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A quantitative study exploring the differences in communication between patients, the family care giver and health care professionals in a palliative care clinic setting.

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SUMMARY

Background: Southern Adelaide Palliative Care Services introduced a nurse-led early introduction to palliative care clinic in 2011. The clinic offers a thorough psychosocial assessment and the provision of information and an introduction to future care planning. The patients and their caregivers are seen together by the nurse practitioner initially for a physical assessment. They are then seen by a social worker to focus on advanced care planning and assessment of social and emotional factors. After the social work visit, the patient and caregiver are separated, and the patient sees the psychosocial nurse for coping and adjustment to illness and the carer sees the caregiver network facilitator to assess their informal supports to assist in the role of community-based caregiving. The pilot study looks at the nature of communication in the clinic where patient and carer are together and compares that to when they are separated.

Methods: A total of 33 patients and their caregivers agreed for their conversations to be tape recorded between May and November of 2013. All tape recordings were transcribed verbatim. Ten patient and caregiver transcripts (*n*=40) have been coded for quantitative analysis. The codes identify content and function of speech, cues for information and emotion and whether they are responded to by clinicians.

Results: Pilot results reveal that caregivers contribute little in the combined consultations but dominate the conversation in the individual consultations. Patients, when seen alone, predominantly express emotional cues, rather than cues for information. The clinicians focus on their area of specialty, which results in little duplication in this clinical setting.

Conclusion: An earlier evaluation of this clinic found that patients and their caregivers appreciate being given separate opportunities to meet with health professionals and the privacy to reveal fears and feelings related to end-of-life care. This current study quantifies the patient and caregiver experience and builds on these earlier findings.

DECLARATION

I declare that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university and that to the best of my knowledge it does not contain any materials previously published or written by another person except where due reference is made in the text.

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CHAPTER ONE
INTRODUCTION

In 2011 the Southern Adelaide Palliative Care Service introduced a new service model. This model was designed to provide integrated care for both the patient and their informal caregiver by providing them with an opportunity to engage together and separately with clinicians. In this way, specific issues can be identified, assessed and addressed proactively dealing with issues that may not be necessarily understood in the traditional patient-informal caregiver meeting. This chapter will examine the role of assessment in palliative care, the origins of the ambulatory clinic in which this study is conducted and the aims and significance of the study.

Palliative care continues to develop and mature as a specialty and the principles that underpin the modern-day hospice movement envisioned by Dame Cicely Saunders continue to provide the foundation of today's palliative care services (Monroe et al 2007). Dame Cicely Saunders had a vision that terminally ill people should experience flexible, individualised and holistic care. Attention to symptom management and support of family and friends were part of this vision. She believed in the importance of an evidence base which could only stem from research and supported the need to ensure rigour in the palliative care setting (Saunders, 2001). Her attention to the psychosocial needs of the dying in particular with reference to spiritual and existential distress heralded the importance of the multidisciplinary team required to provide whole person care (Saunders, 2001).

Her work focused initially on the cancer patient with the dominating symptom of unrelieved pain which she believed stemmed not only from the physical cancer but also from existential suffering (Saunders, 2001). A dedicated standalone hospice was deemed to provide just the right environment to address the needs of the whole person. By promoting a place that offered the comforts of home with the services of a hospital she endeavoured to address the deficits of care that the dying received (Monroe et al, 2007) As palliative care has developed as a specialty there has been a requirement to open it to all life limiting illnesses regardless of diagnosis, and have it readily available at all times across the illness trajectory if and when the need is there. This is reflected in the current definition of palliative care by the World Health Organisation, (2010).

The World Health Organisation defines 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.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of 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 (2010).

Palliative care as a form of health care is well recognised and referrals for assistance with symptom management are increasingly being received earlier in the patient illness journey mostly with pain as the catalyst. This has however been a challenge to specialist palliative care services as resources to meet earlier identification and impeccable assessment cannot be managed in the traditional model of palliative care.

As a Director of a Specialist Palliative Care Service, the student has been challenged with managing tight resources in the face of growing demand. Regular weekly clinical team meetings revealed an increase in the waiting times for new patients to be reviewed in clinic by the palliative medicine specialist. In addition, participation in a self-assessment process against the 13 National Palliative Care Standards through the National Standards Assessment Program (NSAP) (Palliative Care Australia 2007) revealed that psychosocial assessments did not occur routinely and that there were areas for improvement (Swetenham, Tieman, Currow. 2014).

In response to these findings, a quality improvement activity was undertaken leading to the introduction of an early assessment palliative care clinic. This clinic was designed to address the issues of long waiting lists for medical clinics and to regularise psychosocial assessment. By implementing a palliative care clinic for newly referred patients to the service, particularly those that were being referred to be 'introduced to palliative care' they could effectively be triaged for priority of a medical assessment which ensured medical clinic appointments were allocated according to urgency and need.

The clinic was structured in line with the domains covered in the Needs Assessment Tool; Progressive Disease - Cancer (Waller et al 2010) The areas of physical symptom management, social support including advance care planning, the emotional needs of the patient and the emotional needs of the family caregiver were divided among the multidisciplinary team members to form the structure of an introductory clinic which provides information and support at a time that the patient is well enough to process and understand the information provided.

The separation of the patient from their family caregiver was included in the design of the clinic in response to the literature which identifies patients and their caregivers can have very different information needs at all stages of the trajectory of a life-limiting illness (Parker et al 2007).

The role of the palliative care clinic underpins this communication study, as the design of the clinic is unique in that it formally separates the patient from their informal caregiver for an individualised and private assessment. To my knowledge, the assertive separation of patient and informal caregivers is not done formally elsewhere, and it is this clinic structure that enables a comparison between a triadic and dyadic consultation in the palliative care setting, which is the focus of this communication study. The role of community-based clinics and the functional components of the palliative care clinic will now be discussed to inform the reader of the setting that this communication study is set in.

COMMUNITY BASED CLINICS

To fully appreciate the movement of palliative care into the ambulatory space, it is important to understand the social and referral practices that have changed. Early referral to palliative care is recommended by the World Health Organisation for people diagnosed with a life limiting illness. This shift in focus has not been reflected in the way that many palliative care community services are structured, which are mostly still modelled strongly on the home visit evolving from a time when referrals to palliative care were late and death was imminent.

The change in focus to earlier introduction and assessment coupled with a tight economic climate challenges palliative care services to review where and when they become involved and what services they offer determined by the patient need and condition. Palliative Care Australia recommend that 50-90% of all patients diagnosed with a life limiting illness should receive at least a single specialist palliative care assessment, and of these patients that only 10-30% will go on to require ongoing follow up by a specialist palliative care service until death (2003). In conjunction with strong policy regarding hospital avoidance initiatives and returning care of the dying to the community where possible the opportunity exists to explore the use of the ambulatory setting, in particular the outpatient clinic.

The development of the GP Plus Primary Health Care Clinic within local communities has been rolled out in South Australia, refocusing health care access and delivery away from the emergency departments of major hospitals and returning it to the primary care sector. Traditional palliative care services have been based within a dedicated inpatient hospice unit, as a consultative service to the tertiary hospital setting or as a home visiting program. The outpatient department has been introduced more recently as a service option in recognition of earlier referrals for patients who are still able to attend ambulatory clinic appointments with other health care providers.

With the release of Commonwealth Government funds in 2009 to improve services across the sub-acute continuum a focus on workforce development was made a priority.

Advanced practice roles have been introduced to the specialist palliative care team across nursing and allied health with a mandate to support people to be managed in their place of choice.

The expected introduction of activity based funding to community palliative care programs across Australia in 2015/16 means that the services provided by these advanced practice positions need to deliver occasions of service which attract funding whilst ensuring they contribute value to the patient experience. In order to ensure access to these specialist positions, services need to think carefully about where they should be located so that they can be delivered equitably across the region that they serve.

The development of the community based outpatient clinic which would enable comprehensive patient and carer assessment including psychosocial assessment drew upon research and evaluation of models of care that have been trialled and implemented across the world. A literature review highlighted the importance of several key elements which are briefly described below.

Ambulatory setting as an opportunity for shared care and early intervention models.

Studies highlighted that ambulatory services have been established to meet unmet needs (Cowan and Cardy, 2011; Harrison and Watson, 2011; Temel, Greer, Muzikansky et al, 2011), to provide information and education, (Swetenham et al, 2014, Pituskin et al 2010) and as a partnership between specialist groups (Harrison and Watson 2011). The ambulatory services have been reported upon within the literature. Of the articles that related specifically to the palliative care setting many of these clinics are nurse-led, and focus on preliminary results from returned questionnaires, and customer feedback (Cowan and Cardy, 2011; Harrison and Watson, 2011,). Nurse–led clinics are reported to have been established in response to identified unmet need particularly relating to the provision of information and education, (Swetenham et al, 2014, Pituskin et al 2010). Harrison and Watson identified a partnership model between specialist palliative care and chronic renal disease, to better address symptom issues for patients with end stage renal disease that required specialist palliative care advice and management.

The focus of this particular clinic partnership was to provide symptom management, empower patients to make their own choices and support them with advance care planning (2011). With the introduction of self-assessment against National Palliative Care Standards in Australia, there is an expectation that services develop processes to ensure that patients and their caregivers receive a comprehensive assessment (Swetenham et al, 2014). The introduction of an ambulatory clinic for early introduction to palliative care offers a mechanism that could encourage a systematic assessment process for patients and their informal caregivers.

The role of screening tools

There are studies looking at the use of screening tools within an ambulatory clinic to better identify psychosocial needs of not just the patient but of significant family members as well. A variety of tools have been used in this setting including FAMCARE -6 (Carter, Lewin, Gianacas et al, 2011); This tool targets the family's level of satisfaction for the care provided toward the patient within a palliative care unit. Other tools have been developed to assist general practitioners in the community health space, and oncologist in the specialist setting determine whether the assistance of a specialist palliative care service is required. These tools include

- Needs Assessment Tool: Progressive Disease – Cancer (NAT: PD-C) (Waller, Girgis, Lecathelinais et al 2010);
- Palliative care social work assessment tool for patients with advanced cancer (Miller and Walsh 1991);
- Visual Analogue Quality of Life Scale (Bakitas et al, 2009)
- and a range of tools to assess depression (Mitchell et al 2011, Payne et al, 2009, Chochinov, 1997).

Psychosocial Intervention

The palliative care literature has highlighted psychosocial intervention as being an important contributor to the provision of 'total patient care'. In cancer care, understanding of the behavioural and social components informs total patient care (Greer, 1994). While the primary target group for psychosocial intervention is the patient, the second target group are partners and family members (Menerhet and Koch, 2005). People who are diagnosed with a life limiting illness on a background of a severe and persistent mental illness encounter difficulties regarding decision making, access to care and ultimately provision of care (Woods et al, 2008). The importance of incorporating a screening tool to identify a prior or concurrent mental illness and the need for greater education and shared care models with mental health care workers regarding the palliative care needs of their clients has been reported (Taylor, Swetenham, Myhill et al, 2012).

Case Management

Increased satisfaction between patients and caregivers across many of the psychosocial domains of care has been reported where an interdisciplinary, collaborative clinic is utilized to provide information and support (de Vogel-Voogt, van der Heide, van Leeuwen et al 2007). Specialist pallaitive care has an opportunity to provide that single interdisciplinary assessment in an outpatient palliative care clinic to ensure that the primary treating team is supported by the expertise that the interdisciplinary team offers as they manage their own client group through their end of life illness (PCA, 2003).

Meeting the needs of informal caregivers

Informal caregivers who take on the role of primary caregiver will face challenges for an undefined period of time which may be a few short weeks to years. They provide a range of forms of assistance and the impact of caring for many informal caregivers can be significant (Hudson, Hayman-White, Aranda et al, 2006; Dionne-Odom, Azuero, Lyons et al, 2015; Black et al 2010; Thompson and Roger, 2014). Informal caregivers may also be required to learn new skills yet may be reluctant to seek help (Northfield and Neubauer, 2010). However supporting informal caregivers care provide benefits to the carer (Houldin, 2007; Nijboer, Tempelaar, Triemstra et al, 2001).

The findings from the examination of the literature informed the final redesign of the outpatient palliative care clinic and the tools used for the assessment within the clinic.

The structure of the interdisciplinary assessment reflected in the planning of the outpatient palliative care clinic is supported within the literature. A clinic that focuses on screening and identification of issues early is expected to assist not only the cohort of patients and caregivers by way of education and information provision but the primary care providers who coordinate ongoing case management.

The outpatient clinic in palliative care is seeking to provide information and support to clients at a time in their illness where they can be actively involved in the planning of their care. It not only seeks to provide a thorough assessment but education regarding community-based services, and what to expect in the dying process if patients or caregivers wish to discuss this. The transfer of this knowledge and information to both the patient and their caregiver is empowering and recognized to reduce anxiety at a time where they face an uncertain future.

PURPOSE OF THIS STUDY

With all innovative service interventions, the opportunity to evaluate the actual outcomes is necessary to ensure further Health Department support of these initiatives into the future and key findings can be generalised to other services.

The early assessment outpatient palliative care clinic for patients newly referred to palliative care has been operating since late 2011. Patients and their informal caregivers are seen together by the Nurse Practitioner, and then the Social Worker before being separated. The patient is then seen by the Psycho-oncology nurse and the informal caregiver is seen by the Caregiver Network Facilitator (Greene et al, 2012).

The Caregiver Network Facilitator was recently introduced into the palliative care service following a study that demonstrated informal caregivers are more likely to reach out and ask for assistance if they are supported to do so. A satisfaction survey conducted at the end of 2011 and early 2012 revealed that patients and informal caregivers appreciate time on their own to discuss private concerns (Swetenham et al, 2014).

Patients and their informal caregivers often attend palliative care clinic appointments together. The National Standards of Palliative Care identify formal assessment of patients and their informal caregivers as best practice. However, there is very little evidence to support best practice regarding psychosocial assessment for both patients and their informal caregivers within the literature and this study will help to identify enablers that will support health care professionals to meet this objective. This communication study aims to understand the content and function of interactions between clinicians and patients and their informal caregivers. In particular, this study will assess communication differences including the degree of emotional expression that occurs when patients and their informal caregivers are seen together and then separately.

A quantitative study design is chosen to analyse the communication exchange of both the patient and the informal caregiver in attending a palliative care early assessment clinic encounter while also providing insight into the role that the informal caregiver plays within the joint clinic appointment.

AIMS

The primary objective of the pilot study is:

- To understand the differences in communication that occur within the patient, informal caregiver and health professional triadic consultation and compare this to the communication that occurs between the health professional and patient or health professional and informal caregiver in the dyadic consultation.

The secondary objectives are:

- To establish the emotional content of the consultations when patients are seen together with their informal caregivers and compare that to when they are seen apart with specific attention to the use of emotional and information based cues which will assist to quantify the awareness of clinicians in meeting patient and caregiver communication needs; and
- To determine if the outpatient palliative care clinic structure facilitates informal caregiver assessment and support.

CHAPTER TWO
DISSERTATION CONCEPTS-LITERATURE REVIEW

Introduction

Palliative Medicine as a speciality in Australia is still emerging and developing. Over the last 15 years there has been an increased focus on developing the research agenda within palliative care in this country. There have been significant concerns raised by Human Ethics departments in the past on conducting research on people who are considered too vulnerable to participate (Gysels, Evans, Higginson, 2012). Despite these concerns, positive outcomes for those participating in research have been identified. Many patients have identified a sense of altruism in contributing to service improvement, despite the fact that they may not live long enough to experience it (Gysels et al, 2012).

The reluctance of health care professionals to approach patients at the end of life to participate in research has resulted in a paucity of literature being available within the setting of palliative care (Gysels et al, 2012). Much of the communication literature that is related to the study of communication within a life limiting illness context is located within the oncology environment and often directed to early diagnosis, shared decision making regarding treatment, and survivorship, (Laidsaar-Powell, Butow, Bu et al, 2016; Song,Tyler Clayton et al, 2016; Kandsberger, Rogers, Zhou et al,2016; Shaw, Young, Butow et al, 2016; Brown, Butow, Juraskova et al, 2010; Korsvold, Mellblom, Lie et al, 2016).

The literature review was conducted to meet the focus of this study, which is to understand the differences in communication that occurs within the patient, family caregiver and health professional triadic consultation and compare this to the communication that occurs between the health care worker and patient or health care worker and family caregiver dyadic consultations. The setting is a palliative care clinic where patients are referred following the progression of disease with the inevitability of a terminal event being the ultimate outcome.

Four databases were searched to identify literature related to communication and palliative care. They included OVID Medline, CINAHL, PsycINFO, and PubMed via caresearch.com.au.

Search

Search terms and MESH/keyword terms were collated for two key concepts: communication at end of life and Triad and Dyad communication involving family caregivers. The medical librarian from the Repatriation General Hospital guided and informed the search strategy and provided feedback regarding the search terms. (Search History Appendix A).

In order to monitor the literature for currency ongoing access to the literature was supported with Ovid email notifications every week established by the medical librarian at the Repatriation General Hospital.

Given a relative paucity of literature, the time limits were extended to 1 January 2000.

Inclusion/Exclusion criteria

As the focus of this study was palliative care, literature dealing with palliative care and advanced cancer care were included in the review.

Cancer literature relevant to the primary and secondary research outcomes (as defined in Chapter 1) was also included, namely:

- communication skills for clinicians and how they provide information to a patient,
- the role of the informal caregiver, triadic and dyadic consultations, and
- the use of coding schemas to reveal the communication process occurring in the clinic setting

Literature dealing with paediatric palliative care has not been included as the study site is an adult palliative care service.

Only dementia literature dealing with the needs of the informal caregiver has been included as the clinic does not assess and manage dementia patients.

Psychosocial Intervention

Communication is a key aspect to the patient, family and health care provider relationship and it continues to evolve according to the changing need of the patient and family caregiver in the palliative setting. Good communication principles underpin good palliative care and are integral in the provision of any psychosocial intervention.

Early work by Butow identified that there were discrepancies between the patient reported experience of being given their diagnosis of cancer and published guidelines for the telling of a diagnosis. Most of the communication literature focused on a communication event such as breaking bad news. There was little written about subsequent communication processes concerning the implications of the diagnosis and treatment choices or how patients wished to be communicated with (Butow, Kazemi, Beeney et al 1996). In order to understand this better a cohort of melanoma and breast cancer patients were invited to complete a self-report questionnaire on their experience of communication at the time of diagnosis. Of the 187 patients approached, 148 returned the questionnaire detailing their psychologic adjustment, level of social support and quality of life. Psychological adjustment was found to be related to the quality of discussion held by the doctor concerning treatment options (Butow et al, 1996).

A recent quantitative study by Korsvold, Mellblom, Lie et al (2016) studied the adolescent, young adult cancer group in Norway. Despite a very small sample size (n=9) the study explored emotional cues and concerns from adolescents, young adults and their family members when being informed of their cancer diagnosis. Findings from this study demonstrate that when the clinician is faced with an emotional cue or concern they respond with medical facts and do not explore or even comment on the hidden emotion. This is considered to be a missed empathic opportunity, which has the potential to impair the establishment of rapport and trust (Korsvold et al). Communication guidelines encouraging the use of a question prompt list for the patient to better support patients and families as they navigate the cancer trajectory have been evaluated (Clayton, Hancock, Butow et al. 2007). The evaluation of these guidelines was conducted as a randomised controlled trial with a total of 174 patients. There was a strong correlation between physician endorsed use of the question prompt list and the patients of the intervention arm having fewer unmet information needs. A further outcome from this study was that the intervention arm consultation time on average was 7 minutes longer than that of the control group. An invitation to engage the patient in proactive question asking did impact on clinic time for the health care professional, but enhanced the patient clinician relationship (Clayton et al, 2007).

The setting for this study is an outpatient palliative care clinic. Patients and their caregivers are introduced to the palliative care team at a time where they are well enough to absorb information but often grappling with the news that their disease has progressed and end of life care planning is required. While the preceding studies focus on the time of diagnosis in a cancer setting, this clinic focuses on the transition from cure (oncology) to care (palliative care) (Butow et al 1996, Korsvold et al 2016).

This clinic can be very challenging for the clinicians, as patients and their caregivers present at varying levels of acceptance and, as such, the array of emotions can be wide and varied.

Communication skills for health care professionals are recognised as necessary to ensure that a supportive environment is maintained for patients and their informal caregivers, particularly where bad news is being communicated. Psychological adjustment of the patient can be linked to their perception of how they experienced their clinician's behaviour during the diagnostic discussion, particularly how the clinician responded to their emotional distress (Butow et al, 1996; Kandsberger, Rogers, Zhou et al, 2016). Patients, when asked, indicate that subsequent discussions of the meaning of the diagnosis is as important if not more so than the disclosure of the diagnosis (Butow et al 1996). Butow's early work has informed subsequent studies which focus on maintaining and nurturing hope for those with a terminal illness.

Kirk, Kirk and Kristjansen's qualitative study on patient and family dyads identified hope as the second most important content area after prognosis for advanced cancer patients being managed within a palliative care service. The need for hopeful messages was supported by their findings that it was important for patients and families to feel that their clinician was supporting hope (2004).

Clayton, Butow, Arnold et al conducted a qualitative study in 2005 to understand how hope could be maintained as patients approach the end of their life. This study consisted of focus groups with patients, caregivers and health care providers to inform a structure for maintaining hope for those facing a terminal illness. Whilst this study focuses on patients with advanced cancer it was conducted in a palliative care setting and targeted patients in the last 8-12 weeks of life. Reassuring patients that symptoms can be controlled is ranked highest, closely followed by the provision of emotional support and assuring the patient that they will not be abandoned by the health care team. The offer of practical support which can be accessed either via admission to the palliative care unit and or provision of equipment in the home is also ranked as important by participants of the focus groups (2005).

These early studies support the way in which the outpatient palliative care clinic has been structured. Information needs for patients facing a life limiting illness are high; however, they are often not addressed until late in the patient's illness which means that the impact of decision making discussions has limited impact on the care process (Bernacki and Block, 2014).

This clinic offers an opportunity at a time the patient is well enough to engage in active decision making about their future. The clinic commences with the triadic consultation and as such the challenge for the clinician is to ascertain the information sharing that can occur in the presence of the informal caregiver and how the caregiver is engaged in the consultation. The significance of this palliative care clinic compared to an oncology clinic is that shared decision making is no longer required for curative/palliative chemotherapy treatments. Shared decision making and the process of information giving is now to align goals of care that are congruent with the patient and their family member's beliefs and values.

Communication and Information Giving

The literature on communication and information giving covers this transition from curative information giving in order to support decision making regarding treatment options and to carer information giving which balances the patients' needs for information against the needs of the family as the patient approached death.

Meeting information needs of palliative care patients is well represented within the literature. Kirk et al (2004) explored information needs of patients with cancer and their family members. They utilised a qualitative methodology using a single semi-structured interview with 72 participants made up of 35 patient and family dyads, and 2 patients. Of note was that information needs changed as the illness progressed. Often patients chose to know less the sicker they became, with families needing to know more as the patient neared the terminal phase.

Parker et al (2007) conducted a systematic review of end of life communication in an attempt to uncover evidence based recommendations concerning how to discuss dying.

They retrieved 123 studies and refined the search to the 46 articles that included patient and caregiver preferences for content, style and timing of information. They identified the importance of explaining to patients and caregivers the possible symptoms that could be experienced in the future and how they could be managed. General information regarding the process of death and dying was also highlighted to be important, and reflects the need to provide a space where these conversations can be held (Parker, Clayton, Hancock et al, 2007).

Areas identified as requiring the most information included pain management, uncommon symptoms, home care resources and generally what to expect (Parker et al, 2007). These findings of Parker et al underpin the way in which the palliative care clinic has been set up, and while the establishment of this clinic is not the focus of this study, it is relevant to the communication study as it has enabled the triadic issues and dyadic concerns to be studied by virtue of the structure of the clinic. The clinic has been structured so that patient and informal caregiver information needs are addressed prior to exploring deeper psychosocial issues around coping and adjustment to illness or the caregiving role. The clinic also potentially offers an avenue in which the family carer can identify how their information needs can be met over time and as things change.

Timing around the provision of information is something that has been reported upon, and underpins the structure of this clinic targeting early introduction to palliative care. A randomised controlled trial by Hoerger et al looked specifically at communication about prognosis and treatment options in order to assist with informed decision making for the patient and caregivers. This study was conducted within an oncology setting and included 40 oncologists and 400 patients with advanced cancer and their family caregiver. Utilising a two-pronged approach oncologists completed an education intervention to support question asking and patients and family members completed a coaching intervention to facilitate prioritising questions and voicing concerns. Of relevance to this communication study is the need for frank and sensitive discussions to occur before the patient is critically unwell (Hoerger, Epstein, and Winters et al 2013). Bernacki and Block (2014) support the need for early discussions with patients and highlight the ambulatory setting as the place for these to occur.

Their narrative review of the evidence study revealed that it was physician barriers more so than patient barriers that prevented end of life discussions and that the first conversation about end of life care took place on average 33 days before the patient died. A paper written by Mack and Smith also identifies the notion of physician barriers to appropriately timed conversations. They identify myths which support avoidance of end of life conversations, such as they may make people depressed, remove hope, reduce survival or such conversations are not culturally appropriate (2012).

Mack and Smith also highlight how important these conversations are in a fiscally tight climate with an ageing population to ensure best patient outcomes as well as providing a solution to containing increasing health expenditure in the face of futility (2012).

The tension between promoting hope and preparing for the reality of a situation is something that clinicians often grapple with. Clayton, Hancock, Parker et al's systematic review which includes examination of 27 articles related to palliative/terminal care and communication skills training regarding hope, identified that in the context of a serious life limiting illness the patients' desire for information about the future can be an unmet need (2008). The provision of a prompt list to facilitate patients with an advanced cancer and their informal caregivers to ask questions about prognosis and end of life care issues is seen as enabling the patient to ensure that their communication needs are met in a context where clinicians often miss hints or cues for information (Clayton, Butow, Tattersall et al 2007).

Earlier qualitative work utilising thematic analysis obtained from focus group and interviews by Clayton et al identified individual coping styles by patients as a consideration for clinicians attempting to meet prognostic and end of life needs (Clayton, Butow and Arnold 2005).

Patients can either seek or avoid information, and skilful conversations by clinicians are required to ensure information needs are met. Clayton et al develop this theme of coping styles by identifying hope as an important strategy that shifts from seeking a cure in the early diagnosis of a cancer to a multidimensional dynamic process that assists the patient to prepare for a changed future (2005). This is the purpose of the outpatient palliative care clinic. The clinicians provide an introduction to palliative care which is about promoting and maximising quality of life while also ensuring ongoing support and care if and when, the illness progresses.

