

School of Occupational Therapy and Social Work

**An investigation of occupational therapy services for people who are
dying in Western Australia**

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This thesis is presented for the Degree of

**Master of Science
of
Curtin University**

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DECLARATION

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

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ABSTRACT

BACKGROUND

In Western Australia (WA) little is known about the occupational needs of people at the end of life and their primary carers. The role of occupational therapy (OT) in addressing these needs is not documented and the palliative services provided by occupational therapists (OTs) are poorly understood. To address this gap there were several aims of the study. First, to ascertain the number of OTs working in this field across a range of service delivery locations in WA. Second, to explore the self-care, leisure and productive occupations of dying people through carers' reports of their daily experiences and reflections on their occupational needs. Finally, to understand the role of OT in meeting these needs, this research aimed to document the unique kinds of services provided by Western Australian OTs who provide palliative care to a range of service delivery locations in WA.

METHODS

A mixed methods approach in two stages was used to achieve the research objectives. In stage one an email survey was conducted to identify preliminary data that informed the substantive component of the research. This survey determined the number of OTs providing services to people who were dying in WA and the types of services provided, and then calculated a ratio with the number of people dying from conditions considered amenable to palliative care. In stage two, semi-structured interviews were used to gather information from carers (n = 10 metropolitan, n = 4 rural) and occupational therapists (n = 13 metropolitan, n = 5 rural). Data were analysed qualitatively using grounded theory to develop categories. Themes were defined using the constant comparison method.

RESULTS

The survey of OTs indicated that 6.15 full time equivalent OTs were employed to provide palliative services in Western Australia. Compared with the number of

people who died from conditions considered amenable to palliative care over a one year period in WA, this is represented as a ratio of one occupational therapist per 875 people. Two key themes emerged from the interviews with carers, disengagement from occupations with resultant occupational deprivation and disempowerment. The interviews with OTs illustrated that the occupational needs of dying people and their carers were not addressed adequately in palliative care service delivery. Furthermore OTs have limited opportunities to both contribute to the care of dying people and address their core business of 'occupation'.

CONCLUSION

The research demonstrated that Western Australian OTs have limited opportunity to address the occupational needs of people at the end-of-life and their primary carers. Palliative services currently focus on pain and symptom management for their clients. While this is to a large extent understandable, carers also reported the importance of engaging in meaningful and satisfying occupations throughout the palliative period for the dying person and themselves. Occupational Therapists are well placed to address these needs but face a number of personal and organisational challenges in achieving this goal. For change to occur, issues of education and professional development, organisational and policy management would need to be addressed.

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LIST OF PUBLICATIONS

PUBLICATION ONE

The following manuscript was accepted for publication on 18 March 2011 in the Journal of Health and Social Care in the Community. This is a peer reviewed journal and evidence of this can be found in Appendix A.

Keesing, S., Rosenwax, L., & McNamara, B. (2011). 'Doubly deprived': A post-death qualitative study of primary carers of people who died in Western Australia. *Health and Social Care in the Community*, 19(6), 636-644.
doi:10.1111/j.1365-2524.2011.01005.x

PUBLICATION TWO

The following manuscript was accepted for publication on 11 July 2011 in the Australian Occupational Therapy Journal. This is a peer reviewed journal and evidence of this can be found in Appendix B.

Keesing, S., Rosenwax, L. (2011). Is occupation missing from occupational therapy in palliative care? *Australian Occupational Therapy Journal*, 58(5), 329-336.
doi: 10.1111/j.1440-1630.2011.00958.x

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ADDITIONAL PUBLICATION

Halkett, G., Ciccarelli, M., Keesing, S., & Auon, S. (2010). Occupational Therapy in palliative care: Is it underutilised in Western Australia? *Australian Occupational Therapy Journal*, 57(5), 301-309.

doi: 10.1111/j.1440-1630.2009.00843.x (Appendix D).

CONFERENCE PRESENTATIONS

Keesing, S., & Rosenwax, L. (2008, July). *Do OT models support the needs of the dying?* Paper presented at the OT Australia WA State Conference 2008, Perth, Western Australia.

Keesing, S., & Rosenwax, L. (2010, July). *Does occupational deprivation exist for carers of people who are dying?* Paper presented at the 5th International Carers Conference, Leeds, UK.

Keesing, S., & Rosenwax, L. (2010, July). *An investigation of occupational therapy services for people who are dying in Western Australia.* Paper presented at the OT Australia WA State Conference 2010, Perth, Western Australia.

Keesing, S., & Rosenwax, L. (2011, June). *Disengaged and disempowered - findings from a study of people who were dying and their carers in Western Australia.* Paper presented at the Occupational Therapy Australia 24th National Conference 2011 Gold Coast, Queensland, Australia.

