THE PSYCHOSOCIAL IMPACT OF FOOD AND NUTRITION ON HOSPITALISED ONCOLOGICAL PALLIATIVE CARE PATIENTS AND THEIR CARERS

By

Jodie Ellis

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This is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

[redacted]

Jodie Ellis

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

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Cynthia Hunter *Pippa Craig*

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If food and love alone could save a person you would still be here with us today.

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A couple of hours after Uncle Rodney's death I awoke with the words circulating in my head "If food and love alone could save a person you would still be here with us today". For me this sentence is a validation of the findings. A true summary of the sentiments expressed by carers.

Abstract

Background: Food provides more than simply a nurturing of physiological requirements; it encompasses social and emotional aspects that together can create an enjoyable experience. That however, is often altered at the end of life. Currently little is known about the psychosocial impact of food and nutrition in cancer patients admitted to the palliative care unit for end of life care.

Aim: This thesis investigates the lived experience of patients, carers and health care workers dealing with the changes in food intake of terminal cancer patients in the palliative care unit of a Sydney hospital. The meaning of food at this time in one’s life will also be determined.

Method: Nineteen patients, 14 nurses, 10 carers, seven medical officers, and four food service officers participated in phenomenologically informed interviews and focus groups investigating food and nutrition at the end of life.

Results: Themes and sub-themes were derived from the data of each participant group along with overarching themes common across groups. The meaning of food was derived using Max Van Manen’s approach to phenomenological analysis. The three meanings identified were that food means life, food is a demonstration of love and food acts as a social glue bringing people together to partake in a shared experience.

As one’s intake declines at the end of life, significant changes often occur in the relationship between patient and carer as conflict and tension over food divide the two parties. While many patients and carers express the desire to fight for life, participant groups used various strategies to prolong life.

Conclusion: Because of its psychosocial impact, food continues to be of high importance in the terminal phase of life.

Thus clinicians should address the role and concerns of patients and carers around food and nutrition in the last weeks of life because these significantly impact the quality of life of people dying of cancer, along with the harmony in their relationships with loved ones.

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Introduction to nutrition in palliative care

While life is not possible without food and fluid, the wider role and meanings of food and nutrition at the end of life are yet to be adequately researched. Whether the role and meaning is physical, psychological or psychosocial, the impact can be seen on patients, their carers and those around them during the final weeks of life. This thesis aims to investigate food and nutrition in the last stages of life in order to develop a deeper understanding of the issues and complexities experienced by patients, carers and health care workers. The methodology used will allow for the meanings of food at the end of life to be investigated.

The physiological role of food and nutrition in palliative care is a topic that until recently remained relatively unexplored. Despite recent advances, a significant gap in the literature remains, with researchers questioning many previously held beliefs such as the appropriateness of alternate sources of nutrition for cachexic patients (Bozzetti et al., 2014). At the outset of this project, it should be acknowledged that published data on nutrition at the end of life in the form of reflection or opinion were available as were papers on oncology, but these did not consider the role or the meaning of food and nutrition in the last weeks of life.

While evidence is building on the role of food and nutrition in cancer cachexia (Hane et al., 2013; Hopkinson, 2010; Hopkinson, 2014; Oberholzer et al., 2013; Reid, McKenna, Fitzsimons, & McCance, 2009a, 2009b; Reid, McKenna, Fitzsimons, & McCance, 2010) and advanced cancer (Esteves, Roxo, & da Conceicao Saraiva, 2015; Hopkinson, 2007; Hopkinson, Wright, & Corner, 2006; Strasser, Binswanger, Cerny, & Kesselring, 2007) this has yet to be acknowledged in clinical practice (Oberholzer et al., 2013). While it is estimated that 80 per cent of cancer patients develop cancer cachexia prior to death (Bruera, 1997; Poole & Froggatt, 2002), the perspectives of the remaining 20 per cent of patients is also of interest in palliative care. In addition, studies are yet to consider Australian perspectives on the topic or the perspectives of those patients admitted to palliative care wards for terminal care.

Not only is there a paucity of palliative care-specific literature, but existing oncology studies in this area tend to have a differing focus since oncology treatment and research often has a curative intent, and see nutrition as a key component in the overall care of a patient. However, at the end of life when the focus of care becomes palliative, goals and priorities are also often refocused, patient comfort becoming the primary aim. With this in mind, research is required to align the definition and goals of palliative care to inform health care professionals on appropriate ways of managing the challenges associated with food and nutrition at the end of life.

Ethical issues arise in working with and undertaking research with vulnerable palliative care patients and distressed carers (Addington-Hall, 2002; Aoun & Kristjanson, 2005; Bernat, 2001; Chiu, Hu, Cheng, & Chen, 2000; de Raeve, 1994; Grande & Todd, 2000; Janssens & Gordijn, 2000; Kirsh et al., 2004; Kristjanson, Hanson, & Balneaves, 1994; McClement & Woodgate, 1998). During the dying process or in the last hours of life, patients often have a decreased food intake resulting in anorexia, weight loss and wasting of muscle and fat. Patients may also aspirate if feeding is attempted (Ferris, 2004). Many caregivers are not aware intake dwindles as death approaches nor do they seek information on this subject until intake has completely ceased (Meares, 1997). Due to the distress this issue can cause, health care professionals often do not address these concerns (Byock, 1995). The decision to terminate feeding in patients who are unlikely to recover is often difficult for families, who themselves are undergoing a challenging emotional journey (Kowalski, 1996). For these reasons, there has been a reluctance to undertake research in this area.

Because understanding is integral for the development of successful interventions, it is important from a professional evidence-based practice perspective, to understand the basis and influences on behaviours. In the light of the paucity of literature on the topic, a deeper understanding of the phenomenon was required.

Introduction to the Study

Due to the lack of available literature and the need to understand and support patients and their carers at the end of life, this study aims to investigate the meanings of food and nutrition at this stage and to investigate the lived experience of patients, carers and health care workers. A phenomenological approach is taken, enabling the reader to develop a deeper understanding of the issues felt by each of the research groups and how this impacts on their interpersonal relationships.

In Chapter 2, I discuss the background of palliative care internationally as well as in Australia. I then consider the issue of nutrition in palliative care, which will be presented in the form of nutrition-impact symptoms, interventions and psychosocial aspects. Where available, I present literature originating in palliative care and when the palliative care literature is inconclusive or non-existent, advanced cancer literature will be utilised. It is important to recognise that while many advanced cancer patients are on a terminal trajectory, they may not have palliative care services and the goals of treatment may differ from those chosen in palliative care.

Chapter 3 presents the methods used in this study and provides a brief background of phenomenological theory along with the research procedure utilised, including the recruitment and demographic details of participants. Authenticity and credibility will be documented along with an account of research methods used and the inbuilt strategies used to ensure the robustness of results.

In Chapters 4 and 5, I present the results of interviews and the outcomes of focus group discussions of the five participant groups - patients, carers, medical, nursing and catering. Results are presented in the form of themes and subthemes with participant quotes being key to the reader developing a deeper appreciation of the themes and lived experience of participants.

Chapter 6 addresses the meanings of food for people at the end of life, and also for their carers and health professionals working with them. I then report on the overarching analysis of the results where common themes were derived from the topics discussed by the five participant groups.

Chapter 7 discusses the results in the light of available literature while Chapter 8 summarises and concludes the study. Appendices 1 and 2 contain and acknowledge my personal experience of working as a dietitian in palliative care prior to undertaking this research. This is referred to as 'bracketing' in classical phenomenological studies (Byrne, 2001; Strubert Speziale & Carpenter, 2003) however acts to acknowledge experiences in hermeneutic phenomenology (Maura Dowling, 2004). In context of this research, these appendices aim to inform the reader of my experiences of the topic while avoiding any biasing of the data.

Literature search strategy

A search of the literature available on the MEDLINE database regarding nutrition in palliative care was initially undertaken in 2008, including a review of the psychosocial literature available on the topic. Following this the literature search was extended to include common nutrition impact symptoms experienced by patients in palliative care. As little information was located on this subject the search was widened to include literature on advanced cancer. Search terms included: palliative care or advanced cancer combined with nutrition, psychosocial, cancer cachexia, malnutrition, weight loss, anorexia, meaning of food, chemosensory dysfunction, taste changes, constipation, diarrhoea, nausea and vomiting.

A manual search of key palliative care journals not available via MEDLINE in 2008 was also undertaken by the author. Bibliographies of articles were searched manually to find relevant articles.

During writing up of this thesis the search strategy was repeated as new articles were published. In addition, the search terms were entered into Google Scholar to determine whether any relevant articles had been overlooked.

Chapter 2 Literature Review

> *You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully but also to live until you die.* (Dame Cicely Saunders, 1918-2005)

The literature review turned up very little information on the nutritional management of palliative care patients. Literature was available for oncology patients but generally the studies included patients who were undergoing curative chemotherapy or radiotherapy. There were a few personal experience and opinion based articles written from a nursing perspective, however nothing from dietitians with specialised experience in nutritional care.

What is Palliative Care?

The term "palliative" is derived from the Latin word - *pallium* – a cloak, and thus metaphorically speaking, palliative care can be seen as an attempt to throw a cloak of warmth and protection around those with life-limiting illnesses (Lewis, 2007b). While palliative care has been practised from the 1960s onwards, the first definition of palliative care was offered in Britain in 1987 (Lewis, 2007b).

Today the World Health Organisation's (WHO) 1989 description is generally accepted as the best working definition of this concept (D. Clark, 2007). In these terms, palliative care is:

> An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation, 2016)

It is important to emphasise that this definition of palliative care embraces not only the person with a life-limiting illness but also their families. As they too may suffer intensely as their loved one approaches the end of life, with support extending into the bereavement period.

Background to Palliative Care

Historically, while the practice of palliative care can be traced back to the middle ages (Palliative Care South Australia, 2016), it has been argued that the modern palliative care movement began when the subject was considered scientifically (M. B. Taylor, Moran, & Jackson, 1989). I will discuss this in more detail below.

Dame Cicely Saunders has been credited with founding the modern hospice movement and pioneering palliative care (Shotter, 2006). Although she first published on the care of the dying in 1957 (D. Clark, 1998) it was in 1967 when the first patients entered St Christopher's Hospice in the United Kingdom (UK) that the hospice movement can be said to have been born (Cimino, 2003; D. Clark, 1998). Saunders relied not only on her strong Anglican faith (D. Clark, 2007) but also on considerable philanthropic assistance in the development of her vision of palliative care (Lewis, 2007a). And indeed, today many religious organisations continue to rely heavily on philanthropic assistance as they seek to provide palliative care services around the world.

Internationally, timeframes have differed for recognising palliative care as a medical speciality. In Great Britain for example, palliative medicine was established as a subspecialty in 1987, in Ireland in 1995 (D. Clark, 2007) and in the United States (USA) in 2008 (Morrison, 2013). In 2006, 115 of the world's 234 countries were providing some level of palliative care service (D. Clark, 2007).

The Australian Story

In Australia, palliative care is said to have been influenced by the British model of hospice provision and the work of Dame Cicely Saunders (Lewis, 2007b). In the 1980s palliative care was recognised as an academic discipline (Australian Institute for Health and Welfare, 2014; Tieman, Abernethy, Fazekas, & Currow, 2005). In 1991 the first palliative medicine trainees commenced supervised training (Cairns, 2007) while palliative care became a recognised medical speciality in 1999 (Australian Institute for Health and Welfare, 2012) or in 2000 (D. Clark, 2007). However, in fact, the Australian story began somewhat earlier.

In the 1970’s care of the dying was generally provided in hospices run by three main providers, namely; the Little Company of Mary, Sisters of Charity and the Deaconess Society. The average length of stay for patients was high as most remained in these facilities for long periods until death occurred (Currow & Phillips, 2013).

In 1981, the inaugural meeting of doctors and nurses was held in Adelaide to discuss the introduction of palliative care in Australia. It was in 1983 that the report into dying was commissioned by the Anti-Cancer Council of Victoria, with the recommendations shaping palliative care for the subsequent three decades (Currow & Phillips, 2013). The establishment of recognised units within larger hospitals with medical directors was recommended to improve the quality of palliative care (Webster, 1985).

In 1991 the Australian Association of Hospice and Palliative Care Incorporated was formed, being renamed “Palliative Care Australia” in 1998 (Palliative Care Australia, 2013). In 2009 there were 172 specialist physicians and 5,173 nurses working in palliative care in Australia (Australian Institute for Health and Welfare, 2012). In 2012 the number of palliative care specialists decreased to 148 and it was noted that there were considerably more females than males working in the area when compared to medicine in general (Australian Institute for Health and Welfare, 2014). Workforce data is unavailable for other professions, including dietetics that are still finding a pathway in this new and developing discipline.

In 2010 the Australian Health Ministers released the first National Palliative Care Strategy under the title: *2010: Supporting Australians to Live Well at the End of Life* (Commonwealth of Australia, 2010). This document outlined the following aims for moving palliative care forward in Australia. These were:

1. To significantly improve the appreciation of dying and death as a normal part of the life continuum.
2. To enhance community and professional awareness of the scope and benefits of timely and appropriate access to palliative care services.
3. To ensure that appropriate and effective palliative care is available to all Australians, based on need.
4. To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.
5. To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care. (Page 10)

The Commonwealth Government's Department of Health funds the CareSearch database found at www.caresearch.com.au. This palliative care knowledge-network holds detailed evidence-based information on palliative care concerns and services for patients, carers and health professionals. A register of current palliative care research in Australia is also available on this site. In addition, in the academic sphere, Australia has been credited with establishing the world's first chair of palliative care (D. Clark, 2007).

Since Dame Cicely Saunders initially developed palliative care services for people with cancer, this speciality has widened considerably (Eberhardie, 2002). Modern palliative care services cover both malignant and non-malignant conditions; recent statistics have shown that only 56 per cent of the palliative care patients who died had a diagnosis of cancer (Australian Institute for Health and Welfare, 2014). Palliative care has also grown from the provision of services to the terminally ill to include the care of patients anywhere on the disease trajectory of a non-curable illness (Hui & Bruera, 2016).

In 2009-2010, just over half of all deaths occurred in hospitals (Australian Institute for Health and Welfare, 2012). Of these, 62.3 per cent with a cancer diagnosis received palliative care services during their final hospital based episode of care (Australian Institute for Health and Welfare, 2012). In 2011-2012 17,200 palliative care patients died with cancer being the principal diagnosis (Australian Institute for Health and Welfare, 2014).

Enlisting palliative care services at the end of life in Australia is becoming increasingly popular, as evident in the fact that there was a 52 per cent increase in palliative care separations or discharges from Australian public and private hospitals between 2002-03 and 2011-12 (Australian Institute for Health and Welfare, 2014). Today, modern palliative care services are provided in settings such as the home, acute hospitals, nursing homes, outpatient settings, day units and consultative services. This expansion of service provision allows more people to receive palliative care and assists them to die in their place of choice (Munday, Dale, & Murray, 2007).

The expansion of services brings with it the challenge of determining the point at which a patient should receive palliative care. This is an area of contention with professionals offering differing opinions (Addington-Hall, 2002). More treatments are now available for people with advanced disease, with many choosing to receive treatment to slow disease progression and to prevent or control symptoms as death approaches (Addington-Hall, 2002). This has led to many patients often being jointly managed by their primary care physician and a palliative care specialist working in conjunction with a multidisciplinary team to provide holistic care. This multidisciplinary approach allows for physical, social, psychological and spiritual support to be provided (Clark, 2007). Further research is required to determine the optimal time to instigate palliative care services at the end of life.

Conducting Research in Palliative Care

While it has been noted that research into practices in palliative care are often lacking, palliative care professionals are working on bridging the gaps. In 2005 the Birmingham International Workshop on Supportive, Palliative and End-of-Life Care Research pointed out the need for research into societal beliefs and approaches to death and end-of-life care (Hagen, Addington-Hall, Sharpe, Richardson, & Cleeland, 2006). Thereafter many studies evolved to investigate the wider concerns of palliative care, providing valuable information for professionals working within this area. The results of research enable clinicians to provide holistic, patient- and carer-centred care at the end of life. It is argued that without this, the care provided is likely to be based on what the health professional feels the patient needs rather than on the patient's real and experienced needs.

Conducting research in an area in which people are dying is not without controversy (Dean & McClement, 2002; Gysels, Shipman, & Higginson, 2008). In fact, some researchers have argued that there are strong moral objections to any research within this area (de Raeve, 1994), since their debilitating symptoms and the emotional impact of their impending death (Dean & McClement, 2002) makes palliative care patients extremely vulnerable to psychological and emotional harm. However, as best-practice medical care is based around evidence-based treatment (Kaasa & De Conno, 2001) this constitutes a strong argument in favour of undertaking research. Research in palliative care has long been seen as integral to the progression of the specialty with Dame Cicely Saunders herself being an avid researcher in the area (D. Clark, 2007).

Randomised trials have been difficult to execute in palliative care due to ethical concerns (Grande & Todd, 2000; Wright, Hopkinson, Corner, & Foster, 2006) or due to patient death prior to completion of data collection (Hudson, Aranda, & McMurray, 2001). With this in mind, the application of alternative methodologies such as ethnography, phenomenology, textual analysis (J. Clark, 2003), narrative (Hagen et al., 2006) and quality improvement (Aoun & Kristjanson, 2005), have become accepted ways of obtaining evidence.

While some argue it may not be ethical to ask palliative care patients to participate in research (Addington-Hall, 2002; Kaasa & De Conno, 2001) it can be argued that they should be given the opportunity to make their own decisions regarding research participation. Researchers have reported that many palliative care patients are willing to participate in research that could improve quality of care (Lobb, Swetenham, Agar, & Currow, 2011) while others have reported that participation in research provides them with a measure of comfort in the last days of life (Watson et al., 2010). Sharing of problems may be seen as therapeutic and the ability to contribute can be empowering (Gysels et al., 2008). Participants have also expressed appreciation for the time and attention given to them in qualitative studies (de Raeve, 1994).

Since research in palliative care is challenging, qualitative methodologies have been suggested as an avenue for gaining insight into dying patients' perspectives (J. Clark, 2003; Strang, 2000). Qualitative interviews allow patient and carer views to be heard (Gysels et al., 2008) something which can assist in informing the development of treatments and services along with developing an understanding of the problems patients and carers face (Entwistle, Tritter, & Calnan, 2002). With the primary endpoint in many palliative care studies being symptom-management and quality of life issues (Aoun & Kristjanson, 2005; Kaasa & De Conno, 2001), the use of a qualitative methodology can assist clinicians in meeting these endpoints.

Internationally there has been an increase in the development of the understanding of the psychosocial aspects of living with cancer (Esteves et al., 2015; McPherson & Leydon, 2002) including investigating the experience of the family (McClement & Woodgate, 1998). This style of research is well suited to generating information that will help health professionals understand and meet the needs of patients and carers dealing with a life-limiting illness (McClement & Woodgate, 1998).

Nutrition in Palliative Care

Role of Nutrition in End of life care

By definition, palliative care aims to improve patients quality of life (World Health Organisation, 2016) and intervention during the palliative period should be based around this principle. Nutrition support has also been shown to improve quality of life especially in patients who are malnourished (Shaw & Elridge, 2015).

While food and water have long been identified as a basic physiological human need, (Baack, 1993; Maslow, 1943) adequate consumption may not always be possible at the end of life. While it is optimal to identify nutrition risk early in cancer patients (Santarpia, Contaldo, & Pasanisi, 2011), it is well recognised that many palliative care patients experience nutritional problems as their condition progresses (Shaw & Elridge, 2015).

A dietitian's role in palliative care is not limited to nutritional support and includes activities such as nutrition assessment, development and monitoring of nutrition support plans, liaising with food services along with research and training (Pinto, Pereira, Campos, & Thompson, 2016). Anecdotally, dietitian's frequently assists patients with strategies to relieve nutrition impact symptoms such as nausea, diarrhoea, constipation, dysgeusia (taste changes), early satiety, and xerostomia (dry mouth). A dietitian may be involved in providing and educating patients on therapeutic diets designed for their particular condition or post-surgery, for example post a bowel resection, obstruction or a gastrectomy. All of these factors have the ability to impact on patients' lived experience and to influence the psychosocial impact of food and nutrition at the end of life. For this reason, they will be considered below.

While some literature on nutrition in palliative care is available, few studies meet the NHMRC guidelines for high level evidence-based literature (National Health and Medical Research Council, 2009). Many articles originate from nursing or medical studies (Bloch, 2000; Cunningham & Bell, 2000; Eberhardie, 2002; Meares, 2000; Morita, Shima, et al., 2004; Moynihan, Kelly, & Fisch, 2005; Prevost & Grach, 2012; Smith & Andrews, 2000; Stephany, 1991). However, these may not come from the perspective of dietitians trained in human nutrition and metabolic functioning. In addition, since the mid 1980's it has been argued that dietitians are an essential part of the inpatient palliative care team (Gallagher-Allred, 1985; Pinto et al., 2016) and hence evidence is required to inform dietetic practice.

At the end of life it is common to see food intake decline (Ohno, Tamura, Kikutani, Morita, & Sumi, 2016; Stiles, 2013) as metabolic processes slow and interest in food dwindles (Cinocco, 2007). However, it has been reported that 92 per cent of patients are physically able to eat up to the day of death (Feuz & Rapin, 1994). Other studies have found that only half of patients are able to eat four days prior to death (Ohno et al., 2016). The difficulty for palliative care clinicians is that the role of nutrition support in this area is backed by sparse evidence while there is no consensus regarding the efficacy or ethics of providing such support close to the terminal phase. This issue is addressed more fully below.

The majority of patients with advanced cancer develop malnutrition (Bachmann et al., 2003) which affects both survival and quality of life (Prevost & Grach, 2012). Ottery (1996) reported that up to 20 per cent of cancer deaths are due to malnutrition rather than the cancer itself. This malnutrition may be a result of the symptoms experienced by patients with advanced cancer which impede their ability to consume an adequate diet. Although provision of nutrition therapy early in the disease trajectory is optimal (Capra, Ferguson, & Ried, 2001; Paccagnella et al., 2010; Santarpia et al., 2011), the efficacy and role of nutrition and nutrition support in palliative care is yet to be determined. This study will inform clinicians on the psychosocial needs of patients and carers at the end of life.

The management of an advanced cancer patient's symptoms is important given that frequently experienced symptoms impact on survival as described by Trajkovic-Vidakovic, de Graeff, Voest, and Teunissen (2012). Their review of the literature found confusion, anorexia, fatigue, cachexia, weight loss, dyspnoea and dysphagia to be independent prognostic factors (Trajkovic-Vidakovic et al., 2012).

The symptom profile of advanced cancer patients and the severity of changes produced by differing tumour types and location need to be considered by the treating clinician. Each patient should receive a comprehensive assessment to determine their symptoms, the psychosocial impact of those symptoms and at times the aetiology of their condition, to allow for effective symptom management (Mazzocato et al., 2000). Commonly occurring nutrition impact symptoms will be discussed below as these symptoms influence the patient's lived experience and impact psychosocially on the patient and carer.

As it is important to fully understand the issues faced by palliative care patients and the aims of nutrition support, I will briefly discuss gastrointestinal symptoms and chemosensory dysfunction followed by anorexia, weight loss and cachexia. It is important to note here that while not all palliative care patients develop cachexia, most will do so. While the symptoms of cachexia overlap with the other symptoms listed, cachexia must be considered separately due to the complexity of the condition and the differing treatment options available.

Following the discussion of commonly experienced symptoms, I consider available interventions such as nutritional support, medication, artificial nutrition and hydration. I further discuss the psychosocial impact of these symptoms/conditions and where literature is available, consider interventions which involve the meaning of food and nutrition.

Symptoms

Gastrointestinal Symptoms

Gastrointestinal symptoms such as nausea, vomiting, constipation and diarrhoea are prevalent in palliative care patients and impact on a patient's ability to eat and drink.

I will briefly consider these symptoms below in relation to their impact on a patient's ability to eat and how this affects their nutritional status.

Bowel Management

While many definitions of constipation are available, constipation is often referred to as the infrequent and difficult passage of small hard faeces (Candy et al., 2015; Fallon & O'Neill, 1997) and it is the third most prevalent symptom in palliative care patients (Gonzales et al., 2016). With 32-80 per cent of patients experiencing constipation (Friedrichsen & Erichsen, 2004; Potter, Hami, Bryan, & C., 2003; Rhondali, Nguyen, et al., 2013), bowel function needs daily assessment (Clemens & Klaschik, 2008; MacLeod, Vella-Brincat, & Macleod, 2015).

The causes of constipation include dietary changes, intestinal obstruction, reduced mobility, medications, dehydration, metabolic changes and concurrent disorders (Clemens & Klaschik, 2008; Fallon & O'Neill, 1997; MacLeod et al., 2015). This condition thus needs careful management as it can cause anorexia, nausea, vomiting, overflow diarrhoea, abdominal pain, cramping, anxiety, confusion and bowel obstruction (MacLeod et al., 2015).

Current treatment for constipation includes stool softeners and stimulants (Gonzales et al., 2016; Larkin et al., 2008) with around 80 per cent of admitted cancer palliative care patients receiving laxatives (Fallon & O'Neill, 1997). As the evidence base for assessment, diagnosis and treatment of constipation in palliative care is poor this is an area for future research (Clemens & Klaschik, 2008; Larkin et al., 2008).

Diarrhoea, the unusual looseness of stool (Alderman, 2005) is less common with 7-10 per cent of hospice patients reporting the symptom (Fallon & O'Neill, 1997; Mercadante, 1995). Causes include the cancer itself, cancer treatments, neutropenia, psychological factors or medications (Cherry, 2008; Fallon & O'Neill, 1997; MacLeod et al., 2015). As diarrhoea can result in water and electrolyte losses (Mercadante, 1995) treatment focuses on reducing symptoms and maintaining hydration (Cherry, 2008). Altered bowel function including diarrhoea affects a patient's ability to absorb nutrients and to eat and drink (Gorospe & Oxentenko, 2012), and hence needs to be actively managed both to maintain nutritional status and quality of life.

Nausea and Vomiting

Recent research has shown that nausea and vomiting may be less burdensome than previously thought (Glare, Miller, Nikolovska, & Tickoo, 2011). The rates reported for nausea and vomiting in advanced cancer are 60 per cent and 30 per cent respectively (Davis & Walsh, 2000).

The causes of nausea and vomiting are multifactorial and treatments are tailored accordingly (Glare et al., 2011). While nausea can be difficult to control especially in the elderly (Glare et al., 2011; MacLeod et al., 2015), common causes responsive to anti-emetics include; opioid induced vomiting, cytotoxic chemotherapy, renal failure, functional gastric stasis, raised intracranial pressure and vestibular disturbance (Baines, 1997). Treatments should be both pharmacological and non-pharmacological and aimed at improving quality of life (Rhodes & McDaniel, 2001). Non-pharmacological options include behavioural therapy (King, 1997), acupuncture (Rowbotham, 2005), relaxation therapy, desensitization therapy, guided imagery and self-hypnosis (Cotanch, 1991) and interventional gastroenterology and radiology when indicated such as in the case of mechanical obstruction (Glare et al., 2011).

Chemosensory Dysfunction

Individuals perceive food and fluids differently through their experiences of taste and smell (Brisbois, Hutton, Baracos, & Wismer, 2006), with alterations in these senses being referred to as chemosensory dysfunction (Hutton, Baracos, & Wismer, 2007; Spielman, 1998). Taste is said to include the chemical senses of taste and olfaction along with the oral perception of texture (Drewnowski, 1997). Unfortunately for many people with cancer, these experiences are altered due to hypogeusia (reduction in taste sensitivity), ageusia (absence of taste sensation), dysgeusia (distortion of normal taste), hyposmia (reduced ability to detect odours), anosmia (inability to detect odours), parasomia (change in the normal perception of odours) and phantosmia (sensation of an odour that is not present) (Ripamonti & Fulfaro, 1998).

Chemosensory dysfunction is common in cancer patients with up to 86 per cent reporting difficulties (Hutton et al., 2007). Causes are multifactorial and include the cancer treatment or the disease itself (Ravasco, 2005; Zabernigg et al., 2010). Significantly, patients with taste changes have higher incidences of weight loss (DeWys & Walters, 1975).

The symptoms most commonly experienced are persistent bad taste in the mouth, taste distortion and a heightened sensitivity to odours (Hutton et al., 2007). Chemosensory dysfunction is distressing and impacts on the nutritional status of cancer patients (Brisbois et al., 2006). Importantly for some, smell aversions which induce nausea and vomiting may prevent participation in mealtimes and special occasions (Brisbois et al., 2006). This in turn means that patients with severe alterations in taste and smell have lower energy intakes, higher rates of weight loss and lower quality of life (Hutton et al., 2007).

In modern palliative care, patients often choose to commence or continue chemotherapy and radiotherapy to reduce their symptom burden, improve quality of life and survival (Roeland & LeBlanc, 2016). For this reason, it is important clinicians consider the side effects of chemo- and radiotherapy including chemosensory dysfunction when treating palliative care patients who chose to continue with active treatments. Symptom burden must be considered when prescribing palliative chemotherapy (Roeland & LeBlanc, 2016).

Radiotherapy studies have shown that taste alterations are common with 88-93 per cent of head and neck cancer patients reporting changes prior to treatment, which increases to 100 per cent following treatment (Ripamonti & Fulfaro, 1998). Taste sensation is slow to return with full taste sensation returning approximately two to four months post-treatment (Ripamonti et al., 1998; Yamashita et al., 2008).

Nielsen, Theologides, and Vickers (1980) reported that food odours are often responsible for food aversions in cancer patients, with sufferers more frequently experiencing weight loss, decreased appetite and early satiety. Food aversions, weight loss, early satiety and decreased appetite were found irrespective of if the patient was receiving chemotherapy or not and was not influenced by the cancer type (Nielsen et al., 1980).

Under-nutrition (H. I. M. Davidson, Pattison, & Richardson, 1998) and chronic micronutrient deficiencies (Brisbois et al., 2006) have been implicated as a causative factor for chemosensory abnormalities. Heavy metals such as zinc are known to be involved in the physiology of taste, zinc depletion being associated with taste impairment in cancer patients. However, taste alterations also occur within normal serum zinc levels (Ripamonti & Fulfaro, 1998).

Since the psychosocial aspects of food enjoyment are not consciously registered in healthy individuals, patients find that being prevented from participating in social events and meal times due to food smells, can be upsetting (Brisbois et al., 2006). For some cancer patients, almost all foods taste the same, reducing enjoyment and interest in food (Hopkinson, 2007). The finding that changes in food preferences and eating habits can create conflict between the patient and family members (Reid et al., 2009b) is of major interest in the current study.

A final important point is the hypothesis that applying sensory science to the identification and treatment of taste and smell disorders can improve the nutritional status and quality of life of people with life-limiting illness (Brisbois et al., 2006). This is an area for further research.

Anorexia

Anorexia or a loss of appetite is commonly experienced by people with cancer and is considered a normal part of the dying process (Ashby & Mendelson, 2004). Up to 94 per cent of cancer patients experience anorexia prior to death (Morita, Tsunoda, Inoue, & Chihara, 1999). To date, pharmacological and nutritional interventions have shown limited effectiveness in improving this symptom (Hopkinson, 2007), with anorexia being a poor prognostic factor in advanced cancer (Bachmann et al., 2003). Recent studies have shown that decreased dietary intake and decreased intake of protein-rich foods are a predictor of mortality in chemotherapy-suitable cancer patients over 70 years of age (Bourdel-Marchasson et al., 2016). This demonstrates that the devastating effects of anorexia exist from early on in the disease trajectory.

Cause and effect must be considered in anorexia (M. B. Taylor et al., 1989) as the reduction in appetite can be either a cause or a result of other symptoms such as depression (Eberhardie, 2002) or cachexia. In cachexia, anorexia can be a symptom of primary cachexia or the cause of secondary cachexia (McCreery & Costello, 2013). Irrespective of the cause, anorexia has significant psychosocial effects on patients and their carers up to and including the last days of life. Patients report eating is no longer a pleasurable activity (Andreassen, Randers, Naslund, Stockeld, & Mattiasson, 2006).

Weight loss

Ninety eight per cent of cancer patients experience weight loss before death (Lin, Lin, & Liou, 2011). While the incidence of weight loss varies with tumour type and location (DeWys et al., 1980), the average weight change from diagnosis to death has been reported as 9.7 per cent +/- 8.4 per cent of body weight (Martin et al., 2015). This is of significance given that weight loss of five per cent or more prior to chemotherapy has been shown to result in greater loss of fat free mass and shorter survival time (Buskermolen et al., 2012).

The causes of weight loss are multifactorial and include the tumour, reduced caloric intake or anticancer treatments (Buskermolen et al., 2012; Guenter, Ferguson, Thrush, & Voss, 2002; Lees, 1999). Weight loss is of significance given that losses through starvation have been shown to dramatically alter one's personality and may lead to social withdrawal and isolation (Kalm & Semba, 2005). Many patients and carers align changes in physical appearance and body composition with state of health and life expectancy (Ries et al., 2012). Studies validate these concerns as cancer-related weight loss has proven prognostic implications with weight loss at diagnosis an independent prognostic variable in certain tumour types (Andreyev, Norman, Oates, & Cunningham, 1998). While weight loss prior to chemotherapy significantly reduces median survival rate, weight loss during chemotherapy lowers therapy response rates (Andreyev et al., 1998; DeWys et al., 1980) which can result in weight-losing patients receiving lower doses of chemotherapy and developing more dose-limiting toxicity (Andreyev et al., 1998). The degree of weight loss during the disease also impacts survival with those losing more weight having shorter survival times (Palomares, Sayre, Shekar, Lillington, & Chlebowski, 1996).

The studies cited above have been further validated by a large prospective study that demonstrated that per cent weight loss and BMI predict survival independently of conventional prognostic factors, including cancer type and stage (Martin et al., 2015). In general weight loss is associated with poorer survival times, reduced performance status and quality of life (Andreyev et al., 1998; Baldwin et al., 2011; Ovesen, Hannibal, & Lykke Mortensen, 1993). Patients who have stopped losing weight have been shown to have a better overall survival (Andreyev et al., 1998).

The argument for provision of nutrition-support to prevent or reverse weight loss is not straightforward. Davidson et al. (2004) demonstrated that weight stabilisation is possible in patients with unresectable pancreatic cancer and is associated with improved quality of life and survival time. Baldwin et al. (2011) demonstrated that simple nutritional advice such as providing a written diet sheet or nutrition supplements without medical nutrition therapy failed to improve nutritional outcomes or quality of life. Isenring et al. (2007) showed the provision of medical nutrition therapy by a dietitian improved calorie and protein intake in patients receiving radiotherapy as compared with the provision of a standard nutrition talk and booklet alone. In a similar study Isenring et al. (2003) demonstrated that head and neck cancer patients undergoing radiotherapy lost more weight and fat-free mass when receiving usual care as compared with medical nutrition therapy. These studies suggests that intensive dietetic intervention is required to improve nutritional parameters and that this cannot be achieved by the provision of information or supplements alone.

Increased metabolic processes are often implicated in weight loss for advanced cancer patients. However, Moses et al. (2004) demonstrated that although cachexic patients with advanced pancreatic cancer had increased resting energy expenditure, their total energy expenditure was less than that of healthy individuals due to the reduction in physical activity. This is supported by Ovesen and colleagues (1993) who demonstrated that many ambulatory cancer patients do not eat enough to maintain weight.

Cancer Cachexia

Cachexia is a frequent and devastating (Vigano, Watanabe, & Bruera, 1994) unmet need (K. Fearon et al., 2011; Radbruch, Elsner, Trottenberg, Strasser, & Fearon, 2010) even in palliative care, with far-reaching implications for quality of life and survival (Mueller, Burmeister, Bachmann, & Martignoni, 2014; Radbruch et al., 2010; Ries et al., 2012). The word "cachexia" is derived from the Greek words *kakos* meaning "bad" and *hexis* meaning condition (Inui, 2002; MacLeod et al., 2015). It has been estimated that up to 80 per cent of cancer patients develop cachexia before death (Bruera, 1997; Poole & Froggatt, 2002) with up to 20 per cent of cancer deaths being directly attributed to this condition (Bachmann et al., 2003). Cachexia is more prevalent in children and the elderly and becomes more pronounced as cancer progresses (Inui, 2002).

The many differing definitions of cachexia found throughout the literature, prompted an international team of researchers to devise a consensual definition of cancer cachexia as "a multifactorial syndrome defined by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and which leads to progressive functional impairment. Its pathophysiology is characterised by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism” (K. Fearon et al., 2011) (Page 490).

Cachexia involves a series of complicated processes resulting from an interaction between the cancer and its host. It involves cytokine production which supresses orexigenic ghrelin and neuropeptide Y signalling, resulting in anorexia and cachexia (Suzuki, Asakawa, Amitani, Nakamua, & Inui, 2013). Lipid-mobilising and proteolysis inducing factors are produced resulting in alterations in intermediary metabolism (Inui, 2002). The release of proteolysis inducing factors appears to be unique to cancer cachexia as it is excreted in the urine of cachexic patients but not in those with similar tumours without cachexia or in those with other forms of weight loss (Inui, 2002).

Cachexia results in involuntary weight loss, lipolysis, loss of muscle and visceral protein, anorexia, chronic nausea, weakness (Bruera, 1997; Suzuki et al., 2013), fatigue (Hopkinson, 2014), early satiety (Inui, 2002), psychological distress, and reduced quality of life (Inui, 2002). It is more common in those with solid tumours as compared to haematological and breast cancer (Inui, 2002; MacDonald, Alexander, & Bruera, 1995; Oberholzer et al., 2013). Patients with tumours of the gastrointestinal tract are more likely to have greater weight loss and shorter survival time (Renfro et al., 2016). Cachexia is associated with reduced tolerance of cancer treatments and is an independent predictor of poor outcome (Aapro et al., 2014).

Interpretation of the literature on cancer cachexia is not without problems, as the definition of cancer cachexia differs between studies leaving many outcomes non-comparable. In an attempt to solve this, a classification system for the syndrome was developed in terms of which cancer cachexia is defined by weight loss greater than 5 per cent in six months, or weight loss greater than 2 per cent in individuals with a body-mass index (BMI) <20 kg/m^2 or appendicular skeletal muscle mass index consistent with sarcopenia with greater than 2 per cent weight loss (K. Fearon et al., 2011). Three phases of cancer cachexia have been proposed (pre-cachexia, cachexia and refractory cachexia) with patients often progressing through the continuum during their cancer journey (K. Fearon et al., 2011).

The introduction of the pre-cachexia and refractory cachexia as separate categories, made it important to distinguish between these two stages as compared with cachexia itself. To qualify as pre-cachexic, patients must have an underlying chronic disease and an unintentional weight loss of 5 per cent or less in six months and chronic or recurrent systemic inflammatory response, with anorexia (MacDonald, 2012). Whereas in refractory cachexia, the patient is pro-catabolic, is not responsive to anticancer treatment, has a poor performance status and has an expected survival of less than three months (MacDonald, 2012). Reducing serum testosterone levels, increasing serum tumour necrosis factor alpha levels and C-reactive protein levels are prognostic in refractory cachexic patients (Bilir, Engin, Can, Temi, & Demirtas, 2015). Currently there is little consensus regarding the management of refractory cachexia.

The European Palliative Care Research Collaborative has suggested interventions for patients with refractory cachexia, which include-

- identifying simple starvation or secondary nutrition impact symptoms;
- providing appetising food or oral nutritional supplements where they do not exaggerate eating related distress;
- counselling patients and families around eating and weight loss related distress;
- encouraging physical activities related to comfort;
- improving anorexia by the short-term use of progestational agents;
- very short term use of corticosteroids to improve appetite and mood for special life events (Radbruch et al., 2010) (Page 27)

The difficulty for clinicians lies with the lack of simple diagnostic tools available to determine the patient’s position in the cachexia trajectory (Madeddu, Mantovani, Gramignano, & Maccio, 2015). This is further complicated by difficulties in differentiating between age related muscle wasting or sarcopenia and losses due to cancer cachexia (Madeddu et al., 2015).

Signs and symptoms of cancer cachexia, namely anorexia, weight loss, dysphagia and xerostomia, correlate with prognosis in palliative care patients (Maltoni et al., 2005). Low BMI is associated with an increased risk of progression and death in patients receiving treatment for colorectal cancer (Renfro et al., 2016) as is low BMI at diagnosis and per cent weight loss in oncology patients (Martin et al., 2015). Poor appetite has not been shown to correlate with weight loss as conscious control of eating is often used in this patient group to overcome anorexia (T. Solheim et al., 2014).

Interventions

Nutrition Support

Maintaining nutritional status is one of the management problems frequently encountered in people with cancer (Holmes, 1993). This section will discuss forms of nutrition support utilised by dietitians to combat this.

Traditionally, dietitians use evidence-based practices to treat or prevent malnutrition or eating related concerns (Murphy & Steiber, 2015). Nutrition support is the provision of nutrition beyond that provided by normal food by the use of supplements, enteral or parenteral nutrition (National Collaborating Centre for Acute Care, 2006). The appropriateness of the provision of nutrition support in palliative care is somewhat controversial, with some suggesting that there comes a time where it has a limited role. For example when determining if parenteral nutrition would be of use, one should consider if the expected survival of the tumour-spread exceeds that of starvation (Orrevall, 2015).

In palliative care, the aim of nutrition support is not to prolong life or increase survival at any cost. Rather clinicians aim to ensure the best possible quality of life and to manage symptoms which may cause the patient discomfort or distress (Bachmann et al., 2003).

Historical and International Perspectives of Nutrition in Palliative Care

Historically nutrition support was withheld in palliative care due to concerns about prolonging life (M. B. Taylor et al., 1989). When discussing nutrition support it is important to distinguish between changes made to one's oral diet over more invasive methods such as enteral or parenteral nutrition. One must consider the psychosocial impact of providing, withdrawing or withholding nutrition support on both the patient and their family and carers.

In palliative care, the aim of nutrition support changes as the disease progresses (Eberhardie, 2002). However, little has been documented in regards to the recommended changes and how the modification of support provided affects both patients and their carers physically and psychosocially. The primary difficulty faced by clinicians is prognostication so as to determine the appropriate level of intervention to be provided. With death occurring for reasons other than the cancer itself, for example being caused by infection, organ failure, infarction, haemorrhage (Inagaki, Rodriguez, & Bodey, 1974) or malnutrition (Bachmann et al., 2003), this task becomes even more complex. This is also one of the drawbacks of the current literature, as studies investigating the therapies provided near the end of life rarely consider the cause of death.

Opinions differ about the appropriateness of nutrition care at the end of life. Cimino (2003) suggests that life is not possible without food and hence some form of nourishment should be provided to every patient who is capable of eating. Others have questioned this and argue there is no role for nutrition at this stage in one's life (Hughes & Neal, 2000). However, many studies arguing this point fail to identify the psychosocial role that food and nutrition have at this time in one's life along with the effect on family and carers.

Due to the difficulties discussed above, nutrition support goals in palliative care are often ambiguous and differ between individual clients and clinicians. In some cases, clinicians suggest that comfort and choice are the primary goals (Cline, 2006), whereas others have questioned the use of food at all, as can be seen in the following statement: "If food is fuel for nourishment, growth and repair, what is its purpose in a phase of life which is characterised by dissolution and decay?" (Hughes & Neal, 2000) (P1103). On the other hand it has been said that for most people food symbolises life and hope (Cimino, 2003) and food therefore is of high importance due to its psychosocial implications. But while such statements are based on assumptions made by clinicians working in palliative care, patients' and carers' perspective on this topic have not yet been thoroughly investigated.

Impact of Dietetic interventions on the lived experience in palliative care

Anecdotally the advice of a dietitian is often sought by patients and carers at the end of life. The goals are tailored to patient's needs and may include improvement in the patient's nutritional status, symptom management or the development of strategies that will allow oral intake (Prevost & Grach, 2012). Symptoms impacting on intake are prevalent in the terminal phase of life, but professional caregivers have consistently been shown to be poor reporters of symptoms and the quality of life of patients (Trajkovic-Vidakovic et al., 2012). Studies have shown that in the last six months of life, 95 per cent of cancer patients suffered from anorexia, 88 per cent from weight loss, 73 per cent dry mouth, 56 per cent constipation, 39 per cent nausea, 23 per cent vomiting, and 22 per cent dysphagia, with higher numbers of symptom clusters being associated with shorter survival times (Jimenez et al., 2011).

To determine the appropriateness of nutrition support in palliative care, one must consider both the benefits and burdens of treatment. In a speciality (Palliative care) in which time is precious, a good clinician would never force nutrition support on a patient who is not willing to accept it, nor would they insist on a treatment that was overly burdensome (Cline, 2006).

Clinicians have argued that if the goal of palliative care is to improve quality of life then nutrition plays a key role (Prevost & Grach, 2012). Good nutritional advice from a dietitian in palliative care has been shown to improve quality of life (MacLeod et al., 2015), with nutritional counselling being recommended to maintain oral intake (Prevost & Grach, 2012). In radiotherapy, nutritional counselling has been shown to reduce the number of patients presenting with malnutrition and increase protein intake one month post-therapy and improve nausea and insomnia (Um et al., 2014). Other studies have demonstrated intensive nutrition counselling reduces weight loss, with more patients meeting their estimated energy requirements during treatment (Poulsen, Pedersen, Osterlind, Baeksgaard, & Andersen, 2014). A systematic review of patients with head and neck cancer receiving chemo- or radiotherapy found provision of individualised dietary counselling beneficial to nutritional status and quality of life when compared to no counselling or general nutrition advice given by a nurse (Langius et al., 2013).

Benefits of Nutrition Support

Reported benefits of nutritional support in palliative care include nurturing the patient, thereby preventing starvation, reducing fatigue, improving the sense of well-being and having the potential to slow weight loss (Fuhrman & Herrmann, 2006). Food has also been shown to reduce the psychological stress associated with breast cancer treatment (Adams & Glanville, 2005).

Malnutrition impacts on quality of life and on bodily functions such as immunity and physical performance and is, moreover, linked to an increased mortality (Bachmann et al., 2003). For these reasons, palliative care patients often benefit from the provision of nutrition support, not for the reversal of cachexia but to improve factors such as mobility and immunity. Davidson et al. (2004) demonstrated this in pancreatic cancer patients receiving nutrition counselling along with nutrition support.

Wallengren et al. (2005) found a positive association between diet energy density and energy intake in palliative care patients. This supports both the giving of nutritional advice and the adoption of an energy-dense diet to slow weight loss and the onset of malnutrition. In a later study, Wallengren et al. (2013) reported dietary energy density to be positively associated with energy balance in patients with advanced cancer.

They found that survival seems to be positively associated with energy balance. This study highlighted the benefits of providing individualised dietary counselling to increase energy density and the total caloric intake of this patient group.

It has been demonstrated that nutrition support utilising Omega-3 fatty acids in palliative care patients, including those with cachexia, attenuates weight loss (W. Davidson et al., 2004). It also increases lean body mass and weight (K. Fearon et al., 2003), increases physical activity (Moses et al., 2004) and improves quality of life (W. Davidson et al., 2004; K. Fearon et al., 2003; Moses et al., 2004).