The theme of unmet information need is not unique to western cultures. Of particular interest is a qualitative study in Africa which was co-authored by researchers from the United Kingdom to understand experiences of communication and information giving among African patients and their family members with incurable disease. Of the 90 patients enrolled in this study 61 had HIV infection, with 28 having cancer and 1 having motor neurone disease. Thirty eight informal caregivers also enrolled in this study. Despite palliative care teams being involved with this cohort of patients, many patients and their caregivers still had unanswered questions. Unanswered questions contributed negatively to the patient's ability to cope with their illness and the caregivers felt there was a negative impact on their ability to care for the patient. This then increased the sense of anxiety especially in relation to planning for the future. (Selman, L. Higginson, I. Aguipo, G. et al, 2009).

In order to understand what is important in planning for the future in the face of a life limiting illness early work by Steinhauser et al studied the factors deemed to be important by patients as to what constitutes a good death. This study was designed using a qualitative methodology to understand the patient experience. Patients identified the need to have physicians who are comfortable talking about death and dying and who are someone with whom a patient can express their own personal fears (Steinhauser, Clipp, McNelly et al 2000).

Steinhauser et al developed this work further to identify that while physical care is crucial and ranked as important by patients, patients view their end of life with broader psychosocial and spiritual meaning, thus in order to prevent unmet needs at this time in a patients' illness experience they require supportive health care professionals who can communicate openly and who can focus on the broader psychosocial issues (Steinhauser, Christakis, Clipp et al 2000). Psychosocial care is an important aspect of whole person care and rises in prominence once physical suffering has been addressed. This study supports why the development of the palliative care clinic is structured with the physical assessment occurring first, so that the patient is comfortable to explore the psychosocial issues knowing that the physical concerns have been heard and are in the process of being addressed.

The location of the clinic in a primary health community centre affords clinicians the opportunity to commence the conversation regarding future care needs with patients and their caregivers at a time where they can both contribute actively to the discussions. Utilising tools such as the Needs Assessment Tool-Progressive Disease ensures the psychosocial domains are not overlooked in the consultation process (Waller et al 2010).

Temel, Greer and Muzikansky's non-blinded randomized controlled study highlighted that those newly diagnosed lung cancer patients assigned to the intervention arm to receive palliative care integrated with their oncologic care had significantly better quality of life and mood as well as 25% longer survival, with those being treated aggressively having a shorter survival (2010). This finding correlates with the role and purpose of the palliative care philosophy to focus on communication, patient education and planning for care to address future medical realities. A presence in an ambulatory setting also normalises palliative care and reinforces its place along the journey of a life limiting illness and not just at the end point when death is imminent.

Early engagement with a palliative care service also enables a relationship to be developed with the 'significant other/s' of the patient. The planning of care to address future medical realities relies heavily on a willing family member or friend to step into the role of primary caregiver and successful palliative homecare programs are dependent on this reality (Northfield and Nebauer 2010).

In examining the literature special attention was given to the role of the informal caregiver. The study invited a third party to be present to understand the differences that may be experienced in a clinical encounter that includes a patient with their significant other and then a clinical encounter that separates the patient and the significant other to address individual needs in a private and confidential space.

Role of the Informal Caregiver

Many patients diagnosed with a life limiting illness attend appointments with an informal caregiver/ family member and the incidence of informal caregivers is rising as the population ages.

A survey of Organization for Economic Cooperation and Development (OECD) countries estimates that between 8-16% of the population serve as family caregivers (Joyce et al 2014). The statistics for Australia reveal that 12% of the population act as an unpaid carer for someone and provide, on average, care for 40 hours per week (Australian Bureau of Statistics, 2012).

The role of the informal caregiver can be overwhelming and demanding across the physical, emotional, social, and financial spectrums which can lead to feelings of helplessness as other personal responsibilities for the caregiver become neglected (Northfield and Nebauer, 2010; Joyce et al 2014). A coping mechanism identified to assist caregivers is the ability to reach out and accept help from others (Reiss-Sherwood, Given &Given 2002). For those that are not prepared or comfortable to reach out, the structure of the outpatient palliative care clinic facilitates a dedicated support person to assist informal caregivers to develop skills in this area (Greene et al 2012). It also acknowledges their role by extending a direct invitation to the informal caregiver to attend the appointment with the patient (see Appendix A).

The literature on caregiving within the palliative care context identifies gaps between systematic assessment processes to identify caregiver need and actual practical support for informal caregivers (Hudson and Payne, 2011). It is well recognised that the health care system is reliant on the role that informal caregivers take on (Boehmer, Egginton, Branda et al 2014). Informal caregivers are even considered to be co-workers with health care professionals (Currow, 2015).

Good palliative care recognises that quality of life must be improved not only for patients but their caregivers (Hudson P, Quinn K, Kristjanson L, 2008). This requires an assessment of the informal caregiver’s own health needs, as they need to be in good physical and mental health to meet the demands that come with being a caregiver (Currow, 2015).

The lack of psychological support and the lack of information are cited within the literature as the source of unmet need for caregivers (Thomas et al, 2010). Proot et al have identified three key requirements that informal caregivers have of professional home care providers. They require instrumental, emotional and informational support to lessen their sense of vulnerability in providing home care to a terminally ill family member (Proot, Abu-Saad, Crebolder et al 2003).

The outpatient psychosocial clinic does not routinely see people with dementia, however the literature related to caregivers of people with dementia does identify the specific needs that these informal caregivers may face.

Caregivers of those dying with dementia receive attention in the literature mainly due to the length of time a family member may be engaged in the role of caregiving. A study from Canada (which has a similar health system to Australia) estimates that 60-80% of dementia care is provided by informal caregivers, and that this number is projected to rise (Thompson and Roger, 2013).

Dementia caregiving is also often marked by a transition to residential aged care which brings up difficult feelings for informal caregivers as they relinquish care (Thompson and Roger, 2013). The transition to a hospice within the cancer population also brings up feelings of relinquishment for informal caregivers, and can be a source of stress and guilt regarding broken promises to care for a loved one at home (Harrington, Mitchell, Jones et al 2012).

Albinsson and Strang referred to dementia as a disease of the family due to its far reaching effects and the length of time family members can be engaged in the role of an informal caregiver (2003). The prevalence of anxiety and depression in the caregiver spouse of the dementia family member is high and associated with feelings of helplessness, loneliness and fatigue (Joling et al, 2010). Joling's study also identifies that *"The spouses of patients with dementia have a fourfold higher risk of depression than the spouses of non-demented persons (2010)."*

The dementia literature highlights the impact that longer term caregiving may have which may well have a bearing on the disease groups palliative care is engaging with, particularly in the chronic disease groups.

As palliative care services engage with patients earlier within their illness trajectory, support for the impact of long term engagement in the caregiving role along with the potential need to relinquish that care to a formal institution is likely to be encountered more often.

For those managing the caregiving in the community setting the similarities within the dementia and cancer caregiving literature relate to the categories that caregivers require the most support. Broadly the categories fit under the following domains;

- Physical, emotional and psychological needs
- Information and decisional support needs
- Instrumental support. (Thompson and Roger 2013)

Surrogate decision making is something most caregivers will be faced with and the need for conversations while the care recipient is able to express their wishes is necessary to prevent further burden to an already stretched informal caregiver.

This is particularly relevant in the dementia setting where these conversations can be missed as there may be a lack of a sense of urgency, limited knowledge of the disease trajectory or personal discomfort with the topic (Thompson and Roger, 2013).

Davies et al identify that many informal caregivers are unable to think about the death and dying process of their relative with dementia but that this is often confounded by clinician reluctance to discuss this topic (2014).

If patients are to realise a desire to die at home, then it is vital that informal caregivers receive comprehensive preparation and support. Hudson et al describe the informal caregiver as the 'hidden patients', with unmet needs in social support, financial assistance, emotional support and assistance in managing the dying person's symptoms (2008). Informal caregivers are instrumental to the provision of home care and they are relied upon partners of clinicians providing in-home support (Currow, 2015).

In order to better understand the information and support needs of informal caregivers, the literature review proceeded to look at the triadic nature of consultations and how caregivers are incorporated into the clinical encounter.

Triadic Studies

The literature regarding triadic consultations falls largely into two groups; those studies where an interpreter is used to ensure patient understanding and those where a family member is present throughout the consultation. (Eggly et al 2013; Fatahi et al 2008: Laidsaar –Powell et al, 2013; Laidsaar-Powell et al, 2016; Jackson et al, 2009; Merckaert et al 2013). For the purpose of this study the literature regarding the presence of the family caregiver will be the focus as it underpins the structure of the outpatient palliative care clinic.

Early work from Labreque and colleagues identified the differences in communication styles when a family member was present in the consultation. This study involved the observation of physician behaviour in an outpatient oncology setting. Ninety nine interactions occurred when family members were present. Informal caregivers were more likely to attend with a patient who was increasingly unwell as this is the time that information regarding the disease progression is most likely to be communicated. Clinicians were more likely to meet this expectation and time spent in the triadic consultation was longer than when the patient attended alone.

The clinician provided greater emotional support to those patients attending alone than to those who came with a family member. On average a consultation including a family member lengthened the consult on average by 3 minutes (1991).

Burkhalter and Bromberg identified that, on the whole, oncologists prefer a family member to attend a consultation despite the fact it lengthens the interaction as the family member can provide support and encouragement to the patient and bring new information.

However, they also noted that informal caregivers can dominate and set up an adversarial relationship and that oncologists need to be skilled to manage this dynamic (2003).

The area of prognostication and communication involving patients and their informal caregivers precedes the role that informal caregivers play in decision making. For informal caregivers to step into the space of decision making, it is important that they understand that life expectancy is short.

In a cross sectional survey that included 214 participants aged over 60 with chronic illness deemed to be palliative by Fried et al, there was a discrepancy between patients, caregivers and clinicians regarding prognostic communication occurrences. Many more clinicians than patients and caregivers believed that prognosis discussions had taken place (Fried, Bradley, O'Leary 2003)

Clayton's work in providing patients and their caregivers with a prompt tool to facilitate discussions regarding prognosis and end of life care issues identified that caregivers in the intervention group were more likely to ask questions in front of the patient that related to the role of caregiving than the control group where no questions were asked about caregiver issues (2007). Informal caregivers are often welcomed in the oncology setting especially where discussions regarding diagnosis are taking place. Eggly has explored whether informal caregivers process information more accurately than patients as there is concern that once the patient hears the word cancer that they hear little else.

This study assertively invited a third party support person to attend and examined patient, caregiver and clinician beliefs about what occurred in the communication transaction and the findings reveal that patients and caregivers estimate each other's self-reported understanding more accurately than oncologists' estimates of patient and caregivers understanding. They also found that caregivers do not process information more accurately than patients, but that they can add to the clinical encounter by asking questions on behalf of the patient (2013).

The triadic consultation that includes a family member often focuses on the decision making that occurs. A Korean study by Shin et al, focused solely on cancer treatment decision making in the patient/caregiver dyad (2013). They identified differences between a spousal caregiver and an adult child caregiver. Adult children tend to be more proactive in the decision making process than an elderly spousal caregiver.

This is explained by a shift in Confucian philosophy of family harmony to embrace the Western philosophy of autonomy which the older generation do not share (2013). Despite the differences in decision making involvement, a key finding was that both patients and caregivers value and expect family involvement in treatment decision making (2013).

Laidsaar –Powell identifies the confusion experienced by health professionals about the over sharing of information and the difficulty in discussing sensitive needs with a caregiver present (Laidsaar Powell, Butow, Bu et al 2012).

Later work by Laidsaar –Powell identified family member behaviour within the oncology setting specifically within the area of decision making. Specific behaviour traits in the triadic consultation included the family member recalling information about the patient, confirming patient-provided information and asking non decision related questions.

Family members were likely to interrupt the patient when speaking, summarise or repeat information to the patient and occasionally prompt patient questions (Laidsaar Powell, Butow, Bu et al 2016).

A dominating caregiver can be challenging for the health care professional and there is very little written about skills needed to manage this particular communication dynamic. This is also particularly challenging where there is a need for decision making to take place. Some caregivers expect to have an active role in the decision making process with the patient while others do not again leading to confusion and often disruption of the consultation process (Laidsaar-Powell et al 2012).

Street and Gordon support this above finding by identifying that physicians have to deal with two people who have different needs, knowledge, concerns, distress levels and expectations (2008).

Training clinicians in communication skills to manage 'breaking bad news of a new cancer diagnosis in the triadic consultation' has been undertaken by Merckert et al. They focussed their intervention on the pre delivery phase with an emphasis on exploring what both the patient and informal caregiver know, understand and feel about the current situation before proceeding to deliver the bad news. This method engaged the informal caregiver earlier in the consultation and reinforced the patient and caregiver as the unit of care, thus addressing issues of oversharing (Merckaert, Lienard, Libert 2013).

Discrepancy within the information needs between patients and their caregivers has been identified further within the literature. Similarities have been identified within the literature across Western Cultures regarding the need of caregivers and health care professionals to discuss death and prognosis, which is not shared to the same extent by all patients (Parker S, Clayton J, Hancock K et al, 2007). End of life caregivers require information to enable planning and preparation for what lies ahead. Not only do informal caregivers have grief as a significant factor they also face complex responsibilities which add emotional and physical stress (Joyce, Berman, Lau 2014).

Clayton raised the value of having both joint and separate conversations between patients and their caregivers with the health professionals to eliminate the protective barriers that exist between patients and their caregivers and thus uncover individual information needs (Clayton, Butow, Arnold et al 2005).

Patient and Clinician (DYAD) Studies

The outpatient palliative care clinic has been structured to first review the patient with their informal caregiver together in the physical and social work clinics but then separate the patient and caregiver in order to allow privacy and exploration of needs and concerns that may otherwise remain undisclosed for fear of upsetting the other party. Street and Gordon measured patient satisfaction and found that in the triadic consultation where the patient and informal caregiver had similar levels of participation that patient satisfaction was lower (2008).

It can be assumed that the presence of a family member or friend attending a hospital appointment with a patient can be useful especially in assisting with the recall of information (Fentiman, 2007).

A study by Greene et al studied triadic and dyadic first consultations in people attending a medical consultation over the age of 60 years. They found that older patients when in the presence of family or a friend were less likely to ask questions, be assertive, show expression or be involved in the decision making process (Greene, Majerovitz, Adelman et al 1994). This finding underpins Clayton's work which highlights the differing communication needs between patients and their informal caregivers (2005), and supports the value in separating the patients and informal caregivers in the clinic encounter to ensure independent understanding of the situation (Swetenham et al, 2014).

In the setting of cancer and prognosis, it is well documented that many patients do not discuss their prognosis or concerns regarding end of life care with their doctor or family (Gattellari, Butow, Tattersall et al 1999; Gattellari, Volgt, Butow et al 2002). Hagerty identified that 65% of patients reported wanting to know the less positive information regarding survival without treatment as it allowed them to prepare themselves and their families with decision making and life planning (Hagerty, Butow, Ellis et al 2004). This study did identify that it is a challenge for doctors to accurately estimate prognosis and that this is made more difficult if the doctor is guessing the individual patient's preferences for information and involvement (Hagerty et al, 2004).

A follow up study by Hagerty identified that a majority of patients preferred realistic disclosure of their health status by a clinician who is confident, collaborative and supportive and that these qualities engender a sense of hope, more so than an avoidant approach (Hagerty, Butow, Ellis et al 2005). Age differences were also identified within this study. The younger patient is more likely to require emotional support, and have high expectations for medical care, often leading to unmet need. This contrasts to the patient who has been diagnosed longer or has a projected longer survival time and is more likely to require realism from their clinician (Hagerty et al 2005).

The failure to have these discussions can lead to poor decision making particularly related to end of life care choices which can impact on outcomes (Walczak, Butow, Davidson et al, 2011).

Clinicians can avoid having prognostic discussion as they fear that patients may lose hope, however the findings of Walczak's qualitative study that included 34 participants, 26 of whom completed semi-structured interviews and 8 who participated in a focus group revealed that patients experience a sense of greater control when prognosis and end of life issues have been openly discussed (2011).

Norton's qualitative descriptive study on identifying the process of communicating prognosis identified through 66 transcribed audio recordings, explored the communication skill sets of palliative care clinicians and found that they employed techniques which facilitated rapport and support with patients.

The use of metaphors was positively associated with patients' ratings of clinicians' communication skills. Language that is easily accessible to enhance patient understanding is important especially in relation to goal setting and understanding patient values. Once the clinician understands the patient goals and values then the conversation can focus on the maintenance of hope albeit in a changing landscape from cure to care (Norton, Metzger, De Luca et al 2013).

This communication approach underpins the psycho oncology component of the palliative care clinic for the patient and clinician. The development of rapport to build trust so that the patient is able to open up and discuss the psychosocial components of the illness experience is enhanced by combining empathic, exploratory and validating statements as identified in the SPIKES protocol for delivering bad news (Baile, Buckman, Lenzi et al,2000).

The dyadic clinic for the informal caregiver allows an opportunity for a dedicated assessment process of their own health needs, and informal supports to assist them in the role of caregiving (Currow, 2015. Hudson 2008).

Quantitative Content Analysis

The final concept of the literature review to be explored is related to communication studies which used a quantitative content analysis methodology. The quantitative approach to content analysis differs significantly from the qualitative approach to content analysis. Of note is that the qualitative paradigm relies on the identification of themes by the researcher, which introduces a degree of subjectivity which can diminish the validity as it departs from the use of measurement rules to identify meaning (Boettger and Palmer, 2010).

The benefit of quantitative content analysis is that it does not just identify themes but gives weight to the relative level of activity. Boettger and Palmer identify that this methodology is well suited for technical communication studies (2010). This methodology does require that the data are categorized into fixed and mutually exclusive categories. This is best derived by creating a coding scheme for content categories (Boettger and Palmer, 2010).

The use of manual coding is considered to be the simplest method to employ for a conceptual communication study. The categories to be coded are developed from the research question.

Refinement of the categories is undertaken through pilot testing and interrater reliability testing. Once this is determined then the development of the coding sheet can occur which needs to match the input order for Excel or other statistical programs so that basic statistical functions can be applied (Boettger and Palmer, 2010).

Coding Schema

Studies that utilised a coding schema to identify the speech units and content and function of what is being said and responded to within a consultation were reviewed. Mayfield, Laws, Wilson et al, who created a computer program to automatically annotate speech units, identify that the act of coding clinical communication via a manual line by line process comes with a significant barrier. The work required to conduct quantitative analysis of a single outpatient visit via a coding schema requires many man hours even for the experienced coder (2014). This methodology requires time and energy and is costly in terms of work hours. Despite the negative barrier to utilising this methodology, in the absence of an automated annotator, manual coding does enable a better understanding of the participation and engagement of all parties in the triadic consultation as well as understanding the differences in consultation style when moving from the triadic to dyadic setting.

The use of a coding schema along with a coding manual to train raters allows standardisation of the coding process when applying it to a communication study. Coupled with taking a random sample of transcripts to be coded by at least two independent coders researchers can ensure inter rater reliability (Boettger and Palmer 2010; Clayton, Butow, Tattersall et al 2007; Song, Tyler, Clayton et al 2016). Gattellari et al employed a coding schema to identify specific information components of the consultation and to identify how the doctor facilitated patient participation in the clinic encounter. This methodology enables the clinician to see strengths and weaknesses in the areas that they focus on in the clinic encounter by the number of occurrences represented numerically (Gattellari, Voight, Butow et al, 2002).

Another identified use of a coding schema is to assist researchers reach agreement on components that make up the specifics of an area that they wish to study. For example, the notion of Shared Decision Making is understood by those in the oncology setting as the process in which the patient, informal caregiver and clinician reach decisions regarding treatment and clinical trial participation. The elements that make up Shared Decision Making is often a source of disagreement so the development of a specific standardized coding system is seen as a solution to overcome confusion and disagreement (Brown, Butow, Juraskova et al 2010).

Laidsaar-Powell et al developed a coding schema to understand the role of the family member within the consultation through their communication and decision making behaviours as well as understand the family –relevant behaviours of patients and oncologists.

Items from previous studies informed the development of the 80 item KINcode system (2016). The study setting for this coding schema is the oncology setting and the availability of dedicated coding schemas for the multi-disciplinary palliative care setting is not yet developed.

A qualitative study by Dingley et al, utilises *Street's Active Participation Verbal Coding Tool* to explore informal caregiver activation and home hospice nurse communication. This study analysed 60 audio recordings and modified the coding schema from a physician/patient tool to a nurse/caregiver tool. The Street's tool suggested that activation is broadly categorised by being able to ask questions, being assertive and expressing concerns. These functions correlate with the function codes of the quantitative coding schema utilised for this study. The researchers for this nurse led study found congruence with Street's tool and modified it to meet their informal caregiver population (Dingley, Clayton, Lai, et al, 2016).

The secondary aim of the triadic and dyadic study is to uncover if there are emotional differences when patients and their caregivers are seen together in a clinic setting compared to when they are seen on their own. A quantitative study by Shaw et al, utilised two coding schemas when analysing cancer nurse communication using the cancer telephone helpline service. One of the coding instruments used was the Verona coding definitions of emotional sequences – VR- Codes CC - as its specific aim is to assess health professional responses to patient emotional cues. The instrument is designed to provide evidence of the behaviours that the clinician engages in when faced with patient emotion (Shaw, Young, Butow et al, 2016).

A study by Korsvold et al also utilised the VR-Codes CC to explore the emotional cues and concerns expressed by adolescents and young adults at the time that their diagnosis was revealed to them. In this specific population, it was common for an accompanying adult, usually a parent to be present and as the VR-Codes CC is originally developed for dyad consultations it required minor adjustment to accommodate the triadic consultation. A modification that was made to this coding schema was to code the cue/concern based on whether it was initiated by a question and whether it was formulated as a question (Korsvold, Mellblom, Lie et al, 2016)

In developing the coding schema sensitivity required to capture the elements of this triadic and dyadic communication study, the above studies as well as work by Boehmer was reviewed. The methodology that

Boehmer et al used for their video graphic analysis was informed by the review by Laidsaar-Powell (2014). They identified the need to review the contextual fit of the coding schema and they did this by reviewing two videos that were not included in the analysis for completeness against the schema.

The coding schema was broken down to include caregiver engagement in the clinical encounter, clinician facilitation of caregiver engagement in the clinical encounter and the influence of decision aids in the engagement process.

For caregiver engagement four broad areas were included to identify how caregivers contribute in the triadic setting.

- "Detail-oriented" where participation is primarily that of information giving regarding the patient's care.
- "Values and preferences" where the caregiver expresses values and preferences, their own or those of the patient.
- "Small talk" where the caregiver converses about non-medically related topics.
- "Clarification" where the caregiver reiterates information already given by the patient or the clinician (2014).

Caregivers in this study were found to initiate their own participation and they tended to focus on detail oriented topics. Clinicians rarely engaged the caregiver in decision making, leading the researchers to determine that clinical encounters are often a missed opportunity for caregiver participation and engagement (Boehmer, Egginton, Branda et at 2014).

The literature concerning the triadic dynamic that is created by the inclusion of a language interpreter has also been reviewed as the coding schema for this triadic /dyadic study was originally created to manage the presence of the language interpreter -third party in the consultation. Jackson et al, looked specifically at how any alteration in the translation process from clinician to patient could impact on health care delivery. In order to understand what was happening in the triadic consultation. Clinic encounters were audio taped, an independent translator interpreted the translation and then analysis via a coding schema was undertaken to understand deviations or enhancements to the communication process (2010).

Jacksons' study focused on four domains regarding interpretation.1) Deletion, 2) Addition, 3) Change in meaning and 4) Editorialisation. These functions are specific to the interpreter setting and do not apply to the triadic/dyadic study. This methodology is relevant to the study and enabled the researchers to calculate rates of alteration per utterance per encounter, as opposed to total number of encounters. They argue that this methodology enabled them to better isolate the interpreter effect from other potential variables (2010). This contrasts significantly to the methodology employed by Fatahi et al on their study that utilised an interpreter for the GP clinical encounter. Content analysis was the methodology employed and studied the experience of the GP on whether the interpreter actually achieved the objective of being a neutral creator of a bridge to understanding.

This study methodology required GPs to participate in focus groups and recall the experience of using an interpreter. The focus groups are transcribed and then a line by line analysis is undertaken to identify themes until saturation is reached. This methodology uncovers the experience of using an interpreter not the actual outcome of the interpreter process (Fatahi, Hellstrom, Skott et al, 2007).

Summary

The literature in the dedicated palliative care sector is scarce when searching for quantitative communication studies. Broadening out the search to oncology uncovered greater selection; however, the study setting and patient populations are largely geared to early diagnosis where the hope of cure remains the goal.

There were few studies that were focused on advanced cancer patients who were enrolled in a palliative care service and these were reviewed with interest to confirm the key themes that emerged from the literature review, relating to psychosocial interventions, communication and information giving and the role of the informal caregiver in a consultation.

The palliative care clinic which provides the setting for this communication study has been established to better prepare patients and their informal caregivers with approaching end of life. Psychosocial interventions are grounded in good communication principles. The way that information is provided and communicated in a triadic consultation differs significantly to a dyadic consultation. Information needs between patients and their informal caregivers can be quite different and how this is coded and analysed is of relevance in understanding the patient and informal caregiver experience. The emotional support offered by clinicians to patients can vary according to whether the patient attends a clinic alone or with a caregiver as an assumption can be made that the patient is emotionally supported. The behaviour of clinicians in relation to responding to patient emotion can be accurately captured using the emotional coding instrument.

The role that a caregiver plays in attending a clinic and how clinicians engage and interact with the informal caregiver has been highlighted to be somewhat lacking. There is a paucity of data about triadic encounters and as chronic illness increases in an ageing population it will be more likely that patients will be attending clinic appointments with an informal caregiver, so clinicians will need skills in how to manage this communication dynamic.

The literature identifies a systematic assessment approach to caregivers is lacking in end of life care. This study has the potential to identify whether the outpatient palliative care clinic structure which comprises of seeing patients together with their caregivers for the physical and social work components and then separately for the individual psycho-oncology/caregiver assessment functions facilitates a systematic approach to caregiver assessment in particular.

With the above factors considered, particularly the literature regarding the methodology underpinning quantitative content analysis, the coding schema to assess the discrete components of the palliative care clinic were further refined. The Boehmer study (2014) has provided a framework for reviewing and adjusting the coding schema to suit the structure of the palliative clinic and this will be discussed more fully in the next chapter.