STATEMENT OF CONTRIBUTION BY OTHERS

As co-authors of the following article:

Keesing, S., Rosenwax, L., & McNamara, B. (2011). 'Doubly deprived': A post-death qualitative study of primary carers of people who died in Western Australia. *Health and Social Care in the Community*, 19(6), 636-644.
doi:10.1111/j.1365-2524.2011.01005.x

We confirm that Sharon Keesing has made the following contribution:

- Conceptualisation and design of research;
- Collection of data;
- Analysis and interpretation of results; and
- Writing paper and critical appraisal of content

Lorna Rosenwax

Signed: _____

Date: _____

Bev McNamara

Signed: _____

Date: _____

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- Writing paper and critical appraisal of content

Lorna Rosenwax

Signed: _____

Date: _____

GLOSSARY OF TERMS

Diseases amenable to palliative care

Cancer, heart failure, renal failure, liver failure, chronic obstructive pulmonary disease, motor neurone disease/amyotrophic lateral sclerosis, Parkinson's disease, Huntington's disease, Alzheimer's disease and HIV/AIDS (McNamara, Rosenwax, Holman, 2006).

End of life care

End of life care combines the broad set of health and community services that care for the population at the end of their life. Quality end of life care is realised when strong networks exist between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community working together to meet the needs of people requiring care (Palliative Care Australia, 2008a).

Interdisciplinary team

The interdisciplinary team approach acknowledges the diverse skill base and understandings that each profession offers when caring for patients or clients. It seeks to use these in the most effective manner possible to achieve the best possible health outcomes for the patient or client. A variety of team members may make up the team (O'Reilly, 2010).

Multidisciplinary team

A multidisciplinary team consists of a mix of health care disciplines. Team members share common goals, collaborate and work together in planning and delivery of care. Members of a multidisciplinary team could include general practitioners, surgeons, medical or radiation oncologists, palliative care specialists, pastoral care workers, nurses, social workers, occupational therapists, physiotherapists, dieticians, volunteers, pharmacists or care assistants (Palliative Care Australia, 2008a).

Palliative approach

This approach aims to promote both physical and psychological well-being. It is a vital and integral part of all clinical practice, whatever the illness or its' stage, informed by a knowledge and practice of palliative care principles and supported by specialist palliative care (Addington-Hall and Higginson, 2001).

Palliative care

Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life (Palliative Care Australia, 2008a).

Palliative phase

During the palliative phase, a disease is deemed to be incurable and progressive, and the goals of care are modified in favour of comfort, quality of life and dignity. Length of survival is no longer the sole determinant of treatment choice and life-prolongation is advised to be a secondary objective of medical treatment (Department of Health and Human Services, Tasmania, n.d.).

Primary carer

The primary carer is generally in the close kin network of the patient and is usually self-identified. The primary carer can be the patient's spouse, child, another relative, family member or friend. They may be supported by other carers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, e.g. the administration of medications. They provide the primary support role for the patient at all levels of need (Palliative Care Australia 2005a).

Specialist palliative care

Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care homes, hospices and palliative care units (Palliative Care Australia, 2008a).

Symbolic interactionism

All individuals are socially constructed and make sense of the world due to the process of social interaction (Mead, 1962).

ABBREVIATIONS AND ACRONYMS

ABC radio	Australian Broadcasting Commission (radio)
ADL	Activities of Daily Living
COPM	Canadian Occupational Performance Measure
DOHWA	Department of Health Western Australia
FTE	Full Time Equivalent
HREC	Health Research Ethics Committee
JHCHREC	Joondalup Health Campus Health Research Ethics Committee
ICD-10-AM	International Classification of Diseases, 10 th Revision (Australian Modification)
LISA	Lung Impaired Support Association
MOHO	Model of Human Occupation
NPCS	National Palliative Care Strategy
OT	Occupational Therapy
OTs	Occupational Therapists
OTAL	Occupational Therapy Australia Limited
UK	United Kingdom
WA	Western Australia
WACHS	West Australian Country Health Service
WHO	World Health Organisation

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1. INTRODUCTION

1.1 BACKGROUND

Every year in WA approximately 6,000 people die as a result of illnesses that are potentially amenable to palliative care (McNamara, Rosenwax, Holman & Nightingale, 2004). The demand for palliative care services is increasing as health care services respond to increasing rates of life-limiting illnesses, changing patterns of disease, an ageing population and the increasing age of caregivers (Davies & Higginson, 2004; Palliative Care Australia, 2005a; World Health Organisation, 2004). To meet the needs of people who are dying, adequate resources are required across the range of services provided to this group of consumers (Palliative Care Australia, 2008). However, in WA not all people diagnosed with a life-limiting illness are able to access palliative care. Referral to specialised palliative care services may not always occur at the appropriate time and geographical location may also limit access to these services (Department of Health Western Australia, 2005).

Acting as part of an interdisciplinary team, OTs have an essential role in caring for people at the end of life and contributing to the support of primary carers of people who are dying. International studies recognise the unique OT contributions made to assist individuals to manage symptoms, complete self-care tasks as well as enabling valued roles in leisure and productive occupations (Cooper, 2006a; Ewer-Smith & Patterson, 2002). In Australia, however, palliative occupational therapy is under researched and is a relatively new area of occupational therapy practice. In WA there are few OTs employed in palliative care and when compared with the ratio of OTs providing services to dying people in other countries, such as Canada, this number is very low (Halkett, Ciccarelli, Keesing, & Auon, 2010). Consequently, the issues of access and referral to OT continue to be problematic and OT appears to be somewhat invisible in the arena of palliative care.

