad dreams
- CNS chest pain, breathless lying down, dizzy on standing
- Upper GIT – dry mouth, sore mouth, difficulty or pain on swallowing
- GIT – nausea, vomiting, loss of appetite, feeling full after a few bites, weight loss
- Lower GIT – Constipation, Diarrhoea
- GUS - Incontinence, frequency, painful urination

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Slide 9

**Spiritual Screen - FICA**

- F - Faith - Spiritual/Religious
- I - Importance in your life
- C - Community
- A - Assist
Slide 10

If a patient were to tell you that they:

- Worry about the effect that their illness is having on family quite a bit
- Quite a bit distressed by feelings that everything is an effort
- Quite a bit distressed as they are unable to concentrate (Cognition normal)
- Very distressed and bothered by the effect of my condition on my sexual life
- Don't want any more information about financial issues
- & a number of physical symptoms

Slide 11

How would you answer the following questions?

- Are additional supports required?
- Does the patient feel their family is coping with their illness?
- Is the patient satisfied with family communication about the illness?
- Is there a family member that the patient is concerned about?
- Are there indications that the patient might be depressed?
- Are there indications that the patient is experiencing anxiety?
- Does the patient have concerns re financial/legal matters that they want help with?

Slide 12

What might the result of your psychosocial assessment be?

Who would you refer to?
On the day of the admission

- If a patient (cognitively normal, deeply religious, anointed prior to admission) talked about a “cloud on my lung”
  - How would you respond?

Guided Interview
- No more invasive than asking somebody about their bowel movements
  - Understand it before you approach
  - Use what you already know – Sparc
  - Introduce it
  - Use own words – Conversational style
  - Be present - Clarify
  - Use silence
  - Listen Carefully - Use patients words

Psychosocial Cont’d

Listening for
- Understanding of diagnosis & prognosis
- Acceptance of stage of illness
- Resources available to patient to aid resilience
- Family coping
- Past or current life events that may impact
Slide 16

**Psychosocial Cont’d**
- Previous/current psychiatric illness
  - Edinburgh Depression Scale
- Worries financial or legal
- Patients priorities & aims
- Worries for the future
- If appropriate preferred place of care
  - Reference Wright et al

Slide 17

**Edinburgh Depression Scale**
- Only administer if patient answers yes to
  - Are you depressed
  - Have you lost interest in activities you normally enjoy
- Patient Self Administered
- 6 questions
- Possible scores: 3 (yes most of the time), 2, 1 or 0 (no, never/not at all) descending order
- Scored out of 18
- Cut Off Score = 6 or more/18
- Always look at the last question

Slide 18

**Function – Palliative Performance Scale**
- Read horizontally at each level to find a 'best fit' for the patient = PPS% score.
  - Begin at the left and read down until the appropriate ambulation level is reached,
    - read across to the next column and downwards activity/evidence of disease is located.
  - Repeat for all five columns
  - Use a combination of clinical judgment and 'leftward precedence for best fit
Slide 19

Palliative Performance Scale Cont’d

- Patient spends the majority of the day sitting or lying
- Requires considerable assistance to walk even for short distances
- Fully conscious level
- Good intake
- PPS?

Slide 20

Palliative Performance Scale Cont’d

- Patient with quadriplegia who uses a wheelchair
- Requires total care
- Full conscious level
- Normal intake
- PPS?

Slide 21

Palliative Performance Scale Cont’d

- Patient who is paraplegic and bed bound
- Able to do some self-care e.g. feed themselves
- Full conscious level
- Normal intake
- PPS?
Any Questions?
&
Thank you for your time
Appendix T Confidence Questionnaire

MILFORD CARE CENTRE

Initials: Date: 

Title: Participant Number: 

Please circle the relevant number for each question or put N/A if statement does not apply to you.

1. How confident do you feel about discussing psychological problems with patients with advanced life limiting disease?

Very Confident not at all

10 9 8 7 6 5 4 3 2 1

2. How confident do you feel about discussing changes in body image with patients with advanced life limiting disease?

Very Confident not at all

10 9 8 7 6 5 4 3 2 1

3. How confident do you feel about discussing sex with patients with advanced life limiting disease?

Very Confident not at all

10 9 8 7 6 5 4 3 2 1

4. How confident do you feel about providing information to patients with advanced life limiting disease who ask about the efficacy of treatments?

Very Confident not at all

10 9 8 7 6 5 4 3 2 1

5. How confident do you feel about providing complex information to the highly intelligent patient with advanced life limiting disease?

Very Confident         not at all
10  9  8  7  6  5  4  3  2  1

6. How confident do you feel in communicating with the emotionally withdrawn patient with advanced life limiting disease?

Very Confident         not at all
10  9  8  7  6  5  4  3  2  1

7. How confident do you feel about giving complex information to patients who have limited ability to understand?

Very Confident         not at all
10  9  8  7  6  5  4  3  2  1

8. How confident do you feel in communicating with the patient with advanced life limiting disease who is the same age as yourself?

Very Confident         not at all
10  9  8  7  6  5  4  3  2  1

9. How confident do you feel in communicating with the patient with advanced life limiting disease who is either a nurse or a doctor?

Very Confident         not at all
10  9  8  7  6  5  4  3  2  1

10. How confident do you feel about discussing prognosis with patients with advanced life limiting disease?

Very Confident         not at all
10  9  8  7  6  5  4  3  2  1

11. How confident do you feel about discussing death and dying with patients with advanced life limiting disease?
12. How confident do you feel in informing the relatives of patients with advanced life limiting disease that death is imminent?

Very Confident  not at all
10 9 8 7 6 5 4 3 2 1

13. How confident do you feel in providing support for the relatives of a patient with advanced life limiting disease who has just died?

Very Confident  not at all
10 9 8 7 6 5 4 3 2 1

14. How confident do you feel about providing support for junior health professionals who become distressed by the death or imminent death of a patient with advanced life limiting disease?

Very Confident  not at all
10 9 8 7 6 5 4 3 2 1