More aggressive enteral nutrition support has been shown to be of assistance to patients who have a disease which causes swallowing difficulties (Dunlop, Ellershaw, Baines, Sykes, & Saunders, 1995). In this patient group, provision of enteral nutrition results in a higher caloric intake, higher serum albumin, shorter hospital stay and longer median survival (Yang, Lin, Hsieh, & Chang, 2015).

In the light of the move towards more patients receiving palliative treatments, including chemotherapy as death approaches (Matsuyama, Reddy, & Smith, 2006), it is important to note that malnutrition is common in cancer patients, including the elderly (Santarpia et al., 2011; Sarhill, Mahmoud, Christie, & Tahir, 2003). Malnutrition is associated with increased morbidity and mortality, poor quality of life, reduced tolerance and lower efficacy of chemotherapy (Bozzetti, 2015). As evidenced above, nutrition support may be indicated in these patients.

In palliative care, consideration must be given to the patient's position in the disease trajectory, because while commencement of nutrition support would not be indicated in patients who have a very short prognosis, it may be considered in the case of a patient with longer estimated survival time (Shaw & Elridge, 2015). The level of support may also differ with differing prognoses. Clinicians need the skills necessary to determine the suitability of the provision of nutrition support as this will differ for each and every patient according to each individual's clinical and psychosocial condition.

It is recommended that in the absence of formal guidelines, clinicians deciding to provide or withhold nutrition support employ an approach which ensures the patient is an active participant in the process so that the burden of treatment does not outweigh the gains in quality of life (Fuhrman & Herrmann, 2006). Decisions are made using a framework based on principles of ethics, crisis intervention and effective communication (Baack, 1993).

In palliative care, caregivers have been observed insisting on intake by patients who are not willing to accept it (McClement, Degner, & Harlos, 2003). In situations such as this, caregivers need to be reminded that they should never force intake of any kind (Cline, 2006) and benefits and burden of care needs consideration before commencing interventions.

Nutrition Support in Cancer Cachexia

Although nutrition support may slow the progression of cachexia (Barber, 2001; Wallengren et al., 2005), the advances in the understanding of the pathogenesis of cancer cachexia has not resulted in effective strategies to manage this condition (Muscaritoli, Molfino, Lucia, & Rossi Fanelli, 2015). Although the goal of cachexia treatment should be the reversal of weight and muscle loss at a minimum, weight stabilisation and prevention of further loss would be acceptable (Suzuki et al., 2013). In refractory cachexia however, the goal is to alleviate cachexic related symptoms and increase well-being (Suzuki et al., 2013).

Many of the studies investigating the effectiveness of nutrition support in cancer cachexia were undertaken prior to the development and naming of the three different stages of the condition described earlier. It has been suggested that the boundaries of these stages are fluid and that further work needs to be done in developing the continuum (MacDonald, 2012). With this in mind, poor outcomes may not be indicative of a failed intervention but rather that the intervention may not be effective in all stages of cachexia. Many studies may need to be redone or reanalysed, taking into consideration the patient's level of cachexia at the time of the study so as to determine which stages of cachexia respond to the differing treatment options.

With the reversal of weight loss thought not possible in refractory cachexia (Radbruch et al., 2010), Bozzetti et al. (2014) have called for a review of the classification after finding that some patients diagnosed with refractory cachexia had increased survival when given home parenteral nutrition. This finding has been anticipated by Lundholm et al. (2004) who demonstrated an improvement in energy balance and survival in progressive cachexic palliative care patients, utilising nutrition intervention (oral +/- total parenteral nutrition). It is important to note that parenteral nutrition in advanced cancer patients is the exception rather than the rule due to now dated studies which demonstrated a reduction in survival and increase in complications in these patients (Mitchell & Jatoi, 2011). This is an area requiring further research to determine if a role exists for parenteral nutrition in this patient group.

Recently, DeWaele et al. (2015) demonstrated that provision of nutrition support via dietary counselling based on specific biophysical parameters in patients with cachexia resulted in an improvement in survival, reduced weight loss and reduced days of hospitalisation. Further research on this area is required.

When considering the mode of treatment there is strong evidence that in patients undergoing radiotherapy, dietary counselling increases dietary intake, body weight, nutritional status and quality of life. It potentially improves nutrition impact symptoms, treatment response and survival (Isenring & Teleni, 2013). The evidence is less clear for those undergoing chemotherapy.

Despite some studies demonstrating the benefit of nutritional intervention, it has been suggested that cachexia cannot be managed using nutrition alone (Bosaeus, 2008). A multidisciplinary approach has been recommended which includes assessment and intervention in feeding, appetite, swallowing, exercise, psychosocial, and psychological issues (Konishi, Ishida, von Haehling, Anker, & Springer, 2016). Multimodal treatments have shown some success and constitute an area of current research with nutrition remaining a cornerstone in multimodal treatment (Isenring & Teleni, 2013). Del Fabbro et al. (2011) also demonstrated pharmacological and non-pharmacological interventions administered via a cancer cachexia clinic improve appetite with 34 per cent of returning patients gaining weight following dietary counselling and exercise.

More research is required into the nutritional management of cachexia, with a focus on the stages of the condition. With many palliative care patients classifying as refractory cachexic, it is important to consider the effect this has on the patient, the disease and treatment recommendations. Recent research has raised questions about the definition of refractory cachexia, demonstrating that nutrition support can have a positive outcome on survival in this patient group (Bozzetti et al., 2014).

In addition, the suggested management of refractory cachexia fails to consider other benefits of nutrition support such as physical benefits in activities of daily living, quality of life and psychosocial aspects. This is an area for future research, although it is acknowledged that this raises ethical concerns. Further research is needed to determine the wishes of refractory cachexia patients to ensure patient-centred care.

Omega-3 Fatty Acids as a Treatment for Cancer Cachexia

Omega-3 fatty acids found in fish oils have been postulated as a treatment for cancer cachexia due to their known anti-inflammatory properties (Madeddu et al., 2015) with the proposed mechanism being the reduction of Interleukin-1 and tumour necrosis factor-alpha production (Inui, 2002). A 2015 review of the use of eicosapentaenoic acid in cancer revealed its ability to reduce inflammation while modulating nutrition status and body composition which is thought to be capable of improving quality of life (Pappalardo, Almeida, & Ravasco, 2015).

Multiple systematic reviews have been undertaken on the effectiveness of Omega-3 fatty acids in cancer cachexia, but these have produced conflicting results. While Colomer et al. (2007) concluded Omega-3 supplements were indicated in tumours of the upper digestive tract and the pancreas because they increased weight, appetite, quality of life, and reduced post-surgical morbidity. However, Mazzotta and Jeney (2009) were unable to demonstrate clinically or statistically significant results for Omega-3's effects on symptoms, survival or quality of life.

Ries et al. (2012) found strong evidence to support the use of fish oils, concluding that due to their mild side effects and lack of severe adverse events, therapeutic trials are justified in the absence of refractory cachexia. Van der Meij et al. (2013) found fair evidence of Omega-3 fatty acids being safe and improving quality of life and physical activity. However, no improvement in appetite, energy or protein intake or reduced post-operative complications could be demonstrated. The evidence for the effect on body weight, fat free mass and performance status was inconclusive (van der Meij et al., 2013). Ma et al. (2015) demonstrated significant increases in body weight and lean body mass with Omega-3 fatty acids, while reducing resting energy expenditure and increasing overall survival in patients with pancreatic cancer (Ma, Yu, Xiao, & Cao, 2015).

Other smaller studies have demonstrated that Omega-3 fatty acid rich supplements increase total energy expenditure and physical activity in cachexic pancreatic cancer patients which potentially can improve quality of life (Moses et al., 2004). Bauer et al. (2005) have also demonstrated an improvement in quality of life in cachexic cancer patients when provided with nutritional supplements rich in Omega-3 fatty acids.

Although systematic reviews have not shown Omega-3 fatty acid to reverse cachexia, many small-scale studies have demonstrated improvements in symptoms (Ries et al., 2012) providing hopeful grounds for further research. For this reason, it is recommended that larger, more robust trials be undertaken during the three phases of cachexia to determine at which stage nutrition-interventions of this type are useful. Studies should focus on providing nutrition-education along with recommendations of the most effective therapeutic dosages of Omega-3 as previous research has demonstrated the importance of nutrition-education provided by a dietitian to bring about the desired outcome (W. Davidson et al., 2004). Multimodal therapy which combines nutrition education, Omega-3 fatty acids and pharmacological options should also be considered.

Pharmacological Management of Cancer Cachexia

While trials investigating new and emerging pharmacological agents to manage cancer cachexia continue (Madeddu et al., 2015), single agent medications such as dexamethasone, medroxyprogesterone, megestrol, cannabinoids, prokinetic agents, antidepressants, thalidomide, and olanzapine (Bachmann et al., 2003; MacLeod et al., 2015) have shown minimal benefit in cancer cachexia and at best, provide a short-term reprieve from symptoms. While slightly improving weight and appetite, agents such as progestogens can have deleterious side effects such as blood clots, fluid retention and occasionally death (Madeddu et al., 2015; Ruiz Garcia, Lopez-Briz, Carbonell Sanchis, Gonvalvez Perales, & Bort-Marti, 2013) which steers clinicians away from their use.

A systematic review of non-steroidal anti-inflammatories has shown some evidence for improved quality of life, inflammatory markers, performance status, weight gain and survival in cachexic patients with advanced cancer, however, insufficient evidence exists to justify their widespread use (Reid, Hughes, Murray, Parsons, & Cantwell, 2013). Anti-diabetic drugs such as metformin have been postulated to be effective due to their ability to improve insulin sensitivity and reduce gluconeogenesis while having tumour-suppressive properties (Chevalier & Farsijani, 2014). However, both agents require further research prior to their widespread use.

Further research is required into pharmacological management of cancer cachexia. Priority should be given to investigating multimodal treatment as this is an area that shows promise and may address psychosocial concerns experienced by patients at the end of life.

Artificial Nutrition and Hydration

In the belief that caloric intake helps slow disease progression, enhances quality of life and prolongs survival (McClement, 2005; McClement, Degner, & Harlos, 2004; McClement et al., 2003), family members often request artificial nutrition and hydration for their loved one as oral intake wanes. However, while nutrition and hydration can be provided artificially by the means of intravenous (IV) or subcutaneous fluids or by means of enteral nutrition or parenteral nutrition, there is disagreement about the desirability of the use of any of these in palliative care.

While often discussed as a single measure, artificial nutrition and hydration have vastly different aims. The former involves providing a patient the nutrients they require to maintain life and prevent or treat malnutrition; without such nutrients, death could occur within days instead of over months (Druml et al., 2016). Artificial hydration on the other hand, while providing fluid for the body, does not provide the micro- and macronutrients required to maintain life long term (Mercadante, Ferrera, Girelli, & Casuccio, 2005). But without fluid intake, cessation of life would be much quicker than death by malnutrition.

In Australia and the USA, court rulings have led to artificial nutrition and hydration being seen as a single medical treatment, which is not always consistent with the goals of palliative care (Ashby & Mendelson, 2004; Eberhardie, 2002). The goal of food ingestion is generally to maintain nutritional status and functional performance while satisfying hunger and thirst (Goncalves, Mozes, Saraiva, & Sristina, 2006). Yet this is not always possible for oncology patients who may be unable to consume an oral diet due to or following treatment for their cancer. In this situation, clinicians will often consider artificial feeding and have suggested that enteral nutrition and parenteral nutrition should be offered to patients since it compares well with other efficacious treatments (Whitworth et al., 2004). When deciding to start or to continue artificial nutrition or hydration, the question of whether their provision will be consonant with the wishes of the patient while providing them with a reasonable quality of life and survival time, should be considered (Cline, 2006).

One issue which arises when providing artificial nutrition and hydration is determining when palliative benefits have been exhausted (Ganzini, 2006). Withdrawal of treatment is often difficult as this may be viewed as withdrawing care, which is not the same thing. Others prefer that a feeding tube not be inserted from the outset as this may be perceived as allowing a “natural death” (Ganzini, 2006).

Artificial Hydration

The use of artificial hydration at the end of life is contentious (Hui, Dev, & Bruera, 2015) with practices differing internationally (Buiting et al., 2007). Ethical and legal concerns discussed in the literature include the refusal of hydration therapy by some patients and the provision of sedation without hydration (Byock, 1995; Craig, 1994).

The type of dehydration experienced by terminal cancer patients is thought to be different to that experienced by those suffering other causes of dehydration (Smith & Andrews, 2000). While clinicians have reported that improvements can result from the provision of hydration at the end of life (Andrews, Bell, Smith, Tischler, & Veglia, 1993), recent research has shown no clear clinical benefits on symptom-burden or survival for terminally ill cancer patients, with the exception of hydration potentially reversing delirium (Dev, Dalal, & Bruera, 2012).

While there is a low level of evidence suggesting that dehydration in the terminal phase is neither painful or uncomfortable (Bachmann et al., 2003), many families request this treatment due to their distress as they see their loved one’s life nearing its end. It is for this reason that following consideration and discussion of its risks and benefits, artificial hydration is administered to select patients (Hui et al., 2015).

Psychosocial Research

Psychosocial Impact of Bowel Changes

In a Swedish phenomenological study of 11 cancer patients admitted to the palliative hospital-based home care unit, patients described constipation as an intense form of suffering that consumes their whole mental energy. They reported refusing food for fear of filling the bowel with more faeces, their inability to pass the stool causing major distress. Constipation reminded some patients of their closeness to death, while its relief gives them a feeling of starting to live again (Friedrichsen & Erichsen, 2004).

Patients reported feelings of humiliation and shame due to their constipation and often avoided speaking to health professionals due to the intimate nature of the problem. They also voiced concerns that when they did speak up, nurses did not respond (Friedrichsen & Erichsen, 2004).

Constipation often resulted in the patient continuously being in a bad mood, causing them to withdraw from social contact. The irritability caused by constipation resulted in conflicts between the patient and family (Friedrichsen & Erichsen, 2004).

Psychosocial Impact of Nausea and Vomiting

Although this is a relatively understudied area of palliative care, Shragge, Wismer, Olson, and Baracos (2007) undertook a grounded theory study of 9 anorexic patients with advanced cancer and showed nausea or the anticipation of emesis to be the ultimate barrier to eating. Ballatori et al. (2007) surveyed 172 Italian chemotherapy patients and found nausea and vomiting impacted on quality of life with the duration of symptoms being more burdensome than intensity. In considering psychosocial interventions, a randomized controlled trial of sixty patients demonstrated that behavioural approaches such as systematic desensitization can reduce the symptoms of anticipatory nausea associated with chemotherapy in (Morrow & Morrell, 1982).

Psychosocial Impact of Anorexia

Change in appetite is a frequent and distressing symptom reported for patients with cancer (Tanghe, Evers, & Paridaens, 1998). To investigate concerns about eating, Hopkinson and Corner (2006) conducted semi-structured interviews with 30 advanced cancer patients, 23 lay caregivers and 14 specialist nurses. Their thematic analysis revealed patients reported early satiety, loss of appetite, reduced enjoyment of food, food aversions, eating becoming a chore and physical changes which made eating difficult leading to anorexia. Patients also reported changes in the amount and types of foods eaten when compared with their intake prior to illness with foods now labelled as good or bad (Hopkinson, 2007). Good foods generally consisted of fruit and vegetables and high quality cuts of meat (Hopkinson, 2007). Patients tried to eat foods which help maintain their health and well-being (Hopkinson & Corner, 2006).

Holden (1991) interviewed 14 patients and their primary caregivers investigating the emotional impact of anorexia for both parties. Results showed that family members commonly rate anorexia of high concern while patients do not always see it as so important (Holden, 1991). Hawkins survey supported this, reporting that anorexia causes more distress to carers than patients, with 87 per cent (n=72) of relatives experiencing anxiety due to their loved ones' anorexia compared to merely 36 per cent (n=41) of patients feeling that way (Hawkins, 2000). Anxiety was heightened in younger patients and those cared for at home instead of in hospital (Hawkins, 2000). Similarly, Hopkinson et al. (2006) found concerns regarding weight-loss and eating decreased with increasing age, although their findings failed to meet statistical significance.

Anorexia has been associated with upper gastrointestinal malignancies, metastatic disease and short prognosis (Hawkins, 2000). In a Japanese survey carried out by Morita et al. (2004), 63 per cent of bereaved family members reported that their loved one developed appetite-loss often or very often in the week prior to death. In contrast, only 7.2 per cent reported that their loved one was hungry during this period.

Of the families reporting appetite loss, 93 per cent stated that this caused distress of varying intensities (Morita, Hirai, et al., 2004).

Supporting the link between heightened concerns in caregivers, Hopkinson et al (2006) found in their survey of palliative advanced cancer patients living at home, that 79 per cent (n=157) of these lost weight and that 76 per cent (n=151) were eating less. Fifty-two per cent (n=103) of those who completed the questionnaire independently reported being concerned about their weight loss and/or their reduced eating. That a statistically significantly higher number of patients reported concerns when a family member assisted in completing the form, suggests over-reporting by family members (Hopkinson, Wright, McDonald, et al., 2006). This suggests that carers do not have a good grasp of the issues experienced by patients and project their own concerns onto the patient.

Hopkinson and Corner (2006) reported patients' concerns rise when the reality of how they are eating differs from their expectations. In that study, 97 per cent of patients (n=30) experienced a reduction in oral intake which was of concern to 53 per cent of the respondents. Sixty per cent of patients manipulated their intake by adding nutritional supplements or avoiding foods to limit cancer growth (Hopkinson & Corner, 2006) indicating a desire to use diet to influence disease-outcomes.

While concerns around weight loss or eating can occur at any stage across the disease trajectory, these increase as death approaches (Hopkinson, Wright, McDonald, et al., 2006). Caregivers see the loss of appetite in terminally ill patients as a sign of impending death, which causes considerable anxiety (Holden, 1991; Strasser et al., 2007). Holden (1991) demonstrated in her previously discussed semi-structured interviews that loss of appetite causes conflict within the family when the quantity of food and fluid consumed is interpreted in different ways by different family members (Holden, 1991).

Although "good" caregivers were seen to encourage patients to eat, tension around food and eating was reported by one third of the participants studied by Hopkinson and Corner (2006), who noted that caregivers sought rewards in the form of acceptance and enjoyment of food by patients. When asked, patients reported more positively on foods they could eat whereas their carers remarked on how little they ate (Holden, 1991).

Although, loss of desire and or the ability to eat was seen as a loss of control by patients in the study by Hopkinson (2007), McClement et al. (2004) undertook a grounded theory study of advanced cancer patients (n=13), their families (n=23) and health care workers (n=11) and reported patients felt more pressure to eat than their family members estimated. This resulted in the patients feeling upset, angry and harassed. The study by Holden (1991) supported this with patients wishing to determine how much they wanted to consume without being subjected to pressure from family members (Holden, 1991). Hopkinson and Corner (2006) further this in reporting that comments or the behaviour of family or friends present at meal times, definitely influenced the amount of food eaten (Hopkinson & Corner, 2006).

Strasser et al. (2007) investigated eating related distress in men with advanced cancer and their female partners. They reported that many female partners felt compelled to encourage or even force their loved one to eat. Changes in their eating and cooking habits in response to their partner's changing intake sometimes resulted in they themselves gaining weight as a result of consuming high calorie foods or leftovers.

Meares (1997) undertook a phenomenological inquiry study with 12 women who had cared for cancer patients who ceased eating at the end of life. She demonstrated that family dynamics and meal times shift when a patient suffers anorexia. Many patients wanted to eat to relieve their carers' concerns, and tended to eat more in social settings in an attempt to please loved ones.

For relatives, not being able to share or provide food for the patient compounds their sense of helplessness and hopelessness (Hawkins, 2000). Hopkinson (2007) showed that carers felt frustrated when prepared meals went uneaten, leading to patient guilt over waste and expense. Strasser et al. (2007) reported similar findings with female partners expressing deep concern, frustration and feelings of failure when their loving and innovative culinary efforts are rejected by their loved one. Those impacted by cancer spoke about the assumed pleasurable activity of eating becoming burdensome and distressing undertaken merely to stay alive.

In the inpatient setting, McClement et al. (2003) demonstrated that family members attempt to encourage the consumption of additional calories by bringing favourite foods from home or buying large portions for the patient. Some family members actually resort to force feeding when their offerings are refused by the patient (McClement et al., 2003; Meares, 1997). In their study, McClement et al. (2003) noted that family members not yet ready to face the death of a patient, would ensure they were on the ward at meal times to counteract what they believed were the inadequate nutritional-care efforts of palliative care staff. Faced with anorexia, some patients make an effort to eat when they recognise their family members are not ready to let them die (McClement et al., 2004).

Researchers have found that family members often assume that caloric intake will slow disease progression, enhance quality of life and prolong survival (McClement, 2005; McClement et al., 2004; McClement et al., 2003). To such families, the nutritional quality of foods provided was of far less concern than its quantity (McClement et al., 2004) which led to patients being coerced to eat. In the inpatient setting, carers who thought nursing staff were not adequately assisting with a loved one’s oral intake, accused staff members of being negligent or neglectful of their role (McClement, 2005; McClement et al., 2004). However, force feeding a patient aroused care providers’ concern because often the patient no longer had the gag reflex required to protect the airway (McClement et al., 2004).

Hopkinson and Corner (2006) reported that nursing specialists felt that it was better not to discuss eating related concerns with patients and carers since this could increase problems rather than solve them. They reported that it was difficult to access the expertise of dietitians and other health care professionals. McClement et al., (2004); on the other hand reported that dietitians were not accused of neglect by families who complained that health professionals were not providing adequate nutritional care. Dietitians were not seen as being involved in the provision of food but as simply offering consultancy services when specific issues arose due to inadequate staffing levels preventing full care (McClement et al., 2004).

With the majority of concerns around anorexia at the end of life being focused on carers rather than patients, Hopkinson, Wright, McDonald, et al. (2006) raised the possibility of caregivers being given the main responsibility for dealing with interventions to counteract eating and weight loss problems. This course of action is generally approved of by patients who, according to Hopkinson et al.(2005) are mostly enthusiastic about what they feel could help other sufferers with similar problems to their own. Perhaps the way forward on this issue could be provided in studies currently underway into interventions for anorexia, which include dietetic and psychological mindfulness sessions (Focan et al., 2015), development of an item bank of psychosocial consequences of cancer cachexia (Hane et al., 2013), nurse lead interventions for weight loss and eating related distress (Hopkinson, Fenlon, & Foster, 2013), a family approach to weight loss and eating (Hopkinson & Richardson, 2015) and the psychosocial, educational and communicative interventions of Reid (2014).

Psychosocial Impact of Weight Loss

Hopkinson, Wright, and Corner (2006) reported weight to be something patients felt they had control over. But while initially many patients were happy with their weight loss, they were dismayed to find that as their disease progressed their weight loss could not be halted (Strasser et al., 2007), something which was likely to deleteriously affect their morale. Ovesen et al. (1993) reported that in small cell lung cancer patients, even a moderate weight loss was associated with psychological distress and reduced quality of life.

Similarly, in cancer patients with stomas, weight loss is likely to have both physical and psychosocial consequences that compromise quality of life (Hopkinson, Wright, &

Corner, 2006; Sharpe, Patel, & Clarke, 2011). Weight loss concerns patients as it is coupled with physical weakness, reduced activity and more limited independence (Hopkinson, Wright, & Corner, 2006). Weight loss was seen by patients to embody their illness and as such seemingly provided evidence of emotional weakness which in turn led to a sense of helplessness (Hopkinson, Wright, & Corner, 2006). Cancer sufferers also see anorexia and weight loss as an indicator of poor prognosis (McClement, 2005).

Meares (1997) investigated carers' perspectives on weight loss, reporting that caregivers described it by using emotive terms such as "gaunt", "skin and bones", "all bone", "no muscle", "hollow", "wrinkled", "skeletal and stick like". All of these figures of speech evidence the distress carers feel in reaction to their loved one's loss of weight.

Watson et al. (2010) undertook a study investigating the attitudes of hospice staff in United Kingdom and Ireland towards weight loss and weight assessment in the hospice setting. In considering nurses' responses to patients' weight loss, they found nurses considered that weight loss is a distressing symptom for patients, presaging proximity to death, loss of control and physical and emotional weakness. However, this finding must be taken in context as Tanghe et al. (1998) reported nurses frequently failed to observe weight loss in chemotherapy patients (Tanghe et al., 1998). Hopkinson, Wright, and Corner (2006) found that nurses rarely initiate discussions on weight loss as they believe little can be done about it; such discussions on this topic are usually patient-initiated (Hopkinson, Wright, & Corner, 2006). A 2015 review by Cooper et al. (2015) reported that lack of recognition or management of weight loss was not unique to nurses as health care professionals in general failed to manage this condition effectively. This is an issue calling for further research.

As weight loss increases with disease progression, it becomes necessary to consider the implications of measuring weight at the end of life. Watson et al. (2010) reported that weighing patients is not common practice in hospices as many staff feel this is inappropriate. They found 66 per cent of hospices rarely weigh patients with 56 per cent of staff feeling that weighing the patient could cause them to become upset. However, on further investigation they found that 96 per cent of patients did not object to being weighed; in fact 89 per cent of patients reported wanting to know if their weight was changing, 84 per cent wanted to be weighed at future hospital appointments and only 7 per cent preferred not to be weighed as their illness worsened (Watson et al., 2010). This demonstrates lack of synchronicity between the desires of palliative care patients and the possibly mistaken perceptions of hospice staff in regards to weight. This is an area that requires further research. This poses questions regarding other assumptions health professionals make around patients and carers wants as they too may not truly be founded in the patients' wishes and needs.

Psychosocial Impact of Cancer Cachexia

Since the mid-1980's when little was known about the psychological and psychosocial effects of cancer (Pruyn et al., 1986) and cancer cachexia, significant developments have led to a deeper understanding of the topic. Today we know cancer cachexia has a profound existential impact on patients and carers (Reid, 2014) and is a cause of eating-related distress (Johnston Taylor, 2016). However these effects are still not broadly acknowledged in clinical practice (Oberholzer et al., 2013).

The reported psychosocial effects of cachexia include the experienced loss of independence, helplessness, family conflict, social isolation, thoughts of death and distress (Hopkinson, 2014). A review of qualitative studies on cancer cachexia revealed the main worries of patients and relatives to be appetite loss, the changing appearance of the patient, their prognosis and social interactions (Porter, Millar, & Reid, 2012). All of these concerns can be directly related to eating and drinking.

The loss of appetite associated with advanced malignancy and cachexia causes considerable distress for both patients and their carers (Hawkins, 2000; Hopkinson & Corner, 2006; Strasser et al., 2007). Olson et al. (2008) investigated symptom assessment scores for 82 patient on a palliative care database and reported, towards the end of their lives, anorexia is the symptom of most concern for patients both one month and one week prior to death. This highlights the need to develop a deeper understanding of the condition and a need to devise strategies to manage this symptom.

The gap which exists between the ability of patients and carers with regard to their differing appreciation of the emotional and social consequences of cancer anorexia results in heightened difficulties for the patient (Shragge, Wismer, Olson, & Baracos, 2006), although studies show that carers can be even more strongly affected than patients (Hawkins, 2000). Despite this, anorexia remains poorly managed in palliative care patients and the management of anxiety due to anorexia remains an unmet need in advanced cancer cases (Hawkins, 2000).

Oberholzer et al. (2013) undertook a systematic literature review and qualitative analysis of the psychosocial effects of cancer cachexia. They reported anorexia has a profound impact on a patient's oral intake, which results in weight loss and cachexia progression, and that in turn causes concern for carers who fear they will lose their loved ones sooner than expected (Oberholzer et al., 2013). Reid et al. (2009) reported three themes pertinent to oral intake in patients with advanced cancer and their carers; namely- patients eating to please, carers' reaction to food refusal and conflict caused by reduced food intake.

Eating often becomes a tedious chore for people with cancer cachexia (Reid et al., 2009b) as indicated by repeated reports of tensions and conflict over the consumption of food (Hughes & Neal, 2000; Reid et al., 2009a, 2009b). Shragge et al (2006, 2007) reported that patients retained the motivation and ability to eat despite a lack of appetite as long as eating did not provoke nausea or the anticipation of emesis (Shragge et al., 2006, 2007). However, Millar et al. (2013) in their qualitative study involving doctors, nurses and dietitians in a North Ireland cancer center, found that patients will continue to eat to please their carers despite a lack of appetite or the presence of nausea. Others have reported that cachexic patients ate to please family members (Reid et al., 2009b). This eating-to-please is a recurrent theme among the emerging qualitative studies on cancer cachexia.

Patients report that while becoming upset and angry about their carers' focus on food, they continued eating-to-please to avoid conflict and maintain harmony with their carers and families (Reid et al., 2009b). Some patients have reported feeling harassed by carers when it comes to food and eating (Hawkins, 2000). Patients have also reported feeling they were in a food-focused environment from which they were unable to escape (Reid et al., 2009b). Others avoided social interactions in an effort to avoid the pressure to eat (Millar et al., 2013).

That eating-related concerns are widespread is indicated by the fact that 52 per cent of patients receiving specialist home palliative care services reported concerns about weight loss and eating irrespective of proximity to death (Hopkinson, Wright, McDonald, et al., 2006). This issue needs to be screened for and investigated in all patients with advanced cancer so that such issues can be addressed by the health care professional.

The preparation and presentation of food is an emotionally loaded activity for both patients and carers (Millar et al., 2013). Food refusal is seen by carers as a rejection of their love and support (McClement et al., 2004; Reid et al., 2009b) leading to added distress in an already distressing situation. Food refusal further brings about feelings of guilt and anger for family members along with feelings of rejection of their affection, given the care they put into the food preparation (Reid et al., 2009b). A recent qualitative study of ethnically indigenous to the South Pacific, New Zealand hospice patients and their carers demonstrated patients tried hard to consume the food to recognise this, since failure to eat was seen as rejection of the food preparation efforts (Johnston Taylor, 2016).

While patients reported the difficulties experienced around food and nutrition, they nonetheless saw family members' focus on food as a sign of their love and concern and as an expression of their compassion. On their part, family members saw their focus on food as a demonstration of their love and concern for the patient's well-being. Family members adopted strategies such as keeping the patient's favourite foods on hand in order to maximise intake when the patient had a craving for it (Reid et al., 2009b).

What is of note is that family members often have very limited training in caring for someone with cancer while only limited resources are available to assist them through the process (Reid, 2014). Consequently, studies have shown that they fail to see weight loss as an unavoidable consequence of cachexia and believe that food can be used as a means to aid recovery (Reid et al., 2009b). Given their poor understanding of the mechanisms and outcomes of cachexia, it is not surprising that carers fail to identify the futility of eating to counteract the condition (Reid et al., 2009b) and hold the mistaken belief that a patient's weight loss is due to reduced oral intake (Reid et al., 2009b). This leads them to believe that adequate caloric intake can prevent or slow the patient's decline (McClement et al., 2003).

Psychosocial Impact of Weight Loss in Cancer Cachexia

Body weight changes have a profound impact on patients as is evident in the findings of previous studies in which patients have expressed embarrassment about the visibility of their cachexia (Reid et al., 2009a). For advanced cancer patients, body image dissatisfaction is correlated with weight loss, anxiety, depression and reduced sexual interest and enjoyment (Rhondali, Chisholm, et al., 2013). Patients who experienced 10 per cent or more weight loss over six months reported higher dissatisfaction about their body image than their counterparts who had lost less weight (Rhondali, Chisholm, et al., 2013).

Patients with cancer cachexia want three things from health professionals in regards to their weight changes. Firstly, acknowledgement of their profound weight loss, secondly information on how and why it happened and thirdly, interventions to manage it (Reid et al., 2010). This may be linked to the finding of Millar et al. (2013) that patients and their families are often provided with little information on how to cope with the distressing consequences of cachexia, as nurses and dietitians lacked confidence in discussing the issues and saw this as being outside of their scope of practice. While they thought that responsibility lay with the medical officers, medical officers themselves often avoided directly addressing this issue, preferring to allow patients to have hope. This was highlighted in cases of refractory cachexia where physicians were reluctant to tell the truth because of the link between their condition and poor prognosis (Millar et al., 2013).

Psychosocial Interventions in Cancer Cachexia

With a direct relationship between experiencing eating-related distress and death-anxiety hypothesised (McClement & Harlos, 2008), as well as growing evidence of the deleterious psychosocial effects of cachexia, researchers are moving to develop models to address these effects on patients and their carers. It can be hypothesised that interventions in cancer cachexia should aim to reduce the emotional burden of this syndrome by empowering patients and carers to understand the mechanisms and management of cachexia and its symptoms (Reid, 2014). Hopkinson (2016) reported three possible dyadic responses to disruptions in food connections caused by changes in weight and eating habits, namely dual acceptance, dual resistance or a mismatched response. It is postulated that these categorisations will allow for targeting of psychosocial support to those patient and carer groups who will most benefit.

While still in their infancy, areas of current research are promising and include the use of cognitive behavioural therapy as a mechanism to alleviate the distress caused by changes in body image (Hopkinson, 2010). Dietetic and psychological mindfulness workshops have been shown to improve body weight, emotional function, WHO status score, to lessen fatigue and also some digestive disorders in actively-treated cancer patients who are developing cachexia (Focan et al., 2015). However, recruitment in this study has proved difficult with 73 per cent of approached patients declining participation (Focan et al., 2015). A more appealing strategy is required.

The nurse-delivered program, the “Macmillan Approach to Weight and Eating”, has been shown to reduce weight and eating-related distress in carers involved to the program (Hopkinson et al., 2013). Following on from this, Hopkinson and Richardson have developed a “Family Approach to Weight and Eating” psychosocial intervention aimed at reducing weight- and eating-related distress in families affected by refractory cachexia. While still in its infancy, it has been recommended that this program be piloted to determine its effects on the emotional health of patients and their caregivers (Hopkinson & Richardson, 2015).

While the “Item Bank” of Hane et al. (2013) is not yet recognised as an effective intervention for cancer cachexia, it contains useful questions designed to investigate the psychosocial consequences of this disease which can be understood and accepted by patients. It is proposed that these questions will be developed into a measurement tool for future research studies into this condition. Questions considered in this tool include “Does your weight loss trigger deeper fears in you?”, “Does it cause you distress that you don’t have much of an appetite?” and “Does it cause you distress to weigh yourself?” (Hane et al., 2013).

While not yet developed, Johnson Taylor (2016) hypothesised the application of Mauss theory in an attempt to minimise eating-related distress. This involved teaching patients to reframe their gratitude for the gifts of food in ways other than eating it. This is an area for future research.

Given that currently little is available to alleviate the psychosocial effects of cancer cachexia, future interventions need to address the concerns of both patients and carers (Reid, 2014). These concerns are intertwined and provide interventions which satisfy both parties and which are likely to achieve positive outcomes and harmonious relationships between them.

Psychosocial Impact of Parenteral Nutrition and Artificial Hydration

Although this is an understudied area of palliative care, patients receiving home parenteral nutrition reported a sense of relief and security that their nutritional needs were being met. Orrevall, Tishelman, and Permert (2005) studied the experiences of 13 advanced cancer patients and 11 family members reporting a direct and positive effect on quality of life and on body weight, energy levels, strength, and activity.

Van Der Riet et al. (2008) reported palliative care doctors and nurses felt that terminal dehydration at the end of life lessened the burden of suffering for dying patients. However, they identified carer distress when artificial hydration was withheld. They voiced a belief that medically assisted nutrition and hydration at the end stage of life rarely benefits patients when adequate mouth care is provided. However, they highlighted the emotional distress experienced by family members when dealing with this situation.

While invasive treatments such as artificial nutrition are not recommended in the last days of life, artificial hydration may be considered on a case-by-case basis (Hui et al., 2015). Discontinuation of either enteral or parenteral support can cause distress for patients, carers and health professionals (Dev et al., 2012) and this should be taken into consideration when initiating therapy.

Food Has More Than Just Physiological Meanings

Since the anthropological study of food and eating began in the 19th century (Mintz & Du Bois, 2002), and attracted increasing interest from sociologists in the 20th (Lupton, 1998), an abundance of information has become available on this topic. For the purpose of this literature review, I will focus on findings relevant to the topic at hand.

Food is a basic human need which takes priority over other needs (Escott-Stump, 1989; Maslow, 1943). While consumption is essential for survival (Lupton, 1998; Mintz & Du Bois, 2002) it is also central to one’s social life, satisfying emotional as well as physical needs (Counihan, 1999) and providing enjoyment and feelings of contentment (Lupton, 1998). Behaviours related to food are influenced by the individual's social, cultural and religious background (Eberhardie, 2002).

The human relationship with food and eating is complex (Coveney, 2006). Consumption of food is often used in society to define and classify an individual as good or bad. Food treats are used as rewards for achievement and good behaviour (Coveney, 2006; Lupton, 1998).

In modern Western society there is a surplus of easily accessible and affordable food (Rozin, 2005). While food provides nutrition, it also serves many other social functions. In this section I will consider some of the meanings and roles of food in healthy people and how they change with illness.

To influence food and nutrition habits, it is important to understand the symbolic meanings of food as these can determine if a particular type of food is consumed or not (Bruce Moore, 1957). To humans, food is much more than simply its constituents or the micro- and macro-nutrients it provides the consumer. Food behaviours are often developed and cemented early in life (Escott-Stump, 1989), with dietary habits and resultant physical appearance symbolising the individual’s control over their body (Lupton, 1998).

While the meaning of food differs between cultures, common themes are seen throughout. Food has been described as “a prism that absorbs and reflects a host of cultural phenomena” (Counihan, 1999). For this reason, it is impossible to present all of the meanings of food as these change according to the culture in which it is consumed and also to health status and many other influencing factors.

In many cultures, food symbolises love, with the giving of food being a way of demonstrating love for another person or persons in a way which often cannot be put into words (Alexeyeff, 2004; Meares, 1997). Food plays an important role in bringing families together and facilitating the expression of love between them (Lupton, 1998).

It is argued that food preferences and tastes are products of the sociocultural environment into which we are born (Lupton, 1998). Our choices for consumption sustain the self while locating us within society (Wattanasuwan, 2005). As such, the consumption of food is a social activity which has social and psychological significance for individuals (Bayer, Bauers, & Kapp, 1983). Food is intimately linked to group membership and kinship, bringing people together to share in the act of eating (Lupton, 1998). Since the sharing of food has been described as a sharing of oneself (Counihan, 1999), eating serves to solidify membership in a group and sets different groups apart from others (Mintz & Du Bois, 2002). As such, food is often used in religious rituals in which it acts to reaffirm or transform a person’s relationship with others (Mintz & Du Bois, 2002).

Bruce Moore (1957) postulates the association of food and friendship to be very deep within us, with people enjoying eating with those close and emotionally desirable to them such as parents, friends and offspring. She describes eating to be human but feeding to be maternal, linking the provision of food to caring and mothering. This is of interest in this study, given that caregiving is primarily undertaken by women (Kleinman, 2010). Lupton (1998) avers that the greater the time taken to prepare a meal, the higher the symbolic value of the gift offered, the preparation of food being seen as a way of expressing affection and ensuring the contentment of a loved one.

In the palliative context, nutritional issues can release deep emotions for the patients, carers and health professionals involved (Hopkins, 2004). For patients unable to manage an oral diet, their inability to consume food can symbolise loss and failure in contrast to the pleasure it gives under normal circumstances. In head and neck cancer cases, food has been shown to transform from being a normal part of life taken for granted into an activity that becomes a burden as the disease progresses (McQuestion, Fitch, & Howell, 2011). Fatigue and lack of appetite often give rise to feelings of loss and deprivation since patients miss the process of eating and the social environment related to eating (Jacobsson, Pikl, Martensson, & Fridlund, 2004).

Adams and Glanville (2005) demonstrated that during their breast cancer treatment, women use food to gain control over their circumstances, to help them cope with their condition and find comfort and hope. Breast cancer survivors saw food as a source of social comfort as family members prepared foods which eased the physical pain resulting from the treatment such as mouth sores and mucositis. By being able to assist with food preparation, family members felt they were contributing to the patient's psychological wellbeing and the healing process.

With mealtimes said to set the rhythm of the day (Hopkins, 2004), it is fair to assume that changed dietary routines will have a significant impact on a patient's life. Changes in meal times for cancer patients often demand a change in the roles of food preparation. The inability of patients and carers to share or enjoy meal times together have been reported to impact on their relationships (Meares, 1997; Orrevall, Tishelman, Herrington, & Permert, 2004). Patients undergoing breast cancer treatment saw food preparation by a loved one as an act of compassion and affection (Adams & Glanville, 2005). Carers report changing their own eating patterns and weight as a direct consequence of their caring activities (Meares, 1997; Souter, 2005), demonstrating that they were putting the patient's needs ahead of their own.

Hospitalisation brings about a profound change to normal routines since the provision and preparation of food, usually a home-based activity, is now taken over by the institution. Despite patients being offered three meals and additional snacks daily, loved ones frequently continue to provide food as a way of demonstrating their affection. Interestingly, Neergaard et al. (2008) reported that relatives felt pressured by health professionals to take on a "semi-professional" role when caring for their loved one, a concept they termed "professionalisation". As a patient's intake deteriorates, family and carers often see failure to supply their loved one with nutrition as being a sign of abandonment (Bachmann et al., 2003) and it may be to avoid any hint of that that relatives continue to bring food.

In the palliative setting, food is seen to symbolise life and hope and as an important way to offer comfort to patients (Cimino, 2003). In a study of New Zealand hospice patients, food was seen to be essential to prolonging the life of a loved one and as a means for expressing the love which carers found difficult to put into words (Johnston Taylor, 2016). Meares also reported that food has multiple relational aspects including that of a token of love and its important role in social situations (Meares, 1997). Dame Cicely Saunders herself acknowledged this, encouraging family celebrations at the bedside and providing a drinks cabinet on every ward in her hospice (Shotter, 2006).

While eating is said to be one of life's greatest pleasures (Drewnowski, 1997), this often ceases to be true for patients in palliative care. A person's view of food changes from that experienced in times of health and happiness to the stress felt times of illness and pending death. But while in the palliative setting caregivers often assume a responsibility for sustaining their loved one with food (Meares, 1997) with the ultimate goal of keeping their loved one alive (Johnston Taylor, 2016), pressure to eat can arouse negative emotions and tension in patients and lead to conflicts with their loved ones (McClement, 2005).

When providing palliative nutrition support one needs to understand and respect the patient's wishes along with the expectations of their family (Fuhrman & Herrmann, 2006). These demands need to be balanced out against each other and consideration given to the alternative meanings of food during this time in life. Health care professionals can improve a patient's sense of dignity by seeing them as the person they are, rather than identifying them as the illness they have since when a patient's sense of self is not affirmed they are likely to feel they are not being treated with dignity and respect (Chochinov, 2007).

Despite health professionals' disagreements about the physiological role of food at the end of life, also important are the not always transparent psychological, social, spiritual, and cultural roles that food plays in our society (Eberhardie, 2002). If food or nutrition are unlikely to change a patient's prognosis at the end of life, it is these alternative roles which will or should become the focus of the health care professional, as these are just as likely to affect a patient's quality of life as physiological factors.

Unfortunately there is paucity of literature which deals with the effects of these roles at the end of life (Hughes & Neal, 2000).

As the last days approach, oral intake often decreases and it is assumed that cessation is a physiological component of the dying process (Ahronheim & Gasner, 1990). After 24 hours of starvation the body moves to ketonemia, a process in which as animal studies have demonstrated, there is a mild systemic analgesic effect (Byock, 1995) indicating that the patient may not feel discomfort from a lack of food intake at this stage.

In the last days of life oral intake should be offered only as desired by the patient with the aim of maximising comfort while minimising risks of complications such as aspiration pneumonia (Hui et al., 2015). Clinicians should focus on comfort, alleviating undesirable symptoms rather than insisting on oral intake while considering the alternate meanings food holds for the patient and the caregiver, ensuring adequate time is given to address caregivers' concerns around food and nutrition.

Current literature fails thoroughly to describe the patient's perspective of changes in oral intake and symptoms linked to eating and drinking at the end of life. It also fails to consider how food and nutrition impact on the relationship between patient and carer. The meaning of food in such a situation is yet to be determined and may in fact be different to those meanings given to it when one's life is not at stake. Determining these meanings and investigating the lived experience of patients, carers and health care workers in the last stage of life is the aim of this project. This will help to inform health care professionals on how to ensure patients receive the required care at the end of life.

Gaps in the Literature

Numerous areas for further research have been identified throughout the literature review above. Key areas for future research include strategies to manage and prevent nutrition impact symptoms and cancer cachexia along with the development of a deeper understanding of the issues faced by patients, carers and health care workers at the end of life. To date no effective methods have been reported that can help prevent or reverse cancer cachexia in a way that is tolerable to patients. While development of such treatments is underway, research is required into the psychosocial impact of the conditions that will enable clinicians to develop strategies to reduce the burden on both patients and carers.

Determining the effectiveness of interventions in cancer cachexia is currently flawed due to the lack of consensus on the definition of cachexia. Although studies have been undertaken in terms of differing models and understandings of cachexia, systematic reviews have been unable to come to a definitive answer regarding the role and benefits of nutrition. Although individual studies are suggestive of a supportive role, no formal consensus can be recorded at the present point in time.

Future studies need to classify patients according to their stage of cachexia to determine the point nutrition therapy may be of assistance and when it becomes physiologically futile. But in the absence of simple and cost-effective tests which can determine the stage of cachexia, this remains a challenge for researchers. Research needs to focus on the psychosocial impact of cachexia and attempt to develop models of treatment that can help reduce the deleterious consequences of this condition. To begin this process, health professionals require an understanding of the meaning of food at the end of life and how food intake impacts on the relationships between patient and carer.

Research needs to consider the lived experiences of patients, their carers and health care workers around food and nutrition at differing stages across the disease trajectory especially as the end of life approaches. With this and the gaps in the literature in mind the aims of this study are:

1. To investigate the lived experience around food and nutrition at the end of life for patients and carers both personal and professional
2. To determine the meaning of food at the end of life

3. To consider the impact of food and nutrition on the relationship between patients and carers

Chapter 3 Methods

What is Phenomenology?

Phenomenology is the study of the lifeworld, or the world as we experience it pre-reflectively (van Manen, 1990). It is concerned with how the phenomena present themselves to consciousness as consciousness is the way humans relate to and access the world as opposed to how we conceptualise, categorise or reflect on it (van Manen, 1990). Researchers are interested in the common features of the lived experience of individuals who have experienced the phenomena being studied (Leininger, 1985; Starks & Trinidad, 2007), as it is their belief, that truth and understanding can be found from life experiences (Byrne, 2001).

Why Phenomenology?

Phenomenology allows the researcher to develop an understanding of the lived experience of phenomena taking into account the researcher's own experience and beliefs in the area. This is achieved by describing and exploring a participant's personal experiences as they have lived through the phenomena being examined.

Phenomenology was chosen as the aim of this project was to develop an understanding of patients' lived experiences rather than the testing the validity or otherwise of any particular theory. Thus the present project aimed to determine the important aspects and perspectives of the participant groups rather than validating the researcher's preconceived ideas.

Phenomenology was seen to be a research methodology with the least intrusive effects on a vulnerable population, while allowing the stories and experiences of individuals to be heard and retold in their own words. Phenomenology met the aims of this research.