According to the World Federation of Occupational Therapists “Occupational therapy is a client centred profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life” (World Federation of Occupational Therapists, 2011, p. 1). This definition holds true for OTs practising in

the field of palliative care. While the overall focus of care may shift from curative treatment, the philosophy of OT remains constant; OTs are concerned with maximising the client's functional, psychological and social skills, within their chosen environment (Armitage & Crowther, 1999; Cooper, 2006b).

It is widely recognised that dying people have very complex needs, not only medical, but also psychological, social and spiritual needs (Department of Health Western Australia, 2008; McNamara, 2001; Palliative Care Australia, 2009; Steinhauer et al., 2000). Occupational therapists possess unique professional skills that complement other members of the palliative care team to meet these complex needs, with resultant satisfactory outcomes for dying people, their carers and families. Yet, in WA, few people benefit from these OT services (Keesing & Rosenwax, 2011). There are many potential explanations for this, including, models of service delivery, organisational barriers and a lack of understanding by others in the health care team about the OT role. A lack of promotion and education by OTs themselves to the wider community about their contributions to palliative care services also exists (Halkett, et al., 2010). It is important and timely, therefore, to investigate why referral and access to OT or other allied health practitioners does not occur consistently as part of the overall management of a life-limiting condition.

In order to provide suitable and accessible OT services to palliative care consumers, it is also essential to investigate the specific occupational needs of people who are dying and their primary carers. This is an area of palliative care that is relatively under researched, but vital to OTs providing services to this group. The dying person's chosen place of care and place of death may also vary throughout the palliative period and it is therefore important to examine these occupational needs across the variety of contexts of care. Current and future OT services may then be directed to meet the expressed needs of dying people and their carers.

In summary, this research aims to explore the contributory factors that influence OT services for people who are dying in WA. The research objectives focus on the experiences of people who are dying and their primary carers as well as the current practices of OTs working in this area.

1.2 RATIONALE

This research is significant for several reasons. Firstly, the study supports the National Health Priorities, two of which are cardiovascular health and cancer (Commonwealth Department of Health and Family Services, 1997, 1998). While a person with a diagnosis of terminal cancer has historically been considered as suitable for palliative care, there is also evidence that palliative care services should be offered to a much wider group of consumers, including those with non-malignant diseases (McNamara, Rosenwax, & Holman, 2006). This study will contribute to the growing body of knowledge regarding the experiences of people with both cancer and non-malignant diseases in WA.

“Every person in Western Australia with life-limiting illness has a fundamental right to a palliative approach to care” (Department of Health Western Australia, 2005, p. 1). However, it is known that access to services for people who are dying in Western Australia is inconsistent according to diagnosis, place of death and geographical location (Rosenwax & McNamara, 2006). These inconsistencies also apply to referral and access to OT services for people with palliative needs. It is not known how many OTs are currently employed in WA to deliver palliative services and the role of OT within the palliative care team is not adequately defined. Investigation of these issues is justified in order to plan and deliver future OT services for dying people.

Secondly, the study will explore the occupational needs of people who are dying and their primary carers. These needs are underexplored, yet essential from an occupational therapy perspective, because they provide the foundation from which to direct care. Additionally, the contributions made by carers of individuals who die in their own homes are largely unrecognised (Stajduhar et al., 2010). According to Access Economics, in their report for Carers Australia (2010) the cost of this informal (unpaid) care in Australia is conservatively estimated at \$40.9 billion. While this estimate includes all carers across a range of contexts, it can be postulated that without the enormous efforts provided by carers of dying people, there would be further significant economic pressures placed on the health care system. According

to the standards developed by Palliative Care Australia (2005b), carers of dying people must be considered as essential contributors to decision making and care planning and recognised as partners in the delivery of care in order to assist with the development and implementation of essential services to this group of people.

Thirdly, OTs should continue to seek evidence for practice to justify and evaluate services to this group of consumers. There are few recent Australian studies that explore this area of OT practice. Additional research will help to determine the efficacy of an expanded interdisciplinary approach to the care of people who are dying, assist with curriculum and professional development and identify future directions for OT intervention in this field.

1.3 OBJECTIVES

1. Determine the proportion of Western Australians dying from conditions potentially amenable to palliative care and the number of OTs employed to provide these services.
2. Explore the met and unmet needs of people who are dying and their primary carers during the palliative phase, with particular reference to self-care, environmental contexts and occupational needs.
3. Examine the current status of OT services and models of practice in Western Australia with regard to working with people who are dying from the perspectives of policy, organisational issues and individual practices.
4. Provide recommendations for future research, policy formulation and models of practice in order to facilitate continuous improvement in this area of service delivery.

1.4 STRUCTURE OF THESIS

This thesis is presented as an exegesis; the first three chapters provide an introduction to the study, review of the literature and explanation of the methods used to undertake the research. Following this, the key findings are presented as two peer-reviewed, published articles. The first publication (chapter four) entitled 'Doubly deprived': a post-death qualitative study of primary carers of people who died in Western Australia', was accepted for publication on 18 March 2011 in the Journal of Health and Social Care in the Community. The second publication (chapter five) entitled 'Is occupation missing from occupational therapy in palliative care?' was accepted for publication on 11 July 2011 in the Australian Occupational Therapy Journal.