In conclusion, the dedicated palliative care literature is not well represented here and the cancer literature needed to be explored to further understanding on the communication methodology required in order to conduct this study. The discrete differences in palliative care practice is the best practice principle of providing a multidisciplinary assessment with a focus on the ‘goals of care’ being determined for the patient and informal caregiver.

CHAPTER THREE
METHODOLOGY

Introduction

The primary objective of this study is to understand the differences in communication that occurs within the patient, family caregiver and health professional triadic consultation and compare this to the communication that occurs between the health care worker and patient or health care worker and family caregiver dyadic consultations.

The secondary objective is to establish the emotional content that occurs in the consultation clinics when patients are seen together with their caregivers and compare that to when they are seen separately. As part of the secondary objective the use of a coding schema to quantify the differences in the types of communication that occurs is employed, such as exploring the use of open and closed questions, cues that are ignored and who is dominating the conversation.

This study uses a descriptive quantitative content analysis paradigm based on a single initial workup of the four face to face consultations which occurred in a multidisciplinary clinic setting to enable a comprehensive assessment of the patient and informal caregiver.

Each component of the clinic was tape recorded and transcribed verbatim. Participants were recruited over a six month period between May 2013 and November 2013.

Ethics Approval

Ethics approval was sought from Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC EC00188) (Protocol number 38.13) and was granted in March 2013 with site specific approval to commence the study awarded in April 2013.

Selection of Study Population

Participants of the study came from patients and informal caregivers attending the palliative care clinic run by the specialist palliative care service at a community health centre in the suburb of Adelaide SA. The sample was based on those who were scheduled to attend the clinic in the six month period between May and November 2013 and who were willing to participate. For the purpose of the pilot study 10 patient caregiver dyads were coded and analysed and hence four transcripts resulting in 40 analysed transcripts. One patient occasion of service resulted in four assessment points. A convenience sample based on transcription completion and conversion of the Word document to Excel was used to choose the 10 patient transcripts to be analysed for the pilot study.

Recruitment and Informed Consent

The triage nurse screens all new referrals to the service to identify the best service level to meet the need that has been identified on the referral form. For those patients deemed well enough to meet the criteria to attend the outpatient palliative care clinic (AKPS >70 see appendix-B4), service information was provided and permission obtained to discuss the study for their consideration. Further permission was obtained to send out the study information sheet and consent form with the clinic information (See Appendix A). Patients were asked to bring the forms to the clinic with them if they wished to participate.

The triage nurse was trained in presenting the study in such a way that clinical care was clearly seen as the priority and as separate from the study requirements.

All participants were informed that they could withdraw from the study at any time if they no longer wished to participate and this was made clear before consent was obtained. In addition, if a carer did not wish to participate it was explained to them that the medical care of the person for whom they provided care would not be compromised in any way.

On presentation to the clinic the Nurse Practitioner revisited the objectives of the study with the patient and caregiver and witnessed their consent forms once she was satisfied informed consent had been obtained.

Screening Tools

Patients were sent out the consent and information sheet following the triage assessment. All patients attending the outpatient palliative care clinic complete the symptom assessment tool which comes from the Palliative Care Outcomes Collaborative suite of assessment tools which is a national quality improvement program for specialist palliative care services in Australia (Eager, Watters, Currow et al 2010). The completed symptom assessment tool enables the Nurse Practitioner to understand the degree of symptom burden the patient may be experiencing.

The following assessments were completed after patients and caregivers had returned their signed consent form at the clinic and given permission for the tape recording to occur.

- NATIONAL COMPREHENSIVE CANCER NETWORK DISTRESS THERMOMETER

The National Comprehensive Cancer Network (NCCN) Distress thermometer (see Appendix B-1) is a brief screening tool designed to identify distress specifically in cancer patients who warrant further follow up and support from the psychosocial team. A score of 5 or greater should trigger further evaluation and the choice of which service is engaged depends on the problem area specified on the problem list.

The tool identifies social work support for practical and psychosocial problems, mental health support for emotional or psychological problems and pastoral care for spiritual concerns. (NCCN - Distress Management Clinical Practice Guidelines, 2003).

- KESSLER PSYCHOLOGICAL DISTRESS TOOL (K10)

The K10 is a 10 item consumer self-report questionnaire designed to collect information on any anxiety or depressive symptoms a patient may have experienced in the previous 4 weeks (see Appendix B-2). The numbers attached to the patients 10 responses are added up to generate the total score. Scores can range from 10 – 50. Scores ranging 10-15 indicate low or no risk. 16-29 indicates medium risk and 30-50 indicates high risk. (Kessler, Andrews, Colpe et al 2002) The K 10 is ranked as a moderately reliable instrument in the Australian population and is well utilised in General Practice. (Dal Grande, Taylor and Wilson 2000).

- CAREGIVER ASSESSMENT TOOL

The caregiver assessment tool is a tool that was put together by Southern Adelaide Palliative Services when a dedicated study for the Caregiver Network Facilitator was undertaken in 2006 (Greene et al,2012). The tool is a selection of questions from validated tools such as the 11 –item Duke Social Support Index, Catholic Care and the American Medical Association. Copyright was obtained to use questions from each of the specific tools to make up the caregiver assessment tool (see appendix B-3). The tool is divided into physical, emotional, relationship and spiritual domains. It enables a family caregiver to identify any physical issues that they may have and any other barriers that may impact on informal caregiving within the community setting.

- AUSTRALIAN-MODIFIED KARNOFSKY PERFORMANCE STATUS SCALE.

The Australian-modified Performance Status (AKPS) scale (see Appendix B-4) is a gold standard, 11-item categorical scale used in palliative care to assess general functional status in activity, work and self-care. Scores range from 0 to 100 in increments of 10 where a score of 100 indicates normal physical abilities with no evidence of disease (Abernethy et al. 2005).

- SYMPTOM ASSESSMENT SCALE

The symptom assessment scale (see appendix B-5) is a patient tool to identify the degree of distress experienced from physical symptoms. In the event that the patient cannot complete the tool there is a provision for a proxy to complete it on their behalf. The seven most prevalent symptoms experienced by palliative patients are recorded but there is also space for any other symptom to be recorded that the patient may be experiencing. The tool uses a numerical rating scale rated from 0 to 10. A score of 0 indicates absence of that symptom and a score of 10 indicates overwhelming distress caused by that symptom (Aoun, Monterosso, Kristjanson et al, 2011).

Eligibility Criteria

Patient Participants were eligible for inclusion in this study if they were;

- Over 18 years of age with a life limiting illness and had a self-rating performance score of 70% on the Australian-modified Karnofsky Performance Scale (AKPS).
- They had a family caregiver who attended the clinic with them and consented to participate in the study.
- They could communicate in English for the purpose of transcribing the dialogue verbatim
- There was no evidence of cognitive impairment at triage to the service and then on presentation to the clinic.

Caregiver participants were eligible for inclusion in the study if they were;

- Over 18 years of age
- They were identified as the main support person to the person with a life limiting illness, and that person also consented to participate in the study.
- They could communicate in English for the purpose of transcribing the dialogue verbatim
- There was no evidence of cognitive impairment at triage to the service and then on presentation to the clinic.

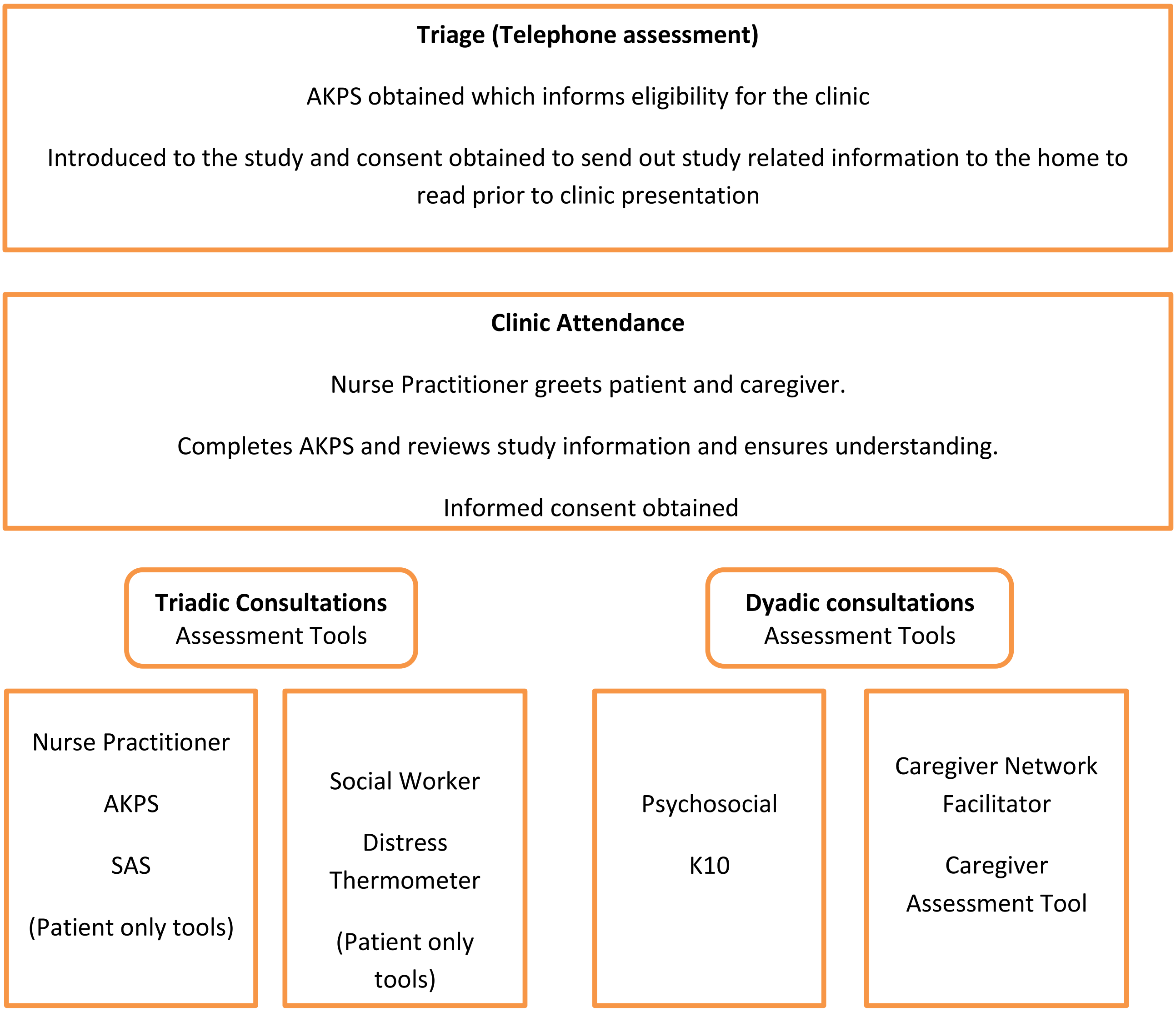
A minimum AKPS score of 70 identifies the patient to be able to care for self, unable to carry on normal activity or to do active work. It was decided by the clinical team that a clinic that requires a patient to sit for 90 minutes requires a high performance score as anything lower is likely to be too burdensome for the patient. As this clinic targets, early introduction to palliative care, the AKPS was used as the overarching screening tool to determine eligibility.

Cognitive impairment was not formally tested as patients attending this clinic were first screened over the telephone by the triage nurse. Any cognitive impairment identified at triage determined suitability for clinic participation in conjunction with the entire triage assessment.

Participants were excluded from the study if cognitive impairment was identified at the triage assessment phase. If the patient attended the clinic without a family caregiver, they were also excluded from the pilot.

Patients and their family caregivers were advised that they had the right to withdraw at any time from the study throughout the clinic appointment.

Figure 1 – Study eligibility and process



Clinician Assessments

The Needs Assessment Tool - Progressive Disease (NAT-PD) was the basis for the assessment tools developed to support the outpatient palliative care clinic (Waller et al, 2010), (see Appendix C). The NAT-PD is designed to be used by a sole practitioner however this clinic is unique in that it utilises the multidisciplinary team with four consultations and hence the NAT-PD was deconstructed and components allocated to the most appropriate clinician to prevent duplication in the assessment process.

Nurse Practitioner Assessment

The Nurse Practitioner conducts a physical assessment of the patient to understand the burden of symptoms, the role of medication and any other underlying medical conditions (see appendix C-2). This clinic operates as a triadic clinic with both the patient and caregiver in attendance. The physical component of the clinic is strategically placed first as it is felt that once physical issues have been identified and addressed that the patient and caregiver will be more willing to discuss psychosocial issues. The patient brings with them to the clinic the completed symptom assessment tool (SAS) which enables identification of physical problems for the Nurse practitioner to focus on.

Social Work Assessment

The social worker focuses on the social construct for the patient commencing the session with a genogram (see appendix C-3). The clinic then moves to explore the patient's living arrangements, transport and finances before focusing on Advance Care Planning and Will preparation. The patient is asked to undertake the completion of the Distress Thermometer so that further psychosocial issues may be identified (see appendix A). This clinic is also operated as a triadic clinic with both patient and caregiver in attendance. The rationale for this is that issues concerning housing, transport finances and future care planning often involve both parties.

Caregiver Network Facilitator Assessment

The caregiver network facilitator is interested in the health and wellbeing of the family caregiver (see appendix C-4). This is a dyadic clinic with the caregiver only. The focus of this assessment is to address informal and formal supports that may be required to assist with managing the patient in their home environment. It is also an opportunity to obtain an honest appraisal as to how the caregiver is coping and whether there are likely to be any obstacles that will hinder community based care.

Psychosocial Assessment

The psycho-oncology nurse conducts a coping and adjustment to illness assessment of the patient (see appendix C-5). This too is a dyadic clinic with the patient only in attendance. The focus of this assessment is to unearth any underlying anxiety or depression.

The K10 tool and a numerical analogue scale to rate the patient's quality of life is used in conjunction with the psychosocial assessment form. Exploration of emotional issues can be discussed privately without the need to protect the caregiver from raw emotions.

DATA ANALYSIS

Data Collection

Data collection commenced in May 2013 and concluded in November 2013. In that time 50 patients attended the early introductory outpatient palliative care clinic. Thirty five patients and their caregivers consented to participate.

Demographic data were collected including frequencies and median for age, sex, diagnosis and relationship of caregiver to patient.

The clinicians were all provided with an Olympus Dictaphone and provided with training in its operation and maintenance. Each clinician was allocated an electronic folder to use to save their voice recording into. This ensured that the transcribers could identify the associated clinical role which was associated with each folder. Dates, time and length of the actual recordings were automatically recorded by the Dictaphone which appeared on the computer screen when the recording was downloaded enabling matching of the consultations.

There are 25 complete sets of transcript. Tape recorder failure and human error resulted in nine incomplete sets of transcripts. One patient consented to participate in the study but attended without a caregiver so was ineligible for inclusion. For the purpose of this pilot study, ten complete interviews were transcribed verbatim onto a word document. The coding schema was then obtained which required copying the text from the word document onto an excel spreadsheet. The coding schema provided by the University of Sydney was modified then applied (see appendix D-1 and D-2).

Quantitative-Coding Schema

The student and a research assistance came together to discuss the approach to coding the transcripts. A transcript was coded independently by both parties to check for consistency. While consistency was achieved, it was felt that the coding schema was not sensitive enough to identify the specific components of the palliative care clinic as covered in the assessment tools. Using the methodology of Boehmer et al 2014, the assessment tools were reviewed for the specific topics covered by each clinician and the coding schema was modified from the original schema which was considered to be very broad to a more sensitive tool that better reflects the topics covered within the palliative care clinic.

The source codes differed from the original with changes to participants: the removal of the medical officer and the interpreter; the addition of the Nurse Practitioner, Social Worker, Psycho-Oncology Nurse and Network Facilitator, Carer and Patient together (see Appendix D 1-3).

The direction of interaction was modified to include all the clinicians as stated above and a field was added to identify where the patient and their caregiver were addressed together.

The content headings identified in the original coding schema were expanded to include specific elements that are covered within the palliative care clinic. This included the addition of social history to the 'history of symptoms' field. The nurse practitioner physical assessment tool covers the history of physical symptoms and past medical history, whereas the social worker covers the social history of the patient and their family. Given that the social worker commences the session by completing the genogram and exploring the social construct of the patient, this field was added in separately.

Past psychiatric history and willingness to participate in research were added to the 'other medical' category which the psychosocial nurse covers, as this is not routinely explored by the Nurse Practitioner as part of the physical assessment. Under the 'psychosocial' heading the distress thermometer, K10 and carer assessment tool were added, which are tools used by the social worker, psychosocial nurse and the network caregiver facilitator. 'Social support' was the field that required the greatest amendment. The topics of finance, transport, advance care planning and housing are explored in detail by the social worker, and again to a varying extent by the nurse practitioner and the caregiver network facilitator and a code to identify spirituality which is explored by the psychosocial nurse was also added.

A significant reason for modifying the coding schema to reflect these discrete elements from the assessment tools was to check for duplication among the clinicians in the clinic process. The assessment tools were all modified at the outset, with elements from the NAT-PD distributed among the individual clinicians where it was agreed they best fit. This process enabled the clinicians involved to ensure the areas they were taking responsibility for, were quarantined for that component of the clinic process and not addressed elsewhere. All clinicians were cognisant that this clinic process could fail if patients and their informal caregivers felt that they needed to tell and retell their story. For the clinician, this requires an inherent trust in the process that their colleagues' will collect the information that they may have otherwise gathered when conducting an assessment as a sole practitioner.

In the function of speech section the only addition made was under the heading 'disclosure' which now includes a category titled reading aloud to self (see Appendix D-3). This was included as many patients and caregivers read the questions of the screening tools aloud to themselves before answering them, and this was the best way to capture this from the transcripts.

With the amended coding schema both the student and research assistant recoded the original transcript and were satisfied that the tool was sensitive to capture the discrete psychosocial elements of the clinic.

Regular meetings occurred between the student and research assistant throughout the coding process.

Data Analysis

The total word count per speaker was analysed using Microsoft Excel (Seattle, USA). Each cell that contained the transcribed text was referenced in a separate cell that used the built in ‘LEN’,‘TRIM’ and ‘SUBSTITUE’ functions that determined character length but at the same time eliminated spaces to determine clusters of characters as words. This was achieved with the following formula:

`=IF(LEN(TRIM(Table!C2))=0,0,LEN(TRIM(Table!C2))-LEN(SUBSTITUTE(Table!C2," ",""))+1)`

*“SUBSTITUTE removes all spaces from the text, then LEN calculates the length of the text without spaces. This number is then subtracted from the length of the text with spaces, and the number 1 is added to the final result, since the number of words is the number of spaces + 1”*https://exceljet.net/formula/count-total-words-in-a-cell

Pivot tables based on built in excel formulae to perform a SUM and percentage analysis were applied to all aspects of the coding schema, pivot tables using dependant variables in the ‘row labels’ and independent variables in the ‘column labels’ and ‘values’ components of the table populated the calculated SUM and percentage for each query conducted in this analysis. The individual code analysis of direction, content and function identified where the communication was being directed within the consultation, whether any party was dominating and whether cues for information and emotion were being responded to by the clinician. The length of the individual consultations was obtained from the transcript data base and averaged to reveal median length of time (see chapter 4 – results).

CHAPTER FOUR
RESULTS

The results will look specifically at the primary and secondary research questions; however, it is also expected that the structure of the clinic will be assessed by the way in which it meets its information and emotional support objectives through the findings.

Participants

The 10 patient and caregiver dyads that form this pilot study are described in Table 1. All life limiting illnesses in this pilot study are due to cancer. Spousal relationships dominate the dyad profile at 7/10, and females outrank males as the patient. Daughters outrank sons as the caregiver in the non-spousal group.

All of those that consented to participate completed the study requirements. There were no requests to cease the tape recording of any sessions.

Table 1- Demographics					
Date of session	Patient Gender		Age	Carer	Diagnosis
22/05/2013	F		70	Spouse	Breast
18/09/2013	F		61	Spouse	Mesothelioma
2/10/2013	F		65	Spouse	Lung
16/10/2013	F		71	Daughter	Lung
30/10/2013	F		71	Daughter	Breast
30/10/2013	M		81	Spouse	Lung
13/11/2013	M		80	Son	Bowel
13/11/2013	M		58	Spouse	GBM
20/11/2013	M		63	spouse	Oesophageal
27/11/2013	F		72	Spouse	NHL

Primary and Secondary Research Questions

Findings are reported against the primary and secondary research questions.

The primary research question is;

Are there differences in communication that occur within the patient, family caregiver and clinician triadic consultation when compared to the communication that occurs between the clinician and the patient or the clinician and the family caregiver in the dyadic consultation?

Secondary questions are as follows;

- Does the emotional content of the consultation vary when patients and their caregivers are seen together compared to when they are seen apart?

- What is the communication dynamic of the clinician? (Explore the use of open and closed questions, response to cues made by patient or caregiver.)
- Does the outpatient palliative care clinic structure facilitate caregiver assessment that would not occur in the presence of the patient?

Communication Differences between the Triadic and Dyadic Clinics

In the study by Boehmer et al it was identified that caregivers were often underutilised in the clinic encounter and opportunities were missed for participation and engagement (2014). This is replicated in this study as one of the key differences between the triadic and dyadic clinic structure.

One of the key additions to the coding schema included the addition of ‘patient/carer together’ in order to identify the direction of the communication interaction. When listening to the social work audio recordings it was clear that the social worker was inviting a response from both patient and family caregiver simultaneously in an attempt to understand the social dynamics of the family unit. This was less prevalent in the Nurse Practitioner clinic, but did occur and thus the findings are reported in Table 2.

The informal caregiver did contribute more in the social work consultation than the nurse practitioner consultation which correlates with the social worker inviting a response from both the patient and informal caregiver together (Table 2).

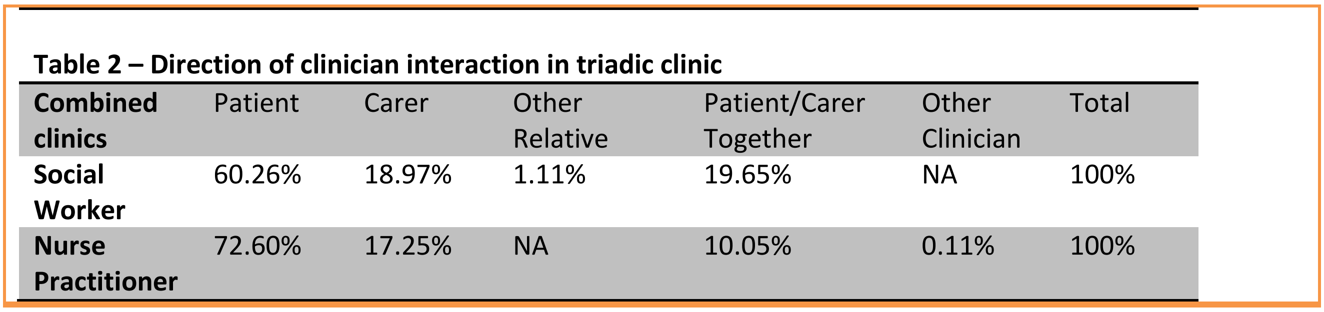


Table 2 – Direction of clinician interaction in triadic clinic

Combined clinics	Patient	Carer	Other Relative	Patient/Carer Together	Other Clinician	Total
Social Worker	60.26%	18.97%	1.11%	19.65%	NA	100%
Nurse Practitioner	72.60%	17.25%	NA	10.05%	0.11%	100%

In the triadic clinics, the direction of communication by both of the clinicians favoured the patient. The caregiver was addressed directly less than 19% of the time.

The nurse practitioner clinic focuses on obtaining a symptom assessment and providing a general introduction to the service.

This clinic is deliberately structured to address physical symptoms first as this is identified in the literature as being of primary concern of both patients and their caregivers (Steinhauser, Christakis, Clipp et al 2000).

The social worker focuses on understanding the social make-up of the patient’s world and asks questions which require the patient and caregiver to provide an explanation.

There is greater direction of the communication process to both the patient and their caregiver as ‘the unit of care’ in the social work consultation. Table 2 demonstrates that the social worker addresses both the patient and their caregiver for 20% of the consultation, whereas the nurse practitioner engages both parties at only 10%. In the social work consultation, the caregiver provides an active role in assisting the patient to appraise the social reality to better inform the social worker about what their psychosocial needs might be. This is reflected in Table 6 where the informal caregiver contributes 33% of the ‘inform, educate, explain’ function codes in the social work consultation compared to 22% with the nurse practitioner.

Word Count

A word count was applied to each participant within the clinic to understand who spoke the most words within the session. Table 3 provides a visual description of the proportion of communication activity by participants in each consultation. The patient speaks more words in the triadic consultation compared to the caregiver and this is most noticeable in the social work consultation.

The nurse practitioner consultation focuses on information provision regarding the referral to palliative care and the impact of symptoms on the patient’s quality of life. It is demonstrated in the results that the nurse practitioner dominates in the number of words spoken at 54%. This is the first consultation for the clinic and there is time spent on introducing the patient and informal caregiver to what they can expect from attending the clinic. The patient speaks 30% of the total number of words spoken with the informal caregiver contributing 16% of the total number of words spoken.

The patient outranks the social worker in number of words spoken in the social work consultation. The patient speaks 39% of words compared to the social worker at 37%. The informal caregiver speaks slightly more in this consultation than they did in the nurse practitioner consultation at 24%.

In comparison, the dyadic consultations are less about providing education and information and more about understanding how the patient and caregiver are adjusting to living with a life limiting illness.

The psychosocial nurse speaks more words in the consultation than the patient at 52%. There is attention by the clinician to the building of rapport so that the patient is comfortable to express feelings of what it is like to live with his/her illness. The patient contributes 48% of the words spoken in this consultation as there is no informal caregiver present.

The caregiver network facilitator consultation is structured to understand what informal social networks the informal caregiver has available. The informal caregiver dominates with 62% the number of total words spoken in this clinic outranking the clinician at 38% (see table 3). This finding alone suggests that there is enormous value in separating the informal caregiver from the patient for a focussed assessment as Clayton et al also identified in their study on communication needs and preferences between patients and their informal caregivers (2005).