History of Phenomenology

The term “phenomenology” was initially used in the 18th century by Kant (M. Dowling, 2007). However, Edmund Husserl (1859-1938) is generally identified as the founder of phenomenology (Jasper, 1994; Kockelmans, 1967; Omery, 1983), his theory having been inspired by Franz Brentano’s (1838-1917) notion of intentionality (M. Dowling, 2007).

Intentionality refers to the concept of the internal experience of being conscious of something; it allows us to question the secrets and intimacies of the world which form it (van Manen, 1990). The advantage of this approach from a research perspective is that it allows us to question the way we experience the world (van Manen, 1990) and in doing so, to become involved in the world in such a way as to become inseparable from it.

In establishing the theory, Husserl developed the concept of phenomenological reduction which enables the essence of the phenomenon to emerge. This process was revised by Heidegger and reinvented by Merleau-Ponty (M. Dowling, 2007).

Husserl also developed the concept of “bracketing”, whereby the researcher puts aside their beliefs and understandings of a phenomenon in an attempt to separate their personal knowledge from their own life experiences (Byrne, 2001). Although not included in all phenomenological approaches (Byrne, 2001) bracketing enables a phenomenon to be revealed to the researcher in its true form (Wimpenny & Gass, 2000) whilst preventing the researcher’s own beliefs and preconceived ideas from biasing the data.

Hermeneutic or interpretive phenomenology followed on from Husserl’s descriptive phenomenology. Hermeneutic phenomenologists such as Heidegger, Gadamer and Ricoeur emphasised the interpretation of the textual meaning of the data, resulting in the researcher uncovering the true meaning of a phenomenon (Cohen & Omery, 1994; Grace & Ajjawi, 2010). Hermeneutic phenomenologists believe, by describing a phenomenon in their own language, the researcher has already made an interpretation of the phenomena (Grace & Ajjawi, 2010). Van Manen supplemented this describing six steps in undertaking hermeneutic phenomenological research (van Manen, 1990). These six steps are enumerated below and constitute what van Manen called the “Human Science Approach”.

Phenomenology as a Research Method

Despite originating as a philosophical concept (Broussard, 2006; Dew, 2007; Richardson, 1999) phenomenology has been developed into a methodology and a qualitative research method (Broussard, 2006). In these terms, phenomenology is an inductive and descriptive methodology (Jasper, 1994; Omery, 1983; Strubert Speziale & Carpenter, 2003) concerned with how people give meaning to their lived experience (Starks & Trinidad, 2007). It provides its readers with an insightful description of the experience pre-reflectively, with the ultimate aim being “to transform lived experience into a textual expression of its essence” (van Manen, 1990). Phenomenology provides a retrospective description of a lived experience as compared to a participant’s understanding of their experience.

Max van Manen’s hermeneutic phenomenological human science approach was the research methodology chosen for this study. The outcome of a phenomenological study, which if done correctly is, in van Manen’s words, a description which “reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner” (van Manen, 1990).

Phenomenological researchers do not set out to validate a theoretical framework and claim not to hold preconceived ideas (Omery, 1983). As such they do not know what they want to discover; rather the process of discovery is oriented towards enabling the meaning/s of a phenomenon to be unearthed. Participants recall an experience in a way in which it brings back the meaning structures of the experience as they were lived through, and hence provide a description which can be identified as a possible interpretation of that experience (van Manen, 1990).

Phenomenology is becoming increasingly popular as a research method in palliative care as it investigates participants' lived experience of a phenomenon of interest, and helps provide an in-depth description of that phenomenon from a participant's point of view (Kleiman, 2004; Omery, 1983; Starks & Trinidad, 2007; van Manen, 1990). Although phenomenology has been successfully used in other specialties to study concepts such as demoralisation (Clarke & Kissane, 2002), empathy (Baillie, 1996), cancer-related weight loss (Hopkinson, Wright, & Corner, 2006) and cancer cachexia (Reid et al., 2009a, 2009b; Reid et al., 2010) it is also becoming popular in palliative care services. Researchers across various disciplines are using phenomenology to investigate topics such as spirituality (Asgeirsdottir et al., 2013; Seccareccia & Brown, 2009), pain and suffering (Morrissey, 2011), experience of dysphagia in oesophageal cancer (Watt & Whyte, 2003), sexuality and intimacy (B. Taylor, 2014) and also hope, in palliative care (Mok et al., 2010).

Phenomenology has been chosen in this study as the most appropriate and logical research method available to investigate the topic of food and nutrition at the end of life because the data analysis it yields can provide a deep understanding of the lived experience and problems faced by patients, carers, and health care workers around food and nutrition in the terminal phase of life. The use of van Manen's Human Science Approach (van Manen, 1990) is employed to enhance the description because of the insights it can provide into the meaning of food at the end of life.

Van Manen's Human Science Approach

Max van Manen's Human Science approach to phenomenology utilises the principles of hermeneutic phenomenology to provide a description of the phenomena under examination whilst providing an insightful interpretation of these through the textual practice of writing (van Manen, 1990). I adopted van Manen's approach because it maintains the sanctity of the unique nature of each human situation while enabling the goals of the research to be met. As recommended by Omery (1983), I did not expect to obtain duplication of data; instead each participant's information was accepted as reflecting his or her own unique experience.

Van Manen has successfully used his research technique for many years in the area of pedagogy. However, this method has also been used by other researchers in health-related disciplines such as nursing, psychology, palliative care and dietetics (Asgeirsdottir et al., 2013; Hakanson & Ohlen, 2015; Rodriguez & King, 2014; Sorrell & Redmond, 1995; Tighe, Blackburn, & Slowther, 2014).

Data Sources

Data can come from a variety of sources such as observation, interviews, reading of existing texts (Byrne, 2001; S. Cooper, Endacott, & Chapman, 2009; Starks & Trinidad, 2007), blogs, verbal diaries, photographs, paintings, storybooks, films (Grace & Ajjawi, 2010), biographies, poetry, and art (van Manen, 1990). However phenomenologists also believe that observing participants in their natural environment over time can provide insights into meaning (Starks & Trinidad, 2007). This form of data can be useful in situations such as when studying participants who may have difficulty in providing data through the more conventional processes of interviewing or studying written descriptions (van Manen, 1990). This was found to be useful in this study, especially in the last days of life when patients were often unable to verbalise due to their medical deterioration or loss of consciousness.

Datum for this study was obtained from interviews, focus groups, and observation. The primary data source was derived from semi-structured interviews conducted by the primary researcher who also convened and ran the focus groups. As per recommendations, a narrative structure was chosen with the interview structure being guided by the participant's stories (Sorrell & Redmond, 1995). Participants were encouraged to describe their own unique perspective of the phenomenon being studied rather than reflecting on or analysing them. The researcher asked further questions and probed more deeply when that seemed to be appropriate (Starks &

Trinidad, 2007). During the interviews, the researcher acted as a silent listener while the participant told their stories with minimal interruption.

Throughout the research period the researcher took notes of her observations relating to the food and nutrition at the end of life along with interactions between patients, cares and staff on the palliative care ward where food and fluids were involved. This note taking included field notes and observations taken during interviews and focus groups. The researcher recorded participants emotions, inferences and body language where appropriate, to add analysis and interpretation of the information received during interviews and focus groups.

Sampling

As recommended, purposive sampling was used to recruit participants who had experienced the subject of interest (S. Cooper et al., 2009; Starks & Trinidad, 2007). Typically the sample size in phenomenological studies can be anything up to ten participants (Starks & Trinidad, 2007). However, smaller sample sizes are acceptable as the researcher does not attempt to generalise their findings (S. Cooper et al., 2009). In this study, additional interviews were undertaken because the researcher was not always able to interview the patient's direct carer due to their unavailability and in some cases, the patient died before they could be interviewed. Data collection continued until theoretical saturation was achieved.

Authenticity and Credibility

The concepts of authenticity and credibility have long been debated in qualitative research. The following attempts to address and overcome some of the concerns about phenomenology and the project at hand.

The result of a hermeneutic phenomenological study is the description and interpretation of a phenomenon from the account of the participants who have experienced it. One however cannot generalise the results to assume the experiences of one group of participants are the same for every person who experiences the same phenomenon (Jasper, 1994). Although the uniqueness of the individual must be taken into account at all times, common characteristics can often be found (Jasper, 1994) and these studies are able to provide an insight into the phenomena which may be used by the researcher or reader in order to better understand the experiences of the subject.

In research, "authenticity" means that the research design does indeed measure what it sets out to measure (Golafshani, 2003; Jasper, 1994). van Manen (1990) avers that phenomenological research continually examines its own goals and methods in an attempt to come to terms with the strengths and shortfalls of the approach and achievements. Throughout this research, the author regularly returned to the goals and research questions to ensure that the project was continuing to work towards answering the research questions.

Some phenomenological researchers go back to study participants to ensure the authenticity of the findings and information received (Byrne, 2001; Jasper, 1994). This was not possible in this study because of the terminal nature of the patient illness, while ethical issues inhibited contacting carers to avoid causing further distress among the newly bereaved (Stroebe, Stroebe, & Schut, 2003). In this study, the researcher summarised the participant's responses with them prior to concluding the interview to ensure the information was understood in the way the participant had envisaged. This was also done with the carers, as it was feared that the participants may have revised or reflected on their experiences following their loved one's death. In addition to these methods, participants were requested to expand further upon their experiences where the researcher did not feel a deep understanding of the information provided had been achieved.

Credibility of qualitative study results can be heightened by using direct quotes from participants (Byrne, 2001; Jasper, 1994) as the resultant descriptions are presented in the participants' own words rather than reflecting researcher's interpretation of them. This is demonstrated in the results chapter which contains direct quotes to enable the reader to experience the results from the participants' perspectives. The authenticity can be improved by using techniques which improve dependability such as inter-rater reliability, team analysis and triangulation at different stages throughout the inquiry (Jasper, 1994). Dependability was also addressed in this research by ensuring an auditable process in which interview transcripts, data analysis and coding record were kept.

It has been suggested that if the phenomenological description is good the reader can give it "the phenomenological nod" because they see it as an experience they have had or could have had (van Manen, 1990). It is the aim of this research project that readers of the thesis will feel they have had or could have experienced the difficulties around eating and drinking experienced by the interviewees at the end of life. It is noted however that each person will have a different experience and transferability of results may not always be possible or appropriate.

Because of the vulnerability and sensitivity of patients as they approach the end of their life, it is important to realise that participants may sift or withhold painful or confidential information (Jasper, 1994). To overcome this tendency, Jasper (1994) recommends the researchers display attitudes that create a sense of safety, trust and acceptance. This researcher therefore strove to offer a warm, safe, trusting and confidential environment to participants. With the exception of one person, all participants were keen to provide information on all questions asked. (The exception chose not to answer one question because of the possibility that her answer could have been presented in a negative light and, as part of her less conventional treatments, she was refusing to consider negative thoughts and potentially poor outcomes).

Bracketing

In order to acknowledge my beliefs, personal experiences and ideas around food and nutrition at the end of life, were documented prior to the research taking place (see Appendix 1). In fact it was these experiences which sparked my interest in the topic and shaped the research question. While some of these ideas were investigated during the interviews, I attempted to ensure my experiences were acknowledged but did not bias the data received. To ensure that the participants' stories were heard, questions were posed in an open-ended manner and participants were encouraged to provide their own perspectives on the topics raised. The results are presented in the participants' own words where possible, to ensure that their stories could be heard in the way they were originally expressed.

Ethics

Ethics approval was initially received from the UNSW Human Research Ethics Committee and the CHCS Human Research Ethics Committee. Following the transfer of the candidate to the University of Sydney, ethics approval was also obtained from University of Sydney Human Research Ethics Committee (2012/1291). Copies of the ethics approval letter, Consent Forms, Revocation of Consent Form, and Information Statements can be found in Appendices 3-8.

Recruitment of Participants

The following inclusion and exclusion criteria were used for this study.

Inclusion Criteria

1. Patient admitted to a Sydney based hospital's palliative care unit,
2. deemed to be admitted for end of life care by the treating medical officer;
3. patient's primary diagnosis of cancer;
4. the carer is the primary carer for the consenting patient.

Exclusion Criteria:

1. Under the age of 18years;
2. unable to speak English;
3. patient admitted for symptom management and respite;
4. the presence of cognitive impairment, confusion, dementia, an altered level of consciousness;

5. actively dying

The study was explained to participants by the researcher prior to obtaining informed consent. This included the researcher reading and providing a written copy of the Participants Information Statement. Participants were informed of the aims of the project which were to look at what food and nutrition means to patients and carers when dealing with a life limiting illness and how changes in food intake impacted on daily living and relationships. Participants were informed of their ability to withdraw from the study and how to make a complaint if they so desired. Participants were given opportunity to ask questions about the study. The researcher then located a staff member from the ward to witness the participant's signature on the consent form.

All focus groups and individual interviews took place on the palliative care ward, either in the patient's room, the tutorial room or an office. The exception was the catering focus group which took place in the Hotel Services Manager's Office located in the kitchen of the hospital. There was one telephone interview. Interviews lasted between ten minutes and one hour eight minutes while the focus groups were between 30 and 46 minutes duration.

Patients

Nineteen patients participated in semi-structured phenomenologically driven interviews between September 2008 and April 2009. Using purposive sampling procedures, patients with a malignancy admitted for terminal care on the palliative care wards of a Sydney based hospital, were identified from the ward list. The researcher then liaised with the medical teams to determine the patients appropriate for inclusion in the study. The researcher approached each patient individually explaining the project and offering him/her the opportunity to participate. Prior informed consent was obtained from all patients who agreed to participate. No approached patients refused to participate although a small number asked the researcher to return at a more suitable time. Unfortunately, two patients' condition deteriorated before the researcher was able to interview them.

Following the interview, the patient was asked to nominate their primary carer. The researcher requested permission to invite their carer to participate. Eight patients were unable to nominate a carer because they lived alone or were not in regular contact with family. One participant died before her nominated carer could be interviewed.

The age of the patients ranged from 42-88 years (mean 66 years). The Patient Generated Subjective Global Assessment tool indicated that 17 of the 19 (89 per cent) patients were malnourished. Eighteen patients had lost weight while two patients were unable to quantify their level of weight loss. More details on weight changes and nutritional status are recorded in Table 6.

Country of Birth (n=19)	**Religion (n=19)**
Australia 12	Catholic 2
England 2	Christian 7
New Zealand 3	Jewish 1
Scotland 1	No religion 9
South Korea 1	

Table 1: Country of birth and religion of study patients

Carers

Carers were contacted using details provided by the patient. No approached carers refused participation. Nine carers participated in semi-structured interviews between September 2008 and January 2009. One carer was interviewed in November 2009 when his father had returned to the hospital after time at home. Informed consent was obtained from all carers. Five carers were currently married to the patient, one was an ex-partner, two were children of the patient, one was a sibling and one a parent.

Carers' ages ranged from 33 to 82 years (mean 61 years). One carer provided verbal consent to a phone interview as she was unable to attend the hospital due to transport issues. Interviews lasted between 15 and 51 minutes.

Country of Birth (n=10)	**Religion (n=10)**
Australia 8	Catholic 2
England 1	Christian 2
Italy 1	Jewish 1
	7th Day Adventist 1
	No religion 4

Table 2: Country of birth and religion of carers

Health Care Workers

Medical Officers

Senior medical officers (registrar and above) were approached to participate in the study. None refused. Medical consultants were given the option of participating in a focus group or individual interview. Three consenting medical officers participated in a focus group and a further four medical officers participated in semi-structured interviews at times which were convenient for them. All focus groups and interviews occurred between December 2008 and February 2010. The longer time period for interviews selected to make accommodate the inclusion of rotational staff who came onto the unit during the study period. Participants in the individual interviews were a palliative care consultant, two palliative care registrars and an oncology registrar completing a term in palliative care.

Consultants and registrars were interviewed separately to prevent registrars feeling uncomfortable in discussing their experiences and opinions in the presence of supervisors who could influence the outcomes of their training. Participants' ages ranged from 31-49 years (one participant chose not to disclose their age). Two were male and five were female.

Participants' qualifications ranged from first year advanced trainees to a medical officer with 16 years of experience in palliative care. The time consultants had spent in the research facility ranged from six months to seven-and-a-half years.

Country of Birth (n=7)	Religion (n=7)	Position Held (n=7)
Australia 6	Catholic 3	Palliative Care Consultant 4
England 1	Jewish 1	Palliative Care registrar 2
	Christian 1	Oncology Registrar 1
	No religion 2	

Table 3: Country of birth, religion and position held of Medical Officers

Nursing

Phenomenologically driven focus groups were conducted with nursing staff during regular in-service time in October and December 2008. All palliative care nursing staff working on shift on the days the focus groups convened, were given the opportunity of attending during work time irrespective of their level of education or experience. Fourteen nurses participated in one of two focus groups. The age of participants ranged from 20 to 57 years. The nurses who participated had been employed at the hospital for between three-and-a-half months and 19 years.

Country of Birth (N=14)	Religion (n=14)	Position Held (n=14)
Australian 6	Catholic 2	Clinical Nurse Specialist (CNS) 1
Chinese 2	Christian 5	Registered Nurse (RN) 9
Dutch 1	No religion 7	Endorsed Enrolled Nurse (EEN) 2
English 2		Enrolled Nurse (EN) 2
German 1		
Japanese 1		
South Korea 1		

Table 4: Country of birth, religion and position held of nurses

Food Service Officers

All food service officers on duty on the day of the allocated focus group in May 2010 were given the opportunity to participate. Only one staff member declined to do so and thus four consenting food service officers participated in a focus group held during work hours. Participants' ages ranged from 43 to 57 years and they had worked at the research facility for between 10 to 22 years.

Country of Birth (n=4)	**Religion (n=4)**
Australia 2	Christian 1
Macedonia 2	Orthodox 2
	Greek Orthodox 1

Table5: Country of birth and religion of Food Service Officers

English was the second language of three participants, as is evident in the direct quotes presented below.

Participants did not receive any reward or remuneration for participating in the study.

The Researcher

As the researcher is also the dietitian allocated to the palliative care unit at the research facility, patients were screened and interviewed prior to any dietetic intervention taking place. Interviews were held after work hours so as not to impact on the researcher's usual work load. Care was taken to ensure that nutritional treatment was not delayed or impacted by the patient's participation in the study. In cases where the patient reported interest in nutritional intervention, the researcher returned to the patient following the interview and provided the requested support.

As the researcher had been working in the palliative care unit for seven years prior to the research interviews taking place, care was taken to ensure preconceived ideas were acknowledged and personal biases did not impact on the analysis. Appendices 1 and 2 provide a description of the researcher's previous thoughts and experiences on the topic which have been documented and acknowledged with the aim of preventing bias.

Data Analysis

With the consent of the participants, all face-to-face interviews and the discussions of the focus groups were recorded using a small digital voice recorder. Files were transcribed verbatim, removing identifying names of individuals and places. Vocal inflections were noted on transcripts including pauses, group consensus, laughter and tears. Data were managed using NVIVO8 software (NVivo 8, QST International). During the phone interview, the researcher took detailed notes, recording quotes where possible. The steps of analysis are discussed below. Focus groups and interviews continued until the participant/s had no further information to offer. The researcher took detailed observational notes during the interview and in contacts with the participants post interview where relevant.

Van Manen's Six steps

Although van Manen reports that phenomenology does not dictate a set of fixed procedures, techniques or concepts that would govern the project, he avers that hermeneutic phenomenology is based on a dynamic interplay among six research activities. In his words, these are

1) Turning to a phenomenon which seriously interests us and commits us to the world.
2) Investigating experiences as we live them rather than as we conceptualise them.
3) Reflecting on the essential themes which characterise the phenomenon.
4) Describing the phenomenon through the art of writing and rewriting.
5) Maintaining a strong and oriented pedagogical relation to the phenomenon.
6) Balancing the research context by considering both its parts and the whole. (van Manen, 1990) (Page 30-31)

The first of van Manen's research activities can be seen in the introduction and the appendix in which the researcher declares her interests in the area of nutrition in palliative care and discusses her experiences which may have impacted on the research. Appendix 1, which deals with bracketing (Byrne, 2001), was written prior to undertaking the interviews and participating in focus groups to prevent the data from being biased.

It was the researcher's prior knowledge and unanswered clinical questions that determined the research question and led to the project being undertaken. The paucity of literature available on the topic further stimulated interest in it.

Van Manen's second step (*investigating experiences as we live them rather than as we conceptualise them*) was undertaken during the interviews in which participants described their experiences rather than reflecting on them. Questions were asked in a way that encouraged interviewees to describe and discuss their experiences rather than to reflect on and interpret them. Probing questions were used to bring the participant back to their lived experience if they deviated from the question posed. Further description was requested if it was felt that adequate information was not forthcoming.

Van Manen's third step (*reflecting on the essential themes which characterise the phenomenon*) was followed by reflecting on the essential themes uncovered during a thematic analysis of each of the interviews and focus groups. In this step, the researcher read and reread interview transcripts recording subthemes in an NVIVO8 database. Each participant type was analysed separately as it was envisaged that each participant group would have a different experience to offer. Subthemes were then analysed and joined to create themes as reported in the results chapter. During the process subthemes were refined, elaborated and when not inconsistent with the emerging theme, discarded. Following separate analysis of all five participant groups, themes common to the participant groups were derived from the data and analysed.

In taking the fourth step (*describing the phenomenon through writing and rewriting*) the researcher developed a deep and rich description of the phenomenon by writing and rewriting the themes uncovered above. In this step, the researcher presented and further developed the description through team analysis with supervisors ensuring that no themes or vital information were lost. Themes found were compared to the existing literature using the process of triangulation to ensure dependability of the data.

In the fifth step (*maintaining a strong and oriented pedagogical relation to the phenomenon*) the researcher strove to maintain a strong and oriented dietetic relation to the phenomenon by keeping to the questions initially posed and deriving themes key to the area of interest. This included implications of advanced cancer-affected dietary behaviours regarding oral intake and mealtimes. The relationship between patient and carer was kept at the forefront during analyses. Appendix 2 discusses the researcher's personal experiences following the death of a relative during the writing-up of this research. This section demonstrates the researcher's relation to the phenomenon following thematic analysis.

Van Manen's sixth step (*balancing the research context by considering both its parts and the whole*) was undertaken by considering the impact of food and nutrition not only on each participant group but also on the group as a whole. Themes uncovered during individual participant group analysis were then reanalysed within the hermeneutic circle process to develop overarching themes leading to a more comprehensive understanding of the complete phenomena. This hermeneutic circle involved rigorous reading, reflective writing and interpretation of the data (Kafle, 2011). Individual group analysis allows for the reader to develop a deep understanding of the issue encountered by patients, carers and health care workers whereas the overarching theme provides the reader with an overview of issues encountered by all participant groups and the effect this has on the relationships between parties. The common meanings of food in the context of palliative care were uncovered in this step.

The outcomes of these analyses follow in Chapter 4 and 5, and in the discussion in Chapter 7.

Chapter 4 Patient and Carer Results

Patient Results

Chapters 4 and 5 present the results of the phenomenological analysis of the data. Chapter 4 presents the patient and carer results while chapter 5 presents healthcare workers results. Chapter 6 considers the meaning of food. Where possible, in keeping with phenomenological methodology, results will be presented in the participants' own words to allow the reader to engage with the participants' thoughts and emotions using their own discourse and allowing the reader to develop an understanding of the participants' lived experiences. It is the aim of the researcher that after reading the results chapter, the reader will be able to understand the differing perspectives of each participant group and develop a deep appreciation of the issues faced in day-to-day life around food and nutrition at the end of life.

In presenting quotes, participants in this study will be referred to using the following designations:
P = patient,
C = carer,
MO/s = medical officer/s,
FSO = food service officer.
The number following designation indicates the participant number in that study group. Patients and carers are matched with C1 being the carer for P1.

Nurses' designations and participant numbers are followed by their highest level of qualification as this is likely to impact the information provided during focus group discussions. Their designations are denoted as follows:
CNS = Clinical Nurse Specialist,
RN = Registered Nurse,
EEN = Endorsed Enrolled Nurse,
AIN = Assistant in Nursing.

Table 6 presents the demographic data for the 19 patient participants and their carers. Two patients had more than one primary tumour at the time of interview.

Patient	Age	Sex	Tumour type	Nutritional Status (PG-SGA)#	Weight Change	Time to death (days)	Carer	Relationship	Age	Sex
P1	66	M	Squamous Cell Carcinoma Scalp	B	-18kg	127	C1	Wife	61	F
P2	47	M	Multiple myeloma	B	-10kg	6	C2	Ex-partner	47	F
P3	69	F	Non-Small Cell Lung Cancer	B	*	53	C3	Husband	77	M
P4	55	F	Renal Cell Cancer	C	-63kg	52	C4	Son	33	M
P5	42	F	Astrocytoma	C	-10kg^	18	C5	Mother	71	F
P6	71	M	Renal Cell Cancer	A	-16kg	1030	C6	Son	36	M
P7	69	F	Breast Cancer & Melanoma	C	-10kg	5				
P8	79	F	Oesophageal Cancer	C	-15kg^	156	C8	Sister	82	F
P9	51	F	Breast Cancer	B	-12kg	11				
P10	66	M	Lung Cancer	B	-15kg	100				
P11	61	F	Melanoma	C	-7kg^	8				
P12	56	F	Small Cell Lung Cancer	A	+6kg^	85	C12	Husband	54	M
P13	86	F	Colorectal Carcinoma	C	-20kg^	42				
P14	81	M	Prostate Cancer	B	-20kg	54				
P15	55	M	Lung (large cell) suspected Previous testicular cancer	B	-3kg	395				
P16	76	M	Mesothelioma	B	-8kg	168	C16	Wife	73	F
P17	84	M	Parotid Cancer &Chronic Lymphocytic Leukaemia	C	*	50	C17	Wife	80	F
P18	88	M	Transitional Cell Carcinoma Bladder	C	-44kg	21				
P19	48	M	Non-Hodgkin Lymphoma	C	-21kg^	unknown				

Table 6 Patient and Carer Demographics

A= well nourished, B= mild or moderate malnutrition, C= severe malnutrition

^ estimated weight change

*patient unable to estimate loss.

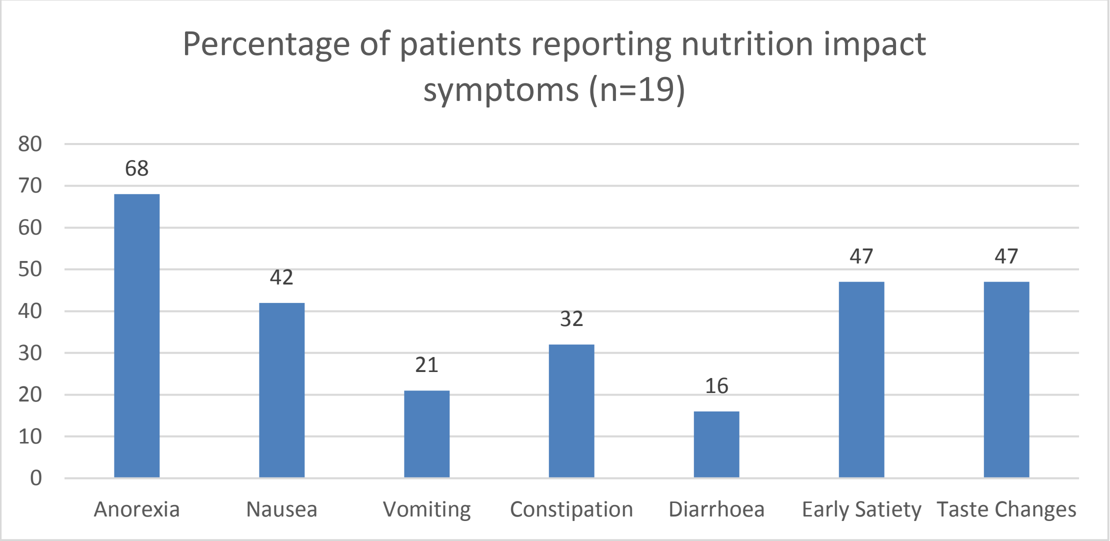

Figure 1: Percentage of patients reporting nutrition impact symptoms

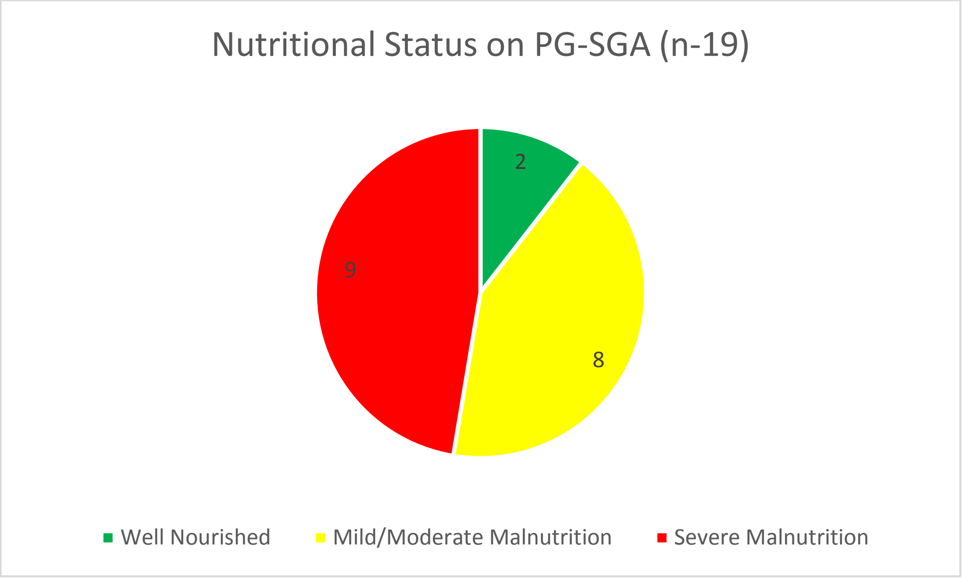

Figure 2: Nutritional status of patients in the study

Patients were keen to participate and have their stories told. At times, it appeared some did not have the strength to go into detail on the questions posed due to fatigue. This may have been a result of their medication but was potentially also due to the effects of caloric restriction or malnutrition.

The following major themes were derived from the data. Sub-themes were found within these themes.

1) The lived experience of weight change.
2) Changes to the meal-time experience.
3) The fight to live on.
4) Pressures to eat.

1 The Lived Experience of Weight Change

All patients experienced weight change. This theme records the lived experience of and reactions to this weight change on the part of both patients and their loved ones. Due to the vast quantity of data provided by participants this theme is presented in sub-themes.

1.1 Patient's reactions to weight change

Patients showed varied personal reactions to changes in their body weight, ranging from no concern and actual happiness to deep concern and apprehension. These three reactions are explored below.

Some patients were not concerned over their weight change.

> No, it [losing the weight] doesn't upset me at all. [I have been] always battling to lose weight. (P4)

> Okay, because I notice ... I have lost it myself, [pause] so it doesn't really upset me. And you have to laugh at yourself sometimes anyway. (P7)

> I did get up to about twelve-and-a-half stone and that was terrible because I was overweight and I knew it. So, when I started losing a bit it didn't bother me that much. (P10)

> No, I wasn't actually concerned about it [weight loss]. (P10)

> I don’t care. Like now I’m at the stage where I don’t care – I don’t care. I mean I don’t care if I put on more weight anymore or if I lose it. Before it did worry me that I was putting on so much weight, but no I don’t care anymore. (P12)

> No, it [the weight loss] hasn’t worried me. (P14)

> No, I’m not concerned about it – I’m losing weight, [pause] full stop. But I’ve been eating alright until the last few days. (P18)

Others were happy with their weight change. For example, P16 saw his weight loss in a positive light.

> At 70 years of age, you don’t worry too much about it. In fact, this weight loss, I thought it was a benefit insomuch as if you haven’t got it you don’t have to try to carry it around. I’m flat-out carrying around what I’ve got in any case, so any weight-loss would be a bonus rather than a hindrance. (P16)

Other patients’ spoke of concerns and worries associated with weight change especially when they did not perceive they had weight to spare.

> Yeah it [the weight loss] does worry me. (P2)

> Well of course it did [worry me], because I was ill and losing weight … I was losing weight, because I wasn’t all that fat to start off with. (P3)

> I’m losing weight and I definitely don’t need to lose that weight. I mean you know it is sort of, scraggy enough really in the skin without sort of losing more. (P7)

> I don’t like losing weight, no, no, no, no. (P11)

> Yeah, it has actually [upset me]. Yeah, [pause] oh I mean, I would have rather have lost weight [pause] than, put it on ... But yes, it does worry me, putting on weight. (P12)

P5 was disheartened by the change in her body-shape just one week after becoming unwell.

> I used to lift weights and stuff like that. So, I used to look considerably different ... I worked really hard to get that way. (P5)

Although initially welcomed, P10 became upset that his weight loss was more than desired.

> Probably pissed off that I was losing weight, but I knew I wasn't eating and I wasn't drinking as much. (P10)

P16 reported a similar reaction to his weight loss.

> Everything has fallen off … It's all skin and bone yeah ... Fading away to a shadow. (P16)

P13 spoke of her concerns regarding the cancer which caused her 20kg weight loss.

> What is it? What is cancer? Something really nasty and ugly, isn't it? Some sort of a growth that alights on your body and burrows into your flesh – that's what I think – and it's still in **ME**. That's why I've got to sort of try and be careful and get rid of it in some way. (P13)

1.2 Reactions of others

Changes in weight resulted in friends and relatives taking more notice of the patient's eating.

> They see me going down and thinner and thinner. Yeah. My family does, Mum does, she's always checking if I'm eating. And you know [pause] stuff like that. (P4)

P4 a 55year old lady who had lost over half of her body weight spoke of how her elderly mother commented on her large weight loss.

> … she'll make a comment like, look at skinny-binny there, and stuff like that. (P4)

Some patients had concerns directly addressed to them.

> My mother comments on how much weight I have lost and that I've got to start eating. So does my Dad … and my sister. (P5).

P7 also had family members comment on her weight loss

> Oh, they have mentioned that I've lost weight, [pause] and it was not very complimentary but (laughs) they're right [pause] yeah. (P7)

P12 commented on how her visitors felt they had the right to comment on her weight gain and how this impacted on her.

> And people comment …. friends and everything, they would say oh you look really fat in the face. You know [pause] that's nice shut up. (P12 laughs). You're fully aware of it yourself; you don't need other people telling you. And then next time they'd visit they'd say you're even fatter in the face than the last time. I'd think oh shut-up. So, people did comment and I didn't appreciate the comments. (P12)

P8 spoke of her family's shock seeing her weight loss.

> Well, my daughter-in-law said … oh my god, (patient laughs) what happened to you? And my daughter has said the same thing – what are you going to wear at Christmas, Mum, nothing will fit you … (P8)

1.3 Meaning of weight loss

Most patients realised that weight loss was deleteriously affecting their physical well-being. It was associated with reduced energy, weakness, or reduced mobility.

> well if I you know ... weight loss … you lack of energy. (P2)

> Yes, it has stopped me doing a lot of things. I used to be a swimmer, I'd go down and swim at the rock pool and stuff like that. I no longer do it because I can't walk that far to get there. (P4)

> And of course, it's affecting my mobility and strength which I'm not doing too well with when it comes to walking around and that. (P7)

> Yes, I haven't got the energy. I get tired very easily [pause]. But ummm I guess that's normal. (P8)

> I'm weaker and weaker. (P18)

P9's concerns originated from caring for her cognitively impaired mother. For her, weight loss was associated with loss of dignity.

> I used to look after my mum, she had dementia, four and a half years. Sometimes after the shower, I didn't have to put her in the wheelchair, just lift, with my two hands … because she was … 34 kilos. So, it reminds me of my mother, I don't want to end up in that way. I don't want … Very hard, lost her dignity … It reminds me, I don't want to die in that way. So, to put on weight is my first goal. (P9)

P15 saw weight loss as a reminder that he was not eating.

> Oh, yeah, I am not eating. (P15)

And for others it was a reminder of their impending death.

> That my life is running out and [pause] I know it. (P8)

Some felt it caused other health effects such as reduced immunity.

> It lowers your immune system … You've just got to keep your immune system working better. (P1)

For others, it merely indicated that something was wrong and that there was a need to determine why.

> Weight loss, what does it mean for me. It means there's something wrong somewhere and I'd like to get to the bottom of it. (P17)

P9's concerns were around not being able to have further chemotherapy because if she was to lose weight, this would impact on her chances of survival.

> In order to do the chemotherapy, [pause] if I lose a lot, I can't. (P9)

P1 who managed to stabilise his weight after significant loss indicated that weight gain helped to improve his strength.

> I do [feel stronger], a little bit. (P1)

1.4 Cause of weight loss

All patients except P16 failed to identify the tumour as the cause of their weight loss. P16 offered the explanation below for his weight loss; however, he too demonstrated a lack of understanding for the reasons for weight loss from advanced cancer.

> When you don’t eat food that you don’t like or you don’t eat food at all and you’ve got a virus that’s telling your body it’s dying, the weight drops off you like you wouldn’t believe … Instantaneously it falls off you. (P16)

P2, bed-bound and suffering anorexia, was in his final days of life at the time of interview. He died six days later, but still remained motivated to eat more in an attempt to keep his energy level up.

> The less food I eat ... The more I’m gonna lose weight [pause] so I need to. I need to try and eat more. So, … It keeps my energy up, sort of thing. (P2)

P13 was left frail and debilitated from her weight loss. To her the loss of weight meant that it was time to start putting it on again.

> Yes. To get well and start putting on weight again … I don’t want to be stuck like this fragile little old lady much longer. (P13)

Most patients were able to attribute their weight loss to a change in diet. For P10 this was a change in his alcohol and soft drink consumption.

> … I used to drink a fair bit, but I’d drink two bottles of scotch a week easy, … so, I suppose, drinking scotch and Coke, I was probably drinking 20 litres of Coke a week, so stopped that, that’s a lot of weight not going on. Yeah, so it did change. (P10)

P13 attributed her weight loss to shock resulting in a reduced intake.

> I think that’s shock – and although the food is very palatable, you don’t really enjoy it [hospital food] as much as you enjoy your own food. (P13)

For many others, the weight loss was simply attributed to a reduction in total intake

> [I was eating] small quantities and that’s when the weight shot down. (P11)

Others were unsure what had caused the loss.

> I’m not sure about that. I mean something obviously has but I’m not too sure exactly what it would be. (P7)

1.5 Desires to regain weight

Throughout the interviews many patients spoke of their desire to regain weight.

> Yes, [I would like] to get well and start putting on weight again. (P13)

Although P10 was not concerned about his weight loss, he spoke of a desire to regain weight.

> ... I’d like to put some back on again now, but not all that much, [pause] a few more kilos would be good. (P10)

Trying to gain weight was a difficult concept for patients who had fought to keep their weight down for much of their life.

> Difficult. Mind concept, … I [have] gone from this set up where I have been fighting to lose weight and now I have to get to a point where I probably have to fight to gain weight again – what’s going on? (P19)

P9 wanted to address her weight loss rather than sitting around waiting to die. The day prior to interview P9 implemented her own exercise regimen in an attempt to gain weight. P9 died 11 days' post-interview.

> You can't just sit down and wait for your death, you can't, you have to do something. (P9)

> It's very hard to gain the weight, in my case, but I try. I try. (P9)

P8 was disappointed when her weight gain attempts failed. She spoke of covering her body due to the shame felt due to her weight loss. She spoke of her inability to find clothes that would fit her now cachexic frame.

> Well I'm disappointed because I keep thinking if I eat, I eat and eat and eat and eat I've got to put it back on – mainly like all women, thinking I'll be able to wear my [pause] normal shoes, normal clothes, but I know I've got Buckley's. I don't think I'm going to put that weight on, and so I'm disappointed. (P8)

P1 admitted himself to hospital at one point to obtain medical assistance for his anorexia.

> It's just that I started to get a bit worried, when I started to lose too much… At one stage I just couldn't eat anything and I presented myself down at [hospital] Emergency and they put me in for seven days. They put me on a drip. (P1)

1.6 The language of weight loss

Patients spoke with great emotion when describing the look of their body following weight loss.

> … I am scrawny. (P5)

> There’s not much left [pause] which is disappointing because as I said I’m eating everything – but you know, the tops of my legs and arms are like sticks. (P8)
>
> Your muscle tone, your arm, everything just falls away, you’re just skin and bone. (P16)
>
> And when I stand up I look very thin … very thin legs and very thin arms. My back looks even worse. (P18)
>
> I’m just skin and bone, there’s nothing there. (P19)

Patients used metaphors or strongly descriptive terms to describe their new physical appearance, highlighting the deleterious effects of the emaciation experienced by these once healthy individuals.

> Mmmm. I have plenty of bones I could make soup with me. (P8)
>
> You can count the knobs on me spine. (P17)
>
> I am a sparrow. (P18)
>
> You could play a tune on my ribs. (P18)
>
> A skeleton [pause] yeah. Its [pause] it’s scary. (P19)

Due to their physical changes, patients found their weight loss to be not only visually disturbing but it also made them physically uncomfortable. P18 described the discomfort of lying down on an emaciated frame with bones sticking out.

> It’s like a bit of corrugated iron to lie on. Look. (P18)

For some patients, the visual image conjured by their weight loss reminded them of experiences from earlier in their life.

> Belsen. I think of Belsen. The prisoners of war. The British prisoners of war and the Australian prisoners of war. How they were treated. Starved to death. (P18)

The researcher found that this Nazi concentration camp image of starving, emaciated people is often held by older palliative care patients and carers as they reflect on experiences from earlier in life. Seeing the emaciation caused by cancer cachexia can be a very traumatic experience for those who knew of someone who had suffered under forced starvation.

2 Changes to the meal time experience

The advanced cancer patients reported changes to their meal time experience which arose either prior to or due to their hospital admission. This theme consists of four subthemes which discuss the changes experienced by patients.

2.1 Meal time frustrations and tensions

Patients spoke openly of the frustrations and tensions experienced at mealtimes.

> The only thing I don't like about it is the kids hassle me to eat. They want me to eat. (P4)

> Yeah Mum gets really frustrated that I am not eating. She thinks if I eat I will get better, so she gets really frustrated. (P5)

> There was just a lot of tension. (P5)

This left both patients and carers feeling annoyed, unhappy and upset.

> He gets unhappy when I don’t eat. (P4)

> I just get upset. (P5)

> That’s frustrating as well, and upsetting. It has affected our relationship. (P5)

> Just trying to eat stuff. They kept getting a bit annoyed with me. Well not really annoyed but. What can I eat? Because that was in the main period anything I ate, nothing would stay down. (P19)

Patients reported the pressure from family members resulted in vomiting or increased nausea as they forced themselves to eat to keep their loved ones happy. During the research interview, P5 indicated that she had vomited on a number of occasions after being pressured to eat. This was something also experienced by P19.

> Frustrating. Probably for them, frustrating, because, have this, you eat it and just about throw up – I can’t eat it, sorry. (P19)

P19, a 48-year-old man with Non-Hodgkin Lymphoma, moved back home with his parents after becoming too ill to care for himself. While he preferred fitting into his parent’s routine where possible, he found this difficult.

> [We sit] around the table together [long pause]. They said you can have a different mealtime if you want, but I preferred not to. I didn’t want to get totally out of it. (P19)

> I found if I fell asleep before it, I’d be annoyed with myself because there’s a fairly high chance of not eating it, because I’ve woken up too close to anything and [my] body won’t touch it. More annoyed bit frustrated. Yeah, it was [pause] difficult at times. (P19)

P16 also reported feeling frustrated when unable to eat the food presented to him.

> Ah well I try to [sit at the table while his wife eats], I front up for the meal but if I don't get through it – I know she goes to a lot of trouble. Again, that's frustration in itself. I try to decide what I'm going to eat, and what I won't, if I'm hungry or not hungry. (P16)

Following her diagnosis with a brain tumour, P5 a single mother and her pre-school son, had moved home with her parents. She now sat alone at meal times to avoid her parents monitoring every mouthful of food. Throughout the interview, it became evident that this upset her greatly.

Other patients reported feeling uncomfortable at meal times with people monitoring their intake. P19 discusses his experience below.

> Yes, I felt self-conscious with them watching what I was doing, what was going on. Even though everyone knows, yeah, I'm sick, you eat to keep the fluids and food on, so you don't get worse. So, it's just, I know that but I can't do anything about it. (P19)

When the pressure became unbearable, P19 found it easier to be admitted to hospital than to deal with the stress of his parents pushing him to eat.

> Quite a bit of pressure put on it – I don't think they realised there were things there I couldn't control and couldn't deal with. I said in the end. If you find that I don't have a problem with it, if you feel it's better for me to go back into hospital, it may be better, it's not [pause] putting a block on what you are trying to do, it's just it may be better for me to be in there. That's what pushed the last part, yeah go back into hospital because I couldn't cope with it and they were finding it difficult. So ... when I [saw] my oncologist [name removed], the last time before I came in here, the topic was raised with him and he said oh no, I think you should go back in. (P19)

P16 spoke of his thoughts on health and social situations in detail demonstrating his awareness of the interrelationship between food, health and social situations suggesting that the tensions and frustrations were inseparable from the food and medical conditions of those present.

> Most people are happy if they eat well and their digestive system and their bowels and everything is working well, they're really pretty happy. But if anything in that chain goes wrong it soon shows up in irritability and they're not happy with what's going on and everything else like that [pause] … But if anyone was crook or the food wasn't happy, or anything like that, it wasn't as happy an occasion. They say happy people are well-fed people. (P16)

P17 spoke of frustrations going to his family's favourite restaurant when he is unable to eat a full meal.

> I've gone in there and just had one entrée. It's not much good me ordering a meal. (P17)

P7 spoke of her frustrations and desires to share some chocolate with a visitor in the hospital, but had felt unwell after doing so. Sharing food was something that she identified she would like to be able to do.

> I'd rather like to be able to have some chocolate or something like that, but no the last time I had chocolate I was rather [pause] dry-reaching quite a bit, I didn't know if it was the chocolate or just that time. (P7)

2.2 Changes to mealtime routines

Patients reported changes to their usual meal time behaviours due to the illness and inability to consume meals. This was reflected in the comments of carers during their interviews.

P2 reported sitting at the meal table with his family prior to admission. However, his carer spoke openly regarding the difficulties they now faced. C2 spoke of how she positioned herself at the meal table to ensure she could keep an eye on P2. His daughter had removed herself from the family meal table as she disliked eating with her father, who now had difficulty eating and would unintentionally "spit" on his daughter whilst trying to consume his meal.

Other patients found that they were unable to participate in family mealtimes due to their illness.

> We used to sit around and eat together, but not anymore. (P4)

Rather than sharing a meal with his mother, C4 now watched her at meal times as he was afraid she would choke.

> No [we don't eat together] just with the choking, I just have to watch her. I'd be sitting there eating my tea and going like how big is her mouthful. (C4)

For other patients who were parents, being ill meant that they were no longer able to share a meal with their children.

> I don't think I've had dinner, or a meal [with my son] since January. (P19) – (interview conducted 27th April).