The thesis concludes with a final chapter whereby the significant findings of the study are discussed using current local and international published evidence. The discussion outlines the implications for service delivery from an individual, policy and organisational perspective. Recommendations for further research are also provided in order to continue the investigations into this area of OT practice and implications for people who are dying and their carers.

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2. LITERATURE REVIEW

2.1 INTRODUCTION

This chapter outlines the main subject areas of the study, beginning with an examination of the literature regarding the role of OTs working with people who are dying and their carers from an historical and current viewpoint. The profession's philosophy, evidence base and practices are discussed as well as the range of factors which influence OT practice in this field. Additionally, an overview of the many variables impacting the care of people who are dying has been provided including service delivery, access to OTs, and the specific contextual issues pertaining to WA.

2.2 OCCUPATIONAL THERAPY IN PALLIATIVE CARE

Since the establishment of the profession in the early twentieth century, occupational therapy practice has evolved as a result of many changes which have impacted the health of the world's population. These include advances in medicine, pharmaceuticals and public health; the advent of new diseases; the state of the economy; the development of rapidly advancing technologies; an ageing population; an increased population; and the impact of community, societal and global issues, with the consequent development of the profession to incorporate these changes into daily practice (Baum & Christiansen, 1997; Kielhofner, 1992, 1985). Traditionally associated with the rehabilitation of people with physical and mental health problems, OTs have also assisted individuals to meet their health needs in a variety of different settings including the domain of palliative care (Bye, 1998; Dawson, 1982).

Modern palliative care has been largely attributed to the work of Dame Cicely Saunders, who, in the 1960s established St Christopher's Hospice in London (Kuebler & Berry, 2002; Woodruff, 2004). Dame Saunders believed that satisfactory care of people who were dying relied upon a multidisciplinary approach to provide pain and symptom management with a focus on patient centred care. This approach has developed over time and is now accepted internationally. The World

Health Organisation (WHO) in 2006 defined palliative care as a holistic form of care which “Improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement” (para.2). Palliative care focuses on managing symptoms and minimising pain rather than curing the disease. It involves the person who is dying, their carers and family and continues into the bereavement phase (Morgan, 1993; Old, 2007). A key principle of palliative care is the team approach for which occupational therapy has been recognised as a significant contributor (Doyle, 2006; George, 2000).

According to Crepeau, Cohn and Schell (2003) “Occupational therapy is the art and science of helping people do the day-to-day activities that are important and meaningful to their health and well-being through engagement in valued occupations” (p. 28). This definition holds true for OTs practising in the field of palliative care. While the overall focus of care shifts from curative treatment, the philosophy of OT remains constant; OTs are concerned with maximising the person’s functional, psychological, and social skills, within their chosen environment (Cooper, 2006b; Holland & Tigges, 1981; Pearson & Todd, 2007; Tigges & Marcil, 1988). Occupational therapy, by the very nature of the profession, provides valuable assistance to people who are dying, their primary carers and families by facilitating occupational performance and modifying valued tasks and roles in order to meet unmet needs (Halkett, Ciccarelli, Keesing, & Auon, 2010).

Historically, the services provided by OTs for people who were dying focused on assessment of the patient’s living situation and prescription of equipment to address environmental and functional barriers (Pearson & Todd, 2007). One of the first publications documenting occupational therapy practice for people who were dying was completed by Gammage, McMahon and Shanahan in 1976. These authors proposed that the role of OTs working in end-of-life care was not well defined and suggested that OTs should focus on the person’s adjustment to new occupational roles during the palliative period. They also recommended that in

order to develop competencies in the field, therapists themselves needed to engage suitable frames of reference and explore their own feelings about death and dying.

The establishment of hospices in the United Kingdom (UK) and North America led to further opportunities for OTs (Flanigan, 1982; Folts, Tigges, & Weisman, 1986; McMichael, 1991; Pizzi, 1984; Tigges, Sherman, & Sherwin, 1984). Dawson (1982) challenged the profession to utilise the opportunities available in palliation and hospice care to create an ongoing role. Some of the additional services recommended at this time included training in activities of daily living (ADL), modifications to the home and group work using crafts and activities. Dawson also identified that the needs of people who were dying were not being met by the existing OT services and suggested a broader focus including strategies for the management of pain. The American Occupational Therapy Association (1986) supported the view that occupational therapy offered an essential service within hospice due to their complementary philosophical bases. Lloyd (1989) and Bennett (1991) added to the growing body of knowledge, suggesting that the range of services for people who were dying should include goal setting, education and support and the provision of opportunities for self-expression in order to maintain quality of life.