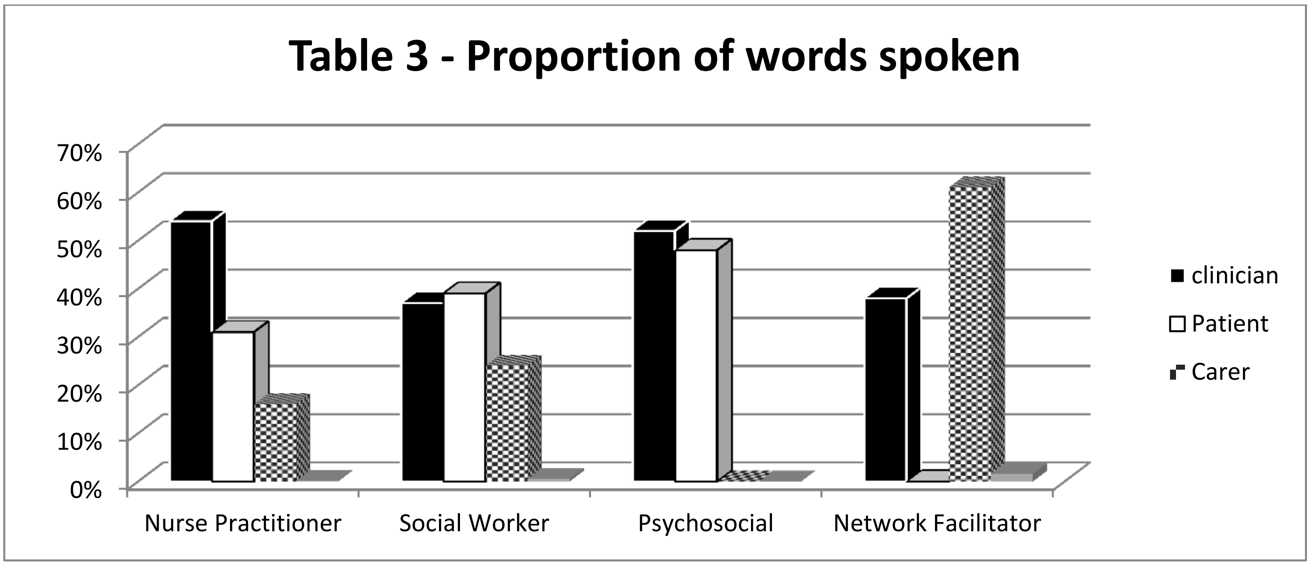


Table 3 - Proportion of words spoken

Coding Schema

The coding schema is divided into discrete elements to identify key occurrences of what actually occurs in the clinic consultation. The tool codes for who is speaking, where the communication is being directed, and the content of what is being discussed. The content is further matched for the function that the communication serves, and whether there are any cues for more information or response to emotion and if so, what level of response the clinician provides.

Content Coding

The coding schema enabled assessment of the content actually discussed in each of the individual consultations. The breakdown of content codes as displayed in Table 4 demonstrates that each clinician focuses on his/her area of expertise.

Content - Nurse Practitioner

The nurse practitioner focuses the assessment on the ‘other clinical’ content code. When combining the content codes for history and symptoms related to cancer, and cancer related treatment more than 58% of the total content discussed in this clinic is related to the physical experience of the patient.

There is some attention paid to social support through the provision of the information of what services may be available and this is occurring 19% of the time. The psychosocial components of care are covered at 7% of the time and the social history of the patient is only explored minimally at 1% of the time. The remainder of the clinic content is social exchange at 12% and the code ‘non-specific’ accounts for the remaining 3% of what is discussed in this clinic.

Content - Social Worker

The dominant content code for the social work consultation is social support/counselling and stress management at 34%. As the coding schema was modified to include social history as a subset of history and symptoms the social worker spends 22% of the interview conducting the social history component of the interview, with 2 % of the interview understanding the medical history. The distress thermometer accounts for 18% of the psychosocial assessment with a further 2% attributed to exploring psychosocial issues. Eleven percent of the interview focuses on other clinical and treatment issues, 10% on social exchange and 1% on other / non-specific elements.

Content – Psychosocial-Oncology Nurse

The content discussed in the patient/clinician consultation focuses on the psychosocial components of the illness with 28% of the interview exploring psychosocial issues and an additional 9% of the interview conducting and discussing the results of the K10 screening tool. Social support and counselling ranks next in prominence with 20% of the interview focused on addressing those concerns. Understanding the medical history is explored at 10% with the previous psychiatric history at 3% and the asking of the research participation question at 4%. Six percent of the interview is in responding to issues regarding diagnosis, prognosis and treatment with 10 % of the interview attributed to social exchange.

Content - Caregiver Network Facilitator

The caregiver network facilitator assesses the specific needs of the informal caregiver. There is almost an equal split between psychosocial issues; which includes the administration of the carer tool (26%), and social support (27%). Twelve percent of the interview is spent understanding the social (8%) and medical (4%) history of the informal caregiver. Social exchange rates between the clinician and the informal caregiver are recorded at 15% of the time. Patient-related concerns such as diagnosis, prognosis and treatment account for 10% of the interview, with a further 6% accounting for other clinical issues that are discussed. Four percent of the interview is attributed to other/non-specific items. This consultation demonstrates the variety of areas that the informal caregiver wishes to discuss and when matched with number of words spoken in Table 3, it is clear that informal caregivers have information needs that a private assessment process enables exploration of.

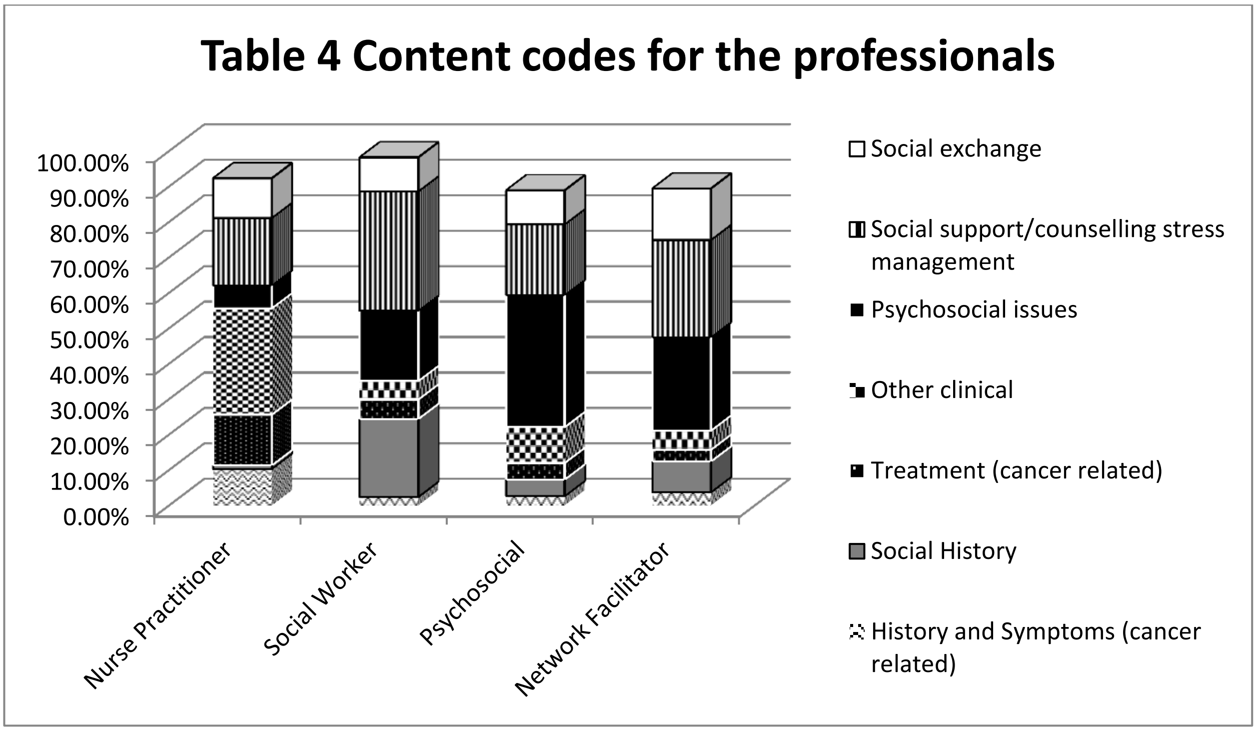


Table 4 Content codes for the professionals

Function

Table 5 identifies the dominant speech functions used most within the outpatient palliative care clinic setting. The broad category of inform, educate and explain is the consistent function across all clinician groups.

Function - Nurse Practitioner

The nurse practitioner consultation focuses on informing, educating and explaining at 34% of the time. Simple closed agreement features next at 22%. The functional code of agreement with enhancement and elaboration occurs at 7% as does the closed questions function also occurring at 7%. Communication is cut off by any party 5% of the time. There is engagement in partnership building with social talk and joking (5%). Open questions are asked (3%) and the nurse practitioner advises or directs the patient/informal caregiver 3% of the time. The patient uses the function ‘disclose/ reads aloud to self’ (4%), and expresses their feelings or seeks reassurance (2%). The remaining 8 % of the functional codes relate to checking the patients understanding (3%), asking leading or multiple questions (3%) and summarising information, and negotiating preferences (2%).

Function – Social Worker

Forty-two percent of the social worker interaction is based around the function ‘inform, educate and explain’. Simple, limited, closed agreement is next at 12%. Closed questions feature at 11%. Agreement with enhancement occurs at 5%, with open questions asked at 4% of the time.

Leading questions (4%) and actively supporting and empathising (4%) along with the function ‘disclose/ read aloud to self’ (4%) are next in frequency of use. Communication is cut off (4%) and partnership building (3%) and checking understanding (3%) with the asking of multiple questions at (2%) and seeking reassurance (1%) and labelling or the use of criticism (1%) occur minimally.

Function - Psycho-Oncology Nurse

In the patient /clinician consultation 36% of the dialogue is attributed to the function ‘inform, educate and explain’. Simple agreement features next at 26% compared to agreement with enhancement at (4%). The use of the closed question to obtain new information is the dominant function occurring 6% of the time, compared to open questions (3%) and leading questions (3%). The function of actively supporting and empathising features at 5%, followed by the patient disclosing or reading aloud to self (4%). Partnership building with the use of social talk and joking features at 3% as does the checking of understanding or clarifying misunderstanding at 3%. The patient expresses feelings or seeks reassurance at just 2% and communication is cut off by either party at 2%. The clinician advises or recommends 1%, and uses multiple questions when seeking new information 1%. The remaining function of the consultation is shared between summarising old information <1%, and providing a warning shot <1%.

Providing a warning shot is used prior to introducing the topic of end of life care in the psycho oncology consultation. This occurs on ten occasions which means 100% of patients in this consultation are provided with a warning shot prior to embarking on sensitive discussions regarding future care and eliciting their preferred place of death.

Function – Caregiver Network Facilitator

The dominating function code for the caregiver network facilitator is ‘inform, educate, explain’ (33%).The use of the closed and simple agreement function is 26% compared to agreement with elaboration at 4%. Partnership building with social talk and joking (6%) along with the function ‘actively supporting, empathising or reassuring’ (6%) both are ranked ahead of closed questions which is the third highest ranking function for the other three consultations at 5%. The caregiver discloses or reads aloud to self (4%) and the caregiver facilitator provides advice or makes a recommendation (4%). Of the questions asked to elicit new information 2% are open ended, 2% are leading questions and 1% are multiple questions. The caregiver expresses feelings or seeks reassurance (2%) and communication is cut off by either party (2%). Understanding is checked (1%) The caregiver receives strong direction <1%, and judgement or criticism is used <1%. The provision of a warning shot before embarking on sensitive discussions regarding the end of life care plans for the care recipient occurs on 8 occasions.

Table 5 depicts the highest ranking function codes that occur in each consultation.

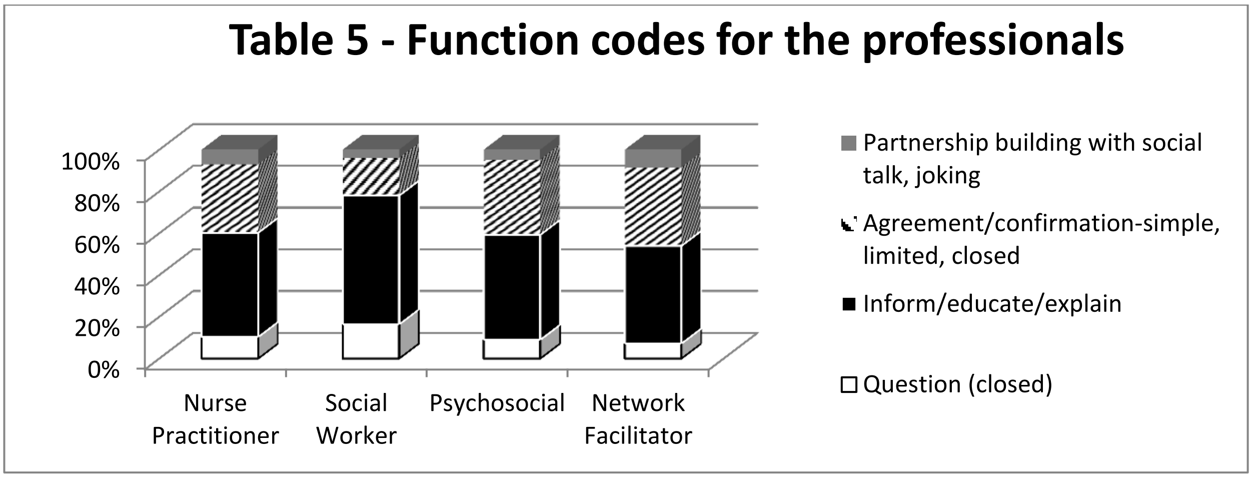


Table 5 - Function codes for the professionals

Function Code 'Inform, Educate, Explain'

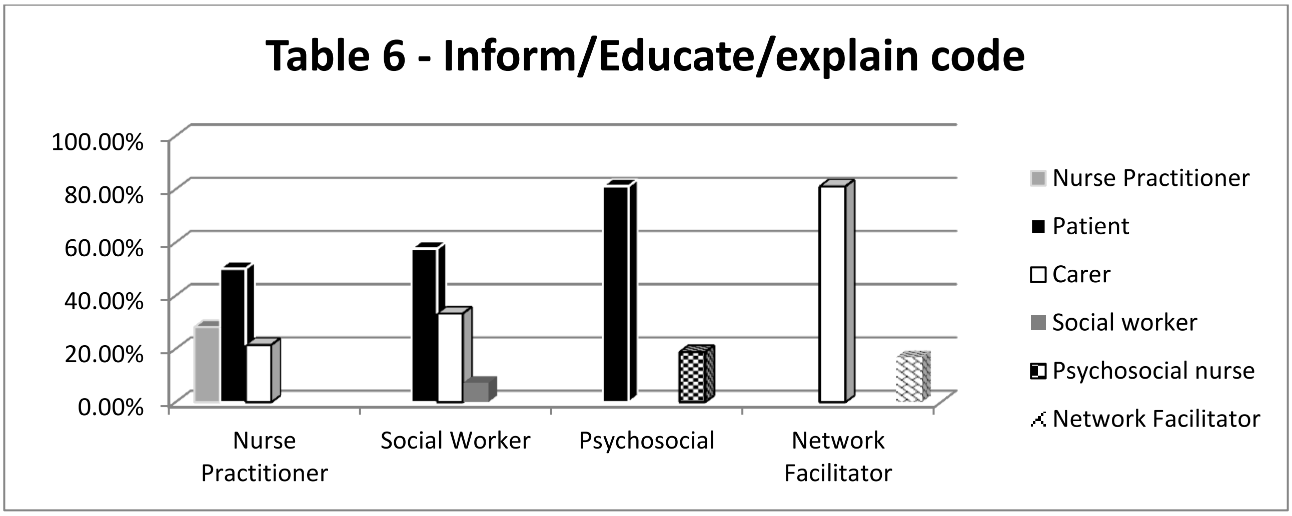
The dominant code for the outpatient palliative care clinic across all discipline groups is inform/educate/explain. It ranked highest in all consultations with it strongest in the social work consultation (42%). Further analysis of this code was undertaken to understand who was dominating when this code was applied.

In breaking down the function code of inform, educate and explain further, it is evident that it is the patient and the informal caregiver who spend most of the clinic session explaining their circumstances and informing clinicians of their illness. The code was analysed against the person speaking and Table 6 demonstrates that, in the triadic consultations, it is the patient who spends most of their time explaining or informing the clinician.

In the nurse practitioner consultation, this function is used by the patient (50%), the nurse practitioner (28%) and the informal caregiver (22%).

The social work consultation has the highest use of this code; however, the social worker uses it the least of all the clinician groups at 7%. The patient dominates at 58% and the informal caregiver contributes at 35%.

In the dyadic consultations, the distribution of this code is similar. The psycho oncology consultation sees the patient (81%) outweigh the clinician (19%) in its use. In the caregiver network facilitator consultation, the carer (83%) outweighs the clinician (17%) in its use.



EMOTIONAL CONTENT VARIATIONS BETWEEN TRIADIC AND DYADIC CONSULTATIONS

In order to understand if there are differences in the emotional expression between patients and their caregivers in the clinic, the use of cues, the level of intensity of the cue expressed and the clinician response to cues was explored (see Appendix D-3). The cues that patients and their family caregivers provide in a clinic session fall into two categories: cues for information; and cues that reveal emotion. The cues were coded separately to reflect the strength of the cue which was rated as weak, medium, or intense. The nature of the cue was coded as either a desire for further information or an ambiguous way of revealing emotion which could be related to fear, uncertainty or concern.

Cue – Nurse Practitioner

In the nurse practitioner consultation, there were 39 cues for information and 64 cues that revealed emotion. Of the 39 information cues 47% were rated as weak cues, with 45% rated moderately. Only 8% of cues for information were strong and stated exactly what the patient/informal caregiver required.

Of the 64 cues that revealed emotion 44% were rated as weak, 44% were rated as moderate and 12% were rated as strong (Table 7).

Cue – Social Worker

In the social work consultation, there were 31 cues for information and 43 cues identifying emotion. Seventy four percent of information cues were rated as weak, 16% were rated as moderate and 10% were rated as strong. Of the emotion based cues 77% were rated as weak, 7% were moderate and 16% were rated as strong (Table 7).

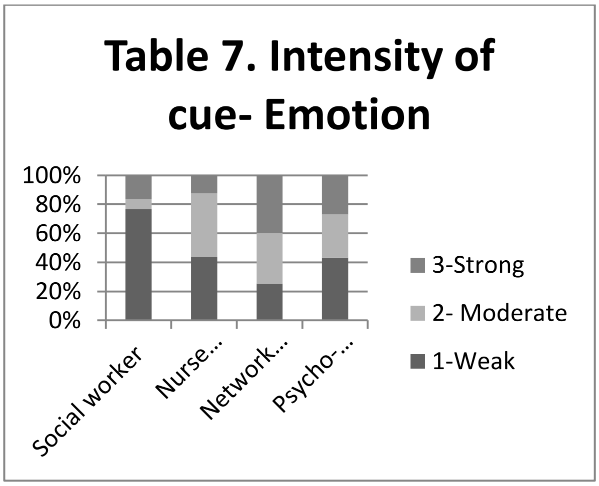
Cue - Psycho-Oncology Nurse

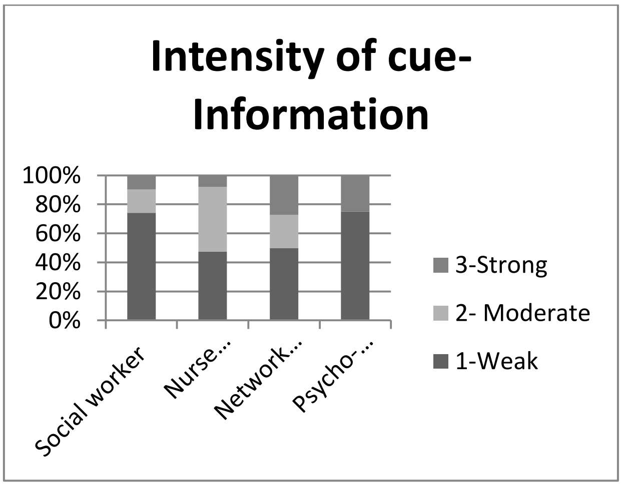
In the psycho-oncology consultation there were only 4 cues for information and 74 cues that revealed emotion. Of the information cues, 75% were rated as weak and 25% as strong. For the emotion-based cues 43% were weak, 30% were moderate and 27% were strong (Table 7).

Cue- Caregiver Network Facilitator

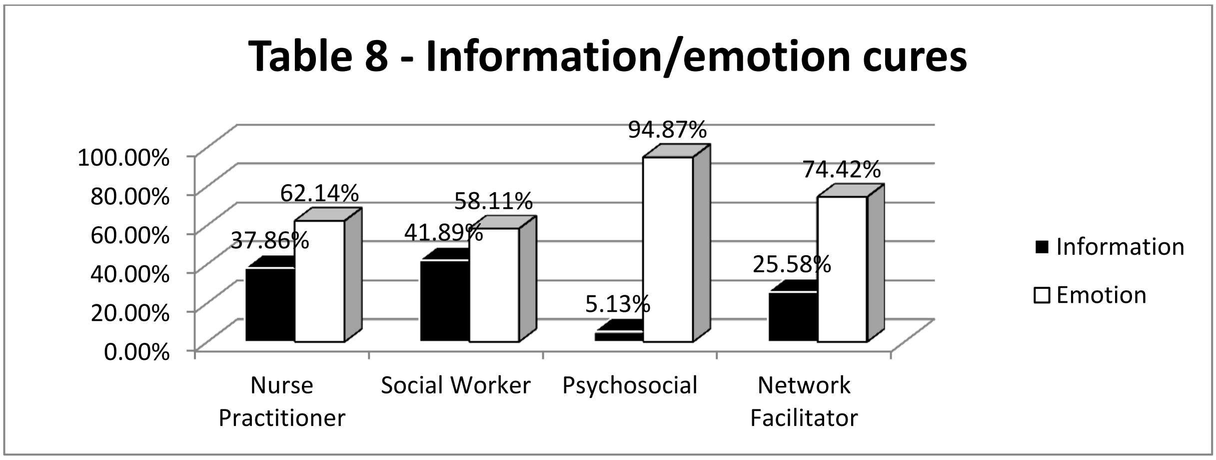
In the dyadic consultations, there are a greater number of emotion based cues than cues for information. The informal caregiver when alone with the caregiver network facilitator expressed 22 cues for information and 64 cues that revealed emotion. Of the 22 information cues, 50% were rated as weak, 23% as moderate and 27% as strong. With the emotion based cues 25% were rated as weak, 35% moderate and 40% strong (table 7).

The strength of the emotion expressed in the dyadic consultation is significantly higher than in the triadic consultation, particularly by the informal caregiver. The patient however has very few information needs and 95% of all cues are based on emotion. This finding does suggest that once the patient and informal caregiver are separated they are free to express emotions and they take the opportunity to do so.





Overall the emotion based cues outrank cues for information as depicted in Table 8.



COMMUNICATION DYNAMIC OF THE CLINICIAN

The clinician response to an emotion or information cue is broken into four groups: no response, minimal response; responds with empathy or explores the response. The results from each clinician highlight that most cues are either left unacknowledged or only minimally acknowledged.

Nurse Practitioner Response

The nurse practitioner responds to information cues in the following ways; 33% of cues are left unacknowledged, 44% are responded to minimally with a single word or utterance, 21% are responded to with empathy and 3% are explored fully. For emotion-based cues the results are 41% for no response, 38% minimal response, 19 % response with empathy and 3% explored fully.

Social Worker Response

The social worker leaves information cues unacknowledged 48% of the time. Forty six percent of cues receive minimal acknowledgement with 6% being responded to with empathy. For the emotion-based cues 47% of cues receives no response, 40% receive a minimal response, 9% are responded to with empathy and 4% are explored.

Psycho-Oncology Response

In the psycho-oncology consultation there are only 4 cues for information making up 5% of the total number of cues in that consultation, of which 50% receives no response and 50%, receives a minimal response. With the emotion based cues, 35% of cues receive no response, 35% receive a minimal response, 25% are responded to with empathy and 5% are explored fully.

Caregiver Network Facilitator Response

In the caregiver network facilitator consultation, 36% of information cues are not acknowledged, 32% of cues receive minimal acknowledgement with a single word or utterance and 32% of cues are responded to with empathy. In the emotion based cues 40% receive no response, 38% receive a minimal response, 20% are responded to with empathy and 2% are fully explored to understand the underlying concern behind the cue.

Information cues are less likely to be explored fully and emotion based cues are fully explored less than 5% of the time by all clinicians.

Average Time Spent on Each Consultation

The pilot data reveal that the triadic clinicians spend an average of 27- 28 minutes per encounter compared to the psycho-oncology nurse who averages 33 minutes and the caregiver network facilitator who averages 41 minutes.

While no clinician is particularly strong at exploring issues in depth with patients and informal caregivers (see Table 9), the dyadic consultation does outrank the triadic consultation in responding with empathy and this may account for the greater time spent on average in the clinic.