Prior to admission P11 enjoyed meal times with her family. She was aware her intake and meal times could be affected as her disease progressed. As a mother of two teenage boys, family meal times were of high importance to her and she had spoken with her husband regarding this. She requested her family continue sitting together for meals and discussing their day after her passing as this was an important and valued social experience for her.

> Probably when I go off my food altogether, I'll be lying in bed most of the time – I've said to my husband you have to keep on sitting at the table and talking about your day, not in front of the television. And I think he'll stick to that and still have it at the table [pause]. And also, I like us to all stay at the table until we all finished. (P11)

2.3 Isolation

Patients reported that broader social activities were impacted by difficulties in eating. Patients' voices reflected the sadness experienced as they longed to return to the normality of their day-to-day life. To avoid the scrutiny of caring loved ones or to conceal their symptoms, thus avoiding embarrassment or sparking concerns in others, many patients opted to eat alone.

> Social life is very limited. … my daughter [lives overseas but talks to mother on the phone] said that's because [pause] I don't eat and don't want to eat with people. (P4)

Prior to her cancer, P8 had been an active member of many social clubs. After having a stent placed for oesophageal cancer she chose not to eat out as her food needed to be pureed and she was not willing to take food with her or ask for her food to be blended in a restaurant as she deemed this socially inappropriate.

> I can't go out to dinner anywhere because I can't eat the food. I belong to two clubs, a View Club and a Probus Club. I can't go there because I can't eat the food. (P8)

> … they wouldn't serve pureed food [pause] so I can't go. And I've lost, well I wouldn't say I've lost friends but I can't go out with my friends, because we used to go out to lunch a lot with a couple of clubs that I belong to and have a good laugh and come home feeling really good … But I can't do that now. And I talk to my friends on the phone but it's not the same. So, it's disappointing. (P8)

Requiring a different diet also prevented P8 from having people over to her place for a meal due to her inability to engage in what she saw as acceptable social norms.

> I can’t really ask people over for a meal when mine is so entirely different. It sort of changes your life completely. I can’t go out to dinner because I can’t eat what they serve. So, it’s really like a, a stop, you can’t do what you want to do anymore. (P8)

P16 also identified difficulties in hosting friends, but associated this with depression.

> I wouldn’t say I’m a very good host for guests or anything, half the time I find it’s a battle to talk about anything, you know and you get a little bit depressed about what’s going on. At the moment, I’d say there are times I wouldn’t be a good host or good conversationalist or anything – just yes, no, get on with it, you don’t really want to talk about it. (P16)

P15 found it difficult to go out at night with friends like he would have previously due to tiredness and difficulties in getting to and from locations.

> ’Cause they know I’m sick [pause], and I probably would have knocked them back anyway so usually it’s a case of tiredness, by 8 or 9 o'clock I’m spent. … so rather than to … get into a lot of weird logistics it’s just easier to say sorry, or we do it during the daytime or something like that. (P15)

P4, who had previously been socially active, also reported reducing her social activities due to lethargy.

> Yeah. Sometimes I’m feeling too unwell to have people over. I very rarely have people over because I’m very lethargic, … my [in]ability to walk is tough. (P4)

P4 associated people not wanting to spend time with her as being due to her weight loss.

> I used to have barbies and people over and stuff like that, but no one wants to really come and see you, [long pause] bedraggled. (P4)

Physical symptoms such as vomiting were a socially isolating factor for P4.

> I used to have it [a cup of tea and be] very social, and I would often have cups of tea, but now I just get sick. (P4)

P4 lamented that she was not good company for others.

> Yeah well, the people you go out with and have dinner and that, it's no fun for them to have you sit there while you don't eat, and if they do order me a meal I only eat a quarter. You know and you feel terrible. My kids are used to "I'll eat your leftovers Mum". (P4)

P8 also lamented that the social interactions she once had were changed and now focused on sickness rather than health and fun.

> I think [my social interactions have changed] quite a bit really. They would probably say no it hasn't, [pause] but we don't have as much in common now because I'm not going to the same places that they are going to. We'll have a chat but every chat is 'how are you', [pause] which is rather depressing. So, you're always talking about your illness. And I'll ask how they are and nine times out of ten, because I've told them I feel lousy, they will say I've got so and so wrong with me. So, we didn't do that before, we'd have a laugh. So, it sort of changes your life [pause] completely. And now I would say 70 per cent of your conversation is about sickness [pause] instead of fun. (P8)

P5 found social situations placed additional pressures upon her and she was no longer able to enjoy the experience. She told the researcher how she now felt “out of the loop” despite her friends still visiting.

> It has [changed] a lot because I used to go out for coffee and cake and that with friends before. But I don’t do that anymore either. (P5)

> I don’t do that anymore. ‘Cause, I can’t eat and I can’t enjoy it [pause] I can’t. There is too much pressure [pause] and I don’t really want to go. (P5).

Changes in social interaction was reiterated by other patients who found they were incapable of undertaking activities previously enjoyed.

> There’s been a lot of changes, depending … what we’re doing – hot days you can’t go out, no barbecues, you have to really watch what you’re doing. (P4)

P19 identified loss of friendships as he was no longer able to engage in social activities with some friends.

> Some of them, which I thought, some of the relationships were breaking down beforehand because you tended to go out more but now it’s limited. Because everyone doesn’t want to, … you go what are we doing now, we are not doing anything. (P19)

P8 reported a similar experience.

> I think that because of my particular illness I’ve lost contact with a lot of people. I wouldn’t say they were really close friends, but … like going out to dinner and just having a chat and walking around the tables and having a bit of a chat and you haven’t seen them for a month, but its still, you’re still talking, you know. (P8)

P16 spoke of the changes in his friendships due to his cancer.

> You just got to accept it, you can’t do anything but accept it and make the most of what you’re going to do for yourself and your family and everything. The family rallies together and you get friends that you didn’t know and friends you thought you had aren’t your friends anymore … Everything changes. So, you go for a total, new living experience. (P16)

2.4 Changes with hospitalisation

Admission to hospital acted as a precursor to social change around food for some patients. Now unable to go out for meals and having the hospital instead of their family members provide food, limited patients’ ability to share the meal time experience.

P7 lived alone and was relatively well until just prior to hospitalisation, when a large hole in her pelvic bone was discovered due to a cancer metastasis. She was now unable to share a meal with friends as she had previously done.

> We used to go down to a café or something. (P7)

P18 and his wife were now unable to share a meal at the local club.

> We ate quite well. We didn’t go out so much, [rather we would go] down to the club. Because the clubs are very good … my wife and I drive down there for the midday meal, for an outing. Did, but that came to an abrupt end. When I came here. (P18)

The changes to meal sharing activities were not only missed by patients.

> My wife misses it as well. (P18)

Shared hospital rooms provided opportunity for social interaction. P8’s deterioration meant she was no longer collocated with other patients. P8 previously discussed with the researcher how she enjoyed the meal time chat with her roommates.

> I am concerned most of the time. I found it a big difference the last time I came in here. I was with other people in the room and we got along pretty well, so that sort of cut the day down. Now that I'm on my own it's a long day, so I guess I'm lacking company. (P8)

P19 spoke of how hospital meal times were solitary experiences with visiting hours preventing meal time socialisation.

> At [the local private hospital] everyone was out by mealtimes. I think they would have allowed it if I'd pushed it. (P19)

However, some visitors purposely came at meal times to share the patient's eating experience or observe their intake. P2 spoke of how his carer would come to visit him in the research hospital and have lunch with him. This was something that he spoke of fondly.

> Oh yeah, she comes in and she eats actually [pause] you know we have lunch together. (P2)

3 The fight to live on

Patients interviewed spoke confidently around expected improvements in their condition. This was despite medical officers having outlined to them the terminal nature of the cancer during the course of their medical admission. Despite all patients receiving information informing them of their impending death, many spoke of their aspirations and plans for the future.

3.1 Not ready to give up

> Yeah. I am not going to be one of these people that sort of gets in bed turns over and looks at the wall and says this is it. (P1)
>
> I am ready to fight. Yeah. As long as I can. (P1)

Around the time of interview, P1 had spoken with the researcher regarding matters in his life that he believed needed sorting before he died. This included business for his clients and taking steps to ensure his wife's comfort after his passing. Between the interview and his death four months later, P1 purchased a new small car for his wife and sorted out his business dealings. He was readmitted to the palliative care unit three times over the following months, each time presenting weaker and frailer. A day after his final admission P1's condition deteriorated and he slept for one week until his passing. P1, his wife (C1) and their extended family kindly shared their journey with me during his last days. His fight to continue ingesting an oral diet and receive adequate nutrition continued until the week before his passing. But finally, only hours after his final admission, he reached out for my hand and too weak to engage in conversation, simply said: "There is nothing that can be done now". He lay there holding my hand looking me in the eye. At this point he was aware that having food would be futile and from that point on, refused meals. This was only one day before he went into a sleep from which he never woke.

P15 demonstrated his reluctance to give up as he discussed his strategy to support himself financially over the years ahead - a plan he was unlikely ever to activate.

> It would be about three or four months ago. The [work place], I've got bags of sick leave. I may have to make a decision. – whether I, 'cause I've just turned 55 – whether I go out under the sickness retirement or I just try and tough it out for the next five years. I have to find out how much leave I actually have left, umm I've still got long-service and sickness, so but by my calculations I had about six or seven months. (P15)

Despite a terminal admission, P15 was discharged and survived a further 13 months' post-interview.

P13 spoke of her desire to improve her health status and enjoy their future.

> I don't want to be stuck like this fragile little old lady much longer, [pause] so that's why I shall look forward to getting better. (P13)

P13 died 42 days after the interview during the same hospital admission.

3.2 Hoping for a cure

P1 spoke of his hopes for a cure.

> Well they reckon there is only 2 per cent get cured so I might be in that cure pot too … You never know. (P1)

P11 turned to her faith in her time of need. From the time of her diagnosis she had looked to God in the hope that God would intervene to cure her. At times, she did not go along with recommended medical procedures and surgery. It is likely that P11's melanoma was curable if removed at diagnosis, but instead she chose to take additional work which had been offered to her as she felt this was God suggesting she did not need to go ahead with the surgery. For P11 there was a total reliance on an external locus of control as she placed all of her faith in God and his healing powers.

> Well, back in 2003 I had a brown patch on my arm and I was sent to a specialist who said I think that's a melanoma I'll cut it out. This is on a Thursday, so I made an appointment for the following Tuesday. But I have a very, very strong faith in God and as I read recently, whatever you have, if it's surgery if it's chemotherapy or radiation, if you don't have much confidence in it, it won't do you so much good. And at that time, I had just, my closest friend, her brother had died, having had a melanoma cut out one year previous. I don't know whether it ended up in his lung or his liver or where it ended up but it

> was inoperable and he died one year later. So here I am over the weekend thinking God, I've got more confidence in you. And then I went to church on Sunday and I just confirmed that I don't have confidence that if you cut that out it won't spread somewhere else. So, I rang and I cancelled that appointment. (P11)

P11 continued her belief in God despite being admitted for terminal care, hoping for the miracle she desired.

> I'm struggling but I'm just keeping God's word in my mind and my heart and believing, 'cause see what's going on in my body man can't fix, but God can. God can. (P11)

3.3 Food as an ally

Some patients identified food as a strategy to help them fight their illness.

> I would like to know what sort of foods are definitely the best for curing the… you know to get your immune system back in order. Because if I knew what the best ones would be I could eat them all. (P1)

> I think it's what you eat that keeps you strong. (P6)

P9, a South Korean-born, lady spoke openly of her food beliefs.

> All the time try to have a meal, as fresh as possible. I don't think I'm doing the wrong thing, because … actually processed food is not for us, even drinking milk is not for human being, it's for the cow … And then Western lifestyle is not right you know… heavy you know, that is not right... Maybe, Indian or Nepal, or some Asian style food is more natural. I've heard dairy product cause the [pause] breast cancer, I have heard. Before I came to this country, you know. I couldn't believe it but it's possible, and meat as well, because in my country now a lot of people they eat dairy product, cheese and creams and

> everything. … Meat was very expensive, not many people eat it, only for special event. So, it's a very, I have heard women has getting breast cancer in my country. But here, I don't know the reason but, maybe it's possible. Dairy product and red meat, lifestyle you know very busy. (P9)

During a nutrition consultation after the recorded research interview, P9 requested a meal of dog meat as she felt that this was a meat which was easy to digest. Dog is a delicacy in her home country, South Korea. P9 did not appear aware that this was not recognised as an acceptable request in mainstream Australia.

P11 also spoke of food choices as being an important principle in longevity.

> See I have always believed I will live a long active life – smoking, drinking, drugs, no way. Well, rich, fatty, sweet food – same thing – it's not going to prolong life. (P11)

> Look, food is your nutrition. It's like the quality of petrol you put in your car. Isn't it? … But I am gaining confidence in the fact that if maybe the food I eat is not quite what I would think is nutritious. God can, … it will still do me good, whatever I eat will build me up. And that's what I want. I am now eating to live. Eating to live. (P11)

Those struggling with eating spoke of their hopes and desires of regaining their appetite and once again eating.

> It will probably build up. Get my appetite properly. Eventually. (P1)

> I think I'll be putting it [the lost weight] back on once I get out and about again. (P7)

> Yes. To get well and start putting on weight again. (P13)

> But I still … I guess there's a certain amount of stubbornness in me that's telling me if I keep eating, I must put a little bit of extra weight back on. Maybe it's not, but I'd like to think that maybe it is. (P8)

P6 summed up his thoughts around food and what encouraged him to eat.

> If you don't eat you don't live, [pause] that's the way I look at it. (P6)

4 Pressures to eat

4.1 Pressures imposed by family and friends

Pressure to meet the expectations of loved ones around food and nutrition was reported by P3, P4, P5. The pressure to eat left P5 unable to enjoy foods offered.

> Cause, I can't eat and I can't enjoy it ... there is too much pressure. (P5)

P5 confessed she stopped eating in an attempt to block the pressure from her family to eat.

> …'cause I think if I eat more, they are pressuring me and they will keep pressuring me. And I think if I don't eat more, they will stop pressuring me. (P5)

Food gifts brought into the hospital by visitors added to the pressure for P5.

Although P4 felt pressured to eat she did so to ease her son's concerns.

> He thinks if I don't eat I'll die. So, it's very important to him for me to do that. (P4)

Although not evident in P3's interview, both C3 and the nursing staff spoke of how she would vomit when pushed to eat.

P5 hoped her mother understood her reasons for not eating were genuine and due to her illness rather than stubbornness.

> I just want her to understand if I can’t eat or drink. It is not because I am being stubborn, it is because I really can’t. It is just going to make it harder for me. (P5)

When asked if hospitalisation had eased the pressures for P5 she responded with.

> No. She is still pushing me. (P5)

P15, a 15-year survivor of testicular cancer spoke of the relief felt this time around when people did not pressure him to eat as they had done after his first diagnosis.

> There was more of an emphasis on you are wasting food, … but this time no one gives a damn whether you eat something or you don’t, which is a lot easier, since one less thing you worry about. (P15)

4.2 Self-imposed pressures

P14 spoke of self-imposed pressures as he felt self-conscious when he was unable to eat the meal he chose.

> It’s a lot smaller. I have got to order less, I usually order small but whether that makes any difference, I don’t know. Because it is wasted if they make a big meal for me… and I feel conscious of that. (P14)

P16 reported feeling guilty when he could not eat the meal prepared for him at home.

> Ah well I try to, I front up for the meal but if I don’t get through it – I know she goes to a lot of trouble. Again, that’s frustration in itself. I try to decide what I’m going to eat, and what I won’t, if I’m hungry or not hungry. (P16)

His concerns continued in hospital when he perceived his food wastage to be disrespectful to the food service officers who he believed were from “deprived” countries.

> ... they prepare beautiful food in this hospital, I come in here and I can’t eat that and I send it back … I know the [pause] staff that work here see all that food going to waste. They come from deprived countries they must think we’re slobs those people over here, you know not eating this. (P16)

4.3 Pressures imposed by health care workers

Difficulty following the advice of hospital dietitians resulted in additional pressure for some patients.

> Well yes [it was stressful following the previous dietitian’s advice], but I don’t find I’m … doing it ... I just get up during the day and think I can go all day without any food and not want it. (P4)

> I told somebody, I said oh that dietitian [name removed] is going to go crook at me again because I have lost weight. And she said I am not picking on you, she said. (P1)

P1 stated he was aware that the dietitian was looking out for his interests.

P5 spoke of her encounter with the acute hospital dietitian prior to her transfer to palliative care. P5 was offered nutritional supplements which she disliked.

> … just the nutrient drinks. That’s all … well I didn’t like them. (P5)

Despite disliking the nutritional supplements offered, P5 reported the dietitian continued to pressure her to drink them. She felt anxious when unable to consume them and when asked to explain her anxieties P5 expressed a fear

> … that I was going to be nagged to drink them again. I didn't want to drink them again. (P5)

Patients attempted to meet the expectations of their dietitian but when they were unable to do so, some modified the advice they had received so that it would be partly achievable for them.

> Oh well. I'm supposed to have two a day [supplement drinks]. The dietitian [name removed] told me that. [I] try and have two a day but if I don't, I have a coffee, and biscuits. Probably does the same thing. (P1)

> … I suppose it does do good. I was only having one a day and when I spoke to the dietitian at [hospital name removed] she said look, you could have two, have three, have four, she said: 'It won't do you any harm and probably do you a lot of good'. So now, that's when I put it up. (P17)

P5 had a closing remark she felt an important message to convey to health professionals to help them address and manage the pressures endured by patients.

> Well I think that maybe [pause] if social workers understand, a bit more about not pressuring people to eating, they could sit down with patients and their family and discuss all that. (P5)

Carer Results

> *Caregiving … is about acknowledgement, concern, affirmation, assistance, responsibility, solidarity, and all the emotional and practical acts that enable life. (Kleinman, 2010)*

Ten primary carers of advanced cancer patients admitted to the palliative care unit for terminal care took part in phenomenologically-driven semi-structured interviews.

Patients were asked to nominate which of their primary carers the researcher could approach to participate. Interviews took place following an initial interview conducted with the patient. Nine patients were unable to nominate a primary carer or passed away prior to a carer being available for interview. Carer demographics can be found in Table 6 in this chapter.

Carers consisted of six females and four males aged between 33 and 82years and included five spouses, two offspring, one parent, one sibling, and one ex-partner. All ten carers were keen to participate because it allowed them to articulate their concerns and experiences of caring for their loved one. One carer terminated her interview near the end, as the patient's lunch had arrived and she did not want to miss the opportunity of feeding her daughter.

The themes in this section are divided into two groups. 1) Those related to preserving life and 2) those related to the caring role. Many themes are interrelated as demonstrated by the quotations that were relevant in more than one area.

The themes relating to preserving life were:

5) Parenting of a sick loved one – a carer's new role.
6) The responsibility for life on one's shoulders.
7) Never giving up hope.
8) "Fighting the Fight" – doing "whatever it takes" to maintain life.

Themes related to the burden of the caring role were:

9) Carer distress.
10) Busyness – the process of always doing something.
11) To really to care means foregoing one's own needs and life.

Themes related to preserving life were as follows

5 Parenting of a sick loved one – a carer's new role:

We can understand that eating is in the beginning a matter of two people - the feeding adult and the eating new-born. (Bruce Moore, 1957)(P78)

In this theme, carers often demonstrated behaviour that infantilised the patient. The following sub-themes demonstrate the infantilising strategies and techniques used to strip the patient of his/her abilities to make decisions around oral intake. In many cases, while carers were aware of their behaviour, they deemed it appropriate because they were focused on the patient's survival.

5.1 Adopting a parenting role

Carers spoke of taking on a parenting role in caring for their loved one, a role that the carer and at times the patient was aware of. While examples of this are also demonstrated in later subthemes, C2 summed it up concisely stating:

> He felt [it] I am sure. He didn't voice it, but he felt like a child. Like I was treating him like a child. (C2)

C2 spoke of managing every part of P2's day, much like a parent would in do order to get their child to school on time.

> Tea time, bath time … toilet time, get dressed, get up, bed time ..., I didn't talk to him like a child. Well God I hope I didn't. But I had to and you know, set routines ... Like, once he got home, 8 am would be the start of his day, because that was when the pills started. So, you would wake him up. You have got to have your pills. You have got to have your breakfast; you've got to get out of the door to go to school. (C2)

5.2 Strategies employed

Carers used both covert and overt strategies to provide food and nutrition to their loved one. Covert strategies included slipping nutrition supplements into foods without the patient's knowledge and carefully monitoring intake, whereas overt methods included "bribery" (holding out rewards for eating), encouraging intake, and force feeding. These strategies are described below.

C5 spoke of adding nourishing supplements to her daughter's milk, much like a mother hiding vegetables in a fussy toddler's meal.

> They gave her some of those drinks, but she didn't like them, and I bought a tin of Sustagen … what she still does, is she'll drink milk and I'd sneak the Sustagen in the milk. (C5)

In a desperate effort to ensure her daughter received the nutrients required for life C5 blatantly denied that she added supplements to her milk. C16, the wife of a 76-year-old man with mesothelioma, also used this strategy.

> Wouldn't have Sustagen, 'cause he thought that was a bit icky, oh dear, so I used to tip that onto the Weet-Bix, sog the Weet-bix and then add the soy milk that we are used to having. He hadn't a clue that he was having it. (C16)

C5 and C16 deemed "sneaking" food supplements into patient's foods as appropriate as it was in what they perceived to be the patients' best interests.

Throughout the interviews carers spoke of closely monitoring a patient's intake. C6 recounted everything his father would eat in a day including the details on portion size. C4 acknowledged that he watched everything his mother ate, much like a parent monitoring the intake of a young child learning eating skills.

> … with the choking, I just have to watch her [pause] … every mouthful, Mum, just have a little bit. (C4)

Carers spoke of using bribing strategies used to encourage nutritional intake.

> Mum you have to eat and [pause] give her a lecture every afternoon and bribe her a lot of the times. She loves a cigarette, so [she had to eat to get a cigarette]. (C4)

> I'd sorta try an' bribe her… 'cause what else can you do? You can't smack mum, go into bed, anything like that. (C4)

For C4 this was a last resort approach when daily lecturing of his mother on the importance of food failed. A dedicated carer, C4 moved back home, taking indefinite leave from his employment and ending his relationship with his defacto partner, to allow him to provide better care for his mother.

Other carers described strategies to encouraging oral intake. C5 discussed encouraging her daughter to eat without pushing too far. She said:

> Well I have learnt, because she keeps saying I pester her. I have learnt not to, I just say … can you have just another mouthful … I try to encourage her to have [pause] just a little bit more than she has had [pause], … she is an adult … you can't force her. (C5)

Similarly, C3 discussed pushing his wife to eat

> I'm … you know pushing her, saying come on, and she says don't nag me. But I say, well, I don't want to nag you but I'm afraid if I'm not insisting – she says no … (C3)

C3 sits beside his wife as she eats, holding a plastic bag ready to catch any vomit when she has an episode of "reflux", indicating P3 was being pushed beyond capacity. This was identified by nursing staff when P3 was admitted to the hospital for terminal care.

> I always have a little a plastic bag [pause]. (C3)

C1 spoke of throwing food out and preparing another option when P1 was unable to eat the meal she prepared.

> I would just take it and throw it out, and say well what do you want now? (C1)

When encouragement failed some carers resorted to force feeding which was observed on a number of occasions during the research period. Nurses reported C3 tickled his wife making her laugh opening her mouth long enough to insert a spoonful of food. Another family played “aeroplanes” with an elderly woman, asking her to open her mouth as the spoon was swung overhead whilst simulating aeroplane noises, just as a mother might try to persuade an infant to open their mouth for another mouthful.

One patient, an elderly woman in the final days of life, had decided she no longer wanted to eat. The researcher observed her daughter force-feed her by “pistol-gripping” her lower jaw and prising her mouth open as if commencing cardio-pulmonary resuscitation and shovelling food in. The patient groaned and threw her head back and from side to side to stop the force-feeding.

5.3 Taking control

C2 knowingly modified her relationship with her ex-partner, P2, treating him like a child. She began making food-related decisions for P2 as if he was incapable of making these decisions alone.

> As for salads, we just point blank said no [pause] if he really wanted Kentucky or something like that, it was, in the beginning it was an out-and-out ‘no’. Well I am sorry. And he sort of, I think he felt like a child. (C2)

In assuming the role of decision maker and food provider, C2 deemed she has the right to tell another competent adult what he could or could not eat, taking P2's responsibility for his actions from him. In this situation, P2 had a low neutrophil count post-chemotherapy, hence consuming foods with a high bacterial load such as pre-made salads, takeaway foods and soft cheese went against by the advice of treating dietitian due to the risk of food borne illness such as Listeriosis, a pathogen known to cause premature death. When the patient requested these foods, C2 took control and refused P2 access to these foods.

C6 spoke of taking control of his father's eating by limiting his access to food. He feared his father would over-consume and gain weight or develop vision problems, due to poorly controlled diabetes. Interviewed months earlier, P6 had reported a 16kg weight loss.

> I actually got to the stage ... [of] taking the bread out of the bread hopper and only leaving 2 slices. So, then I had to control it [food intake] that way. And I will probably still control it that way, for the fact that it will be there, he will see it, he will eat it. (C6)

C6 did not believe his 71-year-old father, a man with terminal renal cell carcinoma, was capable of making appropriate informed decisions for himself. He intended to take his father back to Melbourne with him to live so he could better control his father's diet. This is not dissimilar to a parent controlling the intake of their young child not yet capable of making decisions regarding the types and quantities of foods eaten.

> I will say ok for the fact that he has no control over it. I do the shopping, I do the food preparation. So, he doesn't have a lot of control over it, so then he just accepts it. (C6)

For some carers, the primary daily aim revolved around getting their loved one to eat. C5 took control and assumed the role of food provider while attempting to ensure her daughter ate.

> Everything was about trying to get P5 [pause] to eat something. (C5)

P5 was admitted to the palliative care unit for terminal care after fighting an aggressive brain tumour for five months. She suffered from severe nausea and vomiting during chemotherapy. C5 worked tirelessly to ensure she ate and drank, attending the hospital at meal times, spoon feeding her daughter despite her ability to self-feed. C5 terminated the research interview upon delivery of the patient meals as she did not wish to miss the opportunity of "getting some food" into her daughter.

That C5 found it difficult to move away from her previous mothering role and felt responsible for her daughter's intake is indicated by her statement:

> I just feel, being her mother, I should be able to care for her more or care for her needs more. (C5)

C5 readopted her mothering role despite her daughter being highly intelligent and very capable of making her own decisions.

> Yeah but we go through what you have with young children ... If you don't see it, it doesn't worry you [pause] but when it is right in front of you [pause] it worries you. (C5)

C3, not unlike a parent imposing their own food preferences onto a child, spoke of giving his wife Italian cheese, which he saw as a treat despite her not liking it.

> I'd even buy some Italian cheese, yes. She's not so keen very much for cheese like that but a bit at a time, I give it on the dish, I'll put a little square piece of, feta cheese, and she eat it, a little bit of a treat, [pause]. (C3)

C3's determination and control of P3's diet did not stop when she was hospitalised. C3 requested nursing staff give P3 three Kettle Chips followed by a sip of ginger beer if she complained of nausea, as he thought this would prevent her from vomiting.

5.4 Conflict caused by the change in relationship roles as parenting takes over

Strain was placed on the relationship between patient and carer, as would be expected, when the carer treated an adult patient as they would a young child. C2 acknowledged that this "caused a little bit of conflict sometimes". This was also true of C5, who conceded that her attempts to make her parent (P5) eat were

> … putting a strain on the relationship [due to] the fact that I'm constantly badgering her [pause] to have something, or to eat something, and she's really getting annoyed with me for doing it. (C5)

C4 spoke of P4 realising that her son needed to take on the role of a "food police-person".

> She did realise that I had to try and make her eat too. (C4)

6 The responsibility for life on one's shoulders

As part of their parenting type role, carer's spoke of taking responsibility for their loved ones' intake. For some this included taking control of the patient's dietary options as discussed above. This increased responsibility was based around carers identifying food as essential for life.

> You eat to survive. (C5)

> I mean she has got to eat to keep alive. (C8)

Carers' desires to make the patient eat at times conflicted with those of the patients themselves. None the less, carers felt compelled to continue their efforts for the sake of the patient's survival.

> You have to be cruel to be kind, you have to. If they're going to survive. (C2)

> I've tried to put a big emphasis on eating, on just getting up and eating. Even if you're not hungry, please eat. (C4)

Carers assumed the patient was no longer competent to make food-related decisions. They argued that to maintain life, a patient had to eat and assumed the responsibility for ensuring this happened.

Carers monitored the patient's intake daily. Most carers could recall exactly what a patient ate prior to hospitalisation and how this met or did not meet their nutritional requirements.

C6, the son of an obese man with complicated diabetes and metastatic renal cell carcinoma, provided a detailed description of his father's daily intake, including the weight of cans of soup and the number of slices of bread he consumed.

> Dad's breakfast consists of … a full banana, a full orange then he will have four slices of bread. He could also have … a tin of baked beans, if not then a tin of sardines, so very much carbohydrate overloading … He will have a loaf of bread every day to day-and-a-half... He will have two rounds of sandwiches so four slices, there which consist of corned beef … So, high in salts and then he will have a relish on it, and then he might … have one tomato on each sandwich, or actually the sandwich round, and then some lettuce if he has it there and beetroot. He will have … a Pepsi Max every day, he always has that with his lunch. Then [pause] he doesn't snack so much in the morning but in the afternoon, he will snack a bit more. He will either have cashew nuts, I have found that he has been having chocolate biscuits and chips and stuff … At night,

> he would have meat and veg. This would consist of either … a rump steak which is the size of the plate, and then basically frozen veg, mixed veg, cauliflower and broccoli which he puts in a steamer or the microwave and heat up. Oh, sorry he will have a tin of soup beforehand as well. The tins of soup are 440grams ... And then he will have ice cream if he has got it … so he does eat a lot during the day. (C6)

As in the discussion on carers'-taking-control sub-theme, C6 had strategies that he planned to put in place on returning to Melbourne with his father[1] in order to control his intake and blood glucose levels.

> So yeah, so it will be a lot more controlled. I guess I will have to work more on snacks during the day … I guess I have been mean to a certain extent ... I will have to look at some sort of snacking during the day. (C6)

C6 took responsibility for the number of slices of bread his father consumed daily. He hid the loaf of bread from his father leaving what he perceived to be appropriate in the bread hopper. He decided that his father was no longer capable of making decisions that could impact on his survival. This was a unique situation as generally carers encouraged rather than restricted intake. However, as in all similar situations, the change in intake was focused around improving health outcomes.

When a patient was not eating, carers went to great lengths to ensure they did so, offering many alternatives and purchasing the best produce possible.

> I give him the best [pause]. I buy the best food that I can for him. I buy lamb cutlets for him. (C17)

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[1] P6 had been admitted to the palliative care unit for terminal care one year prior to the time C6 was interviewed. P6 was interviewed during the initial admission after which he unexpectedly recovered somewhat and returned home. His son was interviewed one year later at which point the patient, although approaching the end of his life, was not yet in the terminal phase and was aiming to move to Melbourne to be closer to his son.

When the situation arose where the patient was unable to eat, carers became alarmed and identified this as an area of great concern.

> So again, sweets he's fond of, loved his sweets – [but] then even started to push them aside. And I am thinking I'm in trouble here, because he had lost a lot of weight. (C16)

In this situation, carers resorted to strategies such as hospitalisation, bribery and begging in order to encourage oral intake. Carers spoke freely of the great anguish and pain caused by the difficulties they encountered.

> Oh, I had to go and put him into hospital … because he just wasn't eating, wasn't drinking. Couldn't eat [or] drink, couldn't do anything. It was awful. (C1)

C1 felt responsible for her husband's needs. She believed it was no longer the patient's decision to go to hospital but rather hers. Similarly, C4 felt the need to hospitalise his mother when she was unable to eat. Ultimately it was the carer who made the decision which they believed was necessary to prolong their loved one's life and to prevent a death by dehydration.

During periods of hospitalisation, carers stepped back and allowed medical officers to take responsibility for the patients' intake. At times, they questioned the decisions but, were happy to accept the recommendations of health professionals.

> I am pushing a little bit of sweets because of the weight loss. And then they said his blood sugar levels were up when he was in Hospital X … and I am thinking they're not putting him on a sugar-free diet here, maybe he should be, maybe he shouldn't be, so I said to the lass what's the go, she said oh well, just keep him going as is at the moment until we try and build up things and left it at that and no one said any more. So, I didn't get excited about that, I thought maybe it's not meant to be followed up. Whilst he's happy and he's eating and his condition [is stable] now, just make life happy. (C16)

Carers reported feeling responsible when patients had difficulties with the foods they purchased or prepared for the patient. C4 spoke of his mother choking on a bacon and egg roll that she had requested but which almost prematurely claimed her life.

> I remember one time in here she was getting better and she wanted a bacon and egg roll [pause] and I went and got her a bacon and egg roll [pause] like the second bite [pause] just started choking[pause] and there was like, [pause] got doctors and it was all, [pause]… practically, gone on for a while [pause] and you know you're like I just gave it to you [pause] and just panicking and eventually they got it out. (C4)

Unlike other carers, C8 did not feel responsible for her sister's intake. She had previously cared for her dying husband and appeared more respectful of her sister's wishes. In researcher observations made throughout the interview, C8 appeared to be detached from the situation and was somewhat cold in her responses.

> She is supposed to eat a little bit more often, but she's a very independent person and I don't want to sort of try and take her over. But I don't want to do that. I'd rather her make her own decisions but I'm there to help her if I can. (C8)

Although food appeared to be the primary concern for carers, they also took responsibility for other areas of a patient's life. For example, C2 spoke of caring for her ex-partner and the responsibility she took for not only his dietary intake but also for his activities of daily living.

C3 discussed assuming the responsibility for his wife's diet as he felt if he left her to prepare her own meals or take responsibility for her own intake, she would not have anything at all.

> You have to really experiment … it’s up to [you], and you have to give it to her, you have to try, because otherwise if I just leave it she wouldn’t eat anything at all. (C3)

The relationship between carer and patient will be discussed in later chapters which report the responses of different carer groups.

7 Never giving up hope

This theme considers the carers’ responses indicating they would not give up hoping the patient may survive. In this theme, carers looked for miracles, at times were in denial the patient was approaching the end of life and generally demonstrated they had a poor understanding of the patient’s condition.

7.1 Looking for a miracle

For some carers, “fighting-the-fight” was a recognition they would never give up hoping that their loved one would survive.

C16 discussed how the offer of palliative treatments gave her husband hope that his mesothelioma could be treatable.

> I think … he’s got a little bit more of a future than he had when he started off at Hospital X this trip ... because of the treatments they’ve done. And he was amazed to think they could do what they did. His attitude has changed. I noticed that yesterday. (C16)

P16 survived a further five months due to the additional treatments offered to him during his admission which was thought to be for terminal care.

A patient’s ability to eat was a powerful driver of carer hope for C5. She spoke of her happiness when her daughter ate.

> Excited and happy … Well, we're hoping that it'll just make her a little bit stronger, we know it's probably not going to cure her but you know you have to face reality. But we are hoping that it will make her a bit stronger so that we can take her out, take her home for an hour or two … something like that. (C5)

Despite being informed the end was near, C5 continued to hope for a miracle. It was this desire that drove her continual encouragement of P5 to eat.

7.2 Denial

In the spirit of never giving up hope, some carers were in a state of denial that their loved one had a terminal illness or that they would pass away in the near future. Carers often put their energy into preserving a life which was not humanly possible to prolong. In the following quote, C6 records that he felt that if his father was able to maintain his blood glucose levels, his eyesight would deteriorate only due to ageing, something very unlikely in a man dying at the end-stage cancer.

> If he starts to monitor them and starts to control his sugars then he won't necessarily lose any more sight at this stage. It will only degrade with age. (C6)

Here, C6 demonstrates denial regarding his father's condition, failing to identify that due to advanced cancer, his father is unlikely to live to an old age. C6 further demonstrates this in the following quote

> Well the cancer is actually stable. So, for the last six months, maybe even longer, it has been stabilised. So … what is happening now is all a result of his lifestyle, of what he has done. And the only side effect from the whole cancer and the brain tumours has been his deafness. (C6)

Despite P6 having brain metastasis, C6 feels he is now stable and that his cancer is no longer of concern, demonstrating his poor understanding of, or his unwillingness to acknowledge the terminal nature of his father's condition.

On the other hand, while C5 is aware of the gravity of her daughter's condition, it is clear that she has not come to terms with the poor prognosis.

> After having spoken to the doctors and they said that ... it doesn't make a huge difference what she eats, what she doesn't [pause]. I tried to come to terms with that but I don't think I have [pause]. And I'm still doing it [pause]. I'm still trying to tempt her [laughs, pause] and at times she says [pause] stop bullying me … [pause], into eating. (C5)

C5 is aware of the terminal nature of her daughter's condition, but cannot bring herself to give up hoping she may survive. She discusses how her husband is also in denial that they will soon lose their daughter.

> My husband is in a bit of denial I think that … he just feels if we can just get her to eat a little bit more, that's going to be a miracle. (C5)

C8 demonstrated denial of her sister's cancer and poor prognosis referring to her cancer throughout the interviews as her complaint rather than identifying the illness for what it was.

7.3 Poor understanding of the condition

Many carers failed to realise that a patient's anorexia or lack of appetite was due to processes caused by their tumour and was not a consciously made choice.

> And my feeling is that she's got to a stage now, [pause] she's turned off food because she hasn't eaten for so long and can't bring herself to [pause.] (C5)

This realisation was a cause of great distress for many carers as they took it personally when the patient would not or could not eat the foods prepared for them.

C2 appeared to be the exception to the theme of "Never Giving up Hope" since she had come to terms with the fact that P2's life was in the terminal stages. For 13 years C2 had not been in a committed relationship with P2, who was the father of her youngest daughter. Throughout the interview, it did not appear that she had any deep feelings for the patient and only took on the caring role when no one else was willing to do so. Although C2 spoke of strictly maintaining P2's dietary recommendations while there was still hope, as the end became imminent she relaxed these restrictions, allowing P2 to have anything he requested.

> When you had the chance of him getting better, a different story. We had to be very [pause] disciplinary [sic]. (C2)

Carers maintained hope by wishing for a miracle or denying the terminal nature of their loved one's condition. Maintaining hope helps carers to continue believing they will not have to live without their loved one.

8 "Fighting-the-Fight": doing "whatever it takes" to maintain life

Carers in this group spoke of doing anything possible to keep their loved one alive.

C4 purchased a puppy to encourage his mother to fight for life and his efforts were rewarded when his mother started to get out of bed more frequently.

> I bought her a little puppy [pause] a couple of months [ago] … and she started getting up [pause]. She's more worried about getting the dog food than her. (C4)

For other carers, the fight involved changing their daily routine to support their loved one. As discussed earlier in this chapter, in an effort to meet her husband's nutritional requirements, C16 changed her cooking routines, which involved cooking fresh meals four times per day

> He wanted just smaller meals – fine – well perhaps you should have four meals, maybe even five small meals … if you're going to keep your strength up. (C16)

C3 went to the supermarket up to twice a day to ensure the food offered was the freshest possible. C17 provided the best foods she could afford for P17.

Many carers days were focused around feeding the patient. C16 used P16's time in hospital to observe the foods he ate with the hope of providing similar foods when he returned home.

> The only thing that I'm thinking of now is what to put in front of him that he will like. That is why I have been observing what he has been eating and what they present to him in hospital. I think I can do better than that. (C16)

C5 tried tempting P5 with foods she had previously enjoyed, often without success. This was a source of frustration for C5 who spent many hours each day focusing on P5's oral intake. When P5 refused the offerings, C5 tried harder to encourage her daughter to eat.

> She's turned completely off food; you can't even tempt her with the things she used to like. (C5)

> Well, the main frustration was the fact that I did offer her everything that I thought she liked and I bought everything she liked, and even sometimes she [when] would say she'd wanted something and I'd specially go and get it for her, she'd have about two mouthfuls. (C5)

C5 admitted lying to P5 in an attempt to get her to eat. She denied adding Sustagen powder to her daughter's milk in a desperate attempt to get additional nutrition into her. In the quote below C5 tells her daughter that a bought meat pie was homemade.

> The other day, it was funny, she wanted a homemade pie so we pretended we home-made it. The butcher up the corner from us makes homemade pies, so we brought one of those and we brought it in and warmed it up in the microwave and we were so happy because she had about [pause] oh [pause] a sixth of this pie [pause] and ate it all and enjoyed it. (C5)

“Bribing” the patient as discussed earlier, can be seen as a strategy adopted by carers to “fight-the-fight” and as a strategy to maintain life. C5, felt the need to take on the role of “fighting-the-fight” when she accepted that her daughter had given up fighting for a while.

> I don’t think she has given up the will to live [pause] as such but I do think she has given up [pause] fighting for a little bit [pause]. (C5)

C5 turned to medical staff to see if anything could be done to encourage P5’s appetite.

> The only thing I am wondering which I am going to ask the doctors [pause] [is whether] she could have something to increase her appetite. You know how you used to have tonics or used to give your children tonics [pause]. [I am wondering] whether that would be of any help to her or not. (C5)

In desperation, C4 spoke of ‘phoning his sister overseas to see if she had any ideas on how to encourage their mother to eat.

> I used to be frustrated and ring my sis. My sister lives in Canada [pause]. What do I do [name removed], [pause] and try drinks, try this, soups, tried everything. (C4)

P3 didn’t skip meals as C3 ensured she ate something at meal times.

> Like she never not ate, ‘cause I’d make her, you have to have something [pause]. (C4)

He acknowledged that at times he pushed her to eat until she vomited.

> There's times like, I would keep feeding her and she'd just vomit it back up. (C4)

Similarly, C3 spoke of discovering a routine which would stop P3 from being sick

> I say okay, stop and stay there, and I just move the food on the side and after about ten minutes with a drink of ginger beer, a little drink she can go back to it. It's amazing. It's all my discovery … you see the food is under control more or less. (C3)

C3 also spoke of his wife needing to fight and be strong as a reward for the medical staff who had said she was lucky to be alive.

> She's really fed up, and I can't blame her, but I said look you have to fight, look you have to be strong. You see it's in your mind. I know the doctor said you're lucky to be alive so we have to pay the price for that care. (C3)

Whilst "fighting the fight", it was noted that carers pushed beyond patients' abilities to consume a little more food. Carers were more focused on obtaining a positive outcome than on the comfort and desires of the patient.

> At times she says, [pause] stop bullying me [pause] you know, into eating. (C5)

Carers often saw their effort in "fighting the fight" to be appropriate and justified. However, it was noted that many professional carers believed that the actions of lay carers were unjustified and inappropriate. For instance, while C3 talked about feeling that he was not coercing his wife, quotes from the nursing focus group in which participants discuss C3's insistence on continuing his routines up until P3's last moments of life, tell a different story. C3 said:

> Well, I feel I am not pushing, I am not insisting, but would you believe it all this time lately she never said no ... It just happens it's the right food for this sort of problem. (C3)

In contrast a participant in the focus group remarked that

> … her husband was obsessed with food. He had a strict schedule for her and when she deteriorated he just could not handle the thought of her not eating. (Nurs8RN)

> He would get cranky with us about the chips. [He insisted that] the chips help the nausea, [that] ginger beer helped the nausea. And she was only allowed three chips [pause] … I got in trouble because I handed her four (laughs). (Nurse8RN)

Like C5, C3 was always in the hospital at meal and snack times to ensure his wife consumed the foods he saw beneficial for her survival.

> Yeah, so I took my little 43 beans (Nescafe Blend 43 brand of coffee) for me and got the coffee with her. Now I'm going to try and do the same thing tomorrow and the day after, I'll come at the right time so she can have the Milo. That's important because the tea, I mean the tea is nothing. (C3)

C1, C3, C4 and C5 felt a sense of achievement when their loved one ate or when they received validation of their efforts from health professionals.

> A little thing like just now she asked for a yoghurt and I gave her a yoghurt and you feel like you've accomplished something. (C5)

> And even when the doctor said that yes, she had put on a bit of weight, I said oh gosh, we got the right stuff. (C3)

These quotes demonstrate the lengths to which carers will go to in a desperate effort to maintain their loved ones' life. They provide the carer with hope that the end may not be as near as health professionals are telling them.

C2 identified the futility in continuing to fight at the end of life. She realised that P2 should be allowed to have anything he desired as the end was near. She identified the time when it was appropriate to give up the fight.

> You have to be cruel to be kind, you have to. If, they're going to survive, definitely you know not like our … one's case. But you have to be cruel to be kind. You don't let them have what they want. Keep them fit and healthy. Put the right things in their mouths and that's about it. But if it is like P2, bloody hell, who gives a shit. If they want to eat a mud cake let them. (C2)

Themes Related to the Burden of the Caring Role

9 Carer Distress

Taking responsibility for maintaining a patient's life was a burden resting on the carer's shoulders like a heavy weight and caused significant distress.

For C3, the caring role was assumed due to their bond with the patient.

> I'm her husband, … 50 years together so we know each other very well. (C3)

For others such as C4 and C8, the role was something they found themselves doing when no other family members were willing to take it on.

> Her daughter lives up near Tweed Heads, and that makes it a bit difficult, it's more or less I feel it's dependent on me because I don't like her to … not have anybody. (C8)

C4 spoke of the pressure put on him in assuming a caring role especially when his mother would not eat.

> So, it did put a lot of stress on me. (C4)

> It was distressing but as I said there’s nothing you can do. (C4)

C4 also spoke of no longer enjoying meal times as his attention moved from enjoying his meal to anxiously watching every mouthful his mother took due to previous choking episodes.

9.1 Physical and psychological implications

C17, the 80-year-old wife of P17, spoke of them both feeling depressed over his condition. Throughout the interview C17 was frequently in tears, as her husband had been during his interview. Despite this, they wished to continue in order to have their stories heard.

> We are very depressed at the moment. (C17)

C17 spoke of her “carer rash” which she had suffered for the past four months. While hospitalised due to her rash, doctors were baffled by the cause which was initially thought to be due to medications, although once that was ruled out, it was put down to carer stress. C17 reported being blotchy and internally itchy, while needing to change the sheets on her bed daily due to bleeding from scratching.

The burden of caring was physically distressing for C8, an 82-year-old carer who needed to have naps to recover from the burden of caring for her sister.

> I was getting a bit tired sometimes and I have said to her you know I am going home earlier I am going to have a lay down … so that I can sort of replenish my energy. (C8)

C1, C4, C5 reported experiencing distress when family members openly doubted their ability to care for the patient despite them trying their hardest to encourage the loved one to eat and drink. C4 felt judged by his brothers when they returned from holidays and saw the weight their mother had lost.

C1 spoke of the distress felt observing P1's deterioration.

> 'Cause you could see them going down and down and down. And that was awful. (C1)

For C5 watching P5's reduction in oral intake was distressing, as it was a reminder her daughter could "starve" to death

> I felt upset [pause] really upset because it's just like watching her there starving and, I said to her you'll starve yourself [pause] I said this disease won't kill you but you'll starve to death, … and it's still ongoing. (C5)

> [P5's lack of appetite] has just caused worry and strain (C5)

For C4, not knowing what his mother wanted to eat was distressing.