The challenge to the traditional medical model and the introduction of a more holistic biopsychosocial model during the 1980s also influenced the development of palliative care. The change enabled consideration of the physical and biological symptoms of the disease but, more importantly, recognised the psychological, social and environmental concerns of individuals (Chochinov, 2007; Pizzi & Chromiak, 2001; Steinhauser et al., 2004). This development provided OTs with the opportunity to offer a broader and valued service for people who were dying. Several authors, including Norris (1999), Rahman (2000), Brandis (2000) and Cooper and Littlechild (2004) emphasised not just the physical aspects of care, but a range of strategies that focused on the occupational, environmental, psychological, social and spiritual needs of the person who was dying. Occupational therapists working in the UK and Canada began to document a variety of specific strategies to assist

dying people including relaxation training (Ewer-Smith & Patterson, 2002; Hindley & Johnston, 1999; Miller & Hopkinson, 2008; Penfold, 1996; Shearsmith-Farthing, 2001), coping skills for breathlessness and fatigue, and management of lymphoedema (Cooper, 2006a, 2006c). Additional recommendations included energy conservation (Egan, 2003), positioning for function (Armitage & Crowther, 1999) and a focus on the maximisation of a person's occupational roles (Marcil, 2006; Pizzi, 1984).

Further opportunities for OT involvement in palliative care have been afforded as the individual's home has become a more viable option as a place of death. In Australia, as has been the case in the UK and North America, there has been a gradual shift away from hospital-based care and many people are now able to die in their own homes with the support of specialist palliative care services. Home deaths have prompted a greater demand for community palliative care services and the engagement of multi-disciplinary teams that include OTs (Cooper, 2006a; Kealey & McIntyre, 2005; Mahmood-Yousuf, Munday, King, & Dale, 2008; National Gold Standards Framework Centre, 2009). While the benefits of this shift have purported to include cost-savings to hospital and primary health care budgets, there have been consequences for the families and carers of individuals who choose to die at home (O'Brien et al., 2011). The potential role of OTs in palliative care has diversified to include services to dying people, their carers and families, yet few studies have been published to reflect this change.

Occupational therapy, like any other area of health practice, relies upon a solid philosophy and evidence base to substantiate and justify chosen assessments and interventions (Cusick, 2001). There has been a paradigm shift in occupational therapy practice more recently, indicating a move away from the mechanistic approach of the 1960s to the so called 'emerging' paradigm of occupation (Whiteford, Townsend, & Hocking, 2000; Yerxa et al., 1989). The benefits of occupational engagement and participation on health and well-being have been well documented throughout the OT literature (Christiansen & Baum, 2010; Kielhofner, 1992; Law, 2002; Molineux, 2004; Wilcock, 1999, 2000), yet there are

only a few studies that have explored how a lack of occupational engagement impacts people who are dying.

Research conducted by Unruh, Smith and Scammel (2000), supported the value of meaningful occupation as a strategy for coping with stress and postulated that this engagement assisted in contributing to the well-being and quality of life for people with advanced cancer. In their ethnographic study, Jacques and Hasselkus (1984), determined that a person's participation in their own unique and everyday occupations continued to be important even when facing death and that these occupations helped to create a 'good death'. Other authors who have acknowledged the contribution made by OTs towards improving quality of life for dying people include Liddle and McKenna (2000) and Marcil (2006). These authors suggested that OTs working in palliative care have much to offer dying people, their carers and families.

In Australia, some gaps in the OT palliative care literature are evident. However, vanderPloeg (2001) introduced the concept of health promotion in palliative care, suggesting this was a useful approach that OTs could incorporate into practice to improve the quality of life of dying people. Another group of Australian authors, Lyons, Orozovic, Davis and Newman (2002) undertook a qualitative approach to examine the occupational experiences of a group of people attending a day hospice and concluded that such experiences assisted with the preservation of physical and mental functioning, helped to maintain social relationships and improved self-worth.

Halkett et al. (2010) documented a variety of issues pertaining to the employment of OTs in palliative care in WA, including insufficient funding, reduced understanding of the profession by others, lack of promotion of the role of the occupational therapist and limited research into the potential role of OT in the multidisciplinary palliative care team. Meredith (2010) found that a relatively small proportion of time (two to ten hours) was dedicated to palliative care in OT undergraduate education in Australia and many therapists felt ill equipped to work in the area.

There is also evidence to suggest there is a significant impact on OTs working in palliative care service delivery and recognition that it is a demanding and challenging field of practice (Bennett, 1991). The work sometimes leads to burnout (Cooper, 2006b). Practitioners become resolved to dealing with dying clients and must manage the intensity, urgency and continual exposure to death and grief (Prochnau, Liu, & Boman, 2003). Bye (1998) highlighted the conflict between practicing within a rehabilitation framework, yet enabling the client to prepare for death. Given these issues, coupled with comparatively few dedicated OT positions, it is not surprising that fewer OTs are currently working in this field.

In the twenty first century, many new roles for OTs in palliative care have emerged including oncology rehabilitation and working with survivors of cancer (Harrison-Paul & Drummond, 2006; Hindley & Johnston, 1999; Lowrie, 2006; Purcell, Fleming, Haines, & Bennett, 2009) and specialised palliative care for children (Tester, 2006). In 2005, The Canadian Association of OTs (2005) produced a position statement regarding end-of-life care with several recommendations. These included a commitment to improved access to OT services; professional development for both OT students and graduates; and advocacy for dying people and their carers. Additionally, research priorities were identified including occupation at the end-of-life, spirituality, pain and symptom management, the psychosocial aspects of care, and service delivery including services delivered at home.