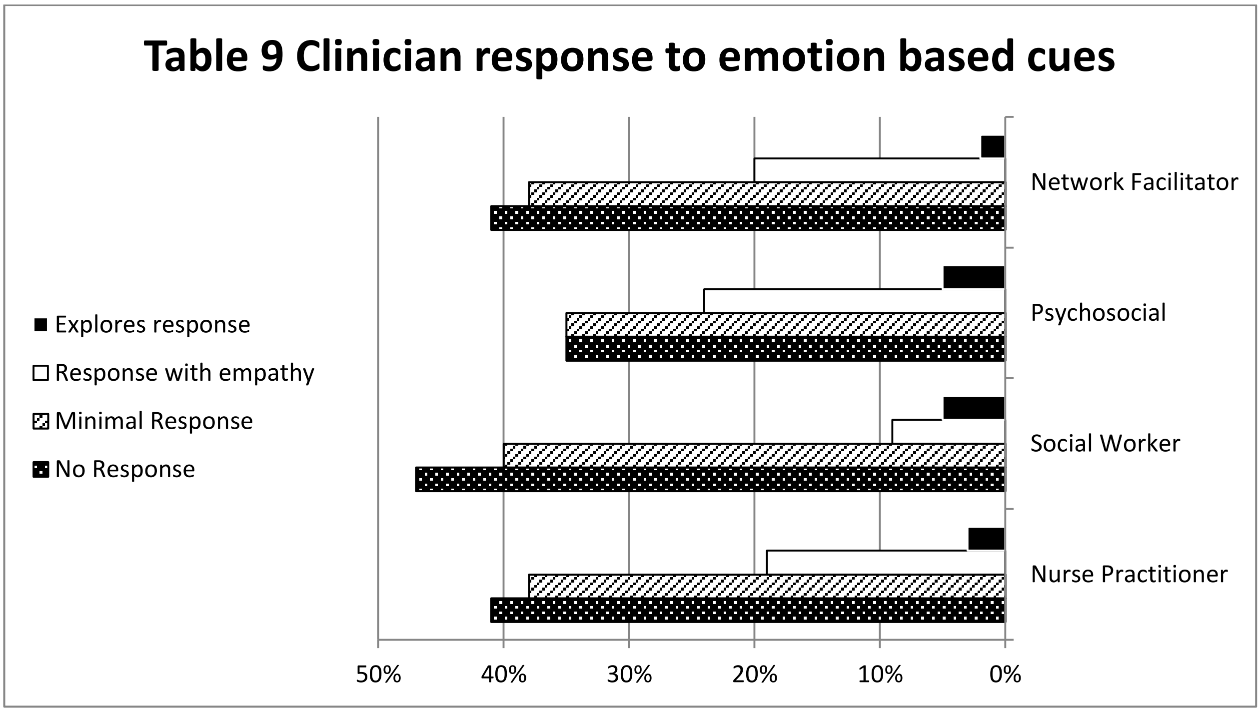


Table 9 Clinician response to emotion based cues

While the length of time the clinician spends in clinic does not determine the communication dynamic of the clinician *per se* it does provide an insight into the differences between the time spent in the triadic clinic which focuses on assessment and planning compared to the dyadic clinic which focuses on assessment and exploration (see Table 9).

Table 10- Average length of clinic time	**Minutes**
Nurse Practitioner	27.55
Social worker	27.05
Psycho -oncology nurse	32.58
Caregiver network facilitator	41.00

CLINIC STRUCTURE AND CAREGIVER ASSESSMENT

The quantitative findings demonstrate that the informal caregiver has a need to be given a voice and have their concerns heard. This is evident through the dyadic consultation in Table 3 by number of words spoken, which dominate number of words spoken by the clinician. The analysis of the cues reveals that the informal caregiver expresses emotional cues strongly in the dyadic consultation (40% - Table 7).

These findings in particular suggest that the clinic structure does facilitate caregiver assessment.

Summary

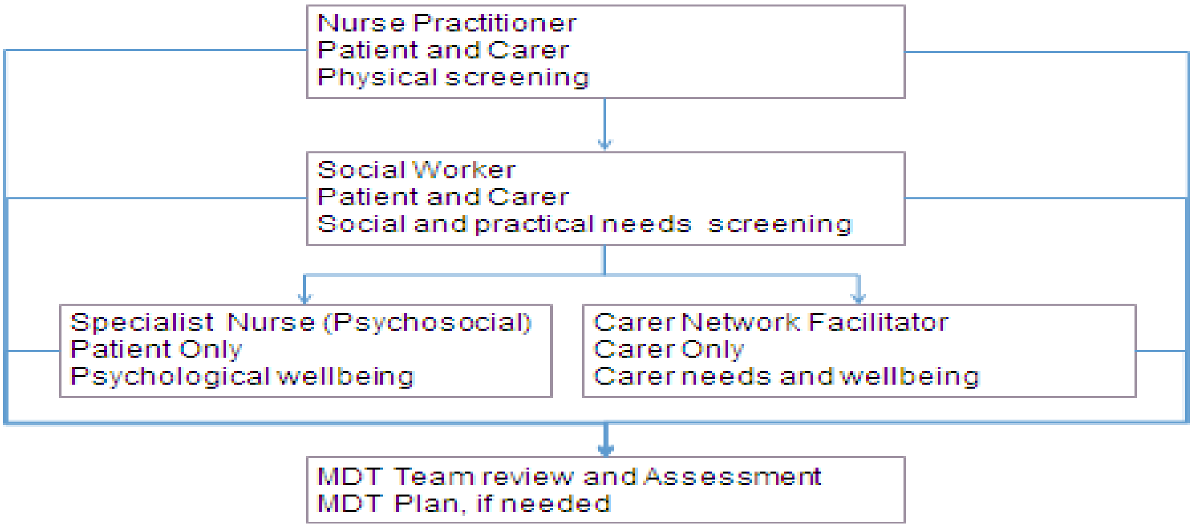
The results of this study not only identify the communication exchange that is occurring but also provides insight into the benefit of the clinic structure and the distinct roles that each clinician plays in this process.

Communication analysis has enabled an understanding of the outpatient palliative care clinic and the evidence from the results supports the investment of resource at the front end of the palliative patient journey in order to ensure that patient and informal caregiver information and emotional needs are identified and a proactive management plan can be tailored to address them.

CHAPTER FIVE
DISCUSSION

The preliminary analysis of the 10 patient/caregiver dyads within this study has demonstrated the feasibility and value of using communication analysis to review activity undertaken by palliative care clinicians in a new outpatient format. This approach provides a means of investigating not only the content of communication but the process of communication within the palliative care clinic which focuses on how and when the patients', carers' and clinicians' voices are heard. The clinic structure also enables a multidisciplinary team (MDT) assessment to be conducted which ensures the whole patient and family experience is understood which should inform ongoing and future palliative care planning.

Figure 2. Schematic representation of the clinic structure.



The clinic structure is designed to allow each clinician 30 minutes to conduct their component of the assessment. This in itself was initially a challenge as most clinicians are trained to explore the total patient experience and restricting the interaction to specific functions was a new experience which also demanded a degree of trust that others in the team would address issues the individual would otherwise explore when operating in isolation. The reason behind structuring the clinic in this way was to minimise any duplication between the individual clinical encounters and to ensure that patients and their informal caregivers understood the distinct differences between the team members. This structure was also considered to provide a mechanism to address the information needs and emotional support requirements of patients and their informal caregivers which are identified within the literature (see Chapter 2).

Triadic and Dyadic Consultation Differences

Two distinct differences are evident from the results of the clinic structure (Chapter 4). The triadic consultations focus on assessment, education and planning, whereas the dyadic consultations focus on assessment and exploration of feelings and coping styles. These are two very distinct functions and both necessary in order to provide a comprehensive assessment whilst also meeting information needs. Patients and their caregivers attend this clinic with the understanding that they will be introduced to what palliative care can offer them as they navigate their way through the later stages of an illness.

The literature highlights that patients and their informal caregivers can have very different information needs (Kirk and Kristjanson, 2004) and the findings of this study reinforce this observation. The standard outpatient clinic is time limited and structured around a specific purpose such as patient assessment and review or ongoing monitoring. Traditionally the informal caregiver attends the cancer clinic with the patient. The patient is the focus of attention and clinicians direct their communication to the patient. This is reflected in Table2 ‘clinician directed interaction’ (Chapter 4). The pilot results demonstrate that the patient is the focus of the triadic consultation and that the informal caregiver plays a supportive but relatively passive role. This may well correlate with Street and Gordon’s findings that patients feel greater levels of satisfaction in the clinic process if their voice is more dominant than the informal caregivers voice (2008).

These findings may also account for the specific function that the triadic consultations focus on, which is based on the collection of information to make an assessment. The dyadic consultations focus on understanding the lived experience of the patient and the caregiver. These consultations are deliberately conducted so that the patient and caregiver are free to speak openly away from each other in order to meet the very different information and emotional needs that are highlighted in the literature (Parker et al 2007). The value of this approach to separate the patient and informal caregiver is evidenced by Table 3, where the voice of the informal caregiver in the dyadic consultation has substantial weight, outranking the number of words spoken by the clinician (Chapter 4).

The role that the informal caregiver plays in a consultation that includes the patient and clinician is important. While the quantitative pilot data from this study does not specifically identify a dominating informal caregiver in the results it is a trait identified within the literature (see Chapter 2). Laidsaar-Powell writes about the dynamic of a dominating informal caregiver in the triadic consultation but most particularly in relation to decision making (2012). It is possible that these traits did not come out strongly in the results of this study as there are very few decisions to be made in this clinic. Laidsaar –Powell was studying the traditional oncology clinic where decisions regarding further chemotherapy treatments are often shared between patients and their family members.

The palliative care clinic can be a bridge to transition patients and their families from the cure paradigm to a care paradigm. Decision making regarding ongoing treatment becomes less important as quality of life and enjoying the time left becomes the focus.

The discrete role and function of each staff member engaged in the clinic aids the patient and their informal caregiver across this transition bridge holding them in a space while they absorb and process the changing nature of their circumstances.

TRIADIC CONSULTATIONS

Nurse Practitioner Consultation

The structure of the new clinic format supports the findings of studies that introduce patients early to palliative care (Temel et al, 2010) particularly where the introduction occurs in the ambulatory setting (Pitsukin et al 2010). Nurse led clinics are gaining popularity in palliative care and there is now growing recognition that collaborative models of care between specialist services such as Renal and palliative care or models that use more than one health care provider such as nursing and allied health are assisting in providing a seamless transition as an illness progresses and the patient deteriorates (Cowan and Cardy, 2011; Harrison and Watson 2011).

The triadic communication literature that informed this study largely occurred in the medical consultation space, predominantly with oncologists dealing with patients and caregivers or general practitioners using interpreters with a patient (Laidsaar-Powell et al, 2012, Fatahi et al, 2008). This study adds another dimension to the literature by focusing on how nursing and allied health practitioners manage the triadic consultation.

The nurse practitioner consultation is the first of the assessments to take place. It has been structured deliberately so that physical symptoms are addressed first as patient’s rate pain control and being free of any other distressing symptoms as a priority (Steinhauser et al, 2000). Psychosocial issues become important once physical issues have been addressed, and Steinhauser makes the point that patients value a warm and caring relationship with their health care provider as this assists them to open up and disclose other concerns which may be spiritual or existential in nature (2000). Allowing time and the opportunity for rapport to be developed is an important component of this clinic structure.

The function of the nurse practitioner consultation is multi-pronged. There is emphasis placed on the giving and providing of information and education about what the palliative care service offers. This constitutes the introduction component of the clinic. The nurse practitioner then engages in a physical assessment of the patient, with an emphasis on symptom management which includes current medication use.

The symptom assessment scale is used in this consultation as this is a patient rated tool and relates to the distress experienced by the identified symptom (see Appendix B-5).

The nurse practitioner directs the communication (73%, Table 2, Chapter 4) to the patient for clarification and thus dominates the communication process in number of words spoken as seen in Table 3, Chapter 4. This dynamic can be attributed to the systematic assessment process which follows the physical history pathway and requires the patient to confirm, or deny and then elaborate on any physical distress. In order to conduct the physical assessment, the direction of communication favours the patients (Table 2, chapter 4) as it is the patient's account of how the symptoms impact their quality of life that is of most concern to the Nurse Practitioner. While there is some direction of communication to the informal caregiver (17%, Table 2, chapter 4), it is evident from the results that the informal caregiver is most passive within this consultation.

The principles that underpin pain management are based on the patient's experience and description of the pain. The informal caregiver's perception of any physical discomfort the patient is experiencing contributes to the collateral history however the clinician is responsible for understanding the experience of the symptom from the patient perspective.

"Pain is a personal experience, occurring when and where the patient says it does" (Palliative Care Expert Group, 2010).

A study by Ewing and Grande identified that informal caregivers feel the need to contribute their perspective on the patient's symptoms especially if the patient is reluctant to do so (2012). The results do not demonstrate this to be a great need in this consultation and may be this is due to the fact that the clinic targets early introduction to palliative care and the patient has relatively well controlled symptoms. The need for the informal caregiver to be more formally supported as a 'co-worker' develops as the illness progresses (Currow, 2015).

The content covered within the nurse practitioner consultation demonstrates that the nurse practitioner does focus of the physical experience of the life limiting illness. Both the current and past medical history is reviewed which includes current treatments and any side effects. Non-pharmacological options are also explored such as nutrition and any other recommendations, along with contingency planning particularly for managing after hour's events.

The dominant function of this consultation hinges on informing, educating and explaining. Any request for new information is asked mainly as a closed question and the closed simple agreement function to encourage talking by the patient is also prominent. At the end of this consultation the nurse practitioner has formulated a plan of care related to the physical presentation of the patient. Rapport is established and an understanding from the patient's perspective of what they can expect is now underway.

The patient and their informal caregiver are then introduced to the social worker at the conclusion of the nurse practitioner consultation.

Social Worker Consultation

The social worker consultation is focused on understanding the family unit and social construct in order to make an assessment of the degree of social support that may be required. This consultation has been deliberately structured as triadic in nature as both the informal caregiver and patient can be experiencing difficulty as a result of the diagnosis of a life limiting illness. Where the caregiver relationship is spousal (70%, Table 1, chapter 4) issues concerning housing, finances and transport are most likely to be experienced by both parties. Advanced care planning requires conversation and understanding of the role the caregiver may be taking on particularly in regards to becoming the substitute decision maker.

A benefit of this consultation is that future planning topics are raised and discussed for consideration. Ewing and Grande identified in their study of bereaved caregivers that some carers found themselves caught between wishing to remain positive and supportive but also wanting to know what the wishes of their relative were. Carers in this study identified the need for more direct help in having difficult conversations with their loved ones (2012). The structure of the social work consultation means that the social worker engages both the patient and informal caregiver in future care conversations and guides both the patient and informal caregiver through the process. The direction of communication still favours the patient at 60%, however the informal caregiver is addressed independently 19% of the consultation and 20% together with the patient (Table 2, Chapter 4).

The collection of the social history (22%) is important to enable understanding of the social resources available to the patient and their informal caregiver. The future need for respite and who may be available within the family or social network can start to be explored while the patient is stable and relatively independent. (Table 4, chapter 4).

The social worker administers the distress thermometer to the patient to complete (see Appendix B-1). This enables the patient and the informal caregiver to engage in discussions about the impact that the illness has across the physical, practical, family, emotional and spiritual domains without the fear of stigma (Holland and Bultz, 2007). Screening for distress is deemed to be as important as screening for temperature, pulse, respiration, blood pressure and pain which has encouraged a call to view ‘distress’ as the sixth vital sign (Holland and Bultz, 2007).

Distress is under recognised by clinicians and under reported by patients (Dabrowski, Boucher, Ward et al 2007). Clinician estimation of patient distress and the actual patient report did not correlate in the study by Dabrowski et al.

The Distress Thermometers' value as a tool is in opening up of dialogue of distress by the clinician (2007). This finding from Dabrowski is supported by this study. The patient is prompted to consider what aspects of their life are causing them most distress and this conversation begins with the social worker consultation. The Distress Thermometer serves as a function to engage the patient and their informal caregiver in practical discussions about issues that may be the basis for concern or fear from the patient perspective.

The function of the social work consultation is heavily weighted at "inform, educate and explain" (42%. Table 5, chapter 4). In further analysis of the code "inform, educate and explain" the social worker used this code the least of all clinical groups (7%) and the patient used it the most (58%. Table 6, Chapter 4). The onus of this consultation is on the patient and the informal caregiver being able to tell their story and this is reflected in the number of words spoken by both the patient (39%) who outranks the social worker (37%) and the informal caregiver (24%) who contributes more in this consultation (Table 3, Chapter 4)

Discrepancy of information needs between patients and their informal caregivers has been identified within the literature (Chapter 2). Ewing and Grande's study identifies that informal caregivers require information to enable planning and preparation for what lies ahead so that they can 'be on the ball' (2012). Clayton, et al raised the value of having both joint and separate conversations between patients and their caregivers to eliminate the protective barriers that exist between them in order to uncover individual information needs (2005). Clayton's study supports the structure of this clinic with the separation of the patient and their caregiver, and the consultation moves to a dyadic interaction.

DYADIC CONSULTATIONS

Psycho-Oncology Consultation

The psycho-oncology assessment is focused on understanding the impact the illness is having on the patient, particularly at a psychological and emotional level. As a follow on to the social work consultation where the Distress Thermometer has been used to identify distress arising from all facets of the patients life, the psycho oncology nurse focuses the session on mental health coping and adjustment to illness. In order to understand this best the session commences with the patient completing the Kessler psychological distress 10 question tool (K10-Appendix B-2). This tool screens for distress related to anxiety and depression, and opens up the communication to directly explore feelings of depression, anxiety, hopelessness and worthlessness. The psycho-oncology nurse (52%) only just outranks the patient (48%) with words spoken (Table 3, chapter 4). There is an emphasis on building rapport and gaining trust to encourage the patient to open up and this is evidenced in the transcripts with the level of introduction provided at the commencement of this consultation.

The content focuses on the psychosocial issues which includes the completion of and discussion regarding the K10. Psychosocial issues are identified within the coding schema as emotion related to the illness, the impact of cancer on the patient’s ability to cope and manage, and the impact to family members. This accounts for 37% of the content covered within this consultation (Table 4, chapter 4).

Social support, counselling and stress management (20%) is also a feature within this consultation as the patient opens up about anything that may be causing them distress or concern. The patient is asked to rate their quality of life on a scale from 0-10 with zero being worst and 10 being best (Appendix C-5). Opportunities to explore the patient experience are derived from the tools and assessment form, and with gentle encouragement patients contribute actively.

The ‘other medical history’ component of the coding schema was modified to include previous psychiatric history and the invitation to participate in further research. This is the third ranking content code (17%) covered within this consultation. Previous psychiatric history is of importance in terms of assessing future coping and adjustment to changing circumstances, and determination of whether a referral to the senior consultant psychiatrist within the palliative care service is required. A previous study within this palliative care service had identified that patients who developed a life limiting illness with an existing severe and persistent mental health diagnosis had complex needs and were often unrecognised until late within the palliative care journey (van Loon, 2011). Irwin and Ferris highlighted the need for palliative care staff to have education in mental health to effectively manage complexities in patient care (2008). It is this approach which underpins the psycho oncology consultation.

The function code of inform educate and explain continues to dominate in this consultation (36%) with the patient being responsible for its use (81%).

Of greatest significance for this consultation is the result from the coding of information and emotion based cues. In this consultation, the cues from patients for information is only 5% whereas the cues that reveal emotion are recorded at 95% (Table7, Chapter 4). In 1999, authors Lo, Quill and Tulsky looked at physician communication with patients transitioning to palliative care. They identified the key enablers to opening up the space for patients to feel safe enough to disclose emotional concerns that they may be experiencing. While some studies had argued for physician self-disclosure as a mechanism to encourage openness, Lo et al identified that active listening and empathic communication actively facilitated personal connection which positively contributed to patient disclosure (1999). This is supported by Detmar et al who also found that patients will disclose more emotion based concerns when they are with a physician/ health care worker who demonstrates a positive attitude to the psychosocial aspects of care (2001).

The result from the emotion based cues for this study support the findings that a health care worker who is concerned with psychosocial aspects of care is likely to encourage an environment where patients feel safe and free to disclose emotional concerns. What is unique to this study is whether this is more likely to occur with patients being afforded privacy away from their informal caregiver to fully express concerns and fears.

Caregiver Network Facilitator Consultation

The consultation for the informal caregiver is designed so that it places the caregiver at the centre of the experience. It recognises the role that they take on as a co-worker simultaneously with being a care recipient (Ewing and Grande, 2012, Currow 2015), and provides a space for them to articulate any needs or concerns that they may have regarding the future. On average this consultation lasted 41 minutes which is fourteen minutes longer than the triadic consultations and 8 minutes longer than the average psycho-oncology consultation (Table 9, Chapter 4).

The informal caregivers in Ewing and Grande's study identified the importance for carers to have a nominated support person. Informal caregivers did not necessarily use the contact person a great deal but they reflected the sense of reassurance from knowing that there was someone that they could call if needed (2012). The value that the role that the caregiver network facilitator provides is structured to meet this exact need. The informal caregiver is provided with a contact person and is given permission to express needs and concerns so that they can be supported in the role of informal caregiving. The caregiver network facilitator is also there to assist the informal caregiver to identify and mobilise their social networks, or where they may be lacking to activate other formal community supports that may be available to them.

There is a degree of invisibility to informal caregiver assessment as most assessments take place on the doorstep, as an afterthought to the patient assessment and are undocumented (Ewing and Grande 2012, Aoun, Deas, Toye et al 2015). Including the dyadic informal caregiver assessment into this clinic ensures the assessment is valued and sought and most of all documented within the patient electronic health record and shared with members of the clinical team.

The content covered within the caregiver network facilitator consultation is almost equally split between social support (28%) and psychosocial issues (26% - Table 4, chapter 4), which include completing the carer assessment questionnaire (Appendix B-3). This position does not duplicate the social work role or function as it focuses on the informal supports that the caregiver may have access to through sporting groups, school or church communities. It explores community and social capacity that may be available to the caregiver and the caregiver network facilitator provides a vehicle to make contact where the caregiver may feel unable. The significant finding from Greene et al's study was that with the introduction of the role of a caregiver network facilitator, caregivers felt more able to ask for help (2012).

The function "inform, educate and explain" dominates this dialogue (33%) with the caregiver being responsible for its use 81% of the time (Tables 5&6, Chapter 4).

Of greatest significance is the number of words spoken by the informal caregiver in this consultation. They dominate at 61%, with the clinician only contributing 38% of the words spoken (Table 3, chapter 4).

In the triadic consultations they have played a lesser role but once they are afforded privacy and provided with permission to speak, the information and emotional needs are able to be expressed.

Does the emotional content of the consultation vary when patients and their caregivers are seen together compared to when they are seen apart?

The 30 minute time frame allocated to each clinician along with the specific content that each clinician is tasked to cover as part of the whole assessment process are factors that need to be considered when discussing the results regarding information-and emotion-based cues. The triadic consultations are focused in terms of systematically going through the assessment items to understand both the physical and social needs of the patient and the informal caregiver. This is most evidenced by the greater number of cues for information that occur in the triadic consultation compared to the dyadic consultation (Table 8, Chapter 4) There is an opportunity for reflection in the triadic consultation through the symptom assessment tool and the distress thermometer (AppendixB-5 and B-1) however privacy is restricted. The dyadic consultations have an assessment format however the questions in the assessment tools (K10, Appendix B-2 caregiver assessment questionnaire, appendix B-3) require the patient or informal caregiver to stop and reflect on their current experience away from one another so there is an opportunity for open, uncensored communication.

The intensity of the cue expressed is the mechanism for determining if the emotional content varies between the triadic and dyadic consultations. The intensity of the cue is graded from weak to moderate to strong. A weak cue is vague in manner and may require some reading between the lines. A moderate cue is determined by the presence of a qualifier, but it is not strong, such as “I am a bit worried”. A strong cue explicitly states the emotion with language such as “I am very worried” or through behaviour such as crying/tears.

The caregiver expresses the greatest level of strong emotion when alone in the dyadic consultation. Forty percent of emotional cues are expressed as strong with 35% of emotion based cues expressed as moderate. In the psycho oncology consultation, the patient expresses strong emotional cues at 27% and moderate emotional cues at 30%, with the remaining 43% expressed as weak. The patient cues were almost all emotion based (95%) and the majority of caregiver’s cues were also emotion based (74%). Caregivers did have some requirement for information (26%). Of the information cues, 27% were expressed as strong, and 23% expressed as moderate.

From a coding perspective crying was automatically coded as strong. The results do show that the caregiver and patient both contain emotional and informational cues in the triadic consultations as the dominating cue is coded as weak (Table 7. Chapter4). The freedom to express feelings is the opportunity afforded through the dyadic consultation and it is taken by the informal caregiver more so than the patient.

Anecdotally the caregiver network facilitator continues to report that once the informal caregiver is alone with them that the flood gates open. Further analysis which includes qualitative content analysis would enhance the understanding of whether there is a precipitant for the level of emotion expressed, or whether it is just the act of being separated and being free to talk openly, that is responsible for the emotion expressed in the caregiver network facilitator consultation.

Communication Dynamic of the Clinician

The two coding fields that review the communication dynamic of the clinician relate to the function of using open and closed questions and the response by clinicians to cues for information or emotion from the patient and informal caregiver.

Open questions are used minimally in all consultations, with clinicians favouring the use of closed questions to collect new information. The closed question featured as the third highest function code for 3 out of the 4 of the consultations (Table 5, chapter 4). The caregiver network facilitator rated equally highly for the function codes “partnership building/actively supporting, reassuring” than the function code for “closed question”. These findings may be attributed to the time allowed for each consultation and the need to cover assessment items in an efficient manner to enable the next patient to be seen on time. It is also important to recognise that traditionally the community palliative care nursing and allied health team are used to conducting a home visit where time structures are more fluid, so operating in a clinic setting where the next patient is in the waiting room is a significant change in approach for this clinician group.

The response to cues reveals a high proportion of cues go unacknowledged and the results are similar for information-and emotion-based cues (table 9, chapter 4). Without qualitative data, it is not possible to further understand why this is the case, however on listening back to the transcripts, often the clinician was writing notes or moving onto the next topic when a cue was revealed in the consultation. From reviewing the literature, the reference for ignoring cues is mainly in relation to training clinicians in developing skills to deliver bad news (Butow, Kazemi, Beeney et al 1996).

Palliative care clinicians are held up as a work group that others can learn from, particularly in the art of using language to develop rapport and support in their patient group (Norton, Metzger, De Luca et al 2013). Despite having expertise in this area, this study reveals that when time is pressured and the next patient has arrived in the waiting room, these palliative care clinicians also fail to respond to cues that indicate an unmet emotion-based or information-based need.

The nurse practitioner consultation experienced the highest number of events of communication being cut off (5%) closely followed by the social work consultation (4%). Despite the numbers being small this occurrence was most prevalent in the triadic consultations and the communication could be cut off by any party. Where the clinician cut across the patient or caregiver it was identified on listening back to the transcripts as a function to move the consultation on.

The social work consultation uses the open question most out of all of the clinicians (4%). The social worker and the psycho-oncology nurse explore the emotion based cues most at 5% and again these numbers are very small and may be reflective of the consultation time frame.

The psycho-oncology nurse has the highest rating for responding to cues with empathy of all clinicians at 24%.

The caregiver network facilitator position is novel in that while the role provides caregiver assessment, the informal caregiver does not see himself/herself as a patient, or having a need that requires addressing, hence the act of partnership building through the use of social talk and joking is more prevalent in this consultation, than the others. The intensity code for emotion is also prevalent in this consultation, more so than any other clinic (Table 7, chapter 4), which would account for the function code actively supporting and reassuring featuring equally with partnership building.