> Every day it would be like, what do you want? What will you eat? What can I get you tonight? [pause] And it was just I never got anything back [pause]. [pause] Got so stressful in the end. (C4)

Inability to find a food P5 would eat caused C5 frustration.

> I got really frustrated because I asked her absolutely everything I knew that she liked and offered her everything I could [pause] and she wouldn't, [pause] she just refused. It was worse than [pause] a little baby you know when they

> won’t eat and you worry about them and you just shovel it in and you make them but you can’t make an adult. (C5)

C4 reported similar frustrations.

> I’d be that frustrated, what will you eat, what can I get you, what’ll you eat and she’d go well, think of something different … (C4)

The weight loss associated with deterioration and advanced cancer appeared to cause distress for many carers as it represented the gravity of the situation.

> It was terrible; I just hated [pause] seeing her getting thinner, losing weight, not eating. (C5)

For C4 and C17, the cachectic appearance of advanced cancer patients was a reminder of the war era and the emaciation suffered by prisoners of war.

> Looks like he has just come out of prison camp. (C17)

Carers identified weight loss as a sign that death was approaching.

> Well it’s probably getting closer to dying. (C12)

C16’s, distress was in the form of guilt around delayed diagnosis. P16’s general practitioner had initially misdiagnosed his cough as an allergy, missing his mesothelioma.

> That’s what makes me so mad, to think that I’ve got guilt for that – why didn’t I see more happening … You do, you blame yourself for these sort of things. (C16)

9.2 Financial burdens

For Carers 2, 3, 4, and 17 financial burdens placed significant strain on relationships especially in the case of C4 who was no longer able to work and relied on the carer's payments or savings to make ends meet.

> Well when you [P2] have an income you can buy a takeaway of your choice whilst we are living off my income this is what we have got, this is what we are eating, your daughter has got to eat too, this is healthy for her, it is healthy for you and you have to put your foot down and feel just [short silence] like nasty. (C2)

> I had money at the start … I had a bit of money and just slowly spent most of it … Like at the start we didn't think, they told us six months [pause]. (C4)

The distress experienced by carers was emotional, psychosocial, physical and financial. Despite this, carers did everything possible to provide the best care they could for their loved one.

10 Busyness – the process of always doing something

As carers filled their days looking after the patient they neglected their own needs. For some, their days were filled with cooking and food preparation and for others it was worrying about what the patient had eaten and what to feed them next. Carers were kept busy assisting the patient with activities of daily living such as showering, dressing and toileting.

C3 reported in detail how he busied himself throughout the day to ensure his wife received the best care possible. He spoke of his detailed food routines, making sure she ate "the right foods" at the right times and how he managed her symptoms. Throughout his interview, C3 provided fine details on every question asked, showing that his busyness involved many regimented routines and working to the clock. Below is a short example of how C3 kept busy:

> And after that she used to have a nice glass of Milo, and still up till two days ago, three times a day, I give it to her. So 10 o'clock, 10.15 all depends, sometimes she was late in the morning, was moved from 10 o'clock to 10:15, 10:30 even, and there I was preparing for her six nice, beautiful, round crackers, and three of them was again cream cheese with a bit of cheese like cheddar, but full cream I tried to because they said it's good for her. (C3)

In addition to monitoring P3's food and fluid intake he also paid a great deal of attention to managing her bowel movements, to her urinary incontinence, nausea and medications.

> So of course, I was with her, cleaning, changing, washing, everything was dirty. (C3)

C3 went to the supermarket up to twice a day to ensure the food he bought for his wife was the freshest possible.

> Yeah, ok. I'm at Coles or the other [Woolworths] every day, even twice. (C3)

Such busyness left C3 little time for himself, little time to consider the future or life without his wife. C3 was in denial of the reality that lay ahead.

C3's and C16's days were filled with preparing meals.

> It was a little bit awkward because having four meals meant that I am sort of eating four little meals too, which wasn't a problem I suppose, but it was just a nuisance – you were forever washing up, cooking, boiling. (C16)

C8, an elderly carer who lived separately from P8, spent her day going downstairs to her sister's unit to check on her.

> I just sort of go down and check on her each day, because we're next door but one. (C8)

C8 admitted she always liked to keep herself busy.

> That's me see, I never sit much of a day. That's the way I am. I've always been used to doing things in the day and sit down of a night. (C8)

C8 had offered to clean and wash for her sister on many occasions, but her offers had been declined. She was aware she could not push P8 into accepting assistance as P8 had always been a fiercely independent woman. When C8 was unable to keep herself busy assisting her sister with household duties, she would attend the local Probus group and go on outings to fill her days.

The process of busyness was exhausting for C2, C3, C4, C5, C12, C16 and C17, both physically and mentally

> It's just so tiring with pills and breakfast before I go [to work], making salads [pause] and then coming home and all that. When she came in here last week I slept for three days. (C4)

For C2 there was an awareness that the busyness would not last for ever.

> To move him by myself and to do things, ... it took a while. Then its lunch time, you know what I mean, and more pills, and prepare lunch, which would be a sandwich, a salad or leftovers, but heated good. Then its pill time again and it just became a real [pause] routine. It's like when you've got a newborn baby. That's how I looked at it. I've got a baby. You've got to get up and down, up

> and down, you know, make the formula up. That how I dealt with it in here. It will be over one day and that he will sleep through the night. (C2)

Carers were happy to be kept busy as long as their busyness revolved around maintaining their loved one's life. However, this left little time for carers to consider life after the death of their loved one.

11 To really care means forgoing one's own needs and life

A common theme identified by carers was the altruistic process of giving up their own needs and sense of self in order to do the best for the patient. It was as if the person they had been before no longer existed or was temporarily left behind, enabling them to become a devoted carer. Their own health and personal needs were no longer a priority as their attention and focus were redirected toward the patient.

11.1 Lifestyle change

Examples under this heading include a son giving up his job and relationship with his de facto partner to become the full-time carer for his mother. C4 disclosed that the relationship breakdown was the direct result of caring for his mother.

> I used to have a girlfriend and you know even when I moved out and moved back at mum's, I still had her for a long time but [pause] decided to eventually move back [pause] and like [name removed] she still comes [back] [pause] but we're not [together]. (C4)

Moving home was a big change for C4 who had to learn new skills to care for his mother.

> Before mum got really sick, I was with a girl and we'd sort of eat together and she'd cook [pause] and then sorta went home and I had to cook. (C4)

C4 spoke of exhausting his savings to financially support himself while caring for his mother. He left full-time employment when his mother was given a six-month prognosis at diagnosis. Two years later, with P4 still alive finances became tight and C4 returned to work to support them both. C4 spoke of his understanding boss when he called in unable to come to work at short notice. On days C4 did work, his day revolved around sorting his mother before he could go to work. Whilst at work he worried if she would still be alive when he returned. Thus, his whole being now revolved around caring for his mother. C4 had forgone his own hopes, dreams, aspirations and goals as a means of trying to keep his mother alive. He now found himself a single 33-year-old male without a permanent job, without savings and the sole carer for his dying mother.

For many carers, their entire day revolved around preparing food and encouraging the patient to eat. This was particularly evident for C5 who consequently felt guilty when she ate a meal due to P5's difficulty with nausea and food in general.

> For a while there, we felt guilty about eating ourselves [pause] Because you felt you were eating [pause] well not a big meal but an ordinary meal and she was having, you know, just a bite of toast or something like that. (C5)

When P5 was admitted to hospital for terminal care, C5 ensured she was at the hospital every lunch time in order to ensure P5 ate lunch despite her unwillingness to do so. C5 left very little time to herself as when she was not at the hospital she was caring for P5's young son.

Doing something for themselves became a treat for some carers. C1 and C4 spoke of their pleasure when able to do something they had done prior to their loved one's deterioration. C1 spoke of enjoying a meal similar to the ones she had cooked before P1's illness.

> The weekend he had meat and vegetables, which is getting back to normal [pause] eating. So that was good. It was really nice I really enjoyed all that instead of all of the fat food I have been eating. (C1)

C4 spoke of sleeping for three days when his mother was admitted to the palliative care unit due to his being exhausted by the effort of caring for his mother. He spoke of his inability to participate in activities many 33-year-old males would do, like going to the pub or out for dinner with mates because he needed to be at home with his mother.

C2 and C3 spoke of missing their independence as they were unable to go about their usual daily activities while ensuring the patient was safe and well. In some situations, the carer was unable to leave the patient alone even for short periods, or if they did, they worried about them the whole time they were away. If she needed to run errands, C2 would arrange for someone to sit with P2.

> You miss not being able to walk out the door. You had to make arrangements for someone else to be available … You can’t leave your 13-year-old at home alone with him, although I had to go to the chemist to get his pain meds sometimes. But you have to arrange for someone else to come to sit at the house while you go and do your shopping. (C2)

C3 spoke of giving up his favourite pastime golf, as he was no longer able to leave his wife at home unsupervised.

> And I can still play golf but I can’t any more. I can’t trust her. (C3)

11.2 Financial implications

Carers 1, 3, 4, 16 and 17 spoke of purchasing more expensive foods for their loved ones to entice them to eat. For some this was in the form of lamb cutlets and for others takeaway foods that the patient had previously enjoyed. Caregivers went without to provide these foods for patients.

11.3 Putting ones’ health needs after that of the patient

Throughout the interviews, carers spoke of forgoing their own health needs to meet those of their loved one. Carers changed cooking habits to support patient’s high caloric or texture-modified requirements. While some carers gained weight, others changed their diet to the detriment of their own health. C1 speaks of gaining weight after changing her cooking habits to meet P1’s needs.

> Stews and fat food, I used to call it. I’ve put the weight on and he’s lost it, ‘cause I wasn’t going to cook extra for me. Well we both ate the same. (C1)

C16 now prepared four meals per day for her husband in an effort to increase his intake. This left her with little time for other chores.

C3 spoke of changing his diet to meet his wife’s needs. While he had hypercholesterolaemia and had previously undergone a heart bypass operation, he prioritised his wife’s health needs over his own.

> I shouldn’t because I have more or less a lot of cheese which is good for her but shouldn’t be for me. (C3)

C3, a Jewish man, had lived through WWII and spent two years on the run as a child eating from garbage bins to survive. He lost contact with his parents during this time while his grandparents had been killed by the Germans. C3’s mission in life was to ensure that his wife was well cared for. Every waking moment was taken up with the routines he had developed in a desperate attempt to maintain his wife’s health. He spoke of not wanting her to experience the hunger he had felt as a young child during the war years.

> Wouldn’t like her to think how bad it is to starve, how bad it is to have to be hungry. (C3)

C3 prioritised his wife's care to the point that at night when he was exhausted he would prepare a lovely meal for his wife and then just improvise for himself. C3 was unable to share mealtimes with his wife as his routines included giving P3 his full attention, attempting to prevent her nausea and vomiting and to increase her oral intake.

C3 went to extreme lengths to provide P3 with the diet he felt would best help her fight her illness. This resulted in providing foods beyond those that the budget would usually allow and going to the supermarket frequently to purchase the freshest ingredients. P3 was given lobster and smoked salmon on a daily basis with the hope that they would help fight her cancer. Everything C3 fed her had the high quality he felt was important in managing her illness.

> Before lunch sometimes she used to have Nudie, it's a beautiful drink. And everything is very costly but we don't care about it ... And then she had this lobster. (C3)

In summary, in terms of the theme of the lived experience of weight change, patients spoke of their initial delight when they lost weight, but this was followed by concern when the loss became unstoppable. They disliked people commenting on their weight. Under the theme "changes to the meal time experience', patients spoke of their frustrations and concerns around these changes. Two further themes derived from the interviews were firstly, the fight to live on and secondly pressures to eat.

For carers, under the theme of busyness – the process of always doing something and to really care means forgoing one's own needs and life - carers demonstrated how they put aside their own needs to provide dedicated care to their loved one. Food was used by carers to demonstrate their deep love for the patient. It was not always possible for patients to return this love and hence carers unknowingly set themselves up for failure. For carers, the ultimate demonstration of love came in doing all they could to prolong life and keep their loved one alive for as long as possible even if this was not in line with the patient's own wish. In terms of the theme "never giving up hope” and “fighting the fight” – “whatever it takes to maintain life”, carers spoke of loving patients so much that they could not bear the thought of being without them.

From here I will move to discussing the perspectives of health care workers including their ideas on the experiences of patients and carers in palliative care. Health care workers’ perspectives on the topic were also sought as they too experienced the impact that food and nutrition has at the end of their patients’ lives.

Chapter 5 Health Care Worker Results

Medical Officer

Seven medical officers participated in the current study. All participants were presented with the same questions whether during a focus group or individual interview. MO1, MO2 and MO3 participated in the focus group while the remaining participants were present during individual interviews.

Compared to other health care worker groups, medical officers provided the most medicalised answers. The following themes were extracted from the data

1) Palliative care requires an evidence-based but flexible approach.
2) Food and nutrition constitute an uncomfortable but essential conversation.
3) Consideration of the needs of families/carers.
4) The medicalised role of food and nutrition in palliative care.

1 Palliative care requires an evidence-based but flexible approach

Medical officers spoke of continually modifying their practice in line with new research. MO3 was more accepting than her colleagues of patients' unwillingness to eat. She also demonstrated an awareness that this was something she should no longer regard as being part of the disease process.

> I mean I tend to feel guilty these days because I tend to be very accepting of that as a symptom, cachexia and anorexia, but I am now told we shouldn't accept it and we should actually really try and manage it much more actively than we have done in the past. (MO3)

MO7 spoke of current evidence-based practices for the medical management of anorexia and cachexia.

> My next strategy would be - kind of a late strategy - would be to consider the use of appetite stimulant medication. I would usually use. The only thing that has a proven benefit in clinical trials is reasonably high doses of medroxy-progesterone acetate and there are trials on going and I did a small clinical trial a while ago on the use of risperidone as an appetite stimulant and I know there is an ongoing trial looking at the cause. The progesterone derivatives are contraindicated in anyone with histories of cording type diathesis due to their underlying malignancy. (MO7)

Another area of evolving scientific literature is that of terminal hydration, a controversial area. The medical officers discussed their ideas on the topic and how their practice has changed over time. There was awareness that this can be particularly distressing for families who often plead for artificial hydration in the later stages of a loved one’s life.

> … and there is some evidence around now actually that a bit more hydration is probably not the worst thing in the world at the end of life anyway, and given all the other things we’re quite happy to give people, why not give them a bit of water? So, I don’t stress about that nearly as much as I used to. I’d much rather fight with the nurses than fight with the family. I think we need to be really flexible and really provide care and recognition of peoples’ distress. (MO3)

> I think the attitude in palliative care today to fluids is very different to how it was ten years ago and even five years ago. I really fight less and less about fluids and I really [pause]. A lot of people have ports so it’s not even so invasive to give IV first then sub-cut[aneous] fluids. Patients in bowel obstruction for example, who are really dry but enjoying their quality of life, fluids can really make a difference clinically to them, and improve patients with delirium, patients with marked constipation, patients who are suffering but not dying, not in the active stage of dying (MO2)

> There’s no evidence to say that giving fluids can cause harm at the end of life … (MO2)

When a less experienced medical officer was aware that they were not up to date with the literature, they valued a more senior medical officer’s opinion.

> There’s been bits of evidence about hydration in that really terminal actively dying phase, and I’m not sure that I’m well enough across the literature to really have an opinion, but the opinion of most senior clinicians and the one I’ve sort of taken on is that subcutaneous or intravenous hydration doesn’t contribute to comfort and may contribute to terminal secretions, and therefore is probably, on balance, causing more burden than benefit. And I think I don’t have enough experience but that is sort of becoming my clinical view. (MO4)

Interestingly this opinion differed from those of MO2 and MO3 and reflected a previously accepted belief about working with patients in the terminal phase.

Due to the lack of agreement about many areas within palliative care, the medical officers interviewed all conceded that they needed to be flexible in their work practices.

> I can well remember as a registrar here, myself and [the senior consultant] having kind of a big kind of altercation with a family about fluids. Not food but about fluids and [the senior consultant] having to calm it all down ... And that was kind of a big turning point for me realising that you didn’t just make these blanket rules of no fluids. The same thing applies to no foods. (MO7)

Despite the desire to be flexible, there was awareness that this was only possible when the patient was not at risk.

> … where if you’re confident, if we’re confident that what we’re doing is neutral and not going to cause any harm, then potentially we may do that. So, it’s a, I think it’s a fairly flexible approach. (MO1)

In extreme cases when dealing with demanding families, medical officer’s managed the risk in a way which put the patient at the least risk of harm while keeping family members happy and minimising their risk of catastrophic distress.

> Even that can get us into trouble with fluid overload. So, some of those cases that I can remember where we have had people who are just adamant that they would not allow no fluids and managing patient fluid overload has been very tricky, and there have been occasions where we really couldn’t even really negotiate stopping fluids in the situation where there was clear harm happening to the patients and I have had to say to the staff just turn the fluids off when they are not around and when they are we will just have to wear it. We have maximised all of the anti-secretive medications. It can be really difficult. People will accept the person is dying but they just will not budge on this one thing sometimes. So again, it is something that I spend a lot of time talking to junior medical staff about … And just emphasised the importance of individual assessment. That it takes a lot of time and care. It is not something you pass off in two minutes on your ward round. You may need to spend an extended time. (MO7)

2 Food and Nutrition constitute an uncomfortable but essential conversation

2.1 Difficult conversation with many connotations

Medical officers admitted that food and nutrition-based conversations are difficult but are an essential part of good medical care. Difficulties arise because a lack of oral intake has many connotations. It is not merely about the physical process of eating.

> It’s just that, they are just hard conversations. There’s a lot more going on than just food usually … It is about prognosis and it is about family dynamics and it is about people’s long-term attitudes to their bodies and the way they’ve lived in their bodies … They’re actually very profound conversations sometimes. (MO3)

> If you take it away from being a doctor and think of it as a lay-person, you do realise how important food is and you know culturally and socially how important it is to people, so you do understand why they’re worried about their food intake. (MO5)

Medical officers found it challenging to address issues when a patient’s food beliefs differed from the mainstream medical model.

> I guess some of my most difficult patients and my most challenging patients and my most unforgettable have actually been alternative therapy patients who have been on crazy insane diets … The hundreds of kilograms of pureed beetroot come to mind when I think of these people and coffee enemas and things like that. And I just find … sometimes people have got such ... strong and basically deluded beliefs, that they’re really difficult to deal with. That’s when I feel really inadequate … (MO3)

MO4 described difficult and exhausting conversations, during which it became necessary to have breaks to relieve the monotony and pressure.

> And sometimes if I’ve got a few families in a row that all have… the same sort of food issues, it can be like oh Lord, I’ve had this conversation today, I have had this conversation three times in a row today, I just need to go to a different ward. (MO4)

MO5 admitted falsely reassuring patients to ease their concerns.

> … you don’t want them to worry and so you falsely … reassure them: ‘Just eat what you can … What you need now is calories, so enjoy the things you thought you … shouldn’t eat, it’s probably fine to eat those now. (MO5)

2.2 Feeling inadequately equipped for vital conversations

Food and nutrition discussions are common practice for medical officers because many families exhibit distress over their loved one’s poor intake. Medical officers at all experience-levels spoke of feeling inadequate when discussing food and nutrition, especially in the presence of conflict between the patient and carers.

> Inadequate [laughs in embarrassment]. (MO3)

> And then I guess, you know, I often feel like my knowledge isn’t quite good enough as well and sometimes it’s just about trying to think laterally and come up with some inspired sort of suggestion and they’re like oh, okay, and then you think, right ok, so I don’t have to have the big deep conversation if I can walk away (laughing). We can live on cauliflower soup or whatever! (MO3)

MO1 recalled his surprise on discovering the importance of food as a new palliative care doctor.

> Starting palliative care and suddenly, in a way that really, I’d never thought about before as a doctor, food being on the table as a critical issue – you couldn’t ignore it, it was there, it was always going to occur, and how to deal with it, and perhaps right at the beginning feeling a great sense of inadequacy as a junior doctor dealing with it and then looking to your seniors in all aspects of palliative care. So that was a revelation, really to me, I remember that clearly. (MO1)

2.3 Finding common ground

Medical officers identified the importance of working with the patient and carer to bring them to common ground on food and nutrition issues.

> Look I think one has to be really careful … for us, you know, we understand the trajectory of the illness. We understand that it is a normal part of illness. For them it is often a big shift in their understanding of where their loved one is in the illness. They have to come to some understanding that the illness is kind of getting close to its end. And that is a really big thing, so I think, I have to be really careful, I have to take time. I have to consider their [carer's] needs as well as the patient's needs which as I said, are often quite different. The patient is often struggling to please them. Sometimes I have to step in and intervene and ask them please not to push the patient. To explain the patient is doing as much as humanly possible and that they have got to understand that the patient's needs are different to their own needs and that the patient's needs for food and drink is completely different to theirs or mine … (MO7)

MO7 spoke of the time spent conversing with patients and carers on food and nutrition with the aim of finding a mutually acceptable solution.

> Our role is to bring people onto the same page, to provide information, to explain the process of what's happening for both the patient and to the carer and being able to negotiate together and find a solution that suits the patient and that the carer is comfortable with, that we find fits in with where they are with their disease … It can be a long discussion just on food and it's really just trying to work it out together. I find that if you don't address it, it can escalate. So, you really need to address it. (MO7)

MO1 found pleasure in helping patient and carer find the common ground

> I suppose the memorable moments come when that asynchronicity if you like, starts to come together, when both the patient and the family are much more

> relaxed about food and things are a lot easier, and that’s a very good point, and hopefully through good communication [pause]. (MO1)

At times reaching common ground between the patient, carer and the medical officer was difficult. MO4 spoke of the frustrations experienced before reaching this understanding with patients and carers.

> It’s part of the clinical practice and it’s about meeting people where they are… and going okay, so where are you at? What’s happening? ... What can I do to alleviate these fears and worries and concerns? It sometimes frustrates the living bejesus out of me because you think oh god, didn’t we have this conversation yesterday? – but that’s often a marker of ‘have I really got to the core or central issue of what’s going on here’. If you’re getting frustrated because you’ve had the same conversation three days in a row, maybe you’re just having different conversations. (MO4)

2.4 Personal influence

Conversations on food and nutrition were confronting for MO2, MO3 and MO4, requiring them to address their own personal issues with food.

> Personally, does food have an underlying meaning? – well yeah, I’m an overweight chick, I’ve been an overweight chick all my life, I’m struggling to lose weight. So, clearly for me there are my own sort of issues with it. (MO4)

MO2 reflected on how her own life choices and innate behaviours impacted on her practice

> So, it’s sort of, I’m very maternalistic probably – or [removed for privacy] (lots of laughter) chicken soup! ... at that very end-stage, I’m far more lenient, but I actually have put a lot of emphasis into finding a diet that is non-burdensome but maintains quality of life. (MO2)

2.5 Focus on Quality of Life

All medical officers reported focusing on caloric intake at the end of life rather than on the nutritional profile of food, with the aim of improving quality of life rather than nutritional status.

> I will mention to them that we will let them eat whatever they want to eat. If they ask, I will say they can eat whatever they want to eat. Say yes, the focus is on quality of life, as opposed to any nutritional benefit. (MO6)

> But you do - even though in palliative care we often say increasing intake may not make a difference in terms of lifespan - you do sometimes feel like -you wish those patients were able to eat more because you think maybe that will make a bit of a difference, in terms of time or just their enjoyment of life towards the end. (MO5)

3 Considering the needs of families/carers

3.1 Importance of addressing carer’s concerns

All medical officers recognised the needs of the carer as crucial in palliative care and that these needs may have effects long after the patient has gone.

> I recognise, as [MO1] said, the real distress that families have. Sitting around the bedside, their trauma is huge, and also I think they carry their memories of that for a long, long time and their sense maybe that of guilt or anxiety, about what was or wasn’t done. So, I think attending to that – again, as long as there’s no harm being done to the patient. (MO3)

The importance of dealing with the concerns of carers increased when the situation had the potential to lead to catastrophic distress.

> However, you can have situations where [pause] you’re pushed, where the whole situation has been pushed to a situation where the family is almost in catastrophic distress. (MO1)

MO4 highlighted that at times the wishes of families could not be met.

> But very often families and patients bring it up – they go ‘he’s not eating, doctor, you have to make him eat’. And you know my response is that I can’t, and this is a really difficult problem for everyone. (MO4)

Sometimes, families become so distressed over food and nutrition issues that medical officers are unable to address it alone and referral for an allied health practitioner is required.

> So, it is kind of a multifactorial strategy guided by the stage of the patient and the family and what they need. Sometimes the distress might be great enough that I would consider the involvement of the social worker for ongoing counselling. I certainly would want to let all of the team members know that this is an issue. So yeah I think this is a huge, huge issue. (MO7)

3.2 Underlying meanings

Medical officers identified that at times food was a surface issue that hid real concerns.

> Sometimes the food is sort of a cover, you know a layer on top of it, and when you get underneath you see they’re really worried that they’re going to die. (MO4)

At times this was seen as a cultural issue.

> There are some Anglo-Celt families that are really, really bothered by it and some people are worried and really consumed – no pun intended – by [pause]

> their loved one’s intake, and I sometimes think that, that’s a marker for their distress around their loved one’s demise. (MO4)

MO7 also identified reduced oral intake as a signal to the family that the end is near. This caused extreme distress for some families.

> I think some deep part of them, instinctively knows that once the patient goes off their food that the outlook is really grim … they absolutely panic and feel very anguished. For some people, they simply haven’t thought it through and they don’t actually have any understanding of what is likely to happen in the trajectory or the terminal illness. So, you know that, whatever the reason, a lot of the support and counselling has to be done for the relatives. (MO7)

3.3 Artificial hydration

Artificial hydration is a frequent concern for carers at the end of life. MO1 stated that concerns over these issues are like an automated response for families and that under those circumstances, the medical role is one of education and reassurance.

> Yes, yeah, well I think our role is very much an educative role and a reassuring role … You know were that’s coming from, that strong, almost instinctive, visceral sort of response to what’s going on – something needs to be done, and we need to do this, sure you’re in a hospital, so, the doctors and nurses can do this – and perhaps, and, and that’s a big part of our role to explain what’s happening in the natural course of things and the potential deficits or detriments of putting up intravenous fluids. So, it’s a difficult one, but yeah, with reassurance often that does settle. (MO1)

MO2 and MO4 complied with carers’ wishes for a period of time, as long as these did not burden the patient.

> If they really push and they don’t settle with my, you know usual explanation of benefit and burden, I will usually say okay, well let’s try … and if we find that

> the hydration is causing a burden then I'm going to stop it and that'll be my decision as a clinician, but I'm happy to go along with them for a time (MO4)

> … And if not giving fluid at the end of life has a negative impact on the family, then a bit of fluid, if it doesn't cause harm, can make a huge difference to somebody's acceptance of where somebody is at that time. I don't think we're artificially prolonging life for [pause] extended periods. And we will have discussions [around fluids being] futile and not futile [pause]. (MO2)

MO5 went along with families' wishes, reporting that families were usually willing to withdraw fluids once their burden on the loved ones was evident.

> It's more distressing really for families to keep the argument going. If they're really insistent, that sub-cut[aneous] … fluids will help, then we know that if we probably put a bag of sub-cut[aneous] fluids up, one litre over twelve hours, it's most likely not going to be detrimental to the patient. Obviously, I think that when they start to gurgle then physically the families can tell ok, perhaps this isn't the best thing, and we are explaining their lungs are probably filling up with a bit of fluid. And then I can't think of any cases when the family have then still insisted on fluids. (MO5)

MO1 concurred and reiterated the need for flexibility in palliative care practices.

> It's a process of discussion and negotiation. You know the whole thing of having very strict rules is, is difficult … takes away flexibility. (MO1)

4 The medicalised role of food and nutrition in palliative care

4.1 Prognostication

MO6 associated nutritional status with albumin and oral intake.

> [Nutrition is] very important. Firstly, from a medical point of view. A lot of prognostic scores are dependent on nutrition and albumin [as] is well known. That correlates with diet. So, there is a clear correlation I think between nutrition and outcome … And I think also from a wellbeing point of view, in chronic illness or in terminal illness, nutrition is effective for many things so, I think if it is neglected it does correlate with poor outcomes at the end of the day. (MO6)

> Nutrition definitely, … I mean, so many diseases depend on your albumin but also like COPD, motor neuron. Once you start to lose weight, it is a bad sign. (MO6)

A patient's ability to eat is also used as a prognostic indicator.

> The ability to eat is a huge discriminator in who is doing well versus who is doing extremely poorly. And those who can't eat, … [pause] they are doing very, very badly. (MO6)

Anorexia and cachexia is also seen as an indicator of poor prognosis.

> If I have got a diagnosis of someone who is obviously already anorectic and cachectic, I think their prognosis is not long. (MO7)

> Cachexia anorexia is a sign that the cancer is progressing … But I mean it is usually the sign of aggressive disease, progressive disease, a disease coming close to the last stage. (MO3)

Throughout the focus group MO2 spoke of the discomfort felt when observing patients dying of starvation, MO2 indicated that this subjective feeling can influence clinical decisions.

4.2 The role of nutrition in palliative care and available treatment options

> I think it's really important while that person is maintaining good quality of life [they also] maintain good nutrition. And I think …, if somebody is active, if somebody is having palliative treatment, which most of the patients, whether they're diagnosed here and then a year's time, they'll still be having other treatments. It's very important – for skin integrity it's important, for vitamin deficiency syndromes it's very important, for just maintaining energy levels and good quality of life. And being flexible and understanding and knowing about all these fantastic supplements that are there makes a huge difference… both to the patient. I guess it's really our job is to maintain good quality of life…. but otherwise I think it's [pause] that's why dietitians need to be employed in palliative care – we need them! (MO2)

> Look it depends … what their actual prognosis is in terms of time. So, you know, sometimes being able to optimise nutrition in ways that might not have been explored, you know by a proper dietitian consult and the provision of supplements is hugely important. It will improve people's energy levels, it will improve fatigue. It obviously is going to help, you know resistance to infections, it's obviously a hugely important thing if somebody is having chemotherapy and radiotherapy even if it is palliative. Particularly for things like head and neck cancers. So that you know we might need to, give enteral feeding in those instances. So, it depends where they are at in their illness trajectory. And you know, it needs to be looked at individually. (MO7)

MO6 was willing to provide interventions for patients with poor appetite.

> In this setting I have a very low threshold to give them steroids, to encourage people to eat. The side effects of steroids are irrelevant in this setting… So, if someone can't eat I've got a very, very low threshold for giving them steroids. I think whatever can be done to make them eat. Yeah, I will do it. (MO6)

> The other thing we notice is sometimes when we use drugs like dexamethasone to stimulate appetite it can result in a profound change as well. So suddenly, you know people really are hungry again and they are quite focused on food in a way that's quite interesting, because they value it because you know they'd lost it and it's come back. It's quite interesting to see. (MO3)

MO3 agreed this was an area in which she needed to be more proactive and was indeed a treatable symptom.

At the same time, she provides interventions to assist patients to eat.

> Because eating seems like a voluntary thing, and so when people aren't eating it looks like voluntarily they're giving up … And sometimes I think we can come into that equation with medications and programs and stuff too. (MO3)

MO7 treated symptoms medically and when this failed would consult a dietitian.

> If I have controlled symptoms and things are no better, then I would talk about the options which include a mandatory consult with the dietitian … to talk about dietary supplements and what their actual diet is. I usually have a talk about not worrying about the so called healthy balanced diet. And to be eating … as many of the things that they like that have got as good a calories as possible. I also counsel against fad diets and vitamins and you know, things that restrict protein and calories in particular in an effort to cure cancer which at this stage is obviously incurable. (MO7)

4.3 When food no longer impacts on longevity

MO4 spoke of the usual progression at the end of malignant disease when patients lose their appetite.

> So, depending on the underlying malignancy but for all of them in general, the appetite declines and decreases to the point where people are eating nothing

> or almost nothing in the few weeks or months before their death. And then usually in the last week or two of life people have, almost no intake, and certainly in the last few days of life people tend to have no intake whatsoever. (MO4)

MO2 added to the above by making the point that when nutrition is no longer important, food is for enjoyment only.

> As you head towards the terminal heart of the illness and the person is losing weight despite an adequate intake [or] semi-adequate intake, and the disease is obviously progressing rapidly, then it becomes for pleasure, [pause] to have a nice taste in your mouth – suck a lolly, eat a bit of watermelon, whatever gives you joy and pleasure is far more important. (MO2)

> Well If I have got a diagnosis of someone who is obviously already an anorectic and cachectic and I think their prognosis is not long. It [food and nutrition] may be something that I don't even touch on depending on what concerns are raised by the patient and the family. (MO7)

4.4 Food and Nutrition in a patient's last days

MO 2, MO4, MO5, MO6 and MO7 spoke of the futility of attempting to improve nutrition in a patient's last days.

> At the very terminal stage, … when it becomes futile and it's not improving their quality of life and it becomes a burden – that's very different. (MO2)

> In the terminal phases, I don't think nutrition is as important as the actual process of eating and the satisfaction that that gives. So, in caring for someone with a terminal illness I won't really put too much emphasis on nutrition but be very attentive to their need to eat. They want to eat. I will be very encouraging to eat as much and what they want. Independent of nutritional benefit. (MO6)

MO5 spoke of the psychological importance of food intake for families and their reluctance to address this at times.

> It’s pretty obvious I suppose, but once the swallow goes and they’re semiconscious and their families are really having to [pause] rouse [the] patient in order to try and force some food into them, it’s hard to see the benefit in that. It’s actually quite upsetting and you know we’ve got a particular patient at the moment that I can think of here where that’s kind of happening … because the family is so focused on the fact that it might help or that it’s offering some improved quality of life, I suppose to a certain degree we haven’t really said to the family, that much about that perhaps not being the right thing to do, but in the last few days we’ve started to say that really and truly if mum is comfortable you don’t really need to wake her up at dinner time when food comes around. (MO5)

> I am increasingly aware that … when people have been on nil by mouth and the speech pathologist has been and said they can’t safely swallow, once an end of life situation is declared one of the really important things for the patient in that situation is … in that real terminal phase, it may be really important for them to get the taste of food and drink at the expense of possibly aspirating, so we will have those conversations. (MO7)

MO6 mentioned the psychosocial benefits.

> Psychosocially it is important for patients to maintain adequate nutrition throughout. The pattern reflects that. Also, it is important for their carers, their family members as well. I think they see someone is eating well, obviously, they feel better about it. (MO6)

Three medical officers identified one’s cultural background as impacting on end-of-life food related issues and the need to treat each patient individually.

> The Mediterranean sort of cultures, the Greeks and Italians are very sort of ‘he must eat, doctor, he must eat’. And the Spanish, just around that Mediterranean area. The Chinese get very obsessed about how much they eat, and what they eat and when they eat. The sort of Lebanese/Arabic cultures, … some members of that sort of group get really fixated and others don’t care so very much. And then for some religious groups, I think it’s the Buddhists, … have an idea about feeding. I remember really clearly one Indonesian family that just needed to keep feeding and feeding, and that was from a religious point of view, but I can’t remember what their faith was. They just had to, they said no we can’t not give them the PEG feeds doctor, can’t you, … give them something more. (MO4)

> …For religion it has significant importance, and for Buddhists for example, to die with food in your mouth has significance … (MO2)

> And we have had the occasional patients here, that I can remember well, who needed culturally to have food in their mouth as they died. And there has been huge, negotiations and difficulties with getting the nursing staff to understand that that was ok. So, I guess it is a really individual thing and you know, you must be really individually as well as culturally aware. (MO7)

Nursing

The following themes were derived from the nurses’ lived experiences of working on a palliative care ward.

5) Caring from the heart.
6) Being caught in the middle.
7) Control.

5 Caring from the heart

5.1 Drawing from personal experiences

Nurses' own experiences shaped their practices and beliefs as they related to the patient's situation.

> 'cause even when I was sick I couldn't eat for five, or ten or eleven days. Then after three days I couldn't feel [hunger] anymore. [Agreement from the group]. [During] the [first] three days [I] feel hungry but just couldn't eat. But after three days they had to make me [eat]. Yes [pause] terminal patient, they can't feel it anymore. (Nurse1RN)

> But I understand that point too because my father was dying of cancer and he wanted water. Refused anything else and every time he had something to drink, he choked and he started coughing but he wanted water so I just gave it to him. So, I can understand the people here, they say I want something to drink … (Nurse5RN)

5.2 All intake must be pleasant and necessary

Patients' comfort was at the forefront of nurses' concerns. They did not wish them to experience unpleasant tastes, for example.

> The thing that I hate is when somebody is barely conscious, [and] that every meal time we are giving them crushed up meds in Panadol. What they should be having is something they want and in the last stages and you are giving these bitter awful medications and you think isn't this awful. (Nurse3RN)

Nurse4RN attempted to make taking medications more pleasurable for patients.

> That's why I think it is nice if you crush it and put it in some jam. (Nurse4RN)

Nurse5RN questioned the necessity of many medications in the last days of life.

> I think like we have a lot of people here that are so nauseous and they have a whole bucket full of medication with calcium and potassium and all bloody tablets. [pause] Is it really necessary? [agreement from other participants] at that stage? (Nurse5RN)

At times nurses gave medications to keep family members happy rather than for the patient's comfort.

> You have to take families, Panadol here. Its time [pause] Panadol doesn't do nothing. (Nurse1RN)

> That turns them off their dinner. But I think the family like to see you give a medicine ... It is sad, isn't it? (Nurse4RN)

5.3 Feelings of sadness experienced when a patient can't eat

In caring deeply for their patients, nurses reported sadness when patients could not eat.

> A lot of them don't eat at all. Which is quite sad really. (Nurse4RN)

Nurs4RN spoke in detail about a recent case of a 98-year-old woman who for 14 days had had no food or fluids following a stroke and a failed nasogastric tube insertion. In line with a Speech Therapist's assessment at the acute facility which had deemed the patient unsafe for oral intake, the patient's next of kin had chosen conservative care rather than invasive management, including artificial nutrition or hydration. The patient remained conscious for the majority of her admission and was denied food and fluids until she passed away 14 days' post-stroke.

> It was a sad, a sad sort of thing really. (Nurse4RN)

Other nurses found this case difficult as many did not agree with the management plan chosen by the family. Nurs5RN felt food and fluids should have been offered even if unsafe.

> I really think we should have tried something maybe. (Nurse5RN)

They also spoke of another woman in her fifties with three young adult children. The patient had refused most oral intake and induced vomiting when she did consume small amounts of oral nutritional supplements. This patient's CT scan did not show any active tumour just prior to death. As Nurs4RN stated:

> And there was a sad case too, remember that [name removed] that was on [the ward] and she just literally just starved, didn't she? (Nurse4RN)

Nurs2RN acknowledged it was her job to care in a way unique to a palliative care hospital which was not the case in the acute hospital system.

> But we are paid to care. That's different. That's not a general hospital. (Nurse2RN)

Caring from the heart meant that nursing staff would at times break the rules or hospital policies to provide patients with experiences that they felt would be pleasurable to them.

> During the weekend, we normally have fish and chips and some patients like on [the ward]. We probably will offer them and we will buy for them as well. If down stairs we can order nice hot food. (Nurse2RN)

6 Being caught in the middle

6.1 Feeling trapped

Nurses spoke of feeling that they were caught between the patient's and their family's wishes around food and nutrition. This theme of being trapped was commonly heard in the conversations of nursing staff. For example, Nurse11CNS estimated that around 90 per cent of families approached nursing staff to discuss issues regarding a patient not eating.

> I would say 90 per cent. At least 90 per cent. (Nurse11CNS)

> Yeah [pause] they will confront you about their food. (Nurse8RN)

Nurses spoke of family members resorting to force feeding patients and how this saddened them. Nurses wanted to stop this happening, but felt their efforts would be futile. They spoke of conflict between themselves and families as they fought for the rights and comfort of their patient.

> Often the patient is not swallowing properly and there are aspiration problems and they get chest infections. … the family are feeding, but the person has lost their ability to swallow. And you spend a lot of time trying to explain [agreement from the group] and that is when they don't like them on the thickened fluids and things like that. They want them back on to a soft diet or [pause] but they just can't get things down can they? (Nurse4RN)

> … even when you do explain (Nurse4RN): … then you go to do mouth care and you find all the [pause][giggles] … (Referring to food particles found in patient's mouth.). (Nurse3RN)

Nurses felt caught in the middle when asked by family members to force a patient to eat. Staff recognised that although the family wanted the patient to eat for survival, they were not willing to do so, and the nurse became caught in the middle of the battle between patient and carer. At times nurses went against their better judgement in order to keep persistent family members happy.

> Like I got one patient downstairs at the moment. The sons coming during the weekend said ‘oh my mum’s not eating and drinking very well, should [she have] IV fluids or sub-cut[aneous] fluids. And try to say like, you know, you guys have to **force** her. But I … said to him, no we can’t force a patient to do anything. But he said my mum is coming for respite and also [now she is going to] die. [agreement from other participants] You know, you should ask a doctor to chart something for my Mum, … but obviously, Mum’s condition is deteriorating [agreement from other participants] (Nurse2RN).

> One of the patients who passed away last week - I saw … four family members standing and force feeding [agreement from others] and then I pass [ed by] and then the wife calls me. If you feed my husband he will take [the food] [agreement from other participants]. I say no, no, no, no so we can’t, don’t make him upset. He gets upset and we go away like that [Agreement from other participants]. And then after that there is most, half of the patient’s family that think I have deprived him of his nutrition [Agreement from other participants]. That’s why he made me agree to give, give, give. Yeah, he had IV fluid before he passed away (Nurse1RN).

Nurses felt frustrated when families would not listen to them.

> Frustrated. Sometimes you know, especially if you felt they are really not listening to you. ‘Cause a lot of the time they will be aggressive towards you when you tell them not to do it because they are upset and they are emotional. You know you have to go in there and know you are going to have a conflict and what you are saying is just common-sense really if you thought about it. Someone is not awake so it is probably not a good idea to give them a cup of soup, but you know [family members] don’t generally respond well to being told it is not in the [patient’s] best interest to feed them. (Nurse13EEN)

Nurse4RN spoke of feeling caught between the family's desires and that of the medical team.

> Which I think the family finds really hard because they see their loved one can't eat and they keep saying to you, you know we want to do more, like put up IV fluids and things like that and then you know and that's not the doctors call. (Nurse4RN)

In this case, the family requested IV fluids for a dying patient and the medical team did not feel this was in the patient's best interests. The family then approached nursing staff requesting artificial hydration.

Nurse4RN strategically managed this situation by allowing the family to feel useful while reducing the risk for the patient.

> I have taught a few relatives how to just get a spoon with some water and spoon it into them in like really small amounts. Because they are just so obsessed about them getting a drink. Well sometimes the person is really thirsty aren't they? (Nurse4RN)

6.2 Feeling ill equipped to manage the conversations

Several nurses reported feeling uncomfortable about addressing families' concerns around food at the end of life and expressed a desire to have written information to give to families. They wanted management support when addressing these issues with patients and families.

> I don't know, I think they need some sort of handout … and I know it is confronting maybe like in the sense when they walk in and they are talking about terminal and death and things like that, but the fact is this is the area where it can potentially happen. They need to have that information so we

> have something to say this is what you were given, from the minute they arrive. (Nurse8RN)

In the conversation below, Nurs8RN and others spoke of C3 and how he had given them precise instructions on managing P3’s nausea in his absence. Feeling caught, they found this hard as they knew P3 rarely wanted what C3 was pushing. Nurses spoke of C3’s behaviour bordering on bullying.

> [P3’s] … husband was obsessed with food. He had a strict schedule for her and when she deteriorated he just could not handle the thought of her not eating and the family were saying this is cruel, this is cruel, and she is going to die that night. (Nurse8RN)
>
> Like he said. She will get better. If she can eat she will get better. She will wake up … the poor thing. She will walk. (Nurse8RN)
>
> The one chip and have a glass of ginger beer. (Nurse7EEN)
>
> When she vomited. (Nurse13EEN)
>
> Yes….and he would get cranky with us about the chips. The chips help the nausea, ginger beer helped the nausea. And she was only allowed three chips. (Nurse8RN)
>
> I used to give her a handful. (Nurse7EEN)
>
> I got in trouble because I handed her four (laughs). (Nurse8RN)

6.3 Powerlessness

Nurses were aware they could not physically stop a family member from feeding a patient. And at times no amount of talking would change this.

> ... you can advise them. Advice being the word. You can tell them by doing that potentially this is what can happen. And you try to get the doctors to back you up. If you can see it is being persistent. They do it … You can’t stop them either, and even if the other health professionals go in do it [speak with the family] they are still doing it. (Nurse8RN)

Others avoided addressing this issue with patients as they felt powerless.

> They are being shovelled porridge and, like she used to call out help all the time, didn’t she? Especially when they were there. Human torture. You can’t do that to someone [pause] but we have this funny little line, you know, that we can’t cross. (Nurse13EEN)

Nurse14EN spoke of turning a blind eye to interactions between a patient and a carer to avoid further conflict.

> Her family was persistent that she had to eat, even down to the fact of force feeding. I saw her husband blocking her nose so she would open her mouth to eat and I, I just couldn’t say anything I just turned around and walked away. And they did force feed her a lot. (Nurse14EN)

7 Control

Nurses identified food as being one of the patient’s last domains of control.

> They don’t have much control, but they do have control over [pause] what they are eating. (Nurse3RN)

7.1 Wanting more control

Nurse2RN allowed a patient to determine the number of tube feeds administered to him daily as he had said he no longer wanted to fight for survival.

> You know we got one patient, that is Chinese background that is Mr X and you been having three Jevity's per day and because [in the] morning 6am and 10am we give it. He doesn't want to eat anything actually but the wife try to force him and then [said] stuff like you eat more you got more energy. But he said to me I just had enough and I just really want to die [pause]. You know all the time and I said you have to think about it in a positive way. And you know bad like that and he said no that's enough for me. 2 Jevity in the morning. (Nurse2RN) [2]

This was something Nurse2RN had chosen to keep between herself and the patient rather than informing the prescribing dietitian. This allowed the nurse to maintain control and some autonomy over the situation rather than referring the issue back to the health professional responsible for the dietary prescription.

Nurse13EEN identified nutrition and the prescription of nutritional supplements as something she would like to have more control over.

> The dietary [prescribing nutritional supplements], we should be allowed to do it though. (Nurse13EEN)

Nurse13EEN was very passionate and emotive about her desire to have more control over family members' actions in order to care for her patient.

> It is ridiculous that we don't have the control to go in there and say, no, you can't do that, because that is bordering on torturing someone. Yes, that is your family member, yes you believe that. Unfortunately, we are the professional staff and I am telling you, you can't do that. Even if it causes a bit of conflict, like cause that is awful. You know what I mean. It is someone's life. (Nurse13EEN)

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[2] Jevity is a brand of enteral formula given via a feeding tube

> We should be allowed to stop them though (Nurse13EEN)

Nevertheless, nurses were concerned that they would not be backed up by management if they did speak up.