In addition to the limited research that has been undertaken to examine the occupational experiences of people who were dying, few studies have examined the specific occupational experiences of carers of these people. Pickens, O'Reilly and Sharp (2010) suggested that the occupational needs of family caregivers in end-of-life care were often unmet even though their needs may surpass those of the person who has died. Similarly, research conducted by Hasselkus and Murray (2007) and Hwang, Rivas, Fremming, Rivas and Crane (2009) concluded that carers of people with Alzheimer's disease were unable to engage in meaningful occupations due to the demands of caring.

Much of the early literature published on the role of the occupational therapist in palliative care is descriptive in nature, with few studies focusing on an evaluation of practice. It is imperative that the profession builds a substantial collection of reliable evidence in order to maintain and develop its role in this specialised area. Occupational therapists working with dying people employ a range of resources including various models of practice, assessment and evaluation tools, yet there are few studies that have explored or evaluated these models and tools in order to validate the effectiveness of practice in palliative care.

A number of studies Bye (1998), Eva (2006), Pearson and Todd (2007) and Schleinich, Warren, Nekolaichuk, Kaasa and Watamabe (2008) have emphasised the need for further research in the measurement of outcomes, evaluation of services, and the development of an evidence base in order to build on the current body of knowledge in this area of practice. Models of occupational therapy form a scientific basis for practice; the choice of model may mean the difference between satisfactory and unsatisfactory outcomes for patients (Tornebohm, 1991). Lloyd (1989) utilised the Model of Human Occupation (MOHO) (Kielhofner, 1985) to direct practice, advocating its use to guide therapists when working with people who were dying. Norris (1999) assessed the effectiveness of the Canadian Occupational Performance Measure (COPM) (Law et al., 1998) for use in palliative care and concluded that it was not a suitable tool for use in this area, due in part to its limited capacity for evaluation of psychological difficulties. Further research and evidence will assist to substantiate and evaluate the role and efficacy of OTs working in palliative care.

2.3 PALLIATIVE CARE IN AUSTRALIA

Immigration in Australia has created cultural diversity. The challenge of health services is to meet the needs of all consumers while ensuring that the care of people who are dying meets a variety of needs and preferences (Department of Health Western Australia, 2008; Palliative Care Australia, 2005b). Individuals,

families and communities have different ways of coping with death, dependent in part by differing cultures, values and beliefs. Contextual factors also include awareness and preparation for death, place of death, availability of the health care system and ease of access to supports including palliative care (Kellehear, 2001; McNamara, 2001).

Formal care for people, who are dying, including specialist palliative care, is relatively new in Australia. The past three decades have seen the emergence of different models of care together with the establishment of various organisations set up to develop policy, standards and guidelines to oversee these services (Aranda, 2000). Currently, the Australian Government provides funding via the Department of Health and Ageing to states and territories to administer palliative care services to hospitals, community settings and hospices (Commonwealth Department of Health and Aged Care, 2000). According to Currow, Abernethy and Fazekas (2004), McNamara and Rosenwax (2007) and Palliative Care Australia (2009), recent health reforms in Australia have meant that palliative care services are under review. The current systems of care are struggling to ensure that people who would have benefitted from palliative care services actually received these services.

In the period between 1 July 2000 and 31 Dec 2002, only 68 per cent of people who died from cancer and just eight per cent of people who died from non-cancer conditions in WA received specialist palliative care. This data was extrapolated from the most recent research conducted in this state, which also determined that access to palliative care varies according to many factors including marital status, age and geographical location (Rosenwax & McNamara, 2006). Palliative Care Australia, in 2009, stated that there continued to be difficulties with access to palliative care services in Australia, especially for people residing in aged care facilities, children, those living in rural and remote areas and indigenous Australians. Additionally, it was noted that the provision of services varied according to diagnosis and socio-economic status. In view of these findings, it was recommended that significant changes should be made to these services including

improved access to palliative care, increased funding, additional workforce and improved professional development for the health professionals employed in this area.

Historically, palliative care has been associated with patients with cancer; however, studies have indicated that many life-limiting and chronic conditions may also be amenable to palliative care. These conditions may include but would not be limited to; heart, lung, liver and renal failure, neurodegenerative diseases, stroke, HIV/AIDS, frailty and dementia (Addington-Hall & Higginson, 2001; Ahmed et al., 2004; Auon, Kristjanson, & Oldham, 2006; Lynn, Chandry, Noyes Simon, Wilkinson, & Schuster, 2007). There is also an argument in the literature that many conditions identified as 'chronic' may benefit from a palliative approach to care (Fitzsimmons et al., 2007; Murray, Boyd, & Sheikh, 2005). The demand for palliative care services has increased as health care services respond to increasing rates of life-limiting illness (Palliative Care Australia, 2005a).

Palliative care needs to be made available across the variety of settings in which people choose to die including hospice, hospital, residential aged care facility or the client's own home, supported or not by community-based health practitioners (Rosenwax, McNamara, Blackmore, & Holman, 2005). Not all people with these conditions are routinely referred for palliative care in WA and it is not known if the people who received palliative care services had access to allied health practitioners, including OTs. Correspondingly, little is known about the range and type of services provided by OTs and other allied health practitioners and if the needs of their consumers are being met by existing services.