Clinician Communication Skills

Training of clinicians in discussing end of life care topics is something well represented within the literature as identified in Chapter 2. While the focus is on specific areas such as breaking bad news, basic communication skills such as using open ended questions is identified as best practice to encourage patients to open up and not be forced down a ‘yes, no’ communication pathway (Lo, Quill, Tulsky, 1999). In this study with very experienced palliative care clinicians it was sobering to see that the open questions were used seldom, and that there was a prevalence of information- and emotion-focussed cues that went unacknowledged.

In listening to the audio recordings, it was often evident that as a patient or caregiver spoke the clinician would be writing notes and hence there is an element of distraction from being fully present. The literature identifies the techniques to use open questions but what is missing is how this is incorporated into tight time frames, particularly in a clinic setting, when there is a waiting room with other patients to be seen. It is one thing to ‘allow enough time’ but how much time is enough? Each patient and family unit is different in their ability to absorb information. Some seek information while others avoid it. Getting the balance right is the challenge for service providers who work within defined clinic time frames and need to deliver an equitable service.

The clinic allows 30 minutes per person per session which equates to 90 minutes for the patient and caregiver to be seen by everyone, with a maximum of 3 patients being able to be seen per clinic session.

Ongoing communication skills training would be beneficial to assist experienced palliative care clinicians to acknowledge and respond to cues whilst also teaching the setting of boundaries so that meaningful communication can occur within the tight time frame of an outpatient clinic.

Caregiver Assessment in the Dyadic Consultation

The caregiver network facilitator is a unique role incorporated into the palliative care service. Integrating this position into the clinic structure enables a formal way of identifying needs that the informal caregiver may have and finding ways to address these needs. The content codes (Table 4) reveal that this position does not duplicate the role or function of the other clinicians providing assessment especially of note-the social worker, and instead supports the informal caregiver to speak freely and review their own strengths and abilities in providing care for a sick family member.

The content code (Table 4) demonstrates quite clearly that the caregiver network facilitator addresses concerns across both the psychosocial and social support spheres equally as the caregiver is given permission to state what it is that they need both physically and emotionally in order to take on or continue the task of caregiving.

The findings from the word count (Table 3) are most compelling regarding the need to provide informal caregivers with privacy to express their concerns. With very little input in the triadic clinics they dominate the words spoken when alone with the caregiver network facilitator.

The informal caregiver expresses both information - (26%) and emotion-based (74%) cues within the privacy of the dyadic consultation (Table 7). While the emotional expression outranks the need for information, they still have information needs that they are either not free to express in the triadic consultation or the opportunity does not present itself as less than 19% of the communication is directed to them (Table 2).

The scope of the study does not reveal the extent of informal caregiver assessment. What the results demonstrate is that when informal caregivers are provided with an opportunity for privacy they seize the moment suggesting that they have their own needs for communicating with the care providers of their care recipient and a separate clinic encounter enables this to occur.

Modification of the Coding Schema

The level of detail that occurs within this clinic structure has meant that finding a coding schema to fit all the nuances that are covered by the various clinicians is quite a challenge. Following the literature review and the discovery of Boehmer's paper on modifying the coding schema of Laidsaar -Powell to make it sensitive to capture the content of their videographic study, it became apparent that deconstruction of an existing coding schema would be required in order to capture the detail of what is being discussed in each consultation (Boehmer, Egginton, Branda et at 2014). More recent studies by Laidsaar-Powel et al, 2016; Dingey et al 2016; and Karsvold et al 2016 also modified their coding instruments to improve sensitivity for their study population.

The Verbal Interaction Coding Manual prepared by the Department of Psychology at the University of Sydney was used at the training manual in coding speech units (Dunn and Butow, 2006). The Prognosis Study – Coding Category Summary Guide is the schema that was used and modified.

The original coding schema was designed for the doctor, patient, caregiver and interpreter relationship. The Dimension 1- Source section required alteration as there was no requirement for an interpreter and the doctor was removed and replaced by the nurse practitioner, social worker, psycho-oncology nurse and caregiver network facilitator. The addition of the patient and carer speaking together was also added as this was a common occurrence in the triadic consultation (Dimension 1- Appendix D-3).

Dimension 2- The direction of interaction section required the addition of the patient and caregiver being addressed together. This became obvious in listening to the transcripts, that the clinician was addressing both the patient and their informal caregiver and needed an independent code. The additional clinicians were also added to this section. (Dimension 2- Appendix D-3)

Dimension 3- content section. This section required the greatest level of modification and this was realised after the first 2 patient transcripts had been completed. The coders met regularly to discuss the findings, and it was in these meetings that concerns were raised about some topic items being far too broad. As the original schema was used for a medical consultation, the nurse practitioner elements did not require any modification as they were already accounted for in the physical assessment component of the tool. It was the social worker consultation that started the discussions about social support being too broad. The focus of this consultation was on understanding all of the elements that contribute to patient and caregiver distress and concern across the social spectrum. Finances, advance care planning, transport, home help are consistent topics of this consultation.

The psycho oncology consultation includes spiritual and religious concerns, previous psychiatric history and the enquiry as to whether the patient wishes to participate in research.

None of these items was covered in the original coding schema and as part of a comprehensive psycho social assessment they were included as sub headings under the general code ‘social support, counselling, stress management’.

The function codes of the original coding schema (Dimension 4, Appendix D-1) looked at the broad components of a didactic consultation process and required minimal alteration in the modified coding schema. The additions included adding a field for when the patient or caregiver reads aloud to themselves, which often occurred when they were undertaking one of the screening tools in the social work, psycho-oncology or caregiver network facilitator consultations. This topic was added as an adjunct to the field ‘disclose’ (Dimension 4- Appendix D-3).

The other added fields were in relation to the dynamic of the triadic clinic. ‘Cut off communication’ and ‘prompt’ were added as these were identified when listening back to the transcripts as something that occurred when three people were all attempting to contribute to the communication process. Caregivers and patients would cut each other off regularly as they attempted to convey the details of their illness or family related matters to provide accuracy in the history being collected by the clinicians. Clinicians would also cut across the patient or caregiver particularly when seeking clarification or in an attempt to stop the discussion deviating from the topic at hand.

The prompt code was included because the informal caregiver would intervene in the conversation to prompt the patient to recall information and there was no way of capturing this function within the existing coding schema. Numbers are very small in the final analysis but it occurred most in the social work consultation followed by the nurse practitioner consultation.

From the dyadic consultation transcripts, the field ‘provide a warning shot’ was included as this is where ‘place of care’ and ‘place of death’ is discussed and as this clinic focuses on early introduction to palliative care, it is important to ensure no assumptions are made about the patient’s readiness to discuss confronting topics.

Summary

The primary and secondary research questions have been tested through a quantitative approach and the answers provide insight into the clinic structure, the role of the clinicians and the engagement of the informal caregiver. There is definitely a benefit in separating patients and their informal caregivers in a formalised manner to enable assessment and discussion of sensitive topics to occur where honesty and openness can feature. The emotional content does vary between the triadic and dyadic consultations and the value of this function of the clinic cannot be overestimated. Intuitively it has felt important to separate patients and caregivers. The literature has made this recommendation (Clayton, Butow, Arnold et al 2005), and the outcomes of the study thus far demonstrate that it is the correct way to proceed.

The findings support this clinic structure as a key enabler to ensure both patients and their informal caregivers have their information and emotional needs met.

For clinicians, the benefit of this study is that it demonstrates that there is no duplication of role and function in this model. The preparatory work that was enlisted to ensure that the Needs Assessment Tool -

Progressive Disease (NAT-PD- Appendix C) was divided and questions distributed to the most appropriate clinician also helped to structure the consultations so that information was not duplicated.

This study has raised a mirror to clinician communication skills. The limited use of open questions, the action of cutting off communication, and the level of emotion and information cues that went unacknowledged are areas for continuing professional development for all palliative care clinicians.

The areas for further research are obvious as this component of the study concludes and will be discussed in Chapter 6.

CHAPTER SIX
STUDY IMPLICATIONS

This study adds to the literature as it has evaluated the communication processes that occur in an innovative model of care that formally provides an opportunity for the patient and their informal caregiver to be seen together and then separately in the one outpatient clinic encounter.

The findings from the communication literature have suggested that patients and their caregivers have different information needs (Kirk and Kristjanson, 2004; Parker, Clayton, Hancock et al, 2007). Clayton, Butow, Arnold et al acknowledged this information discrepancy and recommended providing separate consultations with the patient and then with their informal caregiver (2005).

This study uses the quantitative paradigm to understand what is occurring in this setting. It does not reveal the content through the identification of themes; it reveals the action and response to that action between all participants of the individual consultations. This is valuable as it demonstrates to clinicians not only the strengths and weaknesses of the encounters, but whether there is duplication in the various encounters. This also opens up the opportunity to identify the areas that require further communication training for very experienced palliative care staff.

At a time where health care spending is under significant scrutiny it is important to be able to demonstrate where there is genuine patient benefit. Pre-admission clinics and intake clinics are not new to health care and were introduced to ensure that patients were adequately prepared for the hospital service that they were going to receive. This style of clinic also prepares the hospital staff for the care that may be required by the patient in a timely manner so that planning and preparation can take place without compromise to the patient or the organisation.

This study is a cross sectional study so the benefits of investing clinician input at the front end of the admission to palliative care would need to be studied over time. The anecdotal feedback from participants is that they appreciate meeting everyone while they are well enough and this feedback does echo the study findings by Hoerger et al that care planning needs to commence when the patient is well enough to engage in the process (2013). The preparatory work for both the patient and their informal caregiver needs to commence early on as they transition from a curative approach to a care model based on enhancing quality of life.

Further Research

The data from this study are rich and would benefit from further analysis. As only 10 patient encounters were coded and analysed as part of this pilot study, further analysis of the remaining 15 patients is warranted to enhance the understanding already obtained.

- DESIGN, CONDUCT AND ANALYSIS

Further study resulting from this pilot to examine the full data set would require a few adjustments both structurally with the coding schema and methodologically with the inclusion of a mixed methods paradigm. There is also an opportunity to utilise a retrospective approach once the patient dies to match their expressed wishes regarding site of death with actual site of death. Other areas of interest may include the uptake of Advanced Care Directives which are introduced by the social worker, and whether the informal caregiver utilised the services of the Caregiver Network Facilitator.

- CODING SCHEMA

To add to the understanding gained so far, I would alter the coding schema further for the function code ‘Inform, educate, explain’. I would look at these functions independently as it would be of interest to see if the clinicians were stronger in the use of educate and explain and the patient and informal caregiver stronger in the use of inform. It would also be important to understand if the clinician’s use of ‘inform educate, explain’ changes depending on whether the consultation is triadic or dyadic. The dyadic consultations serve a function of exploring issues with the patient or caregiver so the education function may be less in these consultations. Further analysis would illuminate this speech function in the consultations.

- ANALYSIS

Thematic content analysis utilising a qualitative paradigm would enhance the understanding of the communication nuances that occur with the individual clinicians and identify any differences that may be related to physical, emotional, psychological, or social concerns. Identification of triggers for emotional expression particularly that which occurs with the caregiver network facilitator consultation is worthy of further exploration. The subset of studying the informal caregiver consultations I believe would add a significant contribution to the caregiver literature. The findings regarding the number of words spoken (62%) and the intensity of emotional cues expressed (39%) reveal a need with the informal caregiver for privacy with a health care professional to open up and express their fears and concerns. A qualitative paradigm would assist in identifying the nature of those fears and concerns.

The communication aspects of this study would benefit from a mixed methods approach so that triangulation can occur.

Of the literature reviewed the majority of communication based articles were qualitative papers. The thematic analysis enriches the encounter and this would provide valuable information for health service planning to understand the value the patients and their caregivers receive from attending an introductory clinic, particularly in an environment where the patient story is valued. The quantitative data provides information that informs the effectiveness of the clinic. A key performance indicator for palliative care set by SA Health in 2010 was to collect the data on the number of patients that receive a multidisciplinary assessment. This clinic structure not only enables this to occur but also informs the health funders that each component part of the clinic has a distinct role and function and there is no duplication of service provision.

The area of health service research will further identify the value of this clinic structure as a separate entity from the communication focus of this study. With the focus of ambulatory models in palliative care gaining momentum a program logic model could be utilised to identify if the inputs and outcomes deliver the aims in a cost effective manner. Program logic is used by many evaluation groups in government and not-for-profit organisations and provides a solid foundation for health service evaluation (Funnel and Rogers, 2011)

From the specialist palliative service perspective there is an opportunity to conduct a case note audit of deceased patients who attended the clinic to see if they died in their identified place of choice. This data is popular to policy makers and it would be beneficial to identify how many patients identified home as their place of choice given that 70% is the figure most often quoted (SA Health Palliative Care Plan, 2009).

Clinical Practice Opportunities

The philosophy of palliative care practice identifies the family as the unit of care. The therapeutic guidelines state within their core values that palliative care *“offers a support system to help the family and carers cope during the patient’s illness and after the patient’s death”* (Palliative care expert group, version 3, 2010)

The findings from this study that underpin the above core value and can be incorporated to facilitate clinical practice change are related to the informal caregiver. The emotional intensity that is expressed by informal caregivers, matched with the number of words spoken which are greater than the clinician’s, highlight the information and emotional needs that caregivers have but do not express if the opportunity for privacy is not available. The informal caregiver does not identify themselves as having needs and does not want to take the attention away from the patient (Ewing and Grande 2012), so waiting for them to self-identify will continue to add to the unmet need burden already experienced. Specialist palliative care can incorporate opportunities for informal caregivers to be actively supported in a manner that does not make them feel that they are taking the attention from the patient.

Holistic care planning that incorporates assessing social support networks, allows the informal caregiver an opportunity to actively contribute in a manner where that contribution is invited, sought and welcomed.

The key difference that this study identifies is in the separation of the patient from the caregiver. Both parties have very unique and different needs, which are formally assessed for in this clinic structure. The patient is given permission to put the ‘brave face’ down and explore the meaning of what it is like to be living in a dying body. The informal caregiver is also given permission to put the ‘brave face’ down and explore what it is like to be living with a dying family member. Both positions have unique challenges and require space and privacy to foster the safety required to explore the impact of a life limiting illness on day to day life. Formalising an assessment process for informal caregivers, needs to become a priority if community based end of life care is to be a reality.

Communication Training

Palliative care clinicians are identified by their colleagues to possess high level communication skills. Often a referral is received by the palliative care service because a difficult conversation needs to occur and the home team requires support. Conducting a study such as this with clinicians who engage in difficult conversations frequently is quite illuminating. What is evident is that when there is a tight timeframe and an assessment process that needs to occur it is the assessment process that overrides. This is evidenced by the number of missed or minimally acknowledged cues. It may also explain the dominance of closed questions being asked. Closed questions allow new information to be obtained by limiting the answer to a simple yes or no, which acts to contain the communication process.

Communication skills training is something that requires regular attention and updating for all health professionals but particularly for very experienced palliative care staff. The use of role plays is one strategy that can be employed to support clinicians maintain an awareness of their own individual communication style. Self-awareness is a valuable skill but needs to be encouraged to be developed for those working in such emotionally challenging fields.

Awareness of body language is also valuable as it is our behaviour and actions which are powerful communicators. Communication training that focuses on body positioning and listening behaviour has the potential to enable meaningful exchanges to occur in short time frames, and this may be an area for further communication research.

Specific communication training targeting the outpatient clinic setting would be helpful to assist clinicians to support and hold patients and their family members in a supportive space, within the confines of the time allocated.

The results from this study have been shared with all of the clinicians who participated in the consultations and agreed to be audio recorded. They have all received a copy of the findings and a copy of the publication that has resulted.

The Clinic Structure

Additional Commonwealth funding was provided to enhance the palliative care community workforce in 2010, which assisted with the training of nurse practitioners as well as supporting advanced practice roles in allied health and encouraged the consideration of the unique and novel role of the caregiver network facilitator.

With the Nurse Practitioner role becoming more prominent in the health system across Australia, models such as this clinic structure demonstrate an efficient way in which to support patients and their families as well as supporting the palliative medicine consultants and general practitioners. Using the multi-disciplinary team in an ambulatory setting makes sense in an era where patients are being referred to palliative care services earlier in their illness trajectory. The nurse practitioner with their extended scope of practice can commence the preparatory work and in doing so effectively triage patients into the palliative medicine clinic based on priority and urgency. This contributes to the effective resource utilisation of the service.

The other added benefit of this clinic is that patients that are referred early and do not require ongoing follow up and support by the specialist palliative care team have received a comprehensive psychosocial assessment. This information is then provided back to the referrer who is notified that the patient will not be actively followed up but there is an invitation to re-engage at a later date if and when required.

The clinicians that make up the introductory palliative care clinic were originally funded from this Commonwealth government funding source and it became evident that funding was time limited and evaluation would be necessary to embed these roles into an ongoing service delivery model.

Evaluation of the caregiver network facilitator role was deemed most necessary as it is innovative and as yet not widely used in services across Australia. The nurse practitioner and social worker are established roles in health care and along with the psycho oncology nurse their data is easily tracked as the occasion of service is anchored to the patient. For the caregiver network facilitator, this is not the case. The occasion of service is targeting the informal caregiver who is not a registered patient in their own right but has service needs if they are to support their family member to be cared for within the community setting.

As the ageing population of Australia continues to rise the need for informal caregivers is only going to continue to grow. Having supports in place to support our future ‘co-workers’ (Currow, 2015) mobilise their own informal networks is going to be critical if patients are going to realise a desire to die at home, and if governments wish to contain health spending.

Much is written about health care spending and waste within the system. Investing resource at the front end of the admission to a palliative care service proactively provides information and support for what is a very daunting road ahead.

The majority of patients and family members are extremely complimentary about the clinic structure and what it provides. Most tell us that they were afraid of coming but were so glad that they came. They feel reassured and even though they may not need the full suite of what the service offers now it is reassuring to know it is there when the time comes.

Referrers have been equally complimentary. Emails and verbal acknowledgement has been received particularly form the oncologists who find the comprehensive assessment to be incredibly helpful to them if they are still engaged and providing palliative chemotherapy.

The clinicians all convene at the end of the morning to discuss the individual assessments and to understand what follow up is going to be provided. Despite initially having to adjust to focussing on the discrete component of the consultation at hand, the clinicians recognise the expertise within the team and are more than happy to focus on their discrete area feeling confident that areas outside of their skill sets will be captured and assessed for in the remainder of the clinic.

Disseminating the Findings

The findings from this study have been presented as oral presentations at three forums to date. The preliminary data was first presented at the Palliative Care Clinical Studies Collaborative (PaCCSC) in Sydney in March 2015. The findings regarding the informal caregiver were identified as significant within this group and this presentation generated requests for the clinic model and clinic tools from other services that were attending that day.

The model of care that underpins this clinic was then presented at the State-wide Palliative Care Conference at Adelaide Showgrounds in May 2015. It is a model that is being replicated in the other Local Health Networks across Adelaide. Of particular interest is the palliative care presence in the primary health care setting of the GP Plus units. There is general acceptance that this style of early introductory clinic to palliative care makes sense and prepares patients well for what lies ahead.

As an invited speaker to the National Palliative Care Conference in Melbourne, September 2015 I presented the model and findings to a national and international audience. I have since had requests from researchers in the UK and clinicians in New Zealand to share my work with them.

The verbal feedback resulting from this work is the dyadic consultation and providing a formal opportunity to conduct an informal caregiver assessment. While many recommendations are made in the literature to conduct an assessment or provide separate forums to hear patient and caregiver concerns, this is rarely taken up due to restrictions regarding resourcing.

Some anecdotal feedback from conference participants was that caregiver assessment takes place, it just usually occurs at the letterbox or on the door step. Ewing and Grande dispelled this in their interview with caregivers who said this type of assessment was a tacked on after thought and was often generated by the clinician who as they were leaving enquired as to how the caregiver was managing (2012). This is neither formalised nor does it value the role the informal caregiver is taking on if it occurs as the clinician is leaving.

The pilot data have been published in the International Journal of Palliative Nursing, November 2015 (Appendix E-1). This publication has generated further enquiry with a researcher in Scotland, as well as numerous requests for the supply of the article from the social network site, ResearchGate (Appendix E-2).

Conclusion

The completion of this study culminates many years of creating and implementing this model of care. The idea for palliative care service provision to be conducted in a primary health care setting began back in 2007. The successful acceptance of the business case to conduct clinics in primary health care settings was the first step of the process. Patient and caregiver satisfaction was then needed to understand if there was acceptance to this particular clinic style (Swetenham, Tieman and Currow, 2014). Both formal and informal feedback have been obtained and as the clinic has developed over time, further evaluation has occurred to inform the clinicians of the specialist palliative care service of where the value actually resides for patients and their caregivers who attend. There was initially concerns raised that this clinic would be too long and it would be too much for patients to attend. Interestingly it is the patients and their informal caregivers who are most appreciative of being given the time and it is received very well by those who derive the greatest benefit from it.

Communication analysis has provided insight into more than just the dynamic that occurs between clinicians and patients and informal caregivers. It has enabled an assessment of the clinic structure by identifying the points of discussion that occur in each of the individual consultations. This has met the primary aim to identify the differences in communication that occur within the patient, informal caregiver and health professional triadic consultation and compare this to the communication that occurs between the health professional and patient or health professional and informal caregiver in the dyadic consultation. The triadic consultations are grounded in education and explanation whereas the dyadic consultations are grounded in exploration which facilitates emotional expression.

Communication analysis has revealed unmet information and emotional needs for both patients and caregivers from the findings by comparing the triadic to the dyadic consultations. While all clinicians failed at times to respond to cues for information and emotion this analysis was able to demonstrate significant findings in the number of words spoken by informal caregivers when separated from the patients, as well as identify the high level of intensity of emotion-based cues expressed by informal caregivers.

Anecdotally the caregiver network facilitator would report that as soon as the caregiver was alone the tears would flow. This was captured within this analysis through strong emotion-based cues which were expressed at 40% compared to the patient who expressed strong emotion-based cues at 27%.

The informal caregiver attends this clinic as a support person to the patient. They are formally invited to attend the clinic in the letter that is sent out to the patient (See Appendix A). The offering of a separate consultation where an assessment is undertaken to identify caregiver needs is facilitated by the structure of this clinic.

The challenge for the palliative care service is in broadening out caregiver assessment as there is only a small percentage of patients triaged as 'early introduction' that are well enough to attend this clinic. Hence caregiver assessment is not provided routinely or systematically across the service as a whole.

A qualitative analysis is the next logical step as the data is rich and there is more to be learned from the patient and informal caregiver experience. Triangulation of both the quantitative and qualitative components of this study will provide a very clear picture and further answer the research questions posed for this study.

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APPENDIX AA

Search ID#	Search Terms	Search Options	Last Run Via	Results
S5	S1 AND S2 AND S3 AND S4	Limiters - English Language; Human Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE with Full Text	5
S4	(MH "Physician-Patient Relations")	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE with Full Text	60,948
S3	MW caregivers	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE with Full Text	22,421
S2	MW communication	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE with Full Text	138,288
S1	TX dyad* AND TX triad*	Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE	1,826

#	Search History	Results
1	palliative care/ or terminally ill patients/ with Full Text	188
2	exp communication/	3038
3	1 and 2	14
4	limit 3 to english language	14
5	limit 4 to updaterange="psyc8(20130916201452-20130930180431]"	0

This search history is what is set up to provide the weekly Medline Ovid updates each week.

APPENDIX

Government of South Australia

Southern Adelaide Palliative Services

Ms Kate Swetenham, Service Director
Southern Adelaide Palliative Services
700 Goodwood Road
Daw Park, 5041
Ph: 08 8275 1732
Fax: 08 8277 4957

Palliative Care Initial Assessment Clinic	
Where: GP Plus (Marion), 10 Milham Road, Marion	
Date:	**Time:**

Dear ………………………..

You have been referred to Southern Adelaide Palliative Services. We are a team of health professionals who focus on improving the care and experience for people diagnosed with a life limiting illness.

In order for us to best meet your needs you are invited to attend our Initial Assessment Clinic. We request that you allow 2 hours for this initial clinic. At this time, you will be introduced to our service:

Nurse Practitioner

Will undertake an initial assessment of your symptoms and outline the role of our service;

Community Social Worker

To discuss any social, financial or issues related to care planning;

Psychosocial Nurse

Will meet with you to discuss any concerns regarding coping and adjusting that you may have; while the

Caregiver Facilitator

Will meet with your carer and explore any needs in relation to providing care.

We ask that if you have a significant caregiver that you attend together. Please also bring a list of all of your current medications.

This clinic aims to assess your current situation and identify the most important issues from your perspective. The outcomes of this assessment will be discussed with you and your carer and an agreed follow up plan will be established.

If you have any questions, please do not hesitate to contact our staff on 8275-1732.

We look forward to meeting you.

Kind regards

Kate Swetenham, RN, BN, Grad Dip Psycho Oncology, M of Pall Care.
Service Director
Southern Adelaide Palliative Services

APPENDIX A-1

Participant Information Sheet – Care giver

Name of Organisation:

Repatriation General Hospital

Southern Adelaide Palliative Services.

Title of the project:

A mixed methods study exploring the differences in communication between patients, the family care giver and health care professionals in an outpatient psychosocial clinic setting.

Invitation to participate:

Southern Adelaide Palliative Services is conducting a research project to identify if there are differences in the way psychosocial health care professionals (for example, social workers) communicate when they see patients alone and when they are see them with a family caregiver present. The purpose of this study is to gain information, which may improve the care that we provide. We are inviting you to to participate in this research project but whether you participate or not is entirely your decision. Whether you take part or not, your medical care/relationship with Southern Adelaide Palliative Services will not be affected in any way.

Selection:

You have been selected to participate because you are eligible to attend the Triage Assessment Clinic at GP Plus Marion.

Aims of the project:

The overall aim of this project is to conduct an evaluation of this clinic which will inform the way in which we offer services into the future.

Commitments:

By agreeing to participate in this study, you are agreeing to your consultation to be tape recorded. The tape recording will not identify you by name, only by a numerical code. Clinic participants are routinely asked to allocate 2 hours for the clinic visit. Participation in the study will not extend this time.

Assessments

No additional Assessments will be undertaken as part of this study

Benefits:

The study of communication exchange will inform how we structure outpatient consultations in the palliative care population. This has the potential to change our outpatient clinic model of care which will then be adopted as best practice for the Southern Adelaide Palliative Care Service.

Risks:

While there are no foreseeable risks associated with attending the clinic, if feelings of distress are experienced counselling support is available by contacting the Research Coordinator, Aine Greene on 82751732.

Confidentiality:

All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law.