> Because if you end up in a conflict with the family it would be very rare that you would be supported. (Nurse13EEN)

> You wouldn't be supported. (Nurse11CNS)

> You know we don't have that support that we could confidently go in there and say I am sorry but whilst she is in this facility and she is under our care these rules apply. We can stop you from seeing her if you won't stop torturing her. If we did that, man, we would be on our own, you would be hung out to dry. (Nurse13EEN)

Nurse11CNS expressed the belief that the patient's wishes should be a priority.

> I think they [the family] do need to respect the patient's wishes. That's our priority and that's what the patient wants. (Nurse11CNS)

Nurse13EEN wanted to be able to manage the situation when families' actions were not in the patient's best interests.

> And we should be able to enforce that a little bit more. We should be able to say I am sorry, I understand that you are upset, and yes this is your mother, however, we are here to be the patient's advocate, we are telling you this is not in their best interest. (Nurse13EEN)

7.2 Loss of control

Nurse13EEN asserted that food and helping a patient eat and drink was one of the last remaining roles over which a family member had control.

> It depends what relationship they have with the patient as well. Like if it is their wife or stuff like that, they don't tend to listen as much … But I think that a lot of the time with the carers feeding the patient as well, it's out of their frustration that they have no control over the fact that their loved one is dying and the only thing they feel they can do to help them is to feed them and encourage them to eat. So, it's out of frustration really, that they have conflicts, you know. They just love them and they want them to be well. It's the only thing they can do for them. Everything else has been taken, the medical staff, the nursing everyone else. Even their meals are cooked for them now. So, the only thing they can do is to encourage them to eat. That's like all that they have left. (Nurse13EEN)

Nurse12EN highlighted that on admission to hospital, carers' powers were gone or reduced because nursing staff took on many of their roles.

> Because we are taking their power away. Really. (Nurse12EN)

Food Service Officer

Food service officers are often an unthought-of, invisible or unidentified group in nutrition research. Yet their role in providing meals to a patient three times per day required their perspectives to be sought for this study.

Themes derived were:

8) The connections established by food between food service officers and patients.
9) Palliative care patients are special – like no others.
10) Breaking the rules for palliative care patients.
11) The special qualities needed by a food provider - inner strength and an ability to hide emotions.

8 The connections established by food between food service officers and patients

8.1 Attachment

Food service officers considered food as the avenue that enabled them to communicate and connect with patients, even to the extent of forming attachments with some of them.

> We get very attached [to the patients we are providing with food]. (FSO1)

> And day by day you get attached [to patients]. Maybe that patient is there for two, three months and you get attached to them. (FSO1)

This attachment developed despite the FSO not even knowing the patient's name.

> When I first started, I would always get a shock. You work and you go and there is a new person in the room, because you don't know names. You only know bed numbers. So, you can say number 10 and I will know who you are talking about. (FSO2)

8.2 Opening up

Participants felt that their role empowered patients to open up and discuss important information with them.

> They let you in. And [pause] in our position. You know we are from the kitchen. A lot of the patients, they open up to us and say things that they think they can. (FSO2)

FSO1 discussed her interaction with a Macedonian patient who had no "real" family to turn to in her time of need. The patient turned to FSO1 for help which she provided.

> Sometimes they touch your heart when they start crying and talking about family. It’s none of our business. We shouldn’t get involved. That’s the family business, we are here to do our jobs and to respect them and treat them like everybody else but sometimes they cry on your shoulder and say my daughter she doesn’t come. My husband doesn’t talk to me on the phone. He doesn’t pick up the phone. I have got nobody to turn to. No support from anybody and she was happy that I was Macedonian and she can say a few words in Macedonian when I go and deliver the meals. Once I said, is there anything I can do for you? and she said all you can do is just bring a bread roll for me please. (FSO1)

8.3 Becoming family

Food service officers spoke of treating patients like family, with the quantity of time spent at work a key factor in developing relationship strength. Extra care is taken preparing and “plating” meals for patients as they would for their own family.

> They [the patients] are part of the family. We spend eight hours a day, maybe not all the time up on the floors, but we see them. Every single day. And I see probably my kids for 4 or 3 hours a day and I see the patient eight hours a day. So, I have to care for the patient. For me to be here, that means I care for them. (FSO1)

FSO2 discusses becoming “part of the patient’s family” when delivering a meal to a dying elderly gentleman.

> The thing that bought me undone one day was I went in to this very elderly man. I took the meal. And I was actually, part of the family because the wife was [there], he was dying and she was singing. And I still get emotional from that because it was just so beautiful. (FSO2)

FSO2 spoke of how she felt for the mother of a dying man in his 30’s. She likened the patient’s mother to her sister as she bought meals in from home to ease the pain of tirelessly sitting at the patient’s bedside.

> But for [name removed] mother. I felt that [she] was my sister. This is how I felt … but it was the Mum and she was sitting there, and sitting there and … and then I went home and I made lunch for my husband and I thought, I said look you can chuck it out, that’s fine but I bought this in for you today, you look that tired. And she just said. Look God bless you. Thank you. You are very thoughtful. (FSO2)

8.4 Food provision and presentation is a loving and respectful gesture

All food service officers recognised food provision as a loving gesture which allows them to love patients like their own family members.

> Because we love them and care for them. Doesn’t matter if they are black or white or yellow or whatever colour. (FSO1)

> We should love them and respect them like our own family … Because the way you treat them, they will treat you back. (FSO1)

FSO3 spoke of the “plating” and presentation of patient meals as being very important. The standard required was that which you would offer your own mother.

> I tell the cook … When they put the food on the tray I told some cooks. You can’t give it like that. Why not? And they say yes you can. I said no you won’t. I said would you give that to your mother? No and I said well fix it and they were absolutely mortified, when I said that. (FSO3)

In this example FSO3 spoke to her superior colleagues to ensure food was presented to an appropriate standard. Presentation was important for FSO3.

> You look at it, if it was your mother. Would you give that to your mother? Or if you were in the bed, if it didn't look good, would you eat that? (FSO3)

> … so, how you want it? And you want it for your mother, or father or family, whatever. That's how you should present it. And you treat everything the same, every … patient on the tray the same basically. (FSO3)

This sentiment was shared with FSO1.

> When you serve the meal, when you cook the meals. Pretend like you cook for your family. (FSO1)

A well-presented meal is seen as respecting the patient, something that all patients deserve.

> They deserve the respect. (FSO2)

> They deserve respect and good presentation. When the plate goes upstairs. Because if I am a patient, and you serve me burnt pumpkin or whatever or raw vegetables, I won't eat it. I will complain. (FSO1)

9 Palliative care patients are special – like no others

FSO2 and FSO3 spoke of palliative care patients being different to the rehabilitation patients.

> They are different. (FSO3)

> They are so considerate, the ones on (pause) [palliative care]. (FSO3)

Palliative care patients rarely complained in the same way as rehabilitation patients.

> … the ones that are dying, they never ever, ever, complain. (FSO4: that true darling. More the relatives) No matter what you give them. If it's right or it's wrong, that's ok. Don't worry about it we are fine. It's alright. We know you are doing your best. It's ok if you don't have it. Don't worry. (FSO3)

> Yeah, but they are different. They are so much sweeter, so much nicer. They don't, they hardly ever complain. (FSO3)

> I am not talking about palliative care now, but with the rehab patients, and a lot of them are with it. They get annoyed. And sometimes they are quite rude to us. (FSO2)

Although palliative care patients are "special", food service officer's spoke of needing to choose which patients they felt for as it is not possible to care deeply for all patients admitted to the ward.

> It's sad for everybody. It's sad when they are young, it is sad when they are very old, it's sad when they are middle age but if you feel sorry for every single person [you would not manage to work in the organisation]. (FSO3)

FSO3 elaborated on this, relating that the younger the patient the more likely it was to be upsetting, primarily because of their circumstance and what they were missing out on in life.

> The ones that you get really, really upset about, and I reckon the girls would probably agree, are the young ones. The young ones would really effect you. Like if you have got someone in your 20's, 30's or early 40's and they are married and they have got children and they are on their way out. And they don't have long to go and you see the changes that they are going through, they are the ones that you really feel for because the other ones that are in their 60's, 70's or 80's or 90's, I mean they've had a good life … Who are we to judge but the young ones you really feel for. (FSO3)

10 Breaking the rules for palliative care patients

Food service officers spoke of going against hospital policy to provide palliative care patients and their families with what they felt they needed. The offering of this information is significant given it is the dietitian's role to develop and ensure adherence to food related policies within the research hospital. In providing this information, food service officers put themselves at risk of disciplinary action. However, they felt the need to provide the information as they saw it as pertinent to their role and this research.

FSO2 for example brought food from home for the mother of a patient in his 30's as she felt sorry for her as she sat by his bedside day in and day out.

> Oh, a month ago. I think the boy's name was [name removed] on [the ward]. There wasn't a person … in this kitchen that was not concerned about him and the Mum, and you know I even bought some sandwiches in just for the Mum and me … Every nurse was affected by that because you realise that they haven't started their life. (FSO2)

FSO1 connected with a patient from her own Macedonian culture, breaking hospital policies to provide her with culturally appropriate foods. Although FSO1 was not privy to the information, this was the first time the patient had been away from her physically abusive husband in her adult life. She turned to FSO1 to provide food from home like family members will often do because of the cultural bond.

> She had a problem with her [sic] husband and the daughters. ... the husband never comes and visits her. Not even the daughters. … so, she was asking please if you can get me just one bread roll for lunch, I don't like the bread. I don't like the slice from here. So, I was getting the bread rolls for her … I used to buy every day. (FSO1)

During the interview the researcher asked FSO1 if she felt that she was taking the place of the family in providing the bread to which she answered “yeah” and went on:

> So, I, I feel very sad and I said if she dies and she begged me to bring her bread rolls I will feel more bad, not bringing the bread rolls. Maybe I am breaking the rules even here, but it is just a bread roll.

In the conversation below FSO’s acknowledged they were breaking the rules by bringing food from home for patients, something they were not permitted to do.

> Maybe we can do little things for the patient when they ask. (FSO1)

> But we are not allowed. (FSO2)

> We are not allowed but we allowed ourselves to cross the line. (FSO1)

> You know your limits. And not to go over the boundaries. Because you are risking it if you are going over the boundaries. (FSO3)

Despite this, food service officers deemed it appropriate to break the rules for patients in the palliative care unit.

They talked about how they assisted patients at meal times despite this being a nursing role.

> How many times have I gone and I have given afternoon tea, nurses are who-knows-where, and they go ‘I want a drink ...’ and I sit there and I hold it for them and make [them] drink. ‘Can I have more?’ Yes, ok … and you feel so good when you have done it … ‘I am really dry, can you give me a drink, please?’… And then the nurse walks in and they feel bad because you are actually doing their job. Giving them the drink. (FSO3)

Although food service officers are aware that assisting patients with meals is outside their job description, they still felt it is part of their role and it made them feel good.

> Because I can’t say no. that’s, my job is to help. (FSO2)

> … if you spend 5 minutes extra with that patient you feel great. (FSO1)

Stepping outside of the boundaries is not limited to assisting patients. Food service officers provided relatives with refreshments at times despite this being against hospital policy.

> Look. It is not in our policy. It is not in our job description to serve the patients family with a cup of tea and cup of coffee. (FSO1)

> But when you walk in the room and let’s say, the Mrs, very old lady she is dying and the husband is there on the couch, he has been there for half the day and if the Mrs says please can my husband have a cup of coffee. What are you going to say? I am sorry I am not serving the relatives. (FSO1)

In further conversations food service officers reported that they did at times put limitations on the number of relatives they were willing to serve.

11 The special qualities needed by a food provider – Inner strength and an ability to hide emotions

Food service officer’s spoke of needing to be “special” to work in a palliative care hospital. They claimed that many people would be unable to do the work they did. FSO3 said:

> I think you have got to be special to work here. Not anyone can do it. (FSO3)

The qualities required to work in palliative care were explored with this group and are described below.

11.1 Inner Strength

Food service officers reported needing to be strong due to the direct contact with patients in the final hours of life. They spoke of needing to appear as if nothing was wrong. This was a popular discussion point in this focus group, indicating the participants' strong feelings on this aspect of care.

> We are here for eight hours, … we have to be strong. (FSO1)

> Like when you deliver the tray. Do you get like, maybe upset because you are giving it to them because you know it might be their last meal? You have no idea. (FSO3)

> Yeah. But you don't show them anyway. No, you present the food, smile and hello, how are you? But you don't tell them that. No matter what you feel inside you just smile with them. Because I don't want to show them … You know in your head they are dying really. But what can you do. You can't tell them 'oh you are dying' you know. (FSO4)

> We have to be strong ... There are one or two and you look at them and your heart does open up to these patients. (FSO2)

Food service officers were aware that they could walk into the room of a recently deceased patient at any time.

> You have to be a strong person. You can't be weak because you know you are going in there and you have no idea if you are going in to a room and they are still alive or they've died. You can go into the room give them their meal. Then you go and collect their meal and they have just passed on. So within half an hour give or take. See you have no, you have to be a strong character. (FSO3)

11.2 Hidden emotions

Food service officer's spoke of the need to hide their true emotions from patients and carers.

> Even when the people, they are going out [dying]. They are not going to be here for long. We know that. The family knows that but we cannot cry and feel sorry for them because family knows. They know. (FSO1)

This was something that they shared with other staff members in the safety of the kitchen.

> And I mean we talk about it down here (the kitchen). Never in front of the relatives or the patients. Come down here and we go 'the poor thing. Look how young they are. Don't you feel for them?' And you get upset then you change the subject quickly because you are going to get upset so you have to change the subject. (FSO3)

At times, they shed tears for the "special" patients. FSO2 describes the upset when the man in his 30's, referred to earlier, died.

> But we were strong and [pause] you know, we all shed a little tear when we knew he passed. (FSO2)

11.3 Learning from working in palliative care

Participants agreed there were lessons learnt on the job which shaped the person they had become. FSO2 spoke of learning to stop asking patients how they were and providing compliments, especially as patients neared the end of life.

> Sometimes I shed a little tear. One day, and I try to be polite, and I looked at this person that I loved so dearly, that was dying and I said 'how are you today?

> You look great' and she said 'I am ready to die, why are you saying that?' and I thought. How rude and how stupid of me to say that. So, I never say that anymore. (FSO2)

On the other hand, there were times when patients asked more from them than their role entailed.

> They have said to me 'stay here, don't go, I am dying, I want you to stay here with me. I don't want to die alone.' What do you do? I mean, you are put in that predicament situation, you have no idea what, and I mean you have got work to do. You can't stay there, … you try to comfort them as best you can, I mean and you are lost, for starters, because of the way they have come out and they have said it and that. (FSO3)

Food service officers related that they are often the first person seen by patients and relatives after meal times, which puts them in the firing line of someone wanting to complain about the food.

> We are the first ones to cop it. (FSO3)

At times visitors or patients chased them to complain about meals.

> And you know, they will chase you - the patients, visitors. (FSO2)

> Oh yeah. They chase you. They do. (FSO3)

This was something that, if they were suitable for their role, a food service officer had to be able to cope with. They saw this role as highly important within the organisation. They also were aware that they needed to respect other staff members and the patients.

> The patients are very important, … like we said but our job is very important. We want to stay here as long as we can. As long as this kitchen exists. Because

> we have got a family, we have got bills and [if] there is no patients, there is no work here, for us. So, I think that is what we have to respect our jobs, the patients, the staff, nurses, administration. That's why we are here. (FSO1)

In summary, comparing the ideas about their roles of the three groups under discussion, it can be seen that firstly, medical officers emphasised a need to use evidence-based practice in palliative care, although they also saw a need to be flexible and to consider the patient and carer perspectives. They admitted that conversations around food and nutrition were difficult and emotionally draining.

Nurses on the other hand were less focused on evidence-based practice and cared "from the heart", putting their patients' needs first. But this meant that nurses felt they were caught between the demands and needs of the patient and the carer and between the carer and the medical officers. Many nurses wished to they had more control so that they could protect their patients' wishes.

For their part, food service officers spoke of the connections that developed between themselves and patients through food. They would often go out of their way to provide a patient and at times their families with special foods they thought would be comforting. They claimed further that it took a special person to work as a food service officer in palliative care.

Chapter 6: The Meaning of Food

> *The philosophy of palliative care requires acceptance of the complex meaning of food in the lives of all individuals and recognition that its loss has profound importance. (Hopkins, 2004)*

While phenomenology allows the researcher to develop a deep understanding of the lived experience of a phenomenon, as seen in Chapter 4 and 5 Results, interpretive phenomenology allows the researcher to go one step further in determining the meaning of the phenomena. In this section I will present the meanings of food that were derived from the focus groups and from individual interview data across all participant groups.

1) Food means life.
2) Food as a demonstration of love.
3) Food as a social glue.

1 Food Means Life

Participants across all study groups overtly identified the role of food in maintaining life although the context and depth of the meaning differed between groups. Below I will discuss these differences.

Patients' spoke of their lack of desire to eat but did so to maintain life. Food held a primal meaning based on a rudimentary need for survival.

> You don't eat you die. (P1)
>
> Well it should mean a form of sustenance and that's what it is now to me, to live. (P4)
>
> If you don't eat you don't live [pause] that's the way I look at it. (P6)

> Well I eat to live now. (P8)
>
> I eat all the time … whether I'm hungry or not, because I have to survive. (P9)
>
> I need to eat to live. (P11)
>
> If I don't eat I die. (P14)
>
> It's there because you've got to have it. (P17)

Patients spoke of food as the fuel required to preserve life with the type of food less important than the amount consumed. For some this meant a few mouthfuls; whereas for others it was meeting all their nutritional requirements. Food was no longer about enjoyment or as part of social interactions but became merely consuming adequate nutrition for survival.

> Look, food is your nutrition. It's like the quality of petrol you put in your car. Isn't it? [pause] You need it. But I am gaining confidence in the fact that if maybe the food I eat is not quite what I would think is nutritious …, [pause] it will still do me good, whatever I eat will build me up. And that's what I want. [pause] I am now eating to live. Eating to live. (P11)
>
> It [gave] me more pleasure than necessary nutrition, but it's around the other way now. (P11)

Patients spoke of no longer enjoying food in a social context and instead choosing to eat away from friends and family to avoid scrutiny. Meal times were often solitary events or when shared with others, left the patient feeling pressured, uncomfortable and bullied. Patients spoke of longing to be left to choose their own meals and the volume of food consumed. They were aware this was probably minimal but preferred to eat what they could manage and what they felt would keep them alive.

Carers were aware of the importance of food in maintaining life and took it upon themselves to ensure the patient maintained their oral intake using any strategy necessary.

> I mean she has got to eat to keep alive. (C8)

> You have to be cruel to be kind, you have to. If they're going to survive. (C2)

Carers pushed food on patients even when it was not enjoyable for them. For example, C3 who pushed his wife to eat and sat beside her with a vomit bag ready to catch the food when it came back up.

Out of love and compassion, carers felt it was their duty to monitor and control the patient's food intake. A patient's ability to determine their own dietary needs was withdrawn as carers took over control of this vital function. Interestingly the patients who pushed themselves to eat were the ones without carers, probably because they did not have a loved one to whom they could pass this responsibility.

For carers, food was their ally in the fight for their loved one's survival. They refused to give up despite being told the patient was dying. They headed into battle, food being their weapon to protect the sick and dying. Food allowed them to fight against the disease they had been told would take their loved one from them, an ending they wanted to circumvent at all costs. When their attempts to ensure the patient ate failed, a number of carers resorted to hospitalising their loved one in the hope that medical professionals could make the patient eat.

Only one carer, C2, recognised that food was not going to change P2's outcome and during his last week gave in to his requests for the "junk foods" he was previously denied. P2's case was somewhat different to the others because he still had an appetite, but continued to be denied fried foods because they were not good for his diabetes. Six days after being allowed "junk foods", P2 died.

Medical officers saw food refusal as an indicator of a patient’s approaching end, acknowledging that the disease takes away one’s desire to eat and little can be done to change this.

> … it’s a sign that [they] are alive and staying alive because they’re eating. When they stop eating it’s a sign that they’re … you know … departing, they’re leaving, they’re giving up. (MO3)

Nurses also recognised the importance of food in maintaining life, although recognising that it was by no means a cure.

> It sort of buys them more time doesn’t it? If they can eat … it keeps them healthier for a while. (Nurse12EN)

> Well I think they think if they are eating they will last longer (Nurse12EN)

Nurses frequently observed family and carers force feeding patients. At times, they were asked to assist which they found distressing. Carers saw the nurse as someone with the power to make their loved one eat.

With the definition of palliative care in mind, clinicians are faced with a quandary because allowing carers to force-feed patients in a palliative care unit is against the definition of the service they aim to provide. Force-feeding does not improve quality of life nor does it assist in relieving suffering as reported by patients themselves.

What is evident from the results is that while participants accepted the need to eat to live, in order to experience and enjoy life the individual also needs to be able to enjoy their food. But this element of social enjoyment is absent for the terminal cancer patient. This points to life being more than just being physically alive but also consists in the ability to enjoy the simple pleasures in life. For palliative care patients, the aim moved towards meeting the bottom tier of Maslow’s hierarchy of needs, where although food was recognised as being required for survival, that did not contribute to the individual experiencing the joys that life can bring.

When asked what food meant to them, participants in all groups unhesitatingly responded that food meant life. Some patients pushed themselves to eat in an effort to maintain life. Others were less concerned about longevity but rather focused on comfort and quality of life. Whatever the attitudes of patients, carers often pushed their loved ones to eat in a desperate effort to prolong their time together. Although they felt this was in the patients' best interests, it may be asked whether their motives were in fact selfish. Despite resistance from the patient, they continued to pressure their loved one to eat more so that they could spend more time with them and avoid the grief and heartache they knew was near. Carers failed to realise that patients wished to maintain their quality of life and that it was this which accounted for their lack of desire to eat. But since carers' actions were focused on maintaining life, they felt they had the right to override a patient's wishes. However, this also highlights how humans value the sanctity of life and longevity, going to extreme lengths to maintain life irrespective of the costs.

A number of patients forced themselves to eat to maintain their fight for life, only to lose the battle days later. This suggests many patients continue looking for a miracle despite being told their life is coming to an end. Many patients hoped they would be freed of their illness despite being admitted for terminal care. Some patients spoke of food as being their means to fuel ongoing life. To some degree, food is the only remaining option for patients during a terminal care admission as active treatments such as chemo- and radiotherapy have ceased. Food is one of the only options they have control over in a situation that appears to be beyond their control.

Other patients reported that although they felt immense pressure from loved ones they purposely refused food and fluids as their means of maintaining control and comfort. Medical officers used a patient's appetite and oral intake to predict time to death. Food was seen in all groups as being essential and a provider of life and forgoing food and fluids was seen as the end of the battle. Some saw this as giving up, while for others it told the story that the disease had won the battle and the end was near.

Carers spoke of food as a provider of life and in “fighting-the-fight” they pushed loved ones to eat, doing everything they could to provide the best quality and quantity of food for their loved one. As discussed earlier, medical officers saw food as meaning life. However, this was from a different perspective to that of carers, because medical officers realised that time was limited once a patient stopped eating and that oral intake was directly correlated with a patient’s prognosis.

These findings are in line with Maslow’s hierarchy of needs, in terms of which food is rated as the basic principal required for life (Maslow, 1943). I have demonstrated earlier that while this need continues into the terminal stage of life, the food requirement for the maintenance of life is overshadowed by the patient’s desire for comfort. That someone is still eating indicates that they are still feeling normally alive and that there is hope that they will live a little longer. On the other hand, reduced intake or an inability to eat shows the end is near. For carers however, that most of our patients were eating less than usual was a cause of distress and anxiety because in this context of meaning, they were aware that their loved one’s life was coming to an end. In response, they took control of the patient’s eating by attempting to reverse the poor intake and provide themselves with hope that their loved one would be with them on an ongoing basis.

What is clear is that nutritional issues release deep emotions for patients, carers and health professionals (Hopkins, 2004). That all three groups see food as essential for life supports Cimino’s argument that food symbolises life and hope in the palliative context (Cimino, 2003). It is carers’ desire for the continuance of the life of their loved one, that motivates their attempts to compel patients to eat and drink despite their symptoms which inhibit their intake. Patients at times rebel and this dissonance between the wishes of the two parties causes conflict and distress. In the inpatient setting, carers’ desire to prolong life often results in them attempting to persuade health professionals to try treatments they may not always believe are in the patient’s best interests. However, at times medical officers will comply with families' wishes so long as the patient is not harmed.

This study supports the findings of Meares, who found that caregivers often assume the responsibility for sustaining their loved one with food (Meares, 1997). Those findings further validate those of Johnston Taylor (2016), who highlighted carers' ultimate goal of keeping their loved one alive. The current study confirms these findings in the context of a palliative care inpatient unit.

2 Food as a Demonstration of Love

In the later stages of life, love and affection is bestowed on patients with food being a medium by which it is expressed. In the palliative care unit, many caring responsibilities are handed over to the nursing staff leaving food as one of the last duties a carer can assist with. With this in mind, carers often focus their time and efforts on the provision of food. Favourite foods the patient previously enjoyed are purchased and carefully prepared to show the patient their meaning to the carer.

One husband (C3), even spoke of going to the supermarket twice a day to ensure the food he gave his wife was the freshest possible. Obviously C3's every waking moment was focused around P3's food intake and ensuring she enjoyed the fine foods which he had missed out on when he was on the run from the Nazis in his European homeland.

C4 broke off his de facto relationship to move back to his mother's home to care for her. Most of his efforts were focused around her eating and ensuring she received the foods he perceived necessary along with mealtime support and supervision. These efforts are much like the love a mother would provide to a young child, aiming to give them the best start in life. These are not the notions that you would usually see in a relationship between adults, irrespective of the type of their relationship. In relationships between healthy participants, love can be demonstrated in ways that are not always possible at the end of life.

For some carers, forgoing their own dietary needs to ensure their loved one had everything possible to help them fight for ongoing life was a way of demonstrating their love and commitment to the person. Carers related that in prioritising the patient’s needs over their own, they were no longer able to follow their personal diets designed to help them cope with their own heart disease and weight management problems. But while this can be seen as a selfless act or one of martyrdom, a more self-oriented desire to keep their loved one alive also motivated them as they sought to avoid the grief and experience the void in their lives that was near and ultimately unavoidable. In some cases, family members thrust their own desires on the patient despite their reluctance to accept the carer’s wish, which was interpreted as the patient being difficult rather than as something they were unable to manage for medical reasons beyond their control.

Demonstrating love by the means of food preparation was not something directly identified by patients and carers as a meaning but rather something identified by observers.

Medical officers identified food as being the basis of the relationship between patients and carers

> … because [food] it’s the currency of the relationship … (MO3)

They also identified food as a direct expression of love.

> … relatives will think they’re doing good by cooking the food that the patient was used to at home and bringing that in and that gives them a sense of being able to do something – something as an act of love. (MO5)

This was a sentiment shared by nursing staff

> A lot of times you show love by preparing and feeding a person and if they are not able to do that they feel like they are … not showing their love and care for the person. (Nurse3RN)

Interestingly for food service officers, the role of food provider brought about feelings of love and closeness for staff. They reported feeling like part of the patient's family due to their food-provider role and spoke of their desire to treat the patient as their mother would treat them, to ensure meals were provided with love.

> Because we love them and care for them. (FSO1)
>
> I went in to this very elderly man. I took the meal. And I was actually, part of the family because the wife was, he was dying and she was singing. (FSO2)

It is significant that food service officers rarely know a patient's name, rather referring to them by bed number. This demonstrates the power of food in the relationship, as although they did not know a patient's name, due to their role as food provider they expressed feelings for the patient as if they were part of their family.

In the later stages of life when patients are unable to eat, the relationship between patient and carer is often distorted. Often carers found the patient's inability to eat difficult to understand. This seeming rejection of their love and their efforts to please was noticed by health professionals and carers alike.

> Rejecting the life I gave you, rejecting our life together … (MO3)
>
> I feel that she's … punishing me. (C5)

Carers spoke of the distress they felt when their efforts to entice the patient to eat were fruitless. The carers did not realise that due to the patient's medical condition, it was never going to be possible for them to repay the love bestowed on them. By seeing the refusal of carefully prepared food being as unrequited love, carers were in a sense setting themselves up for failure, because it was simply not possible for their love to be repaid in the way they desired. The patient was unable to eat the foods provided and the ongoing life which they wanted, as a result of the love, was one that they could not provide.

Although food was used by carers to demonstrate the intense and warm love they held for the patient, it was rarely seen as such by the patient or carer; however, professionals watching over these behaviours perceived that the behaviours were born from love rather than anything else.

C3 summed up the effort he put into his wife's care when he said:

> Everything I do is for her. (C3)

The efforts and extent this man went to in expressing his love were moulded by his experiences in early life which obviously still had a marked impact on his life.

His love for his wife so deep he did not want her to suffer. However, he did not realise that is force feeding was making her nauseous and vomit because she was unable to tolerate many of the delicacies he bestowed upon her.

The current study supports the recent findings of Johnston Taylor (2016) who reported that New Zealand hospice patients and their carers see food as essential for life and as a means for expressing love, because carers had no words to convey their sentiments. In the same way, carers participating in this study used food to convey their love. However, the current study goes further by reporting that nurses and food service officers also use food to demonstrate their love for a patient. Food as love has also been reported by Meares and hence the findings support this (Meares, 1997).

3 Food as a "Social Glue"

Food was seen by participants in this study as what could be described as a "social glue" essential to bring people together to enjoy a common experience which involves not only eating but also conversation and social exchange. The food eaten or words spoken are of little importance but the sharing of time and interactions form the basis of the social experience. It is food that glues the social experience together as people bond over shared food and drink.

As pointed out by MO5 "part of the pleasure of eating is that social thing of sitting down to a nice meal". Patients and carers spoke of their pre-cancer meal times which provided an opportunity to "catch up" with those who played an important role in their lives. In the words of P18:

> If someone was there to eat the meal with you, you could discuss things. Well not necessarily the meal but, you could discuss the weather. You could discuss anything that is going on. (P18)

However, that experience does not apply when someone has a terminal illness.

As a patient's condition deteriorates, they can no longer participate in many social interactions due to physical constraints, disease symptoms or dietary changes.

> I can't go out to dinner anywhere because I can't eat the food. (P8)

Initially some patients attended social events, selecting reduced portion sizes or sharing their meals with others. Over time they came to see themselves as poor company unable to participate in the exchange, and began seeing themselves as a burden or intruder in the event.

With this in mind, patients reported withdrawing at meal times, opting to eat alone, away from prying and judgemental eyes. Patients expressed their sadness at being unable to participate in social customs around food. As reported in earlier themes, for some this meant friendships were lost and their social life diminished. Carers also identified these changes experienced by patients.

For some this meant missing out on significant cultural events like Christmas,

> He just couldn't make it socially to the boys' place for Christmas or anything like that. (C16)

Patients spoke of wanting to share food or meals with others but being unable to do so due to their symptoms.

> But on the whole, I haven't really been sharing food with other people. I'd rather like to be able to have some chocolate or something like that, but no, the last time I had chocolate I was rather … dry-reaching quite a bit, I didn't know if it was the chocolate or just that [I was unwell]. (P7)

> I used to have it very social, and I would often have cups of tea, but now I just get sick. (P4)

Those who attempted to maintain relationships often felt embarrassment or discomfort about being unable to conform to the social norms.

> Christmas time this year we're going to my son's place. My daughter is flying down from Queensland and her family, but I know that they have to go to a lot of trouble to prepare something, especially for me. And I've said don't worry about it, I'll bring it, but no, no, no, no, it's Christmas. So, I know I'm being a nuisance, which makes me feel a little bit embarrassed. You feel like you're a pest. (P8)

Many longed to be able to share the experiences around food with friends and family again.

> I’m looking forward to being able to be more free [to eat out and enjoy food with friends] so God … can feed me the way He wants to. (P11)

Sadly, P11 died 8 days later, never able to share the experiences around food that she dreamt of doing. Due to her pre-illness anxieties, she had always refused to eat with others; however, in the palliative care unit she had come to the realisation that this was something she longed to do and something she had prioritised for when she returned home. She had come to this decision despite being told her admission was for terminal care.

In some cases, family members brought food to the hospital to eat with the patient in an attempt to encourage their intake. But while some patients enjoyed the experience, for others this was added pressure to eat when they were feeling unwell.

Patients in shared hospital rooms have an opportunity to share the experience of eating with others. P8 spoke of the pleasure she got from discussing menu options with her roommates. For others, however, even the thought of food was merely a burden.

Medical officers identified the social importance of eating, ensuring it was included in the teaching curriculum.

> There is such a social importance around food and eating. It’s also something I am very, very careful to teach the general doctors about and we talk to medical students about it. (MO5)

P5 spoke of this, wishing hospital staff would actively address the psychosocial aspects of food and force feeding with carers to remove some of the anguish endured by patients.

Participants in this study identified food as being a form of “glue” which brought social experiences together. Inability to participate in these events meant friendships were lost or patients missed out on valuable social exchanges, which many longed to regain. This was identified in the patient theme, “Changes to the Meal Time Experience,” where the importance of sharing food coupled with social experience was discussed. Patients spoke of no longer feeling connected once they were unable to enjoy a meal or refreshment with friends and family. Food was identified as being an important medium required for making connections between individuals possible.

Food service officers took this one step further in the theme relating to the connections brought about by food, reporting a strong connection with patients and actually referring to themselves as “family” due to their role as food provider even when they didn’t even know the patient’s name.

In this study, patients and carers spoke of changed social interactions due to variations in the patients’ food intake. This confirms the findings of Jacobsson et al. (2004) who reported that fatigue and lack of appetite gave rise to psychological feelings of deprivation as patients missed the process of eating and the social environment related to eating. Several patients not only spoke of missing the social interaction they once enjoyed but also expressed a longing to share and enjoy those interactions with friends and family once again. Since that impacts on quality of life, alternative ways to help patients feel connected with loved ones need to be explored in both palliative care study and practice.

Three meanings of food were derived from the interviews and focus groups held with patients, carers and health care workers. The meanings identified were food means life, food as a demonstration of love and food as a “social glue”. These three meanings were deeply embedded in everyday life and the culture for the participants in this study and for this reason need to be considered and addressed by health care workers as a key area of concern for patients and carers in the palliative care unit.

Chapter 7: Discussion

This discussion chapter will consider the key findings of the study in the context of the existing literature. Whilst analysis of the data provided by patients, carers, medical officers, nurses and food service officers revealed a number of different and unique themes, similarities were found between the groups. This discussion will consider the three overarching themes common to more than one participant group.

The overarching themes to be discussed are

1) Struggles of Power and Control.
2) Situational distress.
3) Fighting to the end.

1 Struggles for Power and Control

Struggles for power and control recurrently emerged from the transcripts with food acceptance and volume of intake the topics of most contention. For participants, this may have been an overt struggle with others or an inner struggle working against their own beliefs and expectations. Control was an important construct to all participant groups.

1.1 Pressures to eat

Patients reported three sources of pressure to eat – family and friends, themselves, and health professionals. While not all patients reported feeling pressure, those who did so, reported significant consequential distress.

Some patients struggled to maintain control for decision-making over their eating because loved ones pushed them to eat despite their desires not to. In refusing food, patients attempted to gain or regain power they feared they had lost. This was demonstrated in the patient theme "Pressures to Eat". Patient strategies such as food refusal were used to discourage the pressure from loved ones. Others succumbed to the pressure, resulting in them eating until they vomited or felt unwell as a result of force feeding.

The current study supported in part the findings of Reid et al. (2009b) that while patients saw family members' focus on food as a sign of their love and concern, for some this pressure was intolerable and caused existential distress. This finding is important to consider in palliative care as it directly impacts on patients' quality of life, the maintenance of which is the primary focus for palliative care clinicians.

Families and professional caregivers tend to see a patient's cessation of eating as a sign that they had given up, leading to concerns of death by starvation (Ferris, 2004). This was also demonstrated in the course of the current research, in which it was found that all parties interviewed agreed that since food was essential to maintain life, a reduced intake could lead to death. Other research has shown that carers hold greater concerns over a patient's anorexia than the patient themselves (Hawkins, 2000; Holden, 1991). This dichotomy may in part lead to the carer pressuring the patient to eat more than the patient deemed necessary.

The current results differ from those reported by Hawkins (2000) and Hopkinson, Wright, McDonald, et al. (2006)) who concluded that anxieties were not greater in younger patients or those cared for at home rather than in hospital. Although not formally measured in the present study, it emerged that anxieties around eating were seen across all age groups, and that rather than age, the greatest cause of patient and carer anxiety was the realisation of the terminal nature of the patients' disease. While several patients were hospitalised because of eating-related difficulties, their carers' concerns continued in the hospital environment and caused additional distress for those who felt they should be present at mealtimes to encourage oral intake.

The difference between patient and carer concern about anorexia may in part be explained by ketosis, a process which occurs when the body turns to using fat and ketones for fuel because sources of carbohydrate are no longer available (Cahill, 2006). Ketosis is thought to be a protective mechanism which has an anaesthetic-like effect, relieving the patient of pain and increasing their sense of well-being (Ferris, 2004). These physical and psychological side-effects of ketosis protect the patient from concerns and hunger, even when their food intake is limited or even entirely lacking. Carers however, tend to see the quantity of food consumed as an indicator of the patient's overall condition (Holden, 1991). Carers of those with the poorer intakes are likely to have increased concerns.

While eating becomes a chore for people with cancer cachexia (Reid et al., 2009b) this study found a number of patients imposed the pressure to eat on themselves rather than it being imposed by others. But while some ate for survival, others ate simply to please their carers or to avoid frustrations over food wastage.

Additionally, two patients reported having felt pressured to eat by health professionals previously during their cancer treatments. While patients acknowledged medical professional pressure was applied in their best interests, they spoke of their struggles to implement the advice and had difficulty reorienting their focus as their condition changed. No patients reported having conversations with health professionals discussing the reorientation of nutrition priorities and goals when they moved to palliative or end of life care.

1.2 Infantalisation

Throughout the course of this research patients and carers spoke of battles between themselves over control of the patient's intake. In a number of instances, pressure to eat took the fight for control to levels beyond that usually deemed appropriate between two adults. The patient was treated like a child with his/her decision-making capabilities obstructed by the carer. This infantilisation occurred despite patients being between 42 and 88 years of age and therefore quite competent to make their own decisions. The redefining of the parent-child style relationship often included role reversal between children and partners. Interestingly this happened despite all patients enrolled in the study being of sound mind and capable of making their own decisions.

For carers, the parenting-type role resulted in their adopting an authoritative food related decision-making attitude. In many cases, this involved the carer using different strategies necessary to ensure the patient received some type of nutrition. These included “bribery”, hiding nutrient enhancing powders in food and forcefully encouraging intake. These are striking similarities with strategies that a parent might use; “bribing” a child to eat a food they are not fond of or hiding vegetables within a meal, offering multiple choices or forcing the child to eat before being allowed to leave the table.

In some cases, carers resorted to force-feeding patients who refused to eat. Techniques included forcing a patient’s mouth open to place food inside, tickling the patient to make them open their mouth, and playing games such as a mother would often play with a child, pretending the spoon was an aeroplane flying towards the patient’s mouth. No carers reported using these strategies.

The observation of force feeding has previously been reported in the literature and my results further support this finding (McClement et al., 2003; Meares, 1997). I also confirmed the use of strategies such as bringing the patient’s favourite foods from home, ordering large portions from the hospital kitchen and frequent offering of foods (McClement et al., 2004; McClement et al., 2003).

In previous studies it has been reported that the quantity of food consumed is of greater interest to carers that the quality of foods (McClement et al., 2004). The current study found evidence of carer concern over the nutritional quality of food with carers making decisions around foods being good or bad and adding supplement powders to foods where possible. Carers pushed high protein foods such as meats and cheese for their nutritional benefits and monitored adherence to nutritional advice provided by dietitians. Carers appeared caught in a triangulation consisting of the patient’s wishes, the benefits of the food supplement and their own desire to prolong life via nutrition.

Several carers took over decision-making when a patient's intake was not what the carer deemed necessary to maintain life. Carers happily removed decision-making from the patient, taking over the role to ensure patients increased their intake. This continued for most carers up to and beyond the point where intake was futile. This behaviour may be explained in part as being due to family members viewing feeding as an expression of care, love and nurturance (Dixon, Emery, & Smith Hurley, 1985).

It is important to note that all participant patients were admitted to the palliative care ward for end of life care. Despite this, only one carer identified pushing food as futile and ceased to push the patient to eat foods they no longer desired or were unlikely to influence the outcome. This is of interest as it demonstrates the strong desire to feed continues for carers up to and often during the terminal phase of life. The carer who identified pushing food as futile was the ex-partner of the patient and had not been in a relationship with him for 13 years. In this case, C2 took over care when there was no one else available to do so, while she may have had other motivations for her provision of care these went unvoiced during the interview. Distance in the relationship may have been an influence on the strength of her underlying desires to keep the patient alive, as there was no longer a strong bond with the patient driving her need to keep him alive. Moreover, the caring role was burdensome for her, imposing financial and time related pressures. While she did her best to care for the patient, the effect of his imminent loss was likely to be less strong for her than was the loss of a parent, spouse, sibling or child in other relationships investigated in this study.

C8 was the other carer who did not take on a parenting-type relationship. As discussed earlier C8 took on the caring role because P8's children were unable to assist due to location. C8 seemed to be in denial about the cancer because it threatened to make her lose her sister as she had lost her husband. When informed of her sister's one-month survival prognosis, C8 refused to accept it, telling her "they can be wrong".

Carers tended to take over decision-making and control when the patient began making decisions that were incongruent with the medical advice they had been given.

However, carers allowed the patient to make their own choices and only intervened when it seemed the patient’s decisions were likely to reduce life-expectancy or potentially hasten death. This demonstrates the common belief among carers that survival is paramount and takes precedence over the patient’s right to make their own decisions and control their own quality of life.

The nurturing role of feeding is often linked with roles such as parenting and caring. Meares reported that caregivers often assume responsibility for sustaining their loved one with food (Meares, 1997) and this was confirmed in the current study. Furthermore, in patients with cancer cachexia, family members see the provision of food and the act of feeding as expressions of love and care (Reid et al., 2009b). While this was not directly seen as such by carers, their actions support these findings; a continuation of the nurturing process into a patient’s final days including the end of life care admission to the palliative care unit. As the disease progresses and becomes terminal this nurturing role does not diminish; rather it remains strong up until the patient’s dying moments.

In defence of their actions when “parenting” an adult, carers spoke of distinguishing between appropriate and non-appropriate strategies. Carer’s admitted that taking on this role usually led to conflict with their loved one, but argued that their actions were intended to keep their loved one alive.

1.3 Impact of the relationship type on care of the patient

All but one carer demonstrated that they readily, although at times reluctantly, took responsibility for ensuring the patient consumed an oral diet. In doing so they took on the responsibility for ensuring the patient had the opportunity to fight for survival, which seems not to be possible if a patient is no longer eating or drinking. In doing so carers reported that they were aware that their actions were not always congruent with the patient’s wishes; however, they acted to prolong the fight for survival.

At times, carers spoke of their reluctance to accept the carer-role which was the case of a child caring for a parent, a sibling caring for a sibling or caring for an ex-partner.

However, this was not the case when caring for a spouse or offspring, in line with societal expectations that a parent never stops caring for their child or a spouse who, if they have taken marriage vows, they are bound to care for “in sickness and in health”. The reluctance to take on a carer’s role occurred when that was not one automatically assumed by society. However, it often was accepted by the carer as having been made according to their own free will, although in some cases it was accepted only when they felt pressured to care for the patient due to social circumstances or by the reluctance of other family members to assume the caring role.

Previous studies have reported that family members feel caloric intake slows disease progression, enhances quality of life and survival time (McClement, 2005; McClement et al., 2004; McClement et al., 2003). Thus, it is easy to see how carers take the responsibility for maintaining the life of their loved one on their shoulders, encouraging patients to eat and drink, deeming that to be the absolute best course of action under those circumstances.

Strasser et al. (Strasser et al., 2007) reported that female partners of men with advanced cancer felt compelled to encourage or sometimes force their loved one to eat. In contrast in the current study, this action was seen in carers who were offspring, siblings or ex-partners. Spouses of both sexes appeared to take on the caring role, constantly encouraging their partner to eat. The degree of the patient’s weight loss was seen to be a way of assessing the effectiveness of caring. One carer reported that when his mother lost weight, his siblings criticised his caregiving, failing to see weight loss as an unavoidable consequence of the disease.

This study has demonstrated that it was only when carers deemed they were unable to meet the patient’s needs that they had the patient admitted to hospital for specialist care. But while they were apparently handing over the responsibility to health professionals, some carers were unable to step back and instead spent long periods in the hospital, encouraging and at times forcing their loved one to eat.

1.4 Health Professionals’ Struggle for Power and Control

Although issues arose around control on the ward level, all parties were working towards what they perceived to be in the best interests of the patient. It was apparent that once hospitalised, there was little the patient or the family felt they had control over. With the loss of control, many carers turned to “managing” a patient’s food intake. It was this refocusing of priorities that caused difficulties for health professionals who felt ill-equipped to deal with the conflicts that arose in dealing with carer’s behaviours.

This was evident in this study among the nurses who spoke of cases that stayed in their memories throughout their careers. Building on the social loss, nurses were touched by the cases where the families had been so demanding that it was affecting the patients quality of life. Nurses’ desire to care ran deep enough for them to go against families’ wishes if they felt this was not in the patient’s best interest. Nurses saw themselves as an advocate for the patient and the person whose role it was to ensure the patient received the care they felt most appropriate.

In this study, nurses spoke of three concerns – feeling trapped, feeling ill-equipped to manage food and nutrition-related conversation, and feeling powerlessness. These will be discussed below.

Nurses often felt conflicted when dealing with carers’ requests around a patient’s food and nutrition. They felt deeply for their patients and tried to keep the patient’s comfort at the forefront of their concerns, yet when carers’ requests deviated from the nurses’ beliefs, they felt challenged and caught between the patient and the carers’ wishes. This occurred especially when families’ requests to compel unwilling patients to eat and drink was extended to the provision of IV fluids. This was the case when the family deemed the patient unable to consume sufficient nourishment orally and demanded they be nourished with intravenous fluids. However, to force that on a dying patient was incompatible with the nurses’ core professional values.

Despite feeling powerless, nurses expressed a desire to gain control over the situation and to be backed up by management if carers were not happy with their recommendations. This was expressed more strongly by nurses lower in the hierarchy such as ENs and AINs who had less responsibility than the RNs. Some nurses spoke of going against a dietitian's orders or a family's requests and feeling that that ultimately gave them more control at the ward level.

Nurses reported feeling caught in the middle of conflicts between the patient and carer and at times between the carer and the medical officer. In those cases, they gave priority to the patient's perceived requirements. But that had the potential to make carers feel their needs or the needs they felt to be in the patient's best interests were not being considered. McClement et al. (2004) reported that carers who felt their loved one's intake was not sufficient, accused nursing staff of being negligent. While this was not reported by participants in the present study, nurses spoke of some of the demands of carers that may well have led to this response if their requests had not been met by staff.