Australian society faces ongoing challenges as a result of ageing populations, changing patterns of disease and the increasing age of caregivers (Davies & Higginson, 2004). It is anticipated that these changes will correlate to increasing numbers of individuals seeking palliative care services in the future (World Health Organisation, 2004). Stewart (2003) predicted that in Australia, the increasing need for palliation services for those with non-malignant disease will outweigh the availability of these services. This places the overall burden of care of these

individuals onto the existing services which are already experiencing difficulties coping with current demands.

2.4 CONCLUSION

The role of OTs in palliative care has grown and diversified since the initial engagement of therapists in the 1960s. Much of the OT research has centred on the physical and environmental concerns of people who are dying. In Australia, the occupational experiences of these individuals have been under explored and largely undocumented. It is essential to the growth and efficacy of the profession that further research in this area of service delivery is undertaken in order to develop and validate this field of practice. This research project aims to identify the current philosophy, models and practices of OTs working in this field in WA, within the Australian context of health care.

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3. RESEARCH DESIGN

3.1 INTRODUCTION

The study was conducted in two stages using a mixed methods approach to answer the research questions. Stage one aimed to scope the extent of the problem of adequate service provision by calculating the number of OTs who provided services to people who died of conditions considered amenable to palliative care in WA. The substantive component of the research was addressed in stage two which used in-depth interviews to collect data from two groups of participants. Group one consisted of primary carers of people who had died from conditions considered amenable to palliative care (Fitzsimmons et al., 2007; McNamara, 2001; Tearfund, Cowley, Bliss, & Thistlewood, 2003) and group two consisted of OTs employed to provide services to this group of people in WA.

3.2 MIXED METHODS RESEARCH DESIGN

Mixed methods research uses a combination of quantitative and qualitative data collection methods and analyses in order to address the research question (Teddlie & Tashakkori, 2003; Whalley Hammell, 2004). This method is particularly useful when limited data exists on the subject as was the case with this research where little was known about both the number of occupational therapists working in palliative care in WA or the palliative care needs of dying people and their carers. Mixed methods research also enables the triangulation of results from different research methods. Triangulation contributes to the trustworthiness of the research findings (Taket, 2010) and is a method used to ensure rigour of the research design (Liamputtong & Ezzy, 1999).

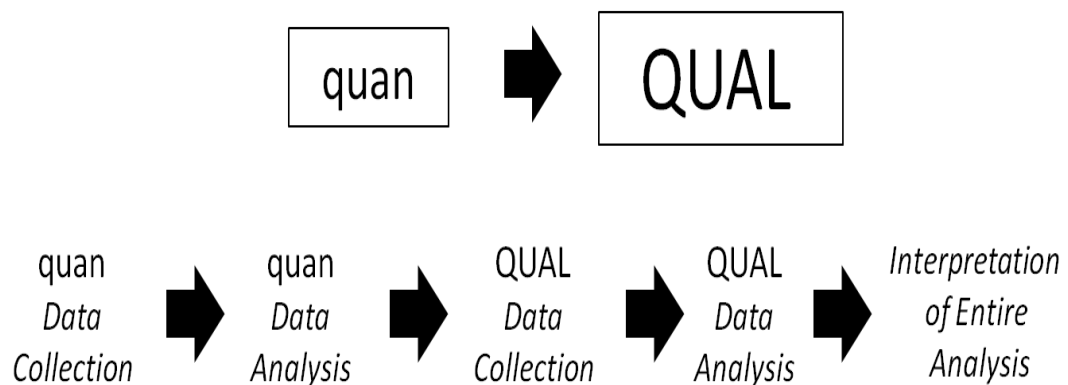
The literature provides many different views on the merit of mixed methods research, including the opinion that the research paradigms of qualitative and quantitative approaches are so inherently different that they should not be combined (Guba, 1987; Sale, Lohfeld, & Brazil, 2002). Discussion amongst researchers about this view in the 1980s gave rise to the 'Incompatibility Theory'; whereby advocates of this theory argued that the epistemological bases of each research design could not (and should not) be used together (Denzin & Lincoln,

2000). In contrast, proponents of this research design consider the benefits from a pragmatic standpoint, that is, the researcher should use whatever means available with which to answer the research question. A mixed method design draws on the strengths of both qualitative and quantitative methods to answer a broad range of research questions. According to Hanson and colleagues (2005), describing and explaining social phenomena is a complex task and different methods are needed. Furthermore, integration of data occurs when the two sets of data are considered side by side in order to develop inferences about the results of the research and to answer the research question (Creswell, Plano Clark, Gutmann, & Hanson, 2003).

In this study, an explanatory design using two sequential stages (Figure 3.1) was employed. According to Creswell, et al. (2003), this design uses results from the quantitative data collected to direct the sampling strategies (participants and techniques) that are used to collect the qualitative data.

Figure 3.1

Sequential Explanatory Design



Source: Adapted from Creswell, J., Plano Clark, V., Gutmann, M., & Hanson, W. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioural research*. (pp. 209-240). Thousand Oaks: Sage Publications.