Publication:

The results of this study are the property of Southern Adelaide Palliative Services and may be published in scientific journals at a later date. It is possible that the results may not be published for commercial, scientific or other reasons.

Withdrawal:

Your participation in this study is entirely voluntary. A returned consent form will indicate your permission for the session to be tape recorded. Failure to bring the consent form and your verbal refusal to participate in the study will be considered as withdrawal from this study and there will be no further mention made regarding this study. Your care will not be negatively impacted if you choose not to participate.

Outcomes:

The study of the tape recordings will be used to inform service delivery for Southern Adelaide Palliative Services. The findings will not be made available to you

What will happen to me at the end of the study?

You will continue to receive routine care and support following the study. You will receive a letter to inform you of what follow up will be provided as a result of having attended the clinic; this forms part of our routine practice following the clinic appointment.

Compensation

You may feel some distress from participation in this study. If this occurs, you may withdraw from this study if you wish and your care will not be affected in any way. By participating in this study, you do not give up any of your legal rights.

Contact:

If you have any questions related to this study please feel free to contact the Chief Investigator, Ms Kate Swetenham on 82751732.

Complaints:

This study has been reviewed by the Southern Adelaide Flinders Clinical Human Research Ethics Committee. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Officer, SAFC HREC at the Flinders Medical Centre (8204 4507) or email research.ethics@health.sa.gov.au.

APPENDIX A -2

Flinders UNIVERSITY

Government of South Australia
SA Health

Consent to Participation in Research

I, (first or given names)-------------------------- (last name)------------------------

give consent to my involvement in the research project

A mixed methods study exploring the differences in communication between patients, the family care giver and health care professionals in an outpatient psychosocial clinic setting.

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by

(first or given name)------------------------------ (last name)-----------------------------

and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. I will attend the clinic for my once off palliative care assessment by four clinicians which will be unchanged apart from the fact the interviews will be taped.
2. I will have no procedures or investigations taken as part of the study however some investigations may be required as part of my clinical care
3. I will not be required to allocate additional time to attend the clinic
4. My confidentiality will be maintained at all times
5. I can withdraw my consent at any time without any impact on my care

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

Signature of Research Participant: ______________________ Date: _____________

I, have described to _______________________________________

the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: Date:

APPENDIX A-3

Government of South Australia
SA Health

Flinders
UNIVERSITY

Participant information sheet -Patient

Name of Organisation:

Repatriation General Hospital Southern Adelaide Palliative Services

Title of the project: ______________________________________

A mixed methods study exploring the differences in communication between patients, the family care giver and health care professionals in an outpatient palliative care clinic setting.

Invitation to participate:

Southern Adelaide Palliative Services is conducting a research project to identify if there are differences in the way psychosocial health care professionals (for example, social workers) communicate when they see patients alone and when they are see them with a family caregiver present. The purpose of this study is to gain information, which may improve the care that we provide.

We are inviting you to to participate in this research project but whether you participate or not is entirely your decision. Whether you take part or not, your medical care/relationship with Southern Adelaide Palliative Services will not be affected in any way.

Selection:

You have been selected to participate because you are eligible to attend the Triage Assessment Clinic at GP Plus Marion. Your caregiver has also been asked to participate and you both need to agree to be eligible. You are encouraged to talk to each other about this and anybody else before making a decision.

Aims of the project:

The overall aim of this project is to conduct an evaluation of how health professionals talk to you, listen to you and respond to your questions. We need to understand this in order to help our staff to do this better. You will be helping us to improve our care.

Commitments:

By agreeing to participate in this study, you are agreeing to your GP Plus clinic appointment to be tape recorded. The tape recording will not identify you by name, only by a numerical code. Clinic participants are routinely asked to allocate 2 hours for the clinic visit. Participation in the study will not extend this time.

Benefits:

The study of communication exchange will inform how we structure outpatient consultations in the palliative care population. This has the potential to change our outpatient clinic model of care which will then be adopted as best practice for the Southern Adelaide Palliative Care Service. It is unlikely that any personal benefit will be gained from participating in this study.

Risks:

While there are no foreseeable risks associated with attending the clinic, if feelings of distress are experienced counselling support is available by contacting the Research Coordinator, Ms Aine Greene on 82751732. If distress is obvious counselling will be offered.

Confidentiality:

All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law.

Payments

Participation in this study is voluntary and there will be no payment or incentives offered

Publication:

The results of this study are the property of Southern Adelaide Palliative Services and may be published in scientific journals at a later date. It is possible that the results may not be published for commercial, scientific or other reasons.

Withdrawal:

Your participation in this study is entirely voluntary. A returned consent form will indicate your permission for the session to be tape recorded. Failure to bring the consent form and/or your verbal refusal to participate in the study will be considered as withdrawal from this study and there will be no further mention made regarding this study. Your care will not be negatively impacted if you choose not to participate. A decision not to participate or to withdraw from the study will not have any impact on your care.

What will happen to me at the end of the study?

You will continue to receive routine care and support following the study. You will receive a letter to inform you of what follow up will be provided as a result of having attended the clinic; this forms part of our routine practice following the clinic appointment.

Outcomes:

The study of the tape recordings will be used to inform service delivery for Southern Adelaide Palliative Services. The tapes will be listened to by the chief investigator who will transcribe the content and then destroy the tapes. The findings will not be made available to you

Compensation

You may feel some distress from participation in this study. If this occurs you may withdraw from this study if you wish, and your care will not be affected in any way. By participating in this study you do not give up any of your legal rights.

Contact:

If you have any questions related to this study please feel free to contact the Research Coordinator, Ms Aine Greene on 82751732.

Complaints:

This study has been reviewed by the Southern Adelaide Flinders Clinical Human Research Ethics Committee. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Officer, SAFC HREC at the Flinders Medical Centre (8204 4507) or email research.ethics@health.sa.gov.au.

APPENDIX A-4

Consent to Participation in Research

I, (First or given names) -------------------------- (Last name) ------------------------

give consent to my involvement in the research project.

A mixed methods study exploring the differences in communication between patients, the family care giver and health care professionals in an outpatient palliative care clinic setting.

I acknowledge the nature, purpose and contemplated effects of the research project, especially as far as they affect me, have been fully explained to my satisfaction by

(First or given name) ------------------------------ (Last name) ----------------------------- and my consent is given voluntarily.

I acknowledge that the detail(s) of the following has/have been explained to me, including indications of risks; any discomfort involved; anticipation of length of time; and the frequency with which they will be performed:

1. I will attend the clinic for my once off palliative care assessment by four clinicians which will be unchanged apart from the fact the interviews will be taped.
2. I will have no procedures or investigations taken as part of the study, however some investigations may be required as part of my clinical care
3. I will not be required to allocate additional time to attend the clinic
4. My confidentiality will be maintained at all times
5. I can withdraw my consent at any time without any impact on my care

I have understood and am satisfied with the explanations that I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research project may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

I acknowledge that I have been informed that should I receive an injury as a result of taking part in this study, I may need to start legal action to determine whether I should be paid.

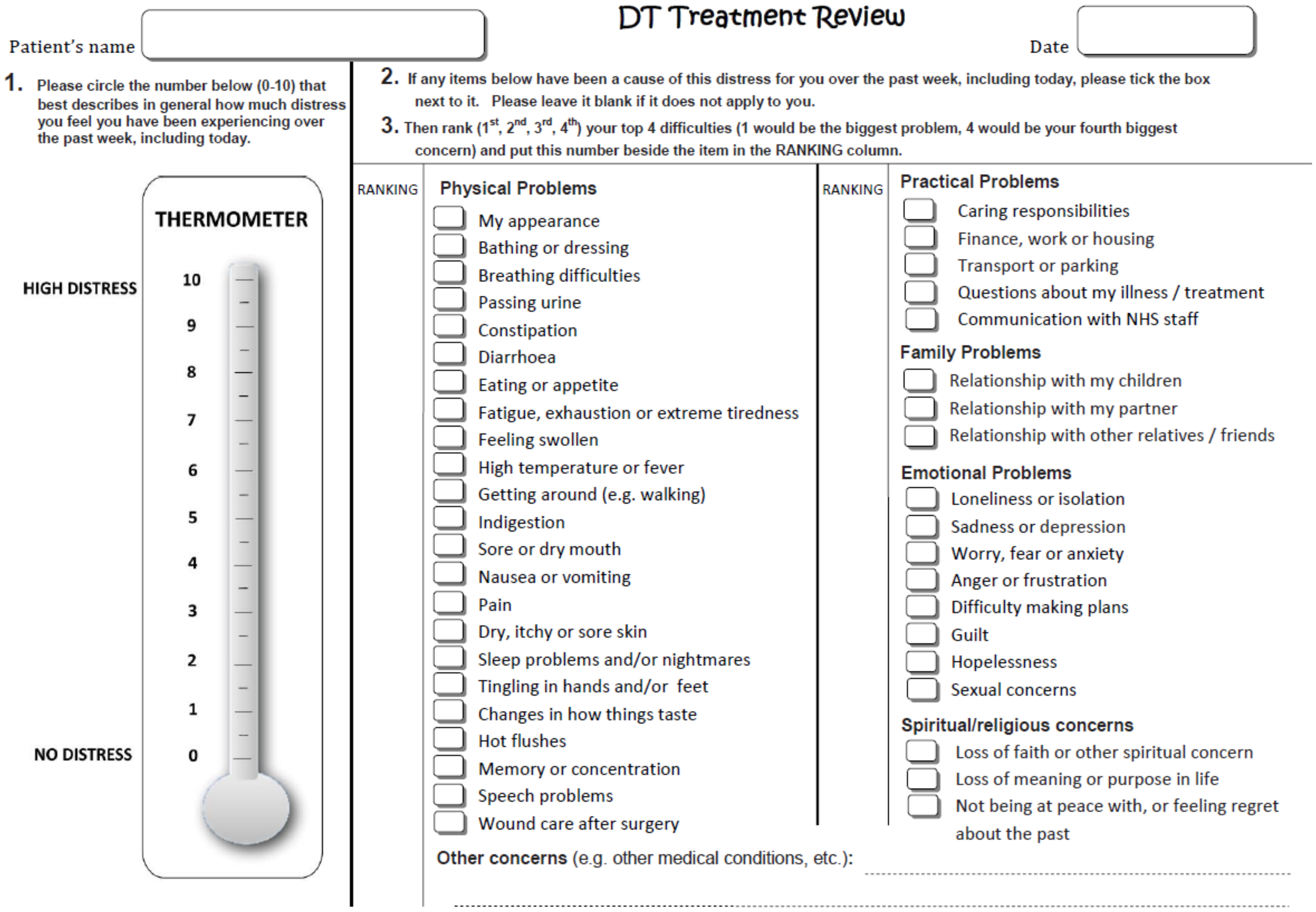
Signature of Research Participant: _______________________ Date: _____________

I, have described to ______________________________________the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: Date:

APPENDIX B -1

Distress Thermometer



DT Treatment Review

Patient's name ______ Date ______

1. Please circle the number below (0-10) that best describes in general how much distress you feel you have been experiencing over the past week, including today.

THERMOMETER

HIGH DISTRESS 10
9
8
7
6
5
4
3
2
1
NO DISTRESS 0

2. If any items below have been a cause of this distress for you over the past week, including today, please tick the box next to it. Please leave it blank if it does not apply to you.

3. Then rank (1^{st}, 2^{nd}, 3^{rd}, 4^{th}) your top 4 difficulties (1 would be the biggest problem, 4 would be your fourth biggest concern) and put this number beside the item in the RANKING column.

RANKING

Physical Problems

- ☐ My appearance
- ☐ Bathing or dressing
- ☐ Breathing difficulties
- ☐ Passing urine
- ☐ Constipation
- ☐ Diarrhoea
- ☐ Eating or appetite
- ☐ Fatigue, exhaustion or extreme tiredness
- ☐ Feeling swollen
- ☐ High temperature or fever
- ☐ Getting around (e.g. walking)
- ☐ Indigestion
- ☐ Sore or dry mouth
- ☐ Nausea or vomiting
- ☐ Pain
- ☐ Dry, itchy or sore skin
- ☐ Sleep problems and/or nightmares
- ☐ Tingling in hands and/or feet
- ☐ Changes in how things taste
- ☐ Hot flushes
- ☐ Memory or concentration
- ☐ Speech problems
- ☐ Wound care after surgery

RANKING

Practical Problems

- ☐ Caring responsibilities
- ☐ Finance, work or housing
- ☐ Transport or parking
- ☐ Questions about my illness / treatment
- ☐ Communication with NHS staff

Family Problems

- ☐ Relationship with my children
- ☐ Relationship with my partner
- ☐ Relationship with other relatives / friends

Emotional Problems

- ☐ Loneliness or isolation
- ☐ Sadness or depression
- ☐ Worry, fear or anxiety
- ☐ Anger or frustration
- ☐ Difficulty making plans
- ☐ Guilt
- ☐ Hopelessness
- ☐ Sexual concerns

Spiritual/religious concerns

- ☐ Loss of faith or other spiritual concern
- ☐ Loss of meaning or purpose in life
- ☐ Not being at peace with, or feeling regret about the past

Other concerns (e.g. other medical conditions, etc.): ....

....

APPENDIX B-2

K10

Patient Name		**Outcome Tool**	**Result**
DOB		**K10**	
Date of Assessment			
GP			

Please place an X in the correct box.Do not answer questions 3-6 if the answer to question 2 is “non of the time” in which case questions 3-6 automatically receive a score of one each.

The maximum score is 50 indicating severe distress and the minimum score is 10 indicating no distress.

In the past 4 weeks		**1** None of the time	**2** A little of the time	**3** Some of the time	**4** Most of the time	**5** All the time
1	**About how often did you feel tired out for no good reason?**					
2	**About how often did you feel nervous?**					
3	**About how often did you feel so nervous that nothing could calm you down?**					
4	**About how often did you feel hopeless?**					
5	**About how often did you feel restless of fidgety?**					
6	**About how often did you feel so restless you could not sit still?**					
7	**About how often did you feel depressed?**					
8	**About how often did you feel that everything is an effort?**					
9	**About how often did you feel so sad that nothing could cheer you up?**					
10	**About how often did you feel worthless?**					

APPENDIX B-3

Caregiver Assessment Questionnaire - Caregiver Network Service

Carer's Name: _______________________________ **Patient's Name** _______________________

MRN No.: __________ **Clinic** : Marion ☐ Noarlunga ☐

Please answer the following questions **based on your life at this time**.

Circle the number from 0 – 10 that best describe your experiences:

Physical Area:

To what extent are the following symptoms a problem for you?

1	**Fatigue**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
2	**Sleep changes**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
3	**Appetite changes**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
4	**Rate your overall physical health**											
	Excellent	1	2	3	4	5	6	7	8	9	10	Extremely poor
5	**I don't like to leave the person I am caring for alone**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
6	**I have difficulties making decisions**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
7	**Since the diagnosis I feel a loss of privacy and/or personal time**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
8	**I am feeling ill (headaches, stomach problems, colds, etc.)**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem

Emotional / Relationship Area

9	**I feel completely overwhelmed**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
10	**I have trouble keeping my mind on what I am doing**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
11	**How much anxiety do you believe you have?**											
	None at all	1	2	3	4	5	6	7	8	9	10	A great deal
12	**How free are you to express feelings of sadness, grief and anger?**											
	None at all	1	2	3	4	5	6	7	8	9	10	Completely
	Comment:											

Emotional / Relationship Area (Cont.)

13	**How do you think you are managing caring for another?**											
	Not at all	1	2	3	4	5	6	7	8	9	10	Completely
14	**Is the amount of support you receive from others sufficient to meet your needs?**											
	Not at all	1	2	3	4	5	6	7	8	9	10	Completely
15	**Are there times that you resent taking on the role of caregiver?**											
	Not at all	1	2	3	4	5	6	7	8	9	10	A great deal
16	**How much isolation do you believe is caused by the cared for persons illness or treatment?**											
	Not at all	1	2	3	4	5	6	7	8	9	10	A great deal
17	**Have you experienced problems receiving needed support to meet your financial needs?**											
	No problem	1	2	3	4	5	6	7	8	9	10	Severe Problem
18	**Do you get enough help obtaining and completing applications and financial forms (eg. Insurance, Centrelink, carer’s benefits, disability etc.)?**											
	Not at all	1	2	3	4	5	6	7	8	9	10	A great deal
19	**What level of assistance do you have finding needed resources and supports**											

	(eg. Transport, home help, personal care, home maintenance)?											
	Not at all	1	2	3	4	5	6	7	8	9	10	A great deal
20	**How confident do you feel about calling others to ask for assistance?**											
	Not at all	1	2	3	4	5	6	7	8	9	10	A great deal

Spiritual Area

21	**How important to you is your participation in spiritual or religious experiences (eg. Meditation, spiritual traditions or rituals, praying, or going to a place of worship)?**											
	Not at all	1	2	3	4	5	6	7	8	9	10	Very important
22	**Is the amount of support you receive from religious activities such as going to church or temple sufficient to meet your needs?**											
	Not at all	1	2	3	4	5	6	7	8	9	10	Completely

APPENDIX B-4

AKPS

Australia-modified Karnofsky Performance Status (AKPS)

How to assess AKPS

AKPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Updated 16122011

APPENDIX B-5

PCOC
palliative care
outcomes collaboration

Symptom Assessment Scale

Form for completion by patients

Name:____

1. Write the day or date in the space provided
2. Select a number between 0 and 10 using the diagram below
3. Record your score
4. Add in any other symptoms or problems that are causing you distress in the blank spaces, below the listed symptoms

Absent or no distress → **Worst possible distress**

0 1 2 3 4 5 6 7 8 9 10

0 = means the symptom is absent or you have no distress caused by the symptom.
10 = means you are experiencing the worst possible distress caused by the symptom.

Date/Day									
Difficulty sleeping									
Appetite problems									
Nausea									
Bowel problems									
Breathing problems									
Fatigue									
Pain									

Updated 16122011

APPENDIX B-6

PROMPT SHEET: ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

PATIENT WELLBEING

Physical symptoms

- Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnoea, vomiting/nausea, persistent cough, pain, oedema, constipation, diarrhoea, sleep problems or loss appetite?

Activities of daily living

- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
- Is there a caregiver to assist the patient?

Psychological

- Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?
- Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?
- Is the patient requesting a hastened death?

Medication and treatment

- Is the patient able to manage complex medication and treatment regimes?

Spiritual/Existential

- Is the patient feeling isolated or hopeless?
- Does the patient feel that life has no meaning or that his/her life has been wasted?
- Does the patient require assistance in finding appropriate spiritual resources or services?

Financial/Legal

- Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?
- Is the family socio-economically disadvantaged?
- Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?

Sexual

- Does the patient have concerns about his/her sexual functioning or relationship?

Health Beliefs, Social and Cultural

- Does the patient or family have beliefs or attitudes that make health care provision difficult?
- Are there any language difficulties? Does the patient or family require a translator?
- Is the family preventing information about prognosis from being disclosed to the patient?
- Is the patient or family feeling socially isolated?
- Does the family live more than 50km from the primary service provider?
- Is the patient of Aboriginal or Torres Strait Islander descent?
- Is the patient over 75 years of age? (NB: older patients are under-represented in SPCSs.)

Information

- Does the patient want more information about the course and prognosis of the disease and treatment options?
- Is the patient aware of the various care services available to assist them and do they need assistance in accessing these?

ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT

Physical symptoms

- Are the patient's physical symptoms causing the caregiver or family distress?

Providing physical care

- Is the caregiver or family having difficulty coping with activities of daily living or practical issues such as equipment and transport?

Psychological

- Is the caregiver or family having difficulty coping with the patient's psychological symptoms?
- Is the caregiver or family requesting a hastened death for the patient?

Medication and treatment

- Is the caregiver or family having difficulty managing complex medication and treatment regimes?

Family and Relationships

- Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles?
- Is the patient particularly concerned about the impact of the illness on the caregiver or family?

Information

- Does the caregiver or family want more information, eg about the course and prognosis of the disease and treatment?
- Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these? (eg respite, financial and legal services, psychological services, support groups, pastoral care.)

CAREGIVER WELLBEING

Physical and psychosocial

- Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances?
- Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed?
- Does the caregiver have spiritual/existential issues that are of concern?
- Does the caregiver have concerns about his/her sexual functioning or relationship?

Bereavement Grief (pre and post death)

- Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?

Funded by the Australian Government Department of Health and Ageing and Cancer Council NSW.

Further copies are available at: http://www.newcastle.edu.au/research-centre/cherp/professional-resources

NEEDS ASSESSMENT TOOL : PROGRESSIVE DISEASE (NAT: PD)

COMPLETE ALL SECTIONS

PATIENT NAME: ________________________________

DATE: ____________ DIAGNOSIS: ________________

PATIENT/ADDRESS LABEL

SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT

	Yes	No	If dotted boxes are ticked, consider assessment by SPCS
1. Does the patient have a caregiver readily available if required?		*	
2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?	*		
3. Do you require assistance in managing the care of this patient and/or family?	*		

SECTION 2: PATIENT WELLBEING (Refer to the prompt sheet for assistance)

	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)
1. Is the patient experiencing unresolved physical symptoms (including problems with pain, breathlessness, sleeping, appetite, bowel, fatigue, nausea, oedema or cough)?						
2. Does the patient have problems with daily living activities?						
3. Does the patient have psychological symptoms that are interfering with wellbeing or relationships?						
4. Does the patient have concerns about how to manage his/her medication and treatment regimes?						
5. Does the patient have concerns about spiritual or existential issues?						
6. Does the patient have financial or legal concerns that are causing distress or require assistance?						
7. Does the patient have concerns about his/her sexual functioning or relationship?						
8. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?						

9. Does the patient require information about: (tick any options that are relevant) ☐ The diagnosis ☐ The prognosis ☐ Treatment options ☐ Medical/health/support services ☐ Financial/legal issues ☐ Social/emotional issues ☐ Advance directive/resuscitation order ☐ Other:

COMMENTS: ________________________________

SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR THE PATIENT (Refer to the prompt sheet for assistance)

Who provided this information? (please tick one) ☐ Patient ☐ Caregiver ☐ Both	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)
1. Is the caregiver or family distressed about the patient's physical symptoms?						
2. Is the caregiver or family having difficulty providing physical care?						
3. Is the caregiver or family having difficulty coping?						
4. Is the caregiver or family have difficulty managing the patient's medication and treatment regimes?						
5. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?						
6. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?						

7. Does the caregiver require information about: (tick any options that are relevant) ☐ The diagnosis ☐ The prognosis ☐ Treatment options ☐ Medical/health/support services ☐ Financial/legal issues ☐ Social/emotional issues ☐ Advance directive/resuscitation order ☐ What to do in event of patient's death

COMMENTS: ________________________________

SECTION 4: CAREGIVER WELLBEING (Refer to the prompt sheet for assistance)

Who provided this information? (please tick one) ☐ Patient ☐ Caregiver ☐ Both	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)
1. Is the caregiver or family experiencing physical, practical, spiritual, existential, sexual or psychological problems that are interfering with their own wellbeing or functioning?						
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their own wellbeing or functioning?						

COMMENTS: ________________________________

IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS REFERRAL SECTION

1. Referral to: (Name) ________________________________
2. Referral to: (Specialty) ☐ General practitioner ☐ Social worker ☐ Psychologist ☐ Specialist palliative care service ☐ Physiotherapist ☐ Community nurse ☐ Oncologist ☐ Cardiologist ☐ Occupational therapist ☐ Other: ____________
3. Priority of assessment needed: ☐ Urgent (within 24 hours) ☐ Semi-Urgent (2-7 days) ☐ Non-Urgent (next available)
4. Discussed the referral with the client. ☐ Yes ☐ No
5. Client consented to the referral. ☐ Yes ☐ No
6. Referral from: Name: ____________ Position: ____________ Signature: ____________

Updated 16122011

APPENDIX C-2

Southern Adelaide Palliative Services Draft

Physical Assessment

PATEINT LABEL

SAPS Community Nurse:_________________________________

Date: __ __ / __ __ / __ __

Location of contact:

Tick one box only.

☐ Home ☐ OPD ☐ Hospital ☐ Hospice ☐ Nursing Home

☐ Hostel ☐ Other ____

Comments (incl. name of facility if applicable):

____

____

Section 1: History of Present Illness and Past Medical History

Major diagnosis:

(including how, where and who diagnosed)

Date of diagnosis: __ __ / __ __ / __ __

Sites of spread:

History of present illness:

(including surgeries and treatments for major diagnosis, chief complaint, distressing symptoms and reason for palliative care referral)

Past medical history:

(including diabetes, renal impairment, cancer, neurological impairment, heart/vascular disease, lung disease and mental illness)

Patient and family’s understanding and expectations of the condition and situation:

Section 2: Medications and Services

Allergies and adverse reactions:

(including adverse reactions to pain medicines)

Medication	Reaction	Date of reaction	Known	Medication	Reaction	Date of reaction	Known
			☐				☐
			☐				☐

Present medications:

(including prescribed and over-the-counter medications)

Generic medication name	Indication	Route	Dose	Frequency	Date initiated

Discontinued medications:

(especially medications for present symptoms that were not successful or intolerable)

Generic medication name	Indication	Reason for discontinuation	Date stopped

Alternative therapies:

Alcohol, tobacco and recreational drugs:

Source of medication history:

☐ GP ☐ Patient/carer ☐ Other Hospital ☐ Current medical notes ☐ Community Pharmacist

☐ Patient list ☐ Nursing Home ☐ Own medicines ☐ Previous medical notes ☐ other ______________________________

Section 3: Healthcare Providers and Services

Healthcare providers:

Tick the box if the indicated healthcare provider participates in the patient's care & provide name and details.

☐ GP ____ Able to Home Visit Y ☐ N ☐

☐ Oncologist____

☐ Radiation oncologist ____

☐ Other specialist 1 ____ Type __________________

☐ Other specialist 2 ____ Type __________________

☐ RDNS ____ Visits/week _____________

☐ Other community services ____ Visits/week _____________

Section 4: Clinical Assessment

Performance status:

Indicate present performance status using the indicated scale.