Of note in this study, was that nurses spoke of conflicts with carers advocating for what they deemed to be in the patient's best interests. Hopkinson and Corner (2005) reported nurses felt it was better not to discuss eating-related concerns with patients and carers because that seemed likely to increase problems rather than solve them. While this was not mentioned by nurses in the current study, they did speak of the difficulties encountered when approached by families with regard to a patients' food and nutrition. Some nurses spoke of walking away from demands they disagreed with in order to prevent conflict.

In contrast Millar et al. (2013) report that while some nurse participants in their study expressed a longing to have conversations with patients and carers around food and nutrition, they felt they would not be backed up by management when things did not go to plan. Thus, food and nutrition was obviously seen as a difficult conversation by nurses, which often did not go as planned. Millar et al. (2013) reported nurses lacked confidence in discussing the issues and saw this as outside their scope of practice. In a similar vein, nurse participants in the present study requested the production of a handout to provide to carers on the topic. This is similar to findings of Hopkinson et al. (2006) who reported that nurses rarely initiate discussions on weight loss as they believe little can be done. While we did not ask those participating in this study about whether they initiated discussions on weight loss, this was not something nurses have been heard to do in the research facility. That was possibly because of workload demands and that this can be a difficult and exhausting conversation. Moreover, AINs and ENs were unlikely to have covered this issue in their brief training program. In addition, the research facility is located in New South Wales (NSW) Australia, where the Ministry of Health Nutrition Care Policy (NSW Ministry of Health, 2011) lays down that patients losing weight are to be referred to a dietitian and hence nurses may see this as being outside of their scope of practice.

This may be somewhat different to the situation in other states and internationally in which previous studies have experienced difficulty in accessing assistance from dietitians and other health care professionals (Hopkinson & Corner, 2006). McClement et al. (2004) on the other hand reported dietitians were not accused by families who believed health professionals were not providing adequate nutritional care for their loved ones. Instead dietitians were primarily used as a consultancy service expected to assist when specific issues arose due to inadequate staffing levels preventing full care. This is very similar to the issues encountered in NSW hospitals where palliative care wards and hospices are rarely adequately staffed with dietitians.

Although they are supposed to be patient advocates, because of perceived organisational policy and processes, nurses felt powerless to stop patients being “tortured” by being forced to eat by carers. However, the fact is that no such policy or processes existed at the research site but were merely perceived to exist by the nurses.

Nurses spoke of their struggles in managing conflict with compassion and empathy for the patient. This was a long-standing emotional issue reflected in their stories about individual encounters from years prior. They spoke with heavy hearts about their defeats and failures but also expressed hope that these could be avoided in the future. The concept of compassion fatigue and “burnout” has been considered previously in palliative care by (Marr, 2009). Palliative care professionals need to take care of their personal wellbeing as difficult and distressing interactions such as those described by the nurses have the ability to cause psychological harm.

For medical officers, issues around power and control arose when working with patients and carers and when faced with the necessity for adjudicating patient/carer power struggles especially in relation to food. This arose under the themes “Considering the needs of families/carers” and “Food and nutrition constitute an uncomfortable but essential conversation”. Medical officers felt obliged to “referee” arguments and altercations between patients and carers in order to maintain quality of life and peace-of-mind for their patients. Medical officers spoke of the necessity of bringing patient and carer to a point at which food was no longer a battleground but rather something to be enjoyed when the patient was capable of doing so. They did, however, see their conflicts with carers as a battle for control in which they were not always victorious. Medical officers admitted giving in to persistent carers, at times going against their better judgement. Still, as noted earlier they would withdraw requested treatments if they felt this harmed the patient. Medical officers acknowledged that their treatment decisions would be remembered by the carer well after the patient’s death and that these would possibly have long-term impacts.

For food service officers, struggles for power and control originated in the theme “Breaking the rules” for palliative care patients. They confessed that they sometimes went against organisational policy by providing patients with what they deemed appropriate. Food service officers happily broke rules if that meant a patient received a food they requested since this could have positive impacts on quality of life.

1.5 Patient Struggles for Power and Control Against the Illness

Patients spoke of the battle for power and control being between them and the cancer as they fought to maintain life. This was well described by P13 who spoke of the need to “get rid of” the cancer that “alights in your body and… burrows into your flesh”.

Others such as P9 and P11 saw the power as belonging to God: “Its divine you know. It’s not in my control. I don’t have the power” (P9). Despite this P9 changed her diet and began exercising in the battle for ongoing life.

P11 used God’s word to fight her battle, changing her behaviours, refusing to speak of anything negative in the quest for life as “the bible says death and life are in the power of the tongue”. She prayed for a miracle as this was her way of maintaining control over the situation. P8 spoke of winning her battle, beating the doctor when she lived beyond the five-month prognosis she was given at diagnosis. For P8 her struggle was not for a cure but to beat the predictions of the medical officers.

Patients spoke of internal struggles to ensure they ate adequate volumes to maintain life. This was particularly noted in patients who did not have a carer supporting them. Once again, the findings of Hopkinson (2007) were relevant, in that loss of appetite and ability to eat was seen as loss of control. Several patients fought against their diminished appetite trying to gain control of their intake and improve their chances of life.

Struggles for power and control can be demonstrated in the language used by participants, with descriptive words such as “pushing”, “fighting”, “nagging”, “insisting”, “controlling”, “power”, “pressure”, “pressuring” and “conflict” emerging from the interviews. This use of language demonstrates the intensity of the desire for control within all participant groups. However, this struggle for power and control often resulted in conflict between the participant groups.

1.6 Impact on Relationship Between Patient and Carer

All participant groups identified food and nutrition as a highly contentious issue that impacted on the relationship between patient and carer and also the staff. Struggles between groups for power and control were numerous and were laden with emotion and fear of food deprivation. These struggles impact on patients’ quality of life and need to be addressed and managed in the palliative care setting.

In support of Holden's findings (Holden, 1991), we demonstrated that reduced appetite causes conflict as carers use the quantity of food consumed as an indicator of the patient's overall condition. This study supports the findings of Hopkinson and Corner (2006) with tension around food and eating being prominent. These tensions were much more notable in the present study, all participant groups speaking of tensions and concerns at some stage over the disease trajectory. In contrast, Hopkinson & Corner (2006) reported only one third of the patients they questioned experienced tensions.

Patients' experiences in the current study followed the finding of Holden (1991) in that patients wanted family members to be less assertive and focus less on encouraging them to eat. Such forceful encouragement was considered to be a cause of significant conflict for three patients in this study.

In contrast to the findings of Meares that patients ate to relieve carers' concerns (Meares, 1997), patients involved in this study would occasionally rebel against carers and resist intake being forced on them. Moreover, these patients did not eat more in a social setting and preferred to eat in isolation away from scrutiny and observation. This may in part be due to cultural differences in the patients studied.

Conflict around oral intake often arose between patient and carer. This impacted the medical officers and nurses involved in the patient's care. Nurses found this especially difficult because they felt powerless to prevent patients from being bullied by carers. Feeling caught between the carer's desires, the patient and medical officers, nurses longed to address the issues in order to bring harmony and peace for the patient. Nurses were distressed by patients' psychological pain as carers fought for control, forcing food and fluids onto the patient in the hope that this would buy more time. Medical officers found arguments around food and nutrition, which often revolved around carers' desires to gain control so as to prolong the patient's survival, to be exhausting and time-consuming.

For patients living with a life-limiting illness, it is important to be able to take charge and to define and actualise their needs from a position of control in order to preserve their dignity (Carter, MacLeod, Brander, & McPherson, 2004). This is an important point for health professionals who often find themselves adjudicating the battles of patient and carer. Patients need for control and their ability to take charge is something palliative care professionals need to recognise and assist patients in achieving to allow dignity preservation. It has further been reported that unmet patient needs have a detrimental effect on their wellbeing (Harrison, Young, Price, Butow, & Solomon, 2009). This research may help health professionals understand the needs of palliative care patients admitted for end of life care and provide evidence for recommendations around food and nutrition at the end of life.

In summary, while fighting for control, many carers took it upon themselves to become responsible for the patient's intake. Carers subconsciously deemed the patient no longer competent to make decisions regarding appropriate food choices or volumes. Thus, they took on a parenting role, monitoring each mouthful consumed to ensure it met their ideas about what is necessary to maintain life. While most patients felt their carer was doing so to support them, some patients refused to eat as a way of regaining control over their situation. Patients and carers alike reported that the struggle for power and control resulted in disharmony in their family relationships, some patients even admitting themselves to hospital to avoid pressure and having to eat in front of others. Carers admitted they imposed these pressures because it seemed obvious to them that without food life is not possible.

2 Situational Distress

Participants across all study groups reported experiencing personal distress relating to issues pertaining to food and nutrition whilst some acknowledged distress experienced by others. Palliative care can be an emotional situation for many and it was identified that distress was derived from different issues for each participant group.

2.1 Patient Distress

Patients reported distress originating from symptom burden, weight loss and cachexia. These areas will be discussed below.

Patients reported experiencing multiple nutrition impact symptoms which reduced quality of life, resulting in situational distress. Sixty-eight per cent of patients reported anorexia, 47 per cent taste changes, 47 per cent early satiety, 42 per cent nausea, 21 per cent vomiting and 16 per cent diarrhoea in the two weeks prior to participation in the research. These percentages are on par with those reported by Vachon et al. (1995) who reported 47-67 per cent of terminal cancer patients suffered appetite disturbances, along with 12-49 per cent nausea. However, these were significantly less than what Davis and Walsh (2000) reported, that is, 60 per cent of palliative care patients suffering nausea.

When combating these symptoms, one's ability to eat and drink is often impaired, with carers reporting increased anxiety as they watched their loved ones decline. Many carers transformed this anxiety into pressure for the patient to eat. This can become unbearable for patients. This results in two issues for palliative care professionals – firstly symptom management and secondly the psychosocial care of patients and their carers.

With the primary goal of palliative care being to improve quality of life for both patients and families (MacLeod et al., 2015) the major treatment goal of clinicians to reduce symptom burden and improve quality of life, becomes increasingly difficult to achieve in the last three months of life (Giesinger et al., 2011). In a study of brain cancer patients, it was reported that quality of life was more important than longevity (Lipsman, Skanda, Kimmelman, & Bernstein, 2007). While this was certainly true for one patient with an astrocytoma in my study, other patients did not share this sentiment but preferred to fight for survival. This highlights the need to treat each palliative care patient as an individual, addressing and treating their needs accordingly.

Weight loss is of high concern causing distress to both patients and carers. According to Lin et al. (2011) weight loss is experienced by up to 98 per cent of terminal cancer patients. Its causes include diminished intake and anorexia; however, it can be accelerated due to cancer cachexia, a condition in which weight loss is difficult to control. While the causes of weight loss in advanced cancer patents are complex and multifactorial (Buskermolen et al., 2012; Guenter et al., 2002; Lees, 1999), it is the physical and psychosocial implications that are of interest to our research.

As the disease progressed, patients suffered weight loss which was often beyond their control and likely, was caused by cancer cachexia and thus was a potentially irreversible process. It was difficult for patients, their friends and families to comprehend this and their negative comments impacted emotionally on patients. This is an area of current research which has the potential to positively impact on patients and carers psychologically if suitable prevention strategies or treatment options can be found.

Three reactions to weight change were reported by study participants. Firstly, some patients reported no concern when directly asked. Other's spoke of happiness over their weight loss after spending much of their life worrying about weight control, but for many this changed when the weight loss became uncontrollable. Lastly, while most patients admitted being concerned about their weight loss, these concerns were primarily linked with body image and subsequent physical changes, which negatively impacted the quality of life of many patients.

Distress from weight loss and change in one's appearance is an acknowledged sign that the patient is losing their battle against their disease. For some, weight loss sparked memories of traumatic historical events such as the extreme weight loss experienced by holocaust victims as well as victims of other significant famines. For others, it was a reminder of illnesses such as anorexia nervosa. Starvation also conjures images of the results of protein calorie malnutrition often seen in third world countries (Ahronheim & Gasner, 1990). Many carers felt the patient's weight loss was something within their control rather than something controlled by the cancer. Carers frequently spoke about the patient needing to fight against their poor appetite much like one would do with anorexia nervosa – a very different condition.

Patient distress was heightened by their loved ones' reactions to their weight loss. Patients found negative comments difficult to accept due to their hurtfulness and soul-destroying nature, especially when the comments came from those closest to them, with the proximity of the relationship being a measure of the distress experienced.

The absence of weighing palliative care patients is in itself an interesting point, since 66 per cent of hospices rarely weigh patients (Watson et al., 2010). It is commonly assumed that patients with life-limiting illnesses do not want to be weighed as doing so may not be in their best interests. Watson et al. (2010) investigated this phenomenon and found 96 per cent did not find being weighed upsetting, while 89 per cent wanted to know if their weight was changing. In contrast 56 per cent of hospice staff reported that they felt being weighed could distress the patient. These discrepancies in understandings between patients' wishes and hospice staff beliefs, highlights the need to undertake further research to ensure patient's needs and wishes are considered and where practicable, met. One must ensure that if weight of patients is to be taken, this is for a valid reason and not simply for data collection.

It has been said that although patients facing imminent death will not benefit from being weighed, such certainty cannot be expressed for those who receive hospice care at an earlier stage of the disease (Watson et al., 2010). Weighing patients can help identify those who would benefit from weight preservation interventions such as nutrition support and appetite stimulants whilst allowing monitoring of the intervention's success, reducing the impact of cancer cachexia (Watson et al., 2010).

Over against health professionals' concerns regarding weighing advanced cancer patients, Watson et al. (2010) reported that 84 per cent of patients attending a hospice wanted to be weighed at future hospital appointments and only 7 per cent of patients preferred not to be weighed if their illness worsened. Interestingly 15 per cent professed that they would be relieved if they lost weight. In this study, many patients were initially happy with their weight loss however, this changed when the weight loss was no longer stoppable indicating that our study may have been undertaken in more advanced cancer patients. This is something health professionals need to consider and patients thoughts around weighing during end of life admissions needs further investigation. Consideration must be given to the reasons for weighting as weighing may take place for therapeutic reasons such as medication dosing.

In previous studies, caregivers have used strong terms such as “gaunt”, “skin and bones”, “all bone”, “no muscle”, “hollow”, “wrinkled”, “skeletal” and “stick-like” to describe their loved one’s weight loss (Meares, 1997). In the current study, strong words such as these were also used to describe weight loss, but more frequently by patients than carers.

In this study, patients used metaphors and powerful and emotional visual imagery to describe their weight loss. This supports the findings of Casarett et al. (2010) who demonstrated that patients reported better communication from their physician when the physician used metaphors and analogies during the consultation. This use of language can be used by health professionals moving forward to address patients concerns around weight changes, food and nutrition at the end of life. The language used by patients was powerful and left a clear picture of the skeletal, emaciated, frail individual left after the cancer had eaten away their flesh. The language used was similar to that used by carers in the study of Meares (1997); an indication that this may not be unique to patients.

Patients spoke of covering themselves and hiding their weight loss from others. This supports research by Reid et al. (2009a) which demonstrated that patients felt embarrassed by the visibility of their cachexia. This activity is significant in palliative care as a review of cancer cachexia studies demonstrates that changing appearance is one of the primary concerns of patients and relatives (Porter et al., 2012).

This study builds on the current literature around weight and weight loss. Both topics are of high concern for patients who mostly believe that weight loss is something to fight against. Patients felt pressure to eat by loved ones but were also concerned by changes in body image; at times, they felt health professionals were hiding the meaning of the weight loss from them. While most patients identified weight loss as a sign that the end was near, they felt the loss remained within their control and could be reversed in the future to help fight illness.

While weight loss in cancer patients has been investigated from a psychosocial perspective, the same cannot be said for patients who gain weight. Situational distress was reported by the one patient who gained weight when she assumed she would lose it. Comments made by family and friends around her weight gain were upsetting, emotionally distressing and impacted on her quality of life. This is an area for future research as it too impacts on patients psychosocially.

Cancer cachexia was also a significant contributor to situational distress. In cancer cachexia, multiple factors result in loss of skeletal muscle mass with or without loss of fat mass (K. Fearon et al., 2011). As was noted earlier the definition of cancer cachexia advanced by Fearon et al (2011) sets out three phases of the condition, namely pre-cachexia, cachexia and refractory cachexia. It is important to consider these in the context of the patients studied. In refractory cachexia, patients are generally pro-catabolic, non-responsive to cancer treatments, have a poor performance status and have an expected survival of less than three months (MacDonald, 2012). Many of the patients included in the present study who were admitted for terminal care met the definition of refractory cachexia. Despite this, many still expressed a desire to gain weight, which according to the current definition of refractory cachexia, was unlikely.

While a more recent study has shown that patients with refractory cachexia can indeed gain weight and have increased survival times when provided with parenteral nutrition (Bozzetti et al., 2014), this was not the case when nutrition was provided orally. This is an area for future research and it is recommended that consideration be given to both the physical and psychosocial impacts of care in willing refractory cancer sufferers to ensure no additional distress is caused. Positive results would allow clinicians to provide treatment options above and beyond the currently recommended alleviation of cachexic-related symptoms and increasing well-being in refractory cachexia (Suzuki et al., 2013).

Both patients and carers experience distress when they observe the loss of appetite associated with advanced malignancy and cachexia (Hawkins, 2000; Hopkinson & Corner, 2006; Strasser et al., 2007). This distress was also the case in the current study in line with Reid's (2014) demonstration of the profound existential distress associated with cancer cachexia in both patients and their carers. The sensitivity of the topic and its potential to cause extreme distress was confirmed by the medical officers who participated in this study, who reported that they were extremely cautious in their consultations with carers in order to avoid causing catastrophic distress.

Historically it was thought that many patients were discharged from acute care facilities without the resources required to maintain their nutritional status (Dixon et al., 1985). As recorded earlier, while the results of this study suggest that patients are grateful of initial weight loss, they frequently fail to see weight loss as affecting their nutritional status. One also needs to consider that due to nutrition impact symptoms and cachexia, it may not be possible for patients to maintain their weight or nutritional status despite their best efforts to ensure an adequate dietary intake.

While many patients in this study wished to gain weight, currently very few treatments are available to help cachexic patients to achieve this. Treatments such as fish oils and appetite stimulants have been trialled to improve appetite in cachexic patients. To date there is insufficient or inconclusive evidence which could lead to their widespread use, with systematic reviews disagreeing on their efficacy (Colomer et al., 2007; Ma et al., 2015; Mazzotta & Jeney, 2009; Reid et al., 2013; Ries et al., 2012; van der Meij et al., 2013). The side effects of high doses further limit their use (Madeddu et al., 2015; Ruiz Garcia et al., 2013) and to date no studies have examined their efficacy in preventing weight loss and cachexia from early after diagnosis.

Interventions in cancer cachexia should aim to reduce the emotional burden of this syndrome by empowering patients and carers to understand the mechanisms and management of cachexia and its symptoms (Reid, 2014). With research demonstrating the lack of a genetic component to cachexia (T. Solheim et al., 2011), future research should investigate strategies to prevent the development of the syndrome in at-risk groups.

Patients reported distress originating from symptom burden, weight loss and cachexia in this study. This is of importance in that distress impacts on a patient's quality of life. Delgado-Guay et al (2016) found that more than 40 per cent of advanced cancer patients reported "spiritual pain" which was correlated with physical and psychological distress. Studies have shown that interdisciplinary management of palliative care patients, including dietetic and social work, improve quality of life, symptoms and decrease distress for patients with non-small cell lung cancer (Ferrell et al., 2015). This is an area that needs further consideration in that the research facility does not routinely provide this level of support for patients which may have influenced the research results. Evidence is also required in other cancer types to further support the employment of a multidisciplinary team.

2.2 Carer Distress

The theme "Carer Distress" exposed the extreme anguish experienced by carers which appeared to originate subconsciously in a fear of losing their loved one. Fear influenced carers' decisions and their communication with the patient. Carer distress is not a new finding in their study, Costa Requena et al (2015) found that up to 78 per cent of carers of advanced cancer patients reported distress. This anticipatory anxiety was amplified when a patient did not eat or when they challenged the carer who felt they had to force the patient to eat because they had the patient's best interest at heart.

The overall responsibilities involved in looking after a loved one with advanced cancer, caused distress and frustration for many carers. They often felt isolated and unable to share the burden with family and friends, leaving them to manage alone, whilst hiding their distress from the patient. This is coupled with carers' generally very limited training and experience of caring for the terminally ill and a lack of resources available to assist them (Reid, 2014).

In the current study, 68 per cent of the patients reported loss of appetite in the two weeks prior to their interview. For caregivers, this symptom of anorexia is seen as a sign of impending death which caused considerable anxiety (Holden, 1991). The current study supports this finding, their loved one's reduction in intake being difficult for carers to accept and in all cases, they had at some point tried to improve it.

Previous research has demonstrated that it is common for family members to rate anorexia to be of high concern whilst patients do not always see it as being important (Holden, 1991). Hawkins demonstrated that 87 per cent of relatives reported anxiety due to their loved one's anorexia as compared with only 36 per cent of patients reporting concern (Hawkins, 2000). In this study, it was found that patients' lack of intake was often associated with the carer's belief that the patient needed an inpatient admission to receive medical management of the anorexia. As shown by Strasser et al. (2007) this deep concern by carers may be driven by their belief that the patient's inability to eat presages the impending loss of their love one.

Morita et al. (2004) documented that 63 per cent of bereaved family members reported loved ones had experienced appetite loss either often or very often in the week prior to death, whereas only 7.2 per cent reported that their loved one was hungry during this period. Of the families who reported appetite loss, 93 per cent reported distress of varying intensity (Morita, Hirai, et al., 2004). In the current study, carers felt a strong sense of distress when the patient was unable to eat the meal prepared for them. Although they aimed at understanding, in many cases the concern remained because, in their eyes the patient's intake remained inadequate for survival.

Hopkinson (2007) reported carer frustration about carefully prepared meals which went uneaten. In the current study, carers responded by preparing alternative meals, bribing or pressuring the patient to eat. Previous studies have shown that patients' refusal of food brought about feelings of guilt and anger for family members because it was seen as refusal of their support and rejection of the affection, concern and consideration that had been invested in food preparation (Reid et al., 2009b). Family members felt guilty that their efforts in persuading their loved one to eat were rejected. That this also caused significant frustration and anxiety was seen in the current study.

In the study of Strasser et al (2007) investigating eating related stress, the female partners of 19 males with advanced cancer expressed deep concern, frustration and feelings of inadequacy because their loving and innovative efforts in the preparation of appealing food failed to persuade the patient to eat. In our current study, both male and female carers spoke of their distress and frustration in sourcing foods their loved one would consume. This was found irrespective of the relationship to the carer, confirming the results found by Strasser et al. (2007).

Carers in this study demonstrated significant distress. They spoke of fatigue, depression and financial difficulties, with one carer being hospitalised due to the pressures placed upon her. This confirms the findings of Rumpold et al. (2016) that 52 per cent of carers had one or more suspected psychiatric disorders and spouses and parents demonstrated higher levels of psychiatric disorders than other caregivers. Oechsle et al. (2013) found that 55 per cent of male carers and 36 per cent of female carers suffered moderate or severe anxiety, with 36 per cent of male carers and 14 per cent of female carers showing moderate or severe depression when caring for a patient with terminal cancer. Spousal relationship and the disruptive impact on one's schedule caused by caring duties has also been shown to be factors for prolonged grief (Thomas, Hudson, Trauer, Remedios, & Clarke, 2014).

2.3 Health Care Workers Distress

For medical officers, the "uncomfortable but essential conversation" they had to have with patients and carers arose from the interplay between their own pre-existing health beliefs and personal relationship with food, and those of the patient and carer. Medical officers found refereeing these conflicts to be tiring, often finding themselves repeating the same information multiple times during their daily rounds. The conversation involves discussions on a topic which impacts on a patient's or carers hopes and fears, and the relationship between the two parties.

While the discussions were deemed essential, professionals realised that they were limited in how frequently they could address such distress-causing issues. Some medical officers admitted that their own personal and pre-existing beliefs around food had the potential to cause them significant distress if exposure to these issues was not limited. Removing themselves from food and nutrition related discussions was a way of caring for themselves. These findings support previous research indicating that palliative care physicians experience low levels of burnout compared with oncologists. While lower than their Oncology counterparts, Palliative Care medical officer's levels of emotional exhaustion and depersonalisation remain significant at 9 per cent and 4 per cent per cent (Dreano-Hartz et al., 2016). It is possible that the levels remain low in palliative care medical officers due to their awareness of the difficulties their job brings and self-protective processes instigated. In this study, medical officers identified when conversations were becoming draining and reoriented their days work to provide emotional relief.

In the "being caught in the middle" theme, nursing staff spoke of the distress they experienced when watching carers force feeding patients and when carers pressured them to make the unwilling patient eat. Nursing distress was based on their feelings of being powerless to act and protect their patients, especially when it was obvious that the patient was not managing an oral diet. Nurses recalled many distressing situations of this kind over their years of practice, demonstrating how specific incidents touched them and stayed with them over time.

Food service officers spoke of returning to the kitchen and shedding tears following the death of death a patient with whom they had developed an almost familial relationship because of their role as food provider. Their tears and situational distress mirrored what one would experience when someone close to them died. It was on this kind of circumstance that they based their claim that one needed to be a special person to fulfil the role of a food service officers because this was not something that the average person would be able to do. This is the first known study to consider the distress experienced by food service officers working within the palliative care context.

2.4 Changes to Mealtime Routine and Social Isolation

Issues such as increased tensions and frustrations, changes to mealtime routines, social isolation and changes experienced with hospitalisation added to the situational distress experienced by patients and carers. Changes were heightened as death approached (Hopkinson, Wright, McDonald, et al., 2006).

Previous studies (Hughes & Neal, 2000; Reid et al., 2009a, 2009b) identified that meal times are a source of tension and conflict between patients and their carers. Mealtimes became the time of day patients least looked forward to. The current study supports these findings and also those of Hopkinson (2007).

In support of the findings of Holden (1991), patients in this study wished to determine the quantity of food they consumed without pressure from those around them. When pressured, some patients became physically unwell, while others removed themselves from the mealtime environment. This phenomenon is similar to that reported among heart failure patients in the study of Jacobsson et al (2004) who spoke of food consumption becoming a burden as their disease progresses.

While Meares (1997) found patients with anorexia ate more in social settings the present study did not support this finding. This study moreover, supports the findings of Meares (1997) and of Overall et al. (2004), in that the diminution of patient’s inability to share and enjoy mealtimes impacts on their relationship with carers. It supports the assertion of McClement (2005) that pressure to eat leads to negative emotions and that the tensions experienced by patients on this issue can lead to conflicts with loved ones.

Recent advances have been made in the development of psychosocial programs aimed at reducing weight and eating-related distress in families impacted by refractory cachexia (Hopkinson et al., 2013; Hopkinson & Richardson, 2015). The present study highlights that this psychosocial distress can be found in patients not yet classified as refractory cachexic, hence the scope of these projects should consider a wider audience than just those with refractory cachexia. This is an area for further research because alleviating the frustrations and tensions spoken of in this study is imperative to improve patient quality of life.

This study supports the finding of Reid et al. (2009b) where some cachexic patients acknowledged that family members' focus on food was a sign of their love and compassion (Reid et al., 2009b), however, most saw their family's concern to be more of a hindrance than a help. Carer concern increased patients' anxieties at meal time and created tensions with patients who wanted family members to stop pressuring them to eat and allow them to make their own decisions.

Significant changes in their social interactions occurred for patients who were unable to or chose not to engage in food-based events. This ranged from the inability to participate in family mealtimes, having dinner with friends or even simply having a cup of tea with visitors because of fear of vomiting. Since prior to illness, food and meal times had been an avenue for social engagement, their inability to participate in these interactions left them feeling isolated and alone.

In heart-failure patients, fatigue and lack of appetite has been shown to give rise to feelings of deprivation as patients missed the process and socialisation linked with eating (Jacobsson et al., 2004). This finding can now be extrapolated to oncological palliative care patients as they too missed the socialisation previously coupled with eating.

The decline in food intake can be difficult for carers to come to terms with. In the light of Bruce Moore's maternalistic view of feeding (1957) it is difficult for a carer to observe their loved one not eating, much like a mother of a young child will go to great lengths to ensure their toddler consumes a meal.

In regards to oral intake, previous studies have demonstrated that patients are often more satisfied with their intake than their carer. Patients reported feeling more pressured to eat than their partners estimated (Strasser et al., 2007). To manage mealtime pressure, some patients isolated themselves socially from family members in an attempt to avoid conflict at meal times (Reid et al., 2009b). The current study supports this finding, although carers were not always aware that patients were isolating themselves to escape carer pressure.

In support of Neergaard et al. (2008), some relatives took on a semi-professional carer role when their loved one was in hospital because they felt health-care professionals' level of care was less than the care level at home. However, carer strategies included force feeding the patient which health professionals would never do.

With over half of all deaths occurring in hospitals (Australian Institute for Health and Welfare, 2012), the impact of hospitalisation on meal times is considerable, as many are hospitalised at the end of life. But while Johnson and Taylor (2016) reported patients felt bullied by nurses as they were too tired to get them to eat this was not a finding in my study. In addressing eating-related concerns with patients and carers along with nursing staff, medical officers' resistance of family pressure to force feed patients may have prevented them from feeling bullied by carers.

Sharing of the mealtime experience is at the heart of palliative care. Dame Cicely Saunders encouraged family celebrations at the bedside and as recorded earlier, encouraged family-patient social interactions by providing a drinks cabinet on every ward in the original hospice (Shotter, 2006). It is of importance that 92 per cent of patients were eating up to the day of death (Feuz & Rapin, 1994). While their intake may be minimal some form of oral intake was possible for the majority of patients. This however is never forced and only offered for patients wishing to eat and drink.

2.5 Busyness and Avoiding Thoughts of the Impending Death

The participating carers in this study were always busy filling up their day by catering for patient needs. While food preparation and meals took up a large proportion of their time, other duties were toileting, cleaning up after the patient and attending appointments prior to admission.

According to Deshields et al. (2012), caregivers spend 7.8-8.3 hours per day providing care when a loved one has cancer. In the present study, respondents suggested that the time required may be greater in advanced cancer cases. One carer spoke of needing to be available “24/7” and if she wanted to run errands, needing to have a substitute carer to be with the patient. Others worried about the patient whenever they had to leave them alone even for short periods and kept wondering if they would be alive on their return. Several carers changed their routines so as to be more available because of concerns over the patient’s safety when they had to be left alone at home. When carers found it necessary to leave the patient, they worried about them continually and thus experienced additional stress. Some no longer had time to engage in their own established social activities.

Carers spoke of putting their own needs aside to make room for those of the patient and rarely had time to socialise with friends and family and to participate in previously enjoyed activities. In summary, irrespective of the quantity of time spent with their loved one, carers became exhausted from the caring process, while their busyness left little time for contemplating or preparing for life without their loved one.

2.6 Conflict and Disharmony Experienced at End of Life

Participant nurses highlighted the emotional distress experienced by family members when dealing with artificial hydration at the end of life, including when fluids were withheld. This supports the findings of van der Riet et al. (2008). Nurse participants found that carers frequently requested artificial hydration when a patient was no longer able to drink an adequate amount of fluids. This became an area of conflict between nurses and medical officers who, at the insistence of carers, had ordered IV fluids. Nurses', however, deemed this provision of fluids as not being in the patients' best interests and in their role as patient advocates questioned it. The medical officer who was engaged in conversation with the carer, took both the patient and carers' wishes into account by allowing fluids until they became burdensome or harmful to the patient. In doing so, medical officers were acknowledging that long after the patient's passing, carers could still be struggling with issues around hydration at the end of life.

This highlights the need for health professions to work together proving a unified front in support of patients. A unified front would assist nurses to feel supported and to prevent the conflict between medical officers and nurses.

Another difficulty for nursing staff is adjudicating the differing opinions of carers and patients in regard to the latter's requirement for food and fluids at the end of life. This leaves the nurse feeling caught in the middle of not only family arguments but also arguments between the carer and the medical team when the two parties do not agree. This was a difficult area for nurses, especially those who preferred conflict avoidance.

Conflict management and strategies for working with different personalities at difficult times is a skill rarely included in either formal or on-the-job training and which therefore often have to be learnt informally on the job. Nurse participants in the present study evidenced that this training was something they felt they would benefit from.

In line with the definition of palliative care including both the patient and their family (World Health Organisation, 2016), medical officers in this study spent significant amounts of time caring for their patients' families. At times clinicians went against their better judgement to accommodate carer's requests as they were aware that not considering their needs could cause suffering at a later stage. This is in line with recommendations in the literature that states patients and/or their families should be offered appropriate support respecting their preferences where possible (Bachmann et al., 2003).

That medical and nursing staff as well as food service officers experience significant distress around the provision of food and nutrition to patients in the last stages of their lives is a new finding. This indicates that since these groups currently receive very little support on these issues, they are likely to benefit from psychosocial support. Hence drawing attention to and taking action to enable them to discuss and debrief about their concerns could assist to reduce “burnout” and fatigue around the issue.

In this study, distress was seen in all participant groups as individuals dealt with highly emotive issues relating to food and nutrition at the end of life which impact on patients, carers and health care workers alike. This concern and distress needs to be addressed by health professionals in their care of patients and carers, while health care workers also need to be aware and practice self-care to ensure these issues do not result in personal ongoing psychological ramifications.

3 Fighting to the End

This third overarching theme was observed in the patient and carers analysis. Health professionals did not fight to the end like patients and carers as their training informed them that at this point the cancer could not be cured and indeed the end was near.

Several patients spoke of their fight to live on despite being told their life was coming to an end. Although all patients were informed by medical officers that they had admitted for terminal care, many refused to accept that and turned to food in search of a cure. With medications controlled by medical officers and bowel habits often out of their control, patients saw food as one of the last domains over which they had control in their battle for independence and/or the fight against their cancer. Interestingly patients either reported fighting for life or feeling pressure to eat. Only one patient went between the two areas. Although he had felt pressure to eat by his treating dietitian during cancer treatment, this was no longer of concern as he reoriented his goals when moving to the palliative context.

The concept of eating to live was one shared amongst many study participants. This supports the findings of Shragge et al. (2006) who recorded that patients often retained the motivation and ability to eat despite a lack of appetite. Millar et al. (2013) found patients continued to eat despite suffering anorexia and nausea. When patients find that food is no longer pleasurable but something they have to force themselves to ingest in order to stay alive, this is often a crucial turning point for them. While traditionally at this point clinicians prescribe an appetite stimulant, to date single agents have not demonstrated side effect-free ongoing benefits (Bachmann et al., 2003; MacLeod et al., 2015).

Despite being told the end was near by palliative care specialists patients saw food as an ally. The researcher observed that this idea continued among patients who fought for life right up to the final days. Only a very small cohort of two patients accepted their diagnosis and did not feel the need to fight.

The fight for life included a desire to regain weight. There was an awareness that weight loss was a negative sign in the disease pathway, but there was a lack of awareness that this was a process they had little control over and its rectification was unlikely given their short life expectancy.

The number of patients discharged from hospital despite being admitted to end of life care highlights the difficulties faced by physicians in prognostication. A number of patients survived for months following interview, thus the role of nutrition and dietetic interventions must be considered at this point. Generally, nutrition support is not instigated for patients admitted for end of life care, therefore a number of patients were not offered nutrition intervention. Several studies have demonstrated improved quality of life in advanced cancer patients receiving nutrition support (Bachmann et al., 2003; Bauer & Capra, 2005b; Isenring & Teleni, 2013; Moses et al., 2004; Pappalardo et al., 2015). This intervention some requested and would have benefited from. A number of participants in this research requested nutrition-support after their interviews which was then provided. It is the researchers experience that this provides the patient with a positive focus allowing them to feel they are attempting to address their weight loss. It should be highlighted though that this was the patients wish and not enforced by health professionals.

Determining which patients would benefit from nutrition support in the palliative care setting is difficult for medical officers due to the problems of prognostication. It was evident in this study that many patients survived much longer than estimated by health care professionals. Those who died within close proximity to the research interview fell into two categories - those with a slow and anticipated decline and those who were well until their unexpected death within a short timeframe. In the second category were patients who would have benefited from support had the unexpected terminal event not occurred.

Clinicians carry the potential burden of nutrition support to ensure it is only provided to willing patients. Nutrition support has the capacity to fulfil a patient's hope that they will be cured. While the nutrition intervention may be futile in the case of sudden death, the hope it gives may at least succeed in improving quality of life. A number of patients benefited psychosocially from nutrition interventions which had them feeling positive and hopeful at the end of life rather than feeling there was no hope and existentially suffering. Traditional nutrition support endpoints used by dietitians such as weight gain and calorie consumption need be reconsidered in this patient group to be something more achievable and quality of life -focused. Nutrition support should never be insisted on if unwanted or if burdensome. The other point of note here is that dietetic intervention in palliative care patients is not purely for nutrition support. It is suggested that dietetic training needs to incorporate graduate education on determining which patients would benefit from nutrition intervention, monitoring burden and supporting patients and families to make appropriate decisions around food and nutrition at the end of life. Clinicians should ensure patient-centred care is at the centre of all decisions, ensuring that patients' needs and wishes are always at the forefront of care.

Despite being informed of their admission for terminal care, patients in this study frequently spoke of their belief that their condition would improve or change for the better. They spoke of their aspirations and plans for the future, demonstrating that their attitude and beliefs were paramount in their fight. There was an awareness that they needed to fight for time on earth and a hope that they could be the one who received the miracle of life.

Several patients spoke of using food to help them search for that miracle and combat their illness while hoping for an outcome other than that predicted by medical officers. They spoke of foods they personally thought would be of use in reversing their illness which were not necessarily foods they had been encouraged to consume by health professionals. There was a general belief that fruit and vegetables were protective and would assist in improving health. There were also other specific foods patients spoke of that may have been culturally significant to them.

Similarly, carers saw food as helping them combat the patient's disease. It was one aspect they felt that could impact a patient's chances of survival. Carers thus went to extreme lengths to provide the foods and diet they felt best for a patient. This went far beyond simply providing food and extended to them becoming responsible for the patient's overall intake. This was seen as a manifestation of "Fighting- the-fight" "Whatever-it-takes" attitude to maintain life and the "Never giving up hope" themes.

Medical and nursing staff however, observed that patients' and carers' struggles against their illness and fight for life, impacting on their health care role. Health professionals particularly observed that the perceived battle engendered struggles between patients and carers for control and power. This was because frequently the two parties were not unanimous in their ideas about the best way to fight for life. Carers often demonstrated frustrations when the patient was not fighting the way they thought they should, but this also impacted the nursing staff because carers pressured them to force feed patients or use other strategies to ensure an adequate oral intake in the fight for life.

Many patients did indeed fight to the end, with many focusing on their oral intake. Two patients realised they had “lost their battle” one week prior to death. At this point they no longer focused on food as a cure. But others only ended the fight when their consciousness failed.

While McClement et al. (2004) reported that some carers fought for their loved one’s life using food (McClement et al., 2004), this study goes one step further by documenting that patients also used food to fight for survival, especially those who did not have a carer looking after them. This was prevalent in the current study and something of high importance to many carers.

Carers went to extreme lengths to encourage the consumption of food and many of their actions were well beyond behaviours normally exhibited in patient care. While this left them exhausted and drained, they willingly did so in the hope of the patient being with them for longer. Carers appeared proud of their actions and efforts, revelling in the patient’s consumption of the food offered and the positive feedback provided by health professionals. Carers appeared to take over the fight for the patient when he/she was too exhausted to fight themselves.

With patient and carers’ focus on food, health professionals need to be aware of this and ensure adequate psychosocial care is provided to support all parties involved at the end of life. Identification of concerns and development of strategies to address these will impact on quality of life for all parties involved.

The fact that the majority of advanced cancer patients develop malnutrition (Bachmann et al., 2003) along with 20 per cent of cancer deaths thought to be due to malnutrition rather than the cancer (Ottery, 1996) and up to 92 per cent of patients eating until the day of death (Feuz & Rapin, 1994), patients and carers have adequate reasons to focus on eating. This however, should never be the focus if it is not in the patient’s best interest physically or psychologically. Maintaining oral intake maintains hope, and while patients and carers are unlikely to obtain the outcome they desire, living with hope is often preferable to dying with helplessness and despair.

3.1 Cultural Impacts

Cultural and religious rituals and activities are known to be fundamentally important in maintaining well-being when one faces an uncertain future (Brady, Peterman, Fitchett, & Cella, 1999; Steinhauser et al., 2000). Eleven out of 19 patients reported that they followed a religion although two were not practising. Several participants spoke of religious and culturally specific influences which were of importance at the end of life.

In considering P9's request for dog meat, the consumption of dog meat originated in ancient times and is linked with South Korea's national identity (Podberscek, 2009). Dog meat is seen as both a medicine and a food (Podberscek, 2009; Simoons, 1994) thought to treat conditions such as male impotence, depression (Simoons, 1994) and Parkinson's disease (Kim, Lee, Kim, Lee, & Chung, 2009). For P9 her request was an expression of hope that her condition could improve.

For P3, it was not her beliefs, but her husband's that influenced her journey at the end of life. C3 did not want his wife to feel the hunger he experienced whilst on the run. C3's food attitudes and behaviours were consistent with those reported in holocaust survivors exhibiting preoccupations with food and anxiety when food is not available (Sindler, Wellman, & Baruch Stier, 2004).

P11's religion dictated her treatment choices**.** The literature refers to this phenomenon as the "God locus of health control" (Wallston et al., 1999) or surrendering control to God (McLaughlin et al., 2013). P11 prayed for her survival and spoke of life post-discharge as she believed God would provide her with the miracle of life. She passed away eight days' post-interview.

While scholars have philosophised that deferring health beliefs to God are positive coping behaviours, research has not confirmed this. McLaughlin et al. (2013) reported negative health outcomes associated with this coping mechanism which included lower level of problem focused coping and active coping which have been associated with lower levels of quality of life.

3.2 Whose Role is it to Fight?

The patients who did not have a carer fought to maintain life themselves. They took responsibility for their own care and actively engaged in activities which they thought would prolong or maintain their life. This is a new finding not previously reported in the palliative care literature. The one exception was an elderly gentleman who had lost his wife two years earlier. While his children provided some care, they did not offer suggestions as to how he should be fighting to maintain life. Although not thoroughly investigated during the interview, it is possible that the patient’s children were fulfilling the fighting role on behalf of their father. While he did not nominate his children as his carers, he did mention that they had been providing some mealtime care. It is possible he wished to join his wife in life after death.

Patients with a carer fell into two categories. The first was the group who fought for life so they could care for their carer. This was generally a patient who had been a provider for a spouse and who did not want to leave them to care for themselves or who wanted to buy time to arrange their affairs in such a way as to reduce the impact of their death on their loved one. The second group had carers who fought strongly for their survival. In these cases, the patient appeared to take a step back and leave the fighting role to the carer. It was noted that this often-caused difficulties within the relationship between the patient and the carer as the patient often felt pushed and pressured into fighting someone else’s fight.

3.3 The Role of Hope in Palliative Care

While carers maintained hopes for longevity and quality of life their predominant wish was that the patient would survive. For others, hope was in the form of denial; by denying the gravity of the situation, the carer could believe that the patient had a positive future. However, carers often had a poor understanding of the patient's condition and were hoping for something that was not possible.

The findings of Millar et al. (2013) demonstrated that medical officers often avoided directly addressing issues around weight loss and cachexia, preferring to allow patients to cling to hope. This was especially the case when, although patients were suffering from refractory cachexia and therefore had a poor prognosis, physicians were reluctant to tell the truth about their non-existent chances of survival (Millar et al., 2013). In the present study, medical officers spoke of the discomfort they experienced in having these conversations with patients and carers. While the more experienced clinicians recognised the need to have these discussions with families, more junior staff tried to avoid them. All staff found these conversations psychologically draining and that they impacted on their experiences and belief systems. This highlights the needs for medical programs to consider the mentoring and support provided to palliative care trainees.

Food-related discussions at the end of life are challenging as food has many underlying meanings for patients, carers and health care workers, which become evident in the course of these critical conversations. Medical officers needed to protect themselves in this situation due to the burden experienced.

Participant carers associated reduced food intake with poor outcomes. Holden (1991) found similar behaviours among the carers involved in his study and saw this as the reason for the carers' continual efforts to make their loved one eat.

This study was unable to determine if carers' poor understanding was due to their not receiving, accepting or being unable to understand key information. These significant gaps in carer knowledge are an area for future research.

The three overarching themes presented in the discussion above highlight the issues experienced by patients, carer and health care workers. All parties experienced distress and as patients and carers fought for life, struggles for power and control tended to dominate relationships between them.

All parties acknowledged the challenges of being within a palliative care context and the importance of food at the end of life. Food has the ability to bring people together, to bring enjoyment and pleasure but also when feeling unwell the opposite can be true with food exacerbating nutrition impact symptoms such as nausea, vomiting and diarrhoea. This often results in patients socially isolating themselves to avoid mealtime scrutiny. Palliative care health professionals need to be aware of the psychosocial impact of food and nutrition at the end of life to ensure quality of life is maximised.

Chapter 8 Conclusion

This is the first known Australian study to investigate the lived experience of palliative care patients and their carers around the meaning of food and nutrition. This study adds to the current knowledge, understanding and literature by considering the perspectives of 54 participants (patients, carers, medical officer's, nurses and food service officers) in the palliative care unit for patients admitted for terminal care.

In considering the topic, it is important to consider food and nutrition as separate entities. Food was seen as something that should provide enjoyment and pleasure and not merely micro and macro nutrients. While nutrition is an important component of food, in this study, food was seen as much more than this alone. Food was shown to play a significant psychosocial role and to act as a social "glue" bringing groups of people together to enjoy a shared experience. That however, was often tarnished at the end of life as patients were found to no longer enjoy meal times and food-based social events. The preparation and provision of well-planned and gourmet meals was seen by carers as an expression of their love for the patient, however food refusal was perceived as a rejection of carer love and a rejection of life.

Although for many patients, at the end of life food became merely a provider of nutrients, eating occurred without any enjoyment. While carers pushed their loved one to eat doing whatever it took to ensure they ate, some patients pushed themselves to fight one last fight for survival. In this circumstance, even the consumption of small amounts of food was seen as a win, as food was ultimately seen as the provider of life. For a few patients, however, food was seen as a burden they wished to be released from.

While patients saw the importance of nutrition in their battle for life, their application of this concept differed, depending on their perceived prognosis and desire to fight. For patients, food gave them hope of survival and this continued into the last weeks and days of life. Patients and carers rarely gave up on the hope that food would prolong their survival time. Food was one of the only perceived strategies available to patients and carers to prolong life. Most other options such as chemo- or radiotherapy were dictated by health professionals and hence patients and carers put much effort into the one avenue felt they had control over. However, the use of that avenue became problematic when the patient felt too ill to eat or when the patient and carers ideals did not align.

Food itself is a complex entity with many properties. Firstly, there are physical characteristics - visual appeal, taste, smell, texture, and the provision of nutrients. Yet food also provides an avenue for social interaction starting with its preparation as a demonstration of love, the more effort required being seen as a deeper show of affection. For this very reason, the refusal of food by a loved one is seen as a rejection of that love and as a sign of loss of the will to live. This is of importance in the palliative care setting and is an area for further research where the effectiveness of psychosocial interventions can be tested.