☐ % Australian-modified Karnofsky Performance Status Scale (AKPS)

Comments (including how the PS has been changing:

____

____

General:

e.g. appearance, cognition, other VS Pulse ☐ Resp ☐ MMSE ☐

Weight :	☐ Extreme loss	☐ Obvious loss	☐ Slight loss	☐ Unchanged
Color :	☐ Jaundice	☐ Cyanosed	☐ Pale	☐ Normal
Mobility :	☐ Bed-bound	☐ Transfers with difficulty	☐ Limited	☐ Mobile

Neurological:

e.g. power, sensation, reflexes, gait disturbance, paralysis, bowel/bladder dysfunction

Gastrointestinal (include mouth/pr)**:**

e.g. thrush, mouth ulcers, bowel sounds, abdominal distension, tenderness, , liver size

Cardiovascular:

e.g. pulse rate and rhythm, peripheral circulation

Skin:

incl. eyes, presence of ulcers, oedema, tissue turger, bruising, wounds, stomas, evidence of DVT

Respiratory:

e.g. tracheal deviation, chest movement, air entry, lung sounds

Musculoskeletal:

e.g. ROM at joints, wasting, areas of tenderness/swelling, vertebral tenderness

Symptom List: (**0** = absent 1 = mild 2 = moderate 3 = severe 4 = extreme) Add Details Please.

Please rate symptom 0-4 and add details on the line provided below:

	Lethargy	
	Pain control	
	Vomiting	
	Nausea	
	Dyspnoea	
	Cough	
	Dysphagia	
	Oral discomfort	
	Anorexia	
	Constipation	
	Diarrhoea	
	Sleep Disturbance	
	Spiritual issues	
	Anxiety	
	Depression	

If pain is identified as a symptom, please complete Appendix 1 (Pain Assessment)

Section 5:

Impression and Plans for this Patient's Future Care and Follow-up:

Summary

(physical assessment findings)

Palliative care phase:*

Tick one box only.

☐ Stable ☐ Deteriorating ☐ Bereaved ☐ Unstable ☐ Terminal ☐ Unknown

What are my plans for this patient's present and future care?

(problem list and plan including medication changes, other treatments, services to involve, etc.)

Problem	Possible causes and/or other comments	Plan (consider disease-modifying and symptomatic interventions)

Potential problems that may come up in the future	Contingency Plan

Follow-up plan:

SAPS Category: ☐ **1** ☐ **2** ☐ **3**

1 = Requires full support of SAPS

2 = OPD only follow-up

3 = Inactive, await contact from primary carers

SAPS Community Nurse visit and telephone follow-up

Follow-up telephone call

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Comments:

Follow up visit

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Where should the visit be scheduled?

☐ Home ☐ Clinic ☐ Hospital ☐ Hospice ☐ Other ___________________________

Comments:

SAPS Consultant visit

Consultant:

When should the visit be scheduled?

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Where should the visit be scheduled?

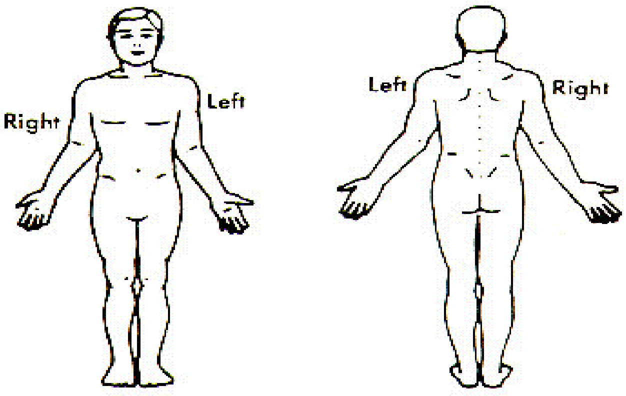
☐ Home ☐ Clinic ☐ Hospital ☐ Hospice ☐ Other ___________________________

Comments:

____

Signature: **Date:**

Pain Assessment



Pain Assessment

Use body chart to identify:

- site where pain is experienced
- site of referred pain

Palliative factors "What makes it feel better?"

____

"What makes it feel worse?" ____

Quality "What is it like?" (please circle)

Aching	Throbbing	Gnawing	Heavy	Cramping
Sharp	Shooting	Stabbing	Hot/Burning	
Tender	Sickening	Fearful	Tiring/exhausting	

Other ____

Radiation "Does it go anywhere else?"

____

____

Severity "How bad is it?"

Present Pain Score 0 – 10 ____

Usual pain score in past 24 hours ____

Worst pain score in past 24 hours ____

Timing "Is it there all the time?" ____

"Does it come and go? What brings it on?"

____

____

____

How do you manage your pain?

____

____

What do you feel provides the best pain relief?

____

APPENDIX C-3

Southern Adelaide Palliative Services Draft

Social Work Assessment

PATIENT LABEL

SAPS Team Member: ____

Date: __ __ / __ __ / __ __

Location of contact:

Tick one box only.

☐ Home ☐ Hospital ☐ Hospice ☐ Nursing Home

☐ Hostel ☐ Other ____

nts (incl. name of facility if applicable):

____

____

Ethnicity:

Country of origin____________________ Language spoken at home________________

Australian Citizen Yes ☐ No ☐

Section 2: Psychosocial Assessment

Family tree *(including significant relationships outside the immediate family)***:**

O	Female
□	Male
Δ	Unknown Sex
O—□	Married
O—/—□	Divorced/ Separated
O----□	Defacto
☒	Deceased Person
O	

Identify patient by using double line.

Usual living arrangements:

Tick one box only.

☐ Lives alone ☐ Lives with family ☐ Lives with others ☐ Nursing Home Hostel

☐ Unknown ☐ Other ____

Comments (e.g. name of facility, partner's location):

____

____

Transport;

Is the patient able to drive?____

Does the patient have access to reliable transport?________________________________

Does the patient have a disabled parking permit?_________________________________

Does the patient have Access Cab Vouchers?___________________________________

Finances:

What is your current income source?_______________________________________

Do you have any financial concerns?_______________________________________

Record relevant details.

Advance directives and legal arrangements:
(*Tick boxes that apply)*

Will ☐ EPOA ☐ EPOG ☐ Anticipatory Directive ☐

Medical Power of Attorney ☐

Record relevant details.

Distress thermometer completed; Yes ☐ No ☐
(*Record relevant findings*)

____

____

____

____

____

Healthcare Providers and Services

Healthcare providers:

Tick the box if the indicated healthcare provider participates in the patient's care & provide name and details.

Healthcare services:

Tick the box if the indicated healthcare service participates in the patient's care.

Domiciliary Care

Case Manager __________________________________ Equipment / Items ____________________________

Other ☐ Type of care

Meals on Wheels ☐ Meals/week ____

DVA Home Care Program ☐ Type of care ____

Respite care ☐ Organisation____

Local council involved ☐ Type of involvement ____

Religious support group ☐ Name ____

Other ☐ ____

Other ☐ ____

Are other informal supports available?

☐ Yes ☐ No ☐ Unknown

Comments

____

____

Is the current level of support adequate?

Tick one box only.

☐ Yes ☐ No ☐ Unknown

Comments

Impression and Plans for this Patient's Future Care and Follow-up:

How are things changing for this patient and their family?

(assessment including psychosocial and spiritual needs)

Follow-up telephone call

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Comments:

Follow up visit

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Where should the visit be scheduled?

☐ Home ☐ Clinic ☐ Hospital ☐ Hospice ☐ Other

Comments:

Signature: **Date:**

APPENDIX C-4

Southern Adelaide Palliative Services Draft

Caregiver Facilitator Assessment

Caregiver's name:____

SAPS Team Member:____

PATIENT LABEL

Date: __ __ / __ __ / __ __

Location of contact:

Tick one box only.

☐ Home ☐ OPD ☐ Hospital ☐ Hospice ☐ Nursing Home

☐ Hostel ☐ Other ____

Comments (incl. name of facility if applicable):

____

____

Relationship to Patient;

Spouse/partner ☐ Parent ☐ Child ☐ Sibling ☐ Friend ☐ Neighbour ☐

Age of carer:______________ Gender Male ☐ Female ☐

Marital status:

Married ☐ Separated/ Divorced ☐ Widowed ☐ Single ☐

Ethnicity:

Country of origin____________________ Language spoken at home________________

Australian Citizen Yes ☐ No ☐

Employment Status:

Employed F/T ☐ Employed P/T ☐ Casual ☐ self-employed ☐ Homemaker ☐

Unemployed and seeking work ☐ self-funded retiree ☐ Retired/pension ☐ Student ☐

Usual living arrangements:

Tick one box only.

☐ Lives with cared for person ☐ Distant carer, living in SA ☐ Distant carer interstate ☐ Young carer ☐Frail aged carer

☐ Caring for multiple people ☐ Carer has a mental health condition ☐ Carer has physical disability

Comments (e.g. name of facility, partner's location):

____

____

Housing:

Own home Y ☐ N ☐ Mortgaged Y ☐ N ☐ Private Rental ☐ Housing Trust ☐

Retirement Village ☐ Granny Flat ☐

Insurance:

Public Liability Insurance as part of home insurance Y ☐ N ☐

Transport;

Drives and owns a car ☐ Dependent on Family/friends/Neighbours for transport ☐

Uses public transport ☐ Has Access Cab concessions ☐ Volunteer transport ☐

Are any community services involved? ______________________________

Is the current level of support adequate? (*Tick one box only)*

☐ Yes ☐ No ☐ Unknown

Comments

____

____

Are you receiving carers payment Y / N **Are you receiving carers allowance** Y / N

Additional Contacts

Contact ____ Relationship: _________________

DOB _____________ Phone No: ________________ Mobile No: _____________________________

Contact ____ Relationship: __________________

DOB _____________ Phone No: ________________ Mobile No:
____

Impression and Plans for the carer's future follow up:

Follow-up telephone call

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Comments:

Follow up visit

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Signature: Date:

APPENDIX C-5

Southern Adelaide Palliative Services Draft

Psychosocial Assessment

PATIENT LABEL

SAPS Psychosocial Team Member: ___________________________

Date: __ __ / __ __ / __ __

Location of contact:

Tick one box only.

☐ Home ☐ OPD ☐ Hospital ☐ Hospice ☐ Nursing Home

☐ Hostel ☐ Other ____

Comments (incl. name of facility if applicable):

____

____

Section 2: Psychosocial Assessment

K10 completed Y ☐ **N** ☐

If Yes record score and any comments. Score _____________

Comments

____

____

On a scale of 0-10 where 0 means no quality and 10 means full quality how would you rate your current quality of life?

No Quality 0____10 **Full Quality**

Is there anything causing you distress in your life at the moment?

If Yes how are you dealing with this?

Spiritual & religious preferences:

Have you ever experienced anxiety/panic/phobias and or depression?

Have you ever sought professional help for any problems/difficulties you may have encountered in life?

Who is the person most affected by your illness :

Has your illness interfered with your relationships?

Has your illness interfered with your wellbeing?

Have you thought about where you would like the majority of your care to be provided when you are no longer able to care for yourself?

Have you had these conversations with your family/friends? **Y** ☐ N ☐

Do you feel as if you need support to have these conversations? **Y** ☐ **N** ☐

We are constantly trying to improve services to our patients at Southern Adelaide palliative Services. One of the ways we do this is through research. Is it OK with you if someone calls to give you more information if there is a study that you might be interested in? This may require a Registered Nurse to view your hospital records to determine which study may be best suited to you.

Yes ☐ No ☐

Section 3:

Impression and Plans for this Patient’s Future Care and Follow-up:

How are things changing for this patient and how are they coping and managing?

(assessment including psychosocial and spiritual needs)

Follow-up telephone call

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Comments:

Follow up visit

☐ 0-3 days ☐ Next week ☐ Fortnight ☐ Next month ☐ None ☐ Other

Where should the visit be scheduled?

☐ Home ☐ Clinic ☐ Hospital ☐ Hospice ☐ Other

Comments:

Signature: **Date:**

APPENDIX D-1

Prognosis Study – Coding Category Summary Guide

DIMENTION 1 **SOURCE**	**D11**	**Doctor**	
	D12	**Patient**	
	D13	**Family/Friend**	
	D14	**Interpreter**	
	D15	**Interruption from outside**	
	D16	**Nurse/ Registrar**	

DIMENTION 2 **DIRECTION OF INTERACTION**	D2**1**	Doctor	
	D2**2**	Patient	
	D2**3**	Family/Friend	
	D2**4**	Interpreter	
	D2**5**	Interruption from outside	
	D2**6**	Nurse	

DIMENTION 3 **CONTENT**	D3**1**	History and symptoms(cancer related)	Previous tumor, discussion of tests/treatments which have been performed to date, symptoms/complaints/abnormalities (cancer related)
	D3**2**	Diagnosis	What has happened, how testing result related to diagnosis, size, severity, spread, how common
	D3**3**	Prognosis	What's gonna happen in future, likely course of disease, chance of survival/cure
	D34	Treatment (cancer related)	current treatment, disadv. adv, goals of treatment, side effects, treatment of side effects
	D35	Other medical	Diet, other recommendation, risk to family, symptoms/ treatments of other medical conditions not related to cancer, other tests, after care, contingency plan if deteriorating, palliative care
	D3**6**	Psychosocial issues	Emotion related to cancer, impact of cancer, family

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	D3**7**	Social support/counselling/stress management	Desire for formal support, doctor inform patient on service available
	D3**8**	Social exchange	Unrelated to medical context
	D3**9**	other/non specific	
	D3**10**	Examination	e.g take a deep breath,etc

DIMENTION 4 **FUNCTION**	D4**1**	Disclose	Reveal thoughts/ perception/ reasons/ motivation, purpose/intention of consultation, reveal intention/moving on
	D4**2**	Advise/ recommend/ influence/ suggest	Attempts to guide behaviour, suggestion for future, assertive statement made by patient
	D4**3**	Direct/ order/ Advise strongly	Command, permission, prohibition
	D4**4**	Question (open)	enquiry about new information
	D4**5**	Question (closed)	enquiry about new information
	D4**6**	Question (leading)	enquiry about new information (framed to favour an answer, forces an expected reply)
	D4**7**	Question (multiple)	enquiry about new information (more than one question / different concepts)
	D4**8**	Label/ judge/ criticize	Evaluation of one's experience/behaviour in negative way
	D4**9**	Express feelings/ seek reassurance	
	D4**10**	Inform/Educate/Explain	State objective, factual info, explain rationale, Yes/no answer which provide/confirm info, telling info
	D4**11**	Actively support/ empathise/ reflect/ reassure	Warmth, provide info to reassure and clam patient, show understanding
	D4**12**	Agreement/confirmation – simple, limited, closed	Yes, uhuh, right, ok, etc
	D4**13**	Agree with enhancement and elaboration	Further elaborate/enhance information given, emphasising, finishing the sentence
	D4**14**	Partnership building with social talk, joking	Recollection of the setting of last consultation, non-medical talk
	D4**15**	Check understanding (patient or doctor) /clarifying misunderstanding	Information already been discussed, further clarifying the same question asked before

	D4**16**	Summarise old information	
	D4**17**	Negotiating preferences	information, decision making, treatment

Additional Notes

- Speech units should only be split into separate units if coding changes, unless the focus of the discussion changes even though the category codes are the same e.g. the doctor speech unit may carry the same content and function but may first address the patient and then a family member. Some point should be made about this in the remarks section.

- For consultations involving an interpreter do not category code the interpreter speech units, they are to be coded on the separate interpretation analysis table, unless there is a unique interaction between interpreter and patient/doctor that is not coded within the doctor/patient codes.

- For speech units that are exclusively made up of confirming, partnership building terms eg. Yes, uhuh, right, ok, etc then on the coding sheet identify the source followed by a dash across the columns which will be understood as content equivalent to previous speech unit and function D312.

- Within the function category a question code (D34, 35, 36, 37) should only be given if it relates to an enquiry about new information. If a patient is just checking their own understanding, confirming then this should be given a D315 code.

- If a sentence is not finished but has got cut off, the fragment of sentence should not be coded until the sentence has been completed.

- For further clarification refer to the verbal interaction coding manual.

APPENDIX D-2

Cue Coding

CUES	**1**	Information	Pt requesting information, clarification regarding symptoms, history, diagnosis, treatment, future etc. May be direct or indirect, measured as intensity
	2	Emotion	Message from the patient that contains some reference to emotional content.

INTENSITY	**1**	Weak	Issue/emotion is raised in a vague manner without explicitly stating emotion or question, may require reading between the lines.
	2	Moderate	Expresses emotion but without strong qualifier (eg. I am a bit worried) or refers to difficulty comprehending all information but does not specifically ask question or demand information (eg. I am not sure exactly what to expect).
	3	Strong	Explicitly states emotion with strong qualifier (eg I am very worried) or explicitly requests information, asking direct questions.

RESPONSE	**0**	No response, delayed or ignored
	1	Responds to content only
	2	Responds to content and expresses empathy
	3	the above as well as inviting elaboration on the issue/emotion.

REMARKS	• Comments on whether the cue was missed completely or delayed, and if there were any **possible reasons for missed cues** such as cultural barriers to identifying them or systematic dismissal by the oncologist. • Also comments on the **effect of responding or missing the cue**. • Any other relevant comments. • Each cue will be looked at individually regardless of who (patients or family) raises them. • Any cue, if it has been interpreted but not responded, the second time this cue expressed should move up intensity to one level up, so on and so forth, until it reaches the maximum of 3. • Dr_Heard variable used to code whether cue is heard by doctor (i.e., interpreted). Other_Response used to code whether cue is responded to by someone other than the doctor (e.g., family member, interpreter).

APPENDIX D-3

Modified Coding Schema

DIMENTION 1 **SOURCE**	D1**1**	Nurse Practitioner	
	D1**2**	Patient	
	D1**3**	Carer-Family/Friend	
	D1**4**	Patient and carer together	
	D1**5**	Interruption from outside	
	D1**6**	Social worker	
	D1**7**	Psychosocial Nurse	
	D1**8**	Network Facilitator	

DIMENTION 2 **DIRECTION OF INTERACTION**	D2**1**	Nurse Practitioner	
	D2**2**	Patient	
	D2**3**	Carer -Family/Friend	
	D2**4**	Patient and carer together	
	D2**5**	Interruption from outside-eg phone call	
	D2**6**	Social worker	
	D2**7**	Psychosocial	
	D2**8**	Network Facilitator	

DIMENTION 3 **CONTENT**	D3**1**	History and symptoms (cancer related)	Previous tumor, discussion of tests/treatments which have been performed to date, symptoms/complaints/abnormalities (cancer related)
	D3**1-1**	Social History	
	D3**2**	Diagnosis	What has happened, how testing result related to diagnosis, size, severity, spread, how common
	D3**3**	Prognosis	What’s gonna happen in future, likely course of disease, chance of survival/cure
	D3**4**	Treatment (cancer related)	current treatment, disadv. adv, goals of treatment, side effects, treatment of side effects

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	D3**5**	Other medical	Diet, other recommendation, risk to family, symptoms/ treatments of other medical conditions not related to cancer, other tests, after care, contingency plan if deteriorating, palliative care
	D3**5-1**	Previous Psychiatric history	
	D3**5-2**	Research question	
	D3**6**	Psychosocial issues	Emotion related to cancer, impact of cancer, family
	D3**6-1**	Distress thermometer	
	D3**6-2**	K10	
	D3**6-3**	Carer Assessment Tool	
	D3**7**	Social support/counselling/stress management	Desire for formal support, doctor inform patient on service available
	D3**7-1**	Finances	
	D3**7-2**	Transport	
	D3**7-3**	Will/ Advance care planning	
	D3**7-4**	Housing	
	D3**7-5**	Spirituality	
	D3**8**	Social exchange	Unrelated to medical context
	D3**9**	other/non specific	
	D3**10**	Examination	e.g take a deep breath,etc

DIMENTION 4 **FUNCTION**	D41	Disclose	Reveal thoughts/ perception/ reasons/ motivation, purpose/intention of consultation, reveal intention/moving on
	D41-1	Read aloud to self	Completing forms/ tools etc.
	D42	Advise/ recommend/ influence/ suggest	Attempts to guide behaviour, suggestion for future, assertive statement made by patient
	D43	Direct/ order/ Advise strongly	Command, permission, prohibition
	D44	Question (open)	enquiry about new information
	D45	Question (closed)	enquiry about new information
	D46	Question (leading)	enquiry about new information (framed to favour an answer, forces an expected reply)
	D47	Question (multiple)	enquiry about new information (more than one question / different concepts)
	D48	Label/ judge/ criticize	Evaluation of one’s experience/behaviour in negative way
	D49	Express feelings/ seek reassurance	
	D410	Inform/Educate/Explain	State objective, factual info, explain rationale, Yes/no answer which provide/confirm info, telling info
	D411	Actively support/ empathise/ reflect/ reassure	Warmth, provide info to reassure and clam patient, show understanding
	D412	Agreement/confirmation – simple, limited, closed	Yes, uhuh, right, ok, etc. Minimal encourager
	D413	Agree with enhancement and elaboration	Further elaborate/enhance information given, emphasising, finishing the sentence
	D414	Partnership building with social talk, joking	Recollection of the setting of last consultation, non-medical talk
	D415	Check understanding (patient or doctor) /clarifying misunderstanding	Information already been discussed, further clarifying the same question asked before
	D416	Summarise old information	
	D417	Negotiating preferences	information, decision making, treatment
	D418	Cut off communication	Being talked over/ interrupted
	D419	Provide warning shot	Prepare for confronting information
	D420	Prompt	Clinician or carer prompts patient for answer

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APPENDIX E-1

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Research

Communication differences when patients and caregivers are seen separately or together

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Abstract

Background: Southern Adelaide Palliative Care Services introduced a nurse-led early introduction to a palliative care clinic in 2011. The clinic offers a thorough psychosocial assessment and the provision of information and an introduction to future care planning. The patients and their caregivers are seen together by the nurse practitioner initially for a physical assessment. They are then seen by a social worker to focus on advanced care planning and assessment of social and emotional factors. After the social work visit, the patient and caregiver are separated, and the patient sees the psychosocial nurse for coping and adjustment to illness and the carer sees the caregiver network facilitator to assess their informal supports to assist in the role of community-based caregiving. The pilot study looks at the nature of communication in the clinic where patient and carer are together and compares that to when they are separated. **Methods:** A total of 33 patients and their caregivers agreed for their conversations to be tape recorded between May and November of 2013. All tape recordings were transcribed verbatim. Ten patient transcripts (*n*=40) have been coded for quantitative analysis. The codes identify content and function of speech, cues for information and emotion and whether they are responded to by clinicians. **Results:** Pilot results reveal that caregivers contribute little in the combined clinics and dominate the conversation in the private clinic. Patients, when seen alone, predominantly express emotion related cues, opposed to cues for information. The clinicians focus on their area of specialty, which results in little duplication in this clinic setting. **Conclusion:** An earlier evaluation of this clinic found that patients and their caregivers appreciate being separated in the clinic setting to have time and privacy to reveal fears and feelings related to end-of-life care. This current study quantifies the patient and caregiver experience and confirms those earlier findings.

Key words: Communication l Triadic communication l Dyadic communication l Family caregiver l Outpatient clinic

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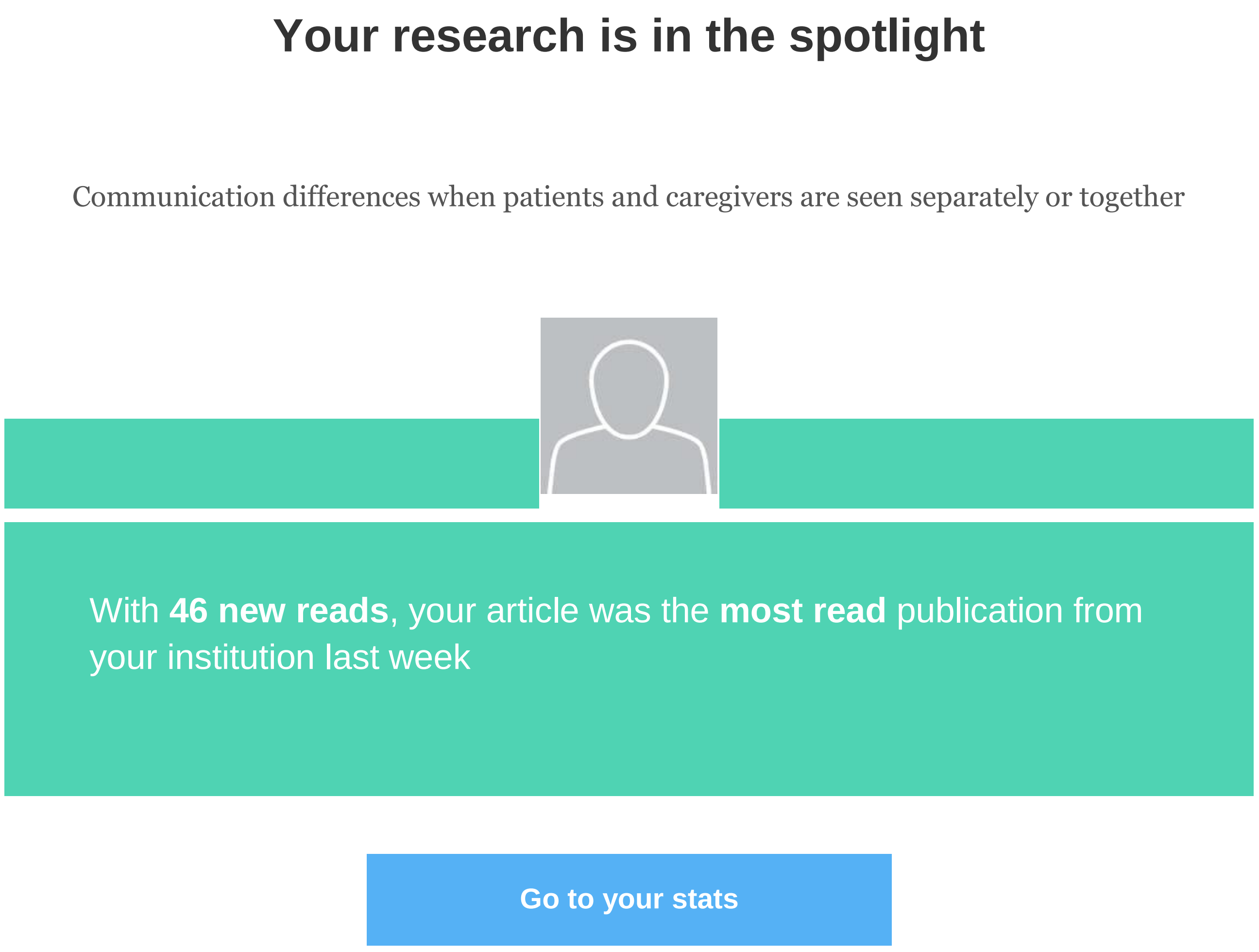
APPENDIX E-2



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Communication differences when patients and caregivers are seen separately or together

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