Despite nutrition seemingly being of little importance in the last days of life, the value of food lies in the fact that it provides not only nutrients but hope, love and comfort. A patient, should of course not be compelled to eat when they have no desire to do so. However, the psychological aspects of food need to be considered in full. It is imperative that this topic is not overlooked and that patients and carers together address their concerns and underlying meanings of food in an effort to bring harmony in the last days and weeks of life. Within the hospital environment this can be facilitated by the multidisciplinary team working together with the patient and carer.

For health professionals, the challenge is to identify the point where nutrition is no longer the primary goal and where the issues around psychological aspects of food become apparent. It is suggested that a multidisciplinary team-approach would best identify and address patient and carers’ concerns. This will require all team members to present in a unified front and hence interdisciplinary cooperation is required. One must keep in mind that the immediate goal is to prevent harm and ensure patient comfort. However, it is imperative to remember that the issues that arise for carers during this time can remain with them long after the patient has gone. By definition, palliative care includes the carer and their needs must not be overlooked as it is the carer that struggles most with issues around food and nutrition at the end of life.

The differences in the lived experiences of the medical officers, nurses and food service officers relating to end of life care may in part be attributed to the level and type of professional training received and the “hands-on” role of the employee with the patient. Medical training relies on many years of evidence-based practice at a university level whereas among the remaining groups, only the RNs are likely to be university-trained. Nursing staff spend significantly more “hands-on” time with patients than medical officers, who usually visit patients only on a ward round or in a clinical situation. In contrast, nursing staff often spend much more time getting to know a patient and their background and personality.

For all health care workers, dealing with the dying on a daily basis can become emotionally draining. This led food service officers to assert that it needs a special personality to be able to work in palliative care. Interestingly all food service officers had worked at the research facility for 10 years or more, suggesting they had managed to maintain their own mental health throughout their time caring for dying patients. The palliative care literature makes it clear that working in this field is not without risk. Marr (2009) spoke of the need for health professionals to avoid “compassion fatigue” by consciously and continuously adopting an approach to patients fully in line with the meaning of the word “compassion” - literally “to suffer with”.

It was evident in this study that medical officers, nurses and food service officers came from different training backgrounds, perspectives and disciplines. Medical officers predominantly relied on evidence-based practice whereas catering and nursing staff spoke of drawing on their experiences and emotions in guiding decision making. When this occurs, staff need to be careful that the patient and carer do not feel health professionals are contradicting one another as relatives feel insecure and do not know who to trust when health professionals insinuate that another professional is incompetent(Neergaard et al., 2008).

What was evident in this study was that health care workers tried to put the patient first. But while they attempted to please and accommodate family members' requests wherever possible, patient safety was at the forefront of their decision-making. Each health care worker cared deeply for the patient and felt they played a role in the patient's quality of life especially on food and nutritional issues at the end of life.

While patients should be given the right to refuse treatment the reverse is also true, in that patients should also be given the right and opportunities to try interventions to determine if they work for them. Once a medical officer has informed a patient of their poor prognosis, the patient should be given the right to choose to try nutritional interventions if they feel this will improve their quality of life. Symptom management should continue due to the impact on quality of life.

Care needs to be taken to identify situations where a patient and their loved one's ideas around food and nutrition at the end of life differ. Support needs to be given to carers to allow them to support the patient in their wishes rather than projecting their own goals and fears upon the patient when this impacts on the patients quality of life.

A multidisciplinary approach is required with patients, carers, medical officer's, nursing staff, dietitians and social workers or psychologists working hand in hand to identify disharmonies and to support patients and their families in reducing existential distress at the end of life. This will require medical administrators to consider the staffing profile in palliative care teams.

While early studies have commented on psychosocial interventions in cancer cachexia (Hopkinson, 2010; Hopkinson et al., 2013; Hopkinson & Richardson, 2015) further research is required to determine the best way of addressing these issues in the palliative care unit. Research is required into the psychosocial as well as physical impact of interventions in cachexia including refractory cachexia.

Food was found to be of high importance impacting daily on patients and carers. Despite participants coming from five different study groups the meaning of food was consistent across all of them. While nutrition was of less importance, food was seen as essential not only to sustain physical life, but also because it symbolised life and love to most people and constituted a “social glue” bringing people together to share in a common experience and maintain and strengthen the bond between patient, carer, family and friends.

When a patient was no longer able to eat and drink as they had once done, relationships broke down or became strained as the patient was no longer able to participate in the events and rituals that bound the parties together. With the shared experience gone, the lack of intake indicated to all parties that the patient was approaching the end of life. For carers, this was often a time of panic in which they resorted to tactics such as treating the patient as a child or turning to hospitalisation to encourage intake. Everything possible was done to prolong survival up until the last week of life. Life was seen as something to fight for and all efforts were directed at maintaining life at any cost.

Patients and carers alike saw the ability to eat as an indicator that there was hope life would continue. Despite being admitted for terminal care patients and carers spoke of the future, often projecting years ahead. Many believed food would provide the miracle they desired and even very small quantities of food consumed indicated that a future was possible and this idea continued up to and at times during the last week of life. Once medical treatment was withdrawn, this was seen as the patient’s only hope as food and oral intake was the one remaining treatment variable the patient or the carer had any control over.

For health care workers working in a palliative care hospital issues around food and nutrition were emotionally demanding as were draining conversations and situations. Health professionals identified that food and nutrition was a source of conflict for patient, carers and health professionals and something that needed to be addressed overtly and quickly to prevent escalation of issues. Nurses wished to take control of the situation while medical officers found these essential conversations to be exhausting given their own admitted limitations in the area.

Control was noted to be a key theme with many parties fighting for control over the situation. In many instances patients were unable to make their own decisions around food and nutrition, being pressured by carers to eat when they felt they were unable. Carers took on the responsibility for a patient's oral intake once the patient was unable to make decisions they deemed appropriate for prolongation of life.

This is the first known study to consider the perspective of food service officers in a palliative care hospital. Food service officers added an interesting depth to this study in that they felt that they were part of the patient's family due to their role as food provider. Despite them often not knowing a patient's name they felt a bond with the patient due to their role in food preparation and delivery. This highlights the importance of food in the relationship and the need to care for these hospital staff who are often a forgotten entity.

Avenues need to be explored to openly address changes in a patient's oral intake at the end of life to allow the relationship between the patient, friends and family to be maintained and nurtured when they can no longer participate in the day-to-day activities they once enjoyed or took for granted, particularly mealtimes. Education of patients and carers is essential to develop understanding of the changes to a patient's appetite and metabolism at the end of life to bring insight and perspective at this time. Interventions need to aim to remove perceived pressures and to improve quality of life while working on the relationship between patient and carer bringing peace to all involved.

While the current findings support some of those reported overseas such as the patient wishing to determine their own level of food intake without pressure (Holden, 1991), other findings of this study did not. The current study did not support the findings of (Meares, 1997) where patients ate more in a social setting, rather our participants preferred to eat alone. This differing of findings shows that the findings of this study may be unique to this participant group. It is probable that findings may not be transferrable to other groups and generalisation should be undertaken with caution. This study could, however, inform further international research to determine if these findings are replicated in other cultural groups.

It is essential for health professionals to consider and address the psychosocial impact of food and nutrition on both patients and carers at the end of life due to the impact on quality of life for both parties. Food is seen as betokening life and love and is the “social glue” linking the patient to friends and family. These meanings need to be addressed at the end of life. This study should also be used to assist health workers communication around the topic of food and nutrition at the end of life. Understanding the differing perspectives of these groups will assist health care workers to work together with the primary goal being the preservation or improvement of quality of life for patients and carers.

Limitations of the Study

The limitations of this study are that it examined the lived experience of only 19 patients, ten carers, seven medical officers, 14 nurses and four food service officers relating to food and nutrition at the end of life. Although interviews continued until no new data was forthcoming from the patient and carer groups this does not guarantee the absence of other perspectives. Similarly, if the same study was undertaken in another geographical location, it might reveal other perspectives including cultural perspectives.

This study will need to be repeated if significant improvements are made in the management of anorexia and cachexia as these significantly impacted on the responses provided by patient and carer. Prevention of weight loss and improved appetite may influence the changes in relationships between the parties involved and many of the findings of this study may indeed change.

Implications for Palliative Care

This study adds to the literature available for palliative care professionals. Interventions can now be planned and tested to address the findings and difficulties highlighted in this study. Further research should focus on psychosocial interventions to reduce the conflict and burden experienced around food and nutrition at the end of life. As patients and carers spoke of the difficulties experienced prior to the admission for terminal care these issues need to be addressed earlier on in the palliative care experience.

This study highlights the need to include nutrition and dietetic professionals in the palliative care team both from the early stages of palliative care but continuing into the later stages of life so the usefulness of nutrition based interventions can be determined. This study highlights the role of social workers and psychologists in the palliative care team and the importance for them to address these issues at the end of life. Many dietitians and social workers would require additional training to understand the issues faced and the highlights the requirement for a multidisciplinary approach to the issue at hand.

This study investigated untested waters in looking at the food service officer's perspectives in a palliative care hospital. The study highlights the need to consider the psychosocial and emotional health of all health workers and in training groups to be resilient and care for themselves when working with people at the end of life.

Implications for Dietitians

The primary implication of this study for dietitians is to inform practice. Dietitians need to be aware of the psychosocial dimensions of food and nutrition at the end of life. Dietitians and health professionals alike need to be considerate of both the difficulties experienced by patients and carers faced with advanced cancer. Each case needs to be considered individually with in-depth investigations into both the patient and carer concerns around food and nutrition so that both party's issues can be addressed and harmony can be paramount at the end of life.

While the conflict around food and nutrition continues for some patients until the last days and hours of life, the same is true for carers. Each party has differing needs and with the definition of palliative care stating that both patients and their families are considered, health professionals need to ensure the carer's perspective is also considered and they are supported both during the patient's life and after.

Dietitians need to be proactive in the care of palliative care patients as this study has demonstrated the role which exists within this area. Dietitians have the ability to influence both patient and care quality of life and should actively engage in the coordination of the nutrition care of patients at the end of life. Dietitians need to take on the role of educating other health care professionals about food provision at the end of life considering the physical and psychosocial influence that food can have on health and quality of life.

Areas for Future Research

With the importance of maintaining even a small level of oral intake being paramount for patients and carers, further research is required into the treatment of anorexia at the end of life, as this impacts psychosocially on patients and carers. Cachexia should be investigated both in the early stages of cancer to see if it can be prevented and within the refractory stage to determine if it can indeed be addressed and managed with current tools available. Consideration needs to be given to psychosocial as well as physiological outcomes as psychosocial outcomes are relevant and important to patients and their loved ones.

It is recommended that this study be repeated in other locations to determine if the findings are unique to the Australian population or if they can be replicated in other cultures. It is recommended that the results of this study be compared to those of patients who choose to die at home to determine how the lack of medical, nursing and allied health staff impacts on that situation.

Further research is required to determine if nursing education on food and nutrition and strategies to manage interactions with patient and carers at the end of life would improve quality of life for both patient and carers in the palliative care unit. The impact of dietitians on the ward also needs further investigation as families are often willing to listen to professionals who expertise lies in nutrition.

Further research is recommended into the psychosocial aspects of care at the end of life. Programs aimed at reducing the impact of differing ideals between patient and carer need to be addressed along with strategies enabling nurses to feel they are able to intervene when a carer's actions are not in the patients' best interests. Studies should consider programs aimed at supporting health professionals to deal with the issues uncovered in this research as it is now clear that it is not only the patient and carer who are impacted by these concerns.

Glossary

Ageusia is the loss of taste functions of the tongue, particularly the inability to detect sweetness, sourness, bitterness, saltiness, and umami.

Enteral feeding involves the provision of nutrition via a tube

External locus of control is where a person believes it is others or other forces which influence their outcomes

Parenteral feeding is the provision of nutrition directly into the blood stream bypassing the gut

Sub-Cut fluids are fluids administered subcutaneously rather than via the vein

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Appendices

Appendix 1 Personal Reflection - A Clinician's Lived Experience of Providing Nutritional Care to Palliative Care Patients

> *Bracketing: A methodological device of phenomenological inquiry that requires deliberate identification and suspension of all judgements or ideas about the phenomenon under investigation or what one already knows about the subject prior to and throughout the phenomenological investigation.* (Stubert Speziale et al., p361, 2003)

I first became interested in nutrition and the meaning of food at the end of life after being seconded to a palliative care hospital. As a clinical dietitian, I quickly identified significant differences in the way food and nutrition were approached at the end of life in the palliative care unit as compared to the acute hospital system. In the acute setting, it was not unusual for staff and families to push oral intake until the last moments of life. If patients were unable to eat, they would commonly be offered enteral feeds as families hoped for recovery. In the acute setting nutrition support was rarely withdrawn as patients were pushed to eat until death.

In the palliative care unit, there was a larger emphasis on quality of life and psychosocial issues with more flexibility to meet patient's needs and desires. Carers psychosocial needs were also identified as being paramount. While I still observed behaviours I had seen in the acute system, the focus and management had changed, however, this change was not always something carers were happy with.

I observed food to impact on the relationship between the patient and the carer frequently bringing tension and disharmony. Disease related weight loss and cachexia impacted on body image further heightening carer concerns. This appendix aims to turn to the nature of the lived experience of working as a dietitian in palliative care by making explicit my understandings, experiences, beliefs, biases, assumptions, presuppositions and theories of the subject area.

Originally termed bracketing by Husserl this process allows the researcher to deliberately hold them at bay allowing for a pure description of the essences to be determined (van Manen, 1990). This chapter was written prior to undertaking any of the interviews or focus groups so as to meet the requirements of bracketing in phenomenological research.

I recall the first deceased patient I saw after starting my career as a dietitian in a Sydney teaching hospital- a middle aged lady who died a horrific death from chronic lung disease. In her final days she was distressed, short of breath and unable to eat due to her fight to take in each breath, the look on her face was one of pain and anguish. While caring for this lady I developed a strong rapport with her and her family and watching this process unfold was a new and difficult experience for me as I had never lost anyone close to me, never witnessed death or loss first hand. After her passing, the nurses urged me to look at her as she lay in her hospital bed waiting to be viewed by her family. The nurses knew I had not seen a deceased person and thought that viewing her body would help me to be more at ease with her passing. There she lay, her arms by her side, no longer in pain, no longer distressed. She looked relieved, even relaxed, she was at peace no longer battling the burden of her disease.

Four and a half years later I accepted a secondment opportunity at a local palliative care and rehabilitation hospital. While I hadn't considered the implications of working in such a facility I was going there from a management perspective, to set up the service so they could employ their own dietitian to care for the patients. Little did I realise that this was where I would be eight years later. As time went on, curiosity got the better of me, and as my role became more clinical, I searched the literature to learn how to best manage palliative care patients.

To my dismay the literature review turned up very little information on the nutritional management of palliative care patients. Literature was available for oncology patients but generally the studies included patients who were undergoing curative chemo or radiotherapy. There were a few personal experience and opinion based articles but these were usually written from a nursing perspective, nothing from dietitians with specialised experience in nutritional care, there was very little evidence-based research available.

As I continued working in this area, many questions arose for me. What was the reason for some of the behaviours that I was observing from patients and from their carers? Over time I considered these and below I have included a description of some of my observations which ultimately led me on the path to the current research. What does food and nutrition mean to patients and carers at the end of life? How do the struggles I observe change the relationship between the patient and the carer? How can I best assist both the patient and the carer in this harrowing time?

Patients admitted to the research hospital's palliative care unit have a life limiting illness, primarily cancer, with approximately one third discharged home and the remaining passing away during their admission. The average length of stay is around 21 days however, patients have been known to stay on the wards for over 12 months`. Over my time in the palliative care unit I have observed first hand patients' and carers' responses as the patient enters the last phases of their life. Below is a description of some of the more memorable experiences and observations that may impact on the analysis of data obtained in the research.

Hope

Hope appears to be a very strong motivator for many patients and carers with the hopeful regularly request active treatment or intervention. Those who no longer hope for improvement in their health or hope to make it through to a special occasion rarely request assistance and treatment. Over the years, I have observed that often the carer is more hopeful than the patient with patients often accepting their fate possibly due to experiencing their symptoms and not wanting to prolong life. Carers on the other hand see what they are losing and hold on to all possible hopes of keeping their loved one alive just that little bit longer. At times, patients request intervention in a last effort to improve their prognosis and when this occurs I have not observed a family member to go against the patient's wishes.

At times, while hoping for a change in prognosis families will ask you to pray with them. I recall the family of an Asian girl in her early 20's whose surgical removal of a glioblastoma had not gone to plan when she failed to regain consciousness postoperatively. Her father, a highly-educated health professional would have been fully aware of the likelihood of any improvement in her condition, despite this she had a tracheostomy to assist her breathing and a percutaneous gastrostomy tube delivering artificial nutrition. The palliative care team had discussed prognosis with the family on many occasions and despite this the family remained hopeful. They assisted with 24hour care of their loved one and prayed continually for a miracle and recovery, they prayed with members of the church and they asked staff to pray with them. They never gave up hope – they prayed for a miracle until she died peacefully a couple of months later. Never once did the family consider withdrawing the young girl's enteral feeds as this would not have been in line with their beliefs and hope, and given that there were no complications observed from her feeding who were we to deny them of their hope? Hope of recovery or hope of prolonging life appears to be a strong determinant for families and at times patients when considering food and nutrition, as food seems to be directly related to the extension of life.

Carers Pushing the Patient to Eat

Over the years, I have observed many family members push their loved one to eat and drink, hoping for even a little more intake. This was described so eloquently to me by an 88-year-old lady who described during a consultation how her son pushed her to eat to the point she became physically ill.

> *"One more mouth full, one more mouthful, then I had to call for a sick bag"*

Over the years, I have observed carers trying many strategies to encourage even one more mouthful of food. Some of the more distressing observations I have made include: - seeing an elderly patient being treated like a child as her children play aeroplanes with her asking her to open her mouth for one more mouthful. I have seen a daughter pistol grip her mother's lower jaw forcing her mouth open to shovel food in. Another gentleman tickled his wife so she would laugh and open her mouth giving him the opportunity to put another forkful in.

These behaviours do not always cease when a patient is in the last stage of life, even as patients gradually become drowsy and lose consciousness, it is not unusual to still find families spooning liquids or puree foods into a patient's mouth. The patient is often unable to swallow and at times it will remain in the patient's mouth for hours until someone cleans it out. I wonder if the family member thinks that their loved one is hungry or are they trying to prevent the impending death?

As a dietitian, I often find myself explaining to families that loss of appetite at the end of life is part of a normal process and that force feeding the patient will not change their prognosis. Despite these conversations, I still see the same families continually day after day pushing their loved one to eat or drink often remarking "Just a little more".

During consultations, distressed patients often ask me to stop family members pushing them to eat, however, despite careful explanation and discussion, families are rarely convinced that force feeding will not be of use. For the patient, not only are they struggling with the symptoms of their illness, quite often nausea, vomiting, diarrhoea, constipation, taste changes, anorexia and dysphagia, but on top of this they are being forced by someone they love and want to please to do something that makes them feel more uncomfortable. Not being able to comply with their loved ones' requests, often appears to make the patient feel inadequate and at times not loved.

I have to ask myself what one is trying to achieve by force feeding their loved one. Carers will say if you don't eat you will die and I think that is what they are trying to achieve for if their loved one does not eat or drink they may die sooner. In delaying or preventing death, the carer is preventing their own heartache and pain. The pain that comes when you lose someone you love, hence in some ways they are simply demonstrating their love for the patient, however, where possible we try to channel this energy into other activities such as mouth care or massaging their loved one's feet. Explaining the negligible effect that force feeding has at this stage on the patient's prognosis rarely seems to make a difference to these carers, for as soon as you leave the room or sometimes even before that, they are again trying to force their loved one to eat. I have observed that cognitive reasoning does not appear to be effective in most of these cases.

Control

Over the years, I have observed numerous patients refusing food and fluids to regain a sense of control within their life. In the inpatient setting, everything is done for the patient, who may have lost control over everything including the ability to control their bladder and bowels. Patients may not be able to mobilise or if they can they are told they can only do so under supervision, leaving only their ability to open their mouth to eat and drink within their control. I have found many patients refuse to open their mouth to receive nourishment, especially when family members are pushing them to eat or drink, either within or beyond their comfort level. This is the last thing patient can refuse as they see it as the only function left within their control.

This is often traumatic for desperate family members who resort to offering the patients' favourite foods and even force feeding, while the patient often refuses food or fluids despite hunger or thirst, purely to demonstrate some control in their life. I have observed this on a number of occasions and patients have confided in me that they are doing so purely because they do not appreciate the pressure. Patients have suggested if their loved one was to “back off” they would be more inclined to eat and drink. Other patients will not eat when family are around, however, when on their own and able to make their own decisions they will eat foods they like and in manageable quantities. Once again, they are in control in a situation that must seem like it is out of control. An example of this is the case of Mr JL

Mr JL was a 70-year-old university graduate who held high ranking positions in his profession, he liked to be in control and be involved in decisions regarding his care.

He had a wife and 2 daughters, one daughter a vet and one a chef who had wanted to be a dietitian, however, failed to meet the grade. All family members held a high regard for the need for nutrition.

At the previous hospital, Mr JL's family had lodged formal complaints about the treating dietitian to the nursing unit manager and to the medical consultants. The medical consultants had informed the family that the dietitian had taken appropriate action and justified actions. The family had requested the provision of TPN, however, their request was denied due to the palliative nature of the treatment.

On transfer to the palliative care unit, Mr JL's attitude remained negative with multiple complaints made against the nursing staff including treatment not being to the standard of the private hospital with agency nurses providing a higher level of care. Mr JL liked his ileostomy and drainage bags to be emptied in a specific manner which was not the way our nurses had been trained to complete the task. During bag changes Mr JL would aggressively instruct the staff on how to empty his bags stating that he knew how to do it correctly as he had been doing so for many years.

On admission, I saw Mr JL to assess his dietary requirements as the family were keen to improve his nutritional status. Initially I met with Mr JL alone, who was willing to try dietary modifications to control his ileostomy output and to trial a lactose free clear liquid nutritional supplement. Mr JL's daughter had previously purchased the same product at a local pharmacy at exorbitant prices to entice her father to consume foods with high nutritional value. Although exhausted, Mr JL had worked with me to trial a diet which would reduce his symptoms and prevent further muscle wasting.

Not long after the initial meeting, Mr JL's wife requested to speak with me regarding her husband's care. Mrs JL stated that her husband had tried the lactose free diet in the community with no reduction in symptoms, she requested he be returned to a lactose containing diet. On further questioning it was noted that whilst trialling a low lactose diet Mr JL had been consuming a high lactose nutritional supplement. She agreed to a one-week trial of the low lactose diet to see if he made any improvements.

Mr JL had been seeing a private dietitian following his initial surgery, he was offered services through the local public hospital, however, he had refused these as he felt he would receive better care privately. Mrs JL estimated that they had spent $2000 on private nutritional treatment since her husbands' surgery.

The family held nutrition in high regard as they saw this as the tool that would help Mr JL survive. In an attempt to increase his intake, the chef daughter would come in the evenings, bringing soup to feed her father, the vet daughter had tried to order nutritional supplements for her father through her veterinary practice, however, these would take a couple of weeks to arrive.

At the initial meeting with Mrs JL, Mr JL displayed very different behaviour from the first meeting when he was alone with me. Mr JL was defiant, refusing to do anything his wife was requesting, he changed the tone of his voice when talking to his wife about food and would become argumentative making comments such as "I told you I don't want to try that". Mr JL was now refusing the nutritional supplements previously offered to him, despite not trying many of the flavours he stated he did not like them. On delving deeper into why this was, he reported that his daughter had been attending at night attempting to coax him into consuming the food.

As time went on Mr JL no longer made eye contact and refused to eat foods his wife brought from home. On one occasion, he unexpectedly ate something his wife put on his bed side table, however, once his wife's attention moved to the fact he was eating he refused to consume anymore. Mrs JL would purchase any foods the dietitian suggested may assist in Mr JL's intake, however, once she asked him to try the foods he would become aggressive and refuse them.

Gradually Mr JL deteriorated, eventually passing away. In his final weeks he was bed bound, he refused to eat and required assistance with all activities of daily living. His last months were stricken with frustration and arguments with his wife over food and what he should consume. My observations were that Mr JL had wanted to maintain some control in a situation where he had lost his ability to undertake normal activities of daily living, his food choices were the last remaining activity he had any control over much to his family's dismay.

Symptoms

The role of a dietitian in palliative care, primarily involves symptom management, with dietitians assisting in the management of symptoms such as nausea, vomiting, diarrhoea, constipation, anorexia, taste changes and dysphagia. It is often thought by other health professionals that the dietitian will force the patient to eat and when I commenced at the hospital, referrals were difficult to obtain as staff had a poor understanding of the aims of the dietetic management. Over time this has changed and the dietitian is now seen as an integral member of the multidisciplinary team.

On the other hand, I have also experienced the contrary, where even in the terminal phase, nurses request nutritional supplements. As a dietitian, I see provision of micronutrients to someone with hours to live as futile, as micronutrients are required to maintain health and prevent disease and hence are unlikely to be of benefit in the last days and hours of life. Despite this, it is common for nursing staff including senior nurses to request some of "those special drinks". Even after continual education that nutritional supplement drinks in this situation will not change the patients' prognosis it is still common for this request to be made repeatedly by the same staff members. It is this behaviour that has led me to including nursing staff in this study as I am keen to determine what the lived experience is for nursing staff when treating palliative care patients and how they feel nutrition can change the course of one's illness.

In terms of my experiences with managing the symptoms of palliative care patients, it is evident that nutritional impact symptoms are plentiful. In a study undertaken in our unit in 2006 of 62 oncological palliative care patients, patients had on average 5.5 out of 10 possible symptoms which impacted on their nutritional intake. These symptoms included weight loss (86 per cent), anorexia (81 per cent), early satiety (77 per cent), constipation (66 per cent), taste changes (61 per cent), nausea (58 per cent), vomiting (48 per cent), diarrhoea (29 per cent), dysphagia (26 per cent), and mouth sores (18 per cent). Many of these symptoms are very distressing for patients and lead to a reduced intake.

In addition to the high level of weight loss that was observed in the above study I have noted that this change in one's physical appearance can be distressing to patients and their loved ones. From my experience, I have had a number of patients and family members report that as they or their loved one develops cancer cachexia a condition in which patients loose both muscle and fat mass that they resemble victims of concentration camps. With this it appears that the patient and loved one, link the weight loss with the deprivation and denial of food that was associated with the weight loss in concentration camps rather than identifying that the loss was due to the cancer or the patients reduced desire to eat. There also appears to be a level of shame or disgust that comes with the severe weight loss, like the patient has been unable to afford food rather than a realisation that the weight loss has been due to a physical process that could not be prevented. Often patients report their need to cover up their bodies so friends and family cannot see their weight loss as they are concerned about their reactions or are tired of hearing how thin they have become.

Initially some patients are happy with the weight loss as many have struggled with weight throughout life and now they are effortlessly losing weight. However, as weight loss becomes more pronounced and when they are no longer able to slow or stop the loss the delight turns to fear.

Patients physically unable to consume an oral diet

I often see patients in palliative care who want to eat and drink to improve their chances at life, however, due to overwhelming nausea, vomiting and anorexia, find this unmanageable. Inability to eat is distressing for many patients and I find careful reassurance and support required as patients often want to eat; after all, for many, eating is a habit. Breakfast, lunch, dinner. Our day revolves around meal time and this provides our opportunity for social interaction with our loved ones. When the patient is no longer able to participate, they can feel isolated and removed from the families' daily activities. In addition, when they can join the family at the dining table or meal area, patients report that their every move is monitored and they feel unbearable pressure to eat. Patients often report the need to leave the meal table as simply the smell or sight of food triggers severe nausea and it is not uncommon for patients to state that they dread meal time which was once one of their favourite pastimes.

Patients and carers appear to be poorly prepared for the fact that most people lose their appetite at the end of life. It is common at the research facility for patients approaching the terminal phase to request a dietitian consultation or medications to improve their appetite. It is my experience that, loss of appetite is a significant concern for many patients which causes high levels of distress to both patients and carers.

Financial

When burdened with palliative cancer, many patients are unable to work and many partners take a break from working to care for their loved one in their final days. In my experience this often leads to reduced income and at times a reliance on government benefits. While the disability pension and the carers pension are available often they do not match the family's previous income. Additionally, financial outlay increases as many patients require numerous medications many of which are expensive. This can impact on the family's financial situation and influences the money remaining for other essentials such as food. In this situation, it is not uncommon for relatives to report that they are going without staples to ensure their loved one receives all that they require.

Studies have shown that nutritional supplements improve the quality of life of patients with cancer cachexia, however, their cost is often beyond the reach of many patients. An ethical issue arises here in that recommending something beyond the financial capabilities of a patient or their family can cause additional distress. As a clinician, this can be a difficult area to manage as we are aware of what is possible, however, at times we may be reluctant to recommend them as if a patient is unable to afford the products, the patients burden may be increased.

Food as a Symbol of Love

I have observed food used as a symbol of love between a carer and the patient with carers going to great lengths and expense to make the patient their favourite meal. I have seen families bring lobster, oysters and other culturally specific dishes into the hospital to entice the patient to eat. The carer is often happy when the patient attempts to try the food, however, when the patient is unable to you can see the distress is far deeper than just because the patient is not eating. Rejection of the time and love put into creating the dish appears evident with food appearing to hold more value than merely its caloric value. The food symbolises the love that the carer has for the patient with the preparation and cooking time along with the financial expense appearing to create the symbol of the love that is shown in the food produced.

To prevent upsetting their loved one, it is common that after friends and family have left the hospital, patients offer the gifts to staff so they do not offend their loved ones if the food is still at the bedside next time they visit. On the other hand, it is common to see yoghurts, flavoured milks and other foods building up in a patient's fridge often beyond their best before dates as families bring more products than the patient can keep up with. This also occurs when family members select the patient's menu, as they often over select the quantity of food the patient will consume and rather than send the food back to the kitchen and upset the food service officer's, the patient will have the food placed into their bedside refrigerator to keep it for a later time.

Ethnicity

In my experiences, food and nutrition appear to be important in most cultures and I have noted that there are a couple of cultures where food appears to be highly important. Firstly, in Asian cultures, food appears to take on a significant role. I have observed that during a hospital admission most Asian families will provide food from home for their loved ones dropping the food in daily. The foods provided are often comfort foods and consist of congee, a simple dish of stewed rice, or other soft and easily consumed meals. The role of bringing food for the sick relative is often delegated to a daughter or daughter-in-law who will provide the food daily with hospital food rarely touched.

I have also experienced many Asian clients stressing the importance of Chinese medicine or herbs at the end of life. Although not possible, in a tube fed stroke patient, the medical team and I were asked to keep a patient alive for a short while whilst the family returned home to make up a herb mixture which they believed would help the patient move on to the next life. Similarly, Buddhist clients often wish to pass away with food in their mouths as they too believe that this will assist in ongoing life.

In the past few years I have had a few experiences with patients and families who have been connected to concentration camps in some way. For these people the weight loss that occurs with terminal cancer is highly distressing, bringing back memories from this emotionally trying time. Other cultures such as the Greek and Italian cultures also seem to put high emphasis on weight change as opposed to the quantity of oral intake.

It is the above experiences that have lead me to the desire to develop a greater understanding of the patient and the carers lived experiences around food and nutrition at the end of life. And as stated by van Manen "It is not until I have identified my interest in the nature of a selected human experience that a true phenomenological questioning is possible (van Manen, 1990) (P 42).

Appendix 2 A Life Ended Too Soon

Cooking is love made visible (unknown)

After having written the results chapters and carers discussion of this thesis I had my first experience of palliative care from the relative's side. At end of April 2013 I received a call from my Mum telling me that my uncle had been diagnosed with oesophageal cancer.

My uncle was 67 years old. He was my Godfather and my only close uncle. He had recently retired and had bought himself a caravan to travel around the country. He had worked hard all his life and had saved up his money so he could have a comfortable retirement. This was not his first battle with cancer. Five years earlier just after he had given me away at my wedding he was diagnosed with prostate cancer. He underwent months of gruelling treatment but had been given the all clear.

Over the coming weeks as he underwent many tests we discovered the cancer had metastasised to the liver. This was not our only concern. The cancer, a poorly differentiated neuroendocrine tumour of the oesophagus, was so rare that the oncologists didn't know what to do about it. Ironically, he was asymptomatic. They had discovered the cancer after he had a syncopal type episode after taking a swig of icy cold beer that a fellow traveller had given him during his first trip away with his new van. This was also to be his last trip. He was admitted to the local hospital where the tumour was discovered on endoscopy.

The oncologist offered chemotherapy which made Uncle Rod really unwell. He was admitted to a local hospital which he vowed he would never return to. He completed the 3 cycles of chemo that were offered, however, sadly the metastases in the liver had grown and palliative care was initiated.

Up until this point I had kept in regular contact with him over the phone helping him out with symptom management as problems arose. I recall my first conversation with him after he was diagnosed, telling him that if he started losing weight or had diarrhoea that he should let me know straight away so we could try to stop its progress. He gave me regular updates on how he was going. Two days after our initial conversation his bowels started to play up. He had urgency and bled from the bowel with every motion although he was too ashamed to tell the doctors but somehow felt comfortable telling me.

After receiving news of the palliative diagnosis my mum, sister, brother-in-law, niece, nephew and I booked our flights to Brisbane to visit Uncle Rod. My Mum had been up a couple of weeks earlier and had noticed some decline. As soon as I saw him I clicked into work mode noticing the muscle wasting, the reduced appetite, the hair loss form chemotherapy and his fatigue. I couldn't help but to be doing a PG-SGA in my head. He would have scored as B or moderately malnourished. He was still eating although probably half the amount of usual. He spent a lot more time in his chair or sitting in the yard. He could still go to the local shops to get the groceries although it was a taxing experience.

Uncle Rod was scared and terrified of dying but didn't want anyone to know. He withheld a lot of information from his doctor as it was not something that was comfortable for him to discuss. I encouraged him to discuss these issues as the doctors would be able to prescribe something to help manage his diarrhoea, however, he was reluctant. I secretly hoped that treating the diarrhoea may slow the progression of his malnutrition and give him a little more time.

We all knew this trip could be a hard one. Would we get to see him again? We all loved him so much. The thought of losing him bought tears to our eyes. Well we had all had many tears over the preceding couple of months. We were all worried that it would be a very sad occasion and that was not how we wanted to spend our precious time with him. One night I had a thought. What if we cooked up all of his favourite foods and took them up there to enjoy with him while he could still eat. I guess it was almost like a last supper where we enjoyed all of our favourites together. Everyone loved the idea and we sprang into action. I cooked my Nan's special "gollywog" biscuits, something we had all grown up with along with macaroons. I wanted to cook Nan's cherry cake, however, Mum was not sure that Uncle Rod liked that. I was prepared to stay up all night the night before if it meant he had what he could enjoy. My sister searched around Sydney until she found a gramma; a special pumpkin that our family had always made a sweet pie out of. My Nan had made this as they grew them on the farm where Uncle Rod and Mum had grown up. My Mum made her special pink lamingtons. When we arrived, it must have looked like we had brought the supermarket with us. The only difference was that each and every piece had been made with love with one special man in mind. My two daughters 3year old Telia and 16month old Liana had even blown kisses to the biscuits before I put them in the oven so that they were made with their love too.

We relished seeing Uncle Rod enjoy the foods that we had made for him. He only managed small portions, however, we saw the enjoyment he received from them. He had mentioned that his sense of taste had changed so we don't know if he managed to taste what we had tasted. Maybe the enjoyment came from the sense that we had gone to a special effort for him or the sense that we were all able to share in this special occasion.

His partner mentioned that one of his favourite foods was a passionfruit sponge cake so the next day I went and bought him one. For me at this point nutrition was no longer an issue, it was about enjoyment and preventing or slowing the weight loss if that was at all possible. I just wanted him to have everything that made him happy, I don't recall if he ate any of the sponge cake although I remember his partner eating it. To be honest I don't think I minded if he ate it or not, it was more the fact that it was there for him if he did want it.

Saying goodbye was not as hard as I had imagined. Uncle Rod, although not his usual self, was still able to walk around, eat a meal at the table and hold a good conversation. Yes, he had lost weight but only about 5kg, he still had plenty of weight to carry him through. He had told us that he had decided not to have a funeral but rather spoke of what he wanted to be done with his ashes; a difficult but essential conversation. When we left, I was sure that we would see him again, I remember thinking I wouldn't be surprised if he was around to celebrate Christmas.

Throughout this journey, I couldn't help but think that as people with oesophageal cancer approach the end of life, many have difficulties swallowing and require texture modified diets. I didn't think Uncle Rod would cope too well with puree as he had always loved his meats, seafood, bacon and an occasional XXXX beer. I had thought about oesophageal stents and whether this was something he would consider or not. As it turned out those concerns were unneeded.

One week after we left, Uncle Rod became more and more tired, after saying goodbye to my cousin on Father's Day he went to bed exhausted and deteriorated quickly from here. I received a call from Mum on Tuesday the 3rd of September, Uncle Rod was becoming more tired. We booked her flights to go back and visit him in just over a week's time. He was starting to have trouble eating although he managed the couple of samples of Sustagen Pudding that I had left with him. The other thing he was managing was cheesecake. I suggested that his partner go and buy him some Sustagen or Ensure just to keep his energy up as they thought he had around a month left at this stage.

The next day I rang his palliative care nurse to see how things were really going. All she could say was that we think it will be sooner rather than later. I discussed the flights that I had booked for Mum in just over a week's time and she wasn't too sure if he would make it that far or not. She mentioned that Uncle Rod had taken his first two Endone pain killers the day before. Although he had been in pain he was able to hold off on anything too strong. The nurse mentioned they were trying to keep Uncle Rod at home for a couple more days and that when the time was near he had requested to go into the palliative care unit for a hospital death.

That day I went to the Post Office and express posted some more samples of Sustagen Pudding to Uncle Rod, I was determined that if this was what he was enjoying then that is what he should have. I spoke with his nurse about what he was able to eat, we were both happy that he could manage cheesecake and encouraged him to have whatever he felt like. We acknowledged that food was no longer about nutrition but about comfort. I even spoke with the company representative to arrange more Sustagen Pudding for him as I was unable to purchase it in the three chemists that I had looked for it in that day.

That evening I did one of the hardest things I have had to do in my life. I had to tell my Mum that her brother had very limited time remaining and that I thought she should consider going to Brisbane sooner rather than on the flights we had booked for the next week. It was a very emotional time for us all.

The next morning, I was thinking about Uncle Rod and thought that as he and his partner could no longer go up to the shop to buy him his cheesecake I would try and see if I could get a decent quality home delivered to him. I wanted them to say it was from all of us in Sydney with love, much like you would send a bunch of flowers really but this was something that he was enjoying. I looked up the number on the internet and called. The phone rang out. I kept the number as I intended to try again at lunch time.

At 11am I received a call from his partner. She was in tears and said she had to admit him to the hospital. I spoke with his palliative care physician who said that his death would be sooner rather than later and that I should arrange to get family there as soon as possible. We were speaking of that night or the next morning.

I rang my Mum and my cousin- Uncle Rod's son and arranged for them to go to Brisbane as soon as possible. My Mum had just arrived in Newcastle so she turned around and came back home immediately. We rushed her out to the airport and managed to get her on a flight which they held open for her. Uncle Rod died one hour after she arrived. It was 10:30pm on the 5th of September after a short four months battle with oesophageal cancer.

The food related story does not end here, on Wednesday the 11th of September the day he was cremated we decided to hold a family dinner for Uncle Rod here in Sydney. He didn't want a funeral so we celebrated and said a toast to a man who will always have a very special place in our hearts. We ate Chinese, toasted him with his favourite beer (which none of us enjoy but we drank it merely for him) and ate the cheesecake that I had tried to send to him on the day he died. We also vowed to do the same thing each year on the 5th of September, the day we lost a special and much loved man.

I learnt so much from this experience. For me I feel I was able to understand where the carers had come from in their interviews for this research, I understood how food could become the centre of their concerns and thoughts. For me food was one of the few things that I could offer to someone I loved as I could not take away his pain. I couldn't stop this disease from taking him but it was a way that I could demonstrate my love for him. I was able to ensure he had access to the things he had always enjoyed in life, the things that had good memories attached for him. I guess it gave me an avenue for feeling like I had a purpose during this whole awful situation.

I feel it is important to clarify that at no point during this process was food about nutrition for me. I was aware that micronutrients were unlikely to make a difference. Food was about comfort and enjoyment and I was aware that a time would come when it was likely that he would not enjoy food anymore. I was prepared to let him make the decision on when and how much he ate and I guess the challenge from here on in is how we assist carers in coming to this same point.

Appendix 3 Ethics approval

Calvary
Health Care
Sydney

!7 December 2007-12-17

To : Ms Jodie Bennett

Dear Jodie,

Re: Project : " The Psycho-Social Impact of Food and Nutrition on Palliative Care Patients and Their Carers"

Your proposal for the above mentioned research was tabled at the Research Ethics & Morals Committee meeting held on 12 December 2007. This letter is to advise you that the proposal was approved.

Your reference number is 2007.12.02

In keeping with SESIAHS policy, you are asked to submit progress reports on a six-monthly basis and a final report on completion. The report should include your reference number and title of research, and, a brief summary of the status of the research.

This research is approved for a period of five years, if not completed in this time frame an extension will need to be requested.

We wish you every success for this project.

Yours sincerely

Susan Uhlmann

Susan Uhlmann
Chairman
Research Ethics & Morals Committee

"The Spirit of Calvary"

Calvary Health Care
Sydney [illegible] Ltd.
[illegible]
Reg. Charity No.
28346
ACN 105 757 453

PO Box 261
Kogarah NSW 1485

Ph: 02 9553 3111
Fax: 02 9587 1421

LOCATION
91-111 Rocky Point Road
Kogarah NSW 2217

A Service of the Sisters of the Little Company of Mary
with values of hospitality, healing, stewardship and respect
Palliative Care Service | Rehabilitation and Geriatric Service

Appendix 4 Consent form

Participant Consent Form

The Psycho-Social Impact of Food and Nutrition on Palliative Care Patients and Their Carers

I ________________________________ agree to participate in this Research study, titled above.

- I understand the aims of this study to be investigating the psychosocial impact of food and nutrition on patients with a life limiting illness and their carers.
- I will be participating in focus groups &/or semi-structured interviews.
- I understand that my Medical Records kept at Hospital XXXX may be accessed from time to time to obtain supporting information.
- The research poses no risks to my health, however, I may not benefit directly from the research.
- I have the right to withdraw from the study at any time and will not be disadvantaged in any way should I decide to do so.
- Any personal information that I provide will be held in confidence by the principal researchers and that none of the personal information will ever be published.
- I do not expect to obtain any direct benefit from the study.
- I do not expect to receive a copy of the results of the study.

I agree that the purpose of this study and the way it will be conducted has been fully explained to me, so that I am able to give my consent freely.

Signature Participant or authorised representative	Date
Signature Investigator	Date
Signature Witness	Date

If you have a concern or wish to make a complaint about any aspect of the research you are asked to contact the senior Social Worker at Hospital XXXX.
Telephone XXXX XXXX

Appendix 5 Revocation of consent form

The Psycho-Social Impact of Food and Nutrition on Palliative Care Patients and Their Carers

The University of Sydney

Revocation of Consent

I hereby wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal ***will not*** jeopardise any treatment or my relationship with the XXX Hospital or my medical attendants.

Full Name (please print) ___________________________

Signature ____________________________________

Date ____________________________________

The Revocation of Consent should be forwarded to:

XXXXXXXXXXXX
Director of Mission
Hospital XXXXX
Address
Address

Phone number

Appendix 6 Patient Information Statement

The University of Sydney

The Psycho-Social Impact of Food and Nutrition on Palliative Care Patients and Their Carers

Subject Information Statement (Patient)

The aims of my project are to look at what food and nutrition means to you as a person with a life limiting illness. It will consider how changes in your food intake have impacted on your daily living and your relationship with your carers.

Participation in this research will involve the primary investigator (Jodie Ellis) asking you a short series of questions regarding your thoughts and experiences.

If you consent the interview will be audio-recorded to allow the investigator to review the information at a later date. All information provided will remain confidential and you will not be identified at any time.

The progress of the interview is entirely under your control. If at any time, you feel too tired to continue, you can indicate this and the interview will be stopped and only recommenced at a later stage if you feel you are able to continue.

Participation in the project is voluntary. If you choose not to participate your decision will not impact on the care provided by Hospital XXXX.

You may withdraw from this project at any time without penalty or prejudice.

If you have any questions regarding this project you may contact Jodie Ellis on (XX) XXXX XXXX at any time to discuss your concerns.

If you wish to make a complaint regarding this research you may contact Director of Mission on (XX) XXXX XXXX to discuss your complaint.

Appendix 7 Carer Information Statement

The University of Sydney

The Psycho-Social Impact of Food and Nutrition on Palliative Care Patients and Their Carers

Subject Information Statement (Carer)

The aims of my project are to look at what food and nutrition means to you as a carer for a person with a life limiting illness. It will consider how changes in your loved one's food intake has impacted on your daily living and your relationship.

Participation in this research will involve attending a focus group where 8-10 carers will discuss a short series of questions exploring your thoughts and experiences regarding food and nutrition.

The focus group will be audio-recorded to allow the investigator to review the discussion at a later date. All information provided will remain confidential and you will not be identified at any time.

Participation in the project is voluntary. If you choose not to participate your decision will not impact on the care provided by Hospital XXXX to you or your loved one.

You may withdraw from this project at any time without penalty or prejudice.

As a participant in a focus group you may be asked to meet one to one with the primary investigator (Jodie Ellis) to discuss some of the topics covered in more detail. Your decision to continue to this stage is also voluntary and if you choose not to continue your decision will not impact on the care provided by Hospital XXXX or your participation in the previous stages of this research.

If you have any questions regarding this project you may contact Jodie Ellis on (XX) XXXX XXXX at any time to discuss your concerns.

If you wish to make a complaint regarding this research you may contact Director of Mission on (XX) XXXX XXXX to discuss your complaint.

Appendix 8 Staff Information Statement

The University of Sydney

The Psycho-Social Impact of Food and Nutrition on Palliative Care Patients and Their Carers

Subject Information Statement (Staff)

This project aims to look at what food and nutrition means to you as a carer for people with a life limiting illness.

Participation in this research will involve attending a focus group where 8-10 staff members will discuss a short series of questions looking at thoughts and experiences regarding food and nutrition.

The focus group will be recorded using a small voice recorder to allow the investigator to review the discussion at a later date. All information provided will remain confidential and you will not be identified at any time.

Participation is the project is voluntary. If you choose not to participate your decision will not impact on the care provided by Hospital XXXX or your relationship with the investigator.

You may withdraw from this project at any time without penalty or prejudice.

If you have any questions regarding this project you may contact Jodie Ellis on (XX) XXXX XXXX at any time to discuss your concerns.

If you wish to make a complaint regarding this research you may contact Director of Mission on (XX) XXXX XXXX to discuss your complaint.