In this study a simple quantitative strategy was employed in stage one to collect and analyse numerical data to assist with the establishment of the determinants for the second stage, the potential size of the two groups of participants, sampling strategies and data collection methods. The second stage involved the use of qualitative methods to explore and analyse participants' experiences using in-depth interviews. Following this, an interpretation of the results and integration of the data was completed from both stages and conclusions drawn.

3.3 STAGE ONE

3.3.1 OBJECTIVES

1. Determine the number of OTs (FTE) providing palliative care services in WA in a one year period.
2. Using published data on deaths from conditions amenable to palliative care (Rosenwax, McNamara, Blackmore, & Holman, 2005) calculate the ratio of OTs providing palliative care services in WA to the number of people who died of conditions amenable to palliative care in WA.

3.3.2 QUANTITATIVE METHODOLOGY

As indicated in Figure 3.1, the quantitative component of the study was minimal. This method was used to develop the data which informed the substantive qualitative part of the research. Quantitative research methods utilise various strategies to collect and analyse numerical data using statistical analysis in order to draw conclusions about the data and answer the research questions. This method enables the researcher to describe the characteristics of data and make generalisations about the population of concern, which contributes to the development of an evidence base for that particular phenomena (Schofield & Knauss, 2010).

In this study, a brief survey to collect demographic and numerical information regarding OTs who worked with people who were dying (Appendix E) was used.

Although complex statistical analysis was not undertaken, the information collected assisted to inform the depth and breadth of the overall study.

3.3.3 STUDY SAMPLE

The number of people who died over a 2.5 year period (1 July 2000-31 December 2002) with conditions considered amenable to palliative care provision was taken from a study conducted by Rosenwax, McNamara, Blackmore and Holman (2005). Given that there are no data available on the number of OTs employed to provide palliative care services to people in WA, a list was constructed using the WA Health Network (Department of Health Western Australia, 2008), Curtin University School of OT Fieldwork data base, Occupational Therapy Interest Groups and personal networks. This list represents a summary of the OTs known to be working in palliative care in WA as at September 2009.

3.3.4 PROCEDURE

In the Rosenwax et al. study (2005), the literature was reviewed and expert opinion sought through focus groups to produce a list of conditions potentially amenable to palliative care. These conditions are listed in Table 3.1. According to the Australian Bureau of Statistics (ABS) (2010), the number of all deaths occurring in WA remained relatively stable from year to year during the period 2000 (10,668 deaths) to 2009 (12,566 deaths), which allowed the use of data from the 2005 published study for the purpose of calculating the ratio of OTs providing palliative care services in WA to the number of people who died of conditions amenable to palliative care in WA.

Table 3.1.

Frequency of the 10 conditions in the minimal estimate of Western Australia deaths from 1 July 2000 to 31 December 2002 (N= 13 453)

Underlying Cause of Death, Part 1 of death certificate (ICD-10AMcodes)	Number and proportion of people who had the condition (%) ^a
Neoplasm (ICD-10-AM C00_ D48)	8007 (59.5)
Heart failure (ICD-10-AM I500, I501, I509, I110, I130, I132 ^b)	2819 (21.0)
Renal failure (ICD-10-AM N10, N11, N120, N131, N132, N180, N188, N189)	1313 (9.8)
Chronic obstructive pulmonary disease(ICD-10-AM J40, J42, J410, J411, J418, J430-J432, J438-J441, J448, J449)	1286 (9.6)
Alzheimer's disease (ICD-10-AM G300, G301, G308, G309)	537 (4.0)
Liver failure (ICD-10-AM K704c, K711 ^c ,K721, K729 ^c)	424 (3.2)
Parkinson's disease (ICD-10-AM G20)	174 (1.3)
Motor neurone disease (ICD-10-AM G122)	122 (0.9)
Huntington's disease (ICD-10-AM G10)	13 (0.1)
HIV/AIDS (ICD-10-AM B20_ B24)	14 (0.1)

^a 1256 people (9.3%) had more than one condition from the Minimal Estimate listed on Part 1 of the death certificate.

^b There were no recorded deaths from I132 (hypertensive heart and renal disease with both CHF and renal failure) during the study period.

^c Acute liver failure is not separated from chronic liver failure on the ICD-10-AM codes.

Source: Rosenwax, L., McNamara, B., Blackmore, A., & Holman, C. (2005). Estimating the size of a potential palliative care population. *Palliative Medicine*, 19(7), 556-562. doi:10.1191/0269216305pm1067oa.

3.3.5 EMAIL SURVEY

Contact was made with the Occupational Therapists' Registration Board of WA and the Department of Health WA; however, despite these attempts aimed at identifying OTs working in palliative care in WA it was not possible to determine the number of OTs working in the state, specific to this field. A survey conducted by the Department of Health WA in 2007 identified a range of demographic data relating to the health workforce and employment of OTs in WA; however, this did not identify the specific area of practice (Chief Health Professions Office, 2008).

A list of metropolitan and rural palliative care services was generated using the WA Health Network (Department of Health Western Australia, 2008), Curtin University School of Occupational Therapy Fieldwork data base as well as personal, professional and employment contacts. Occupational therapists employed by each service were identified and contacted via email and follow up phone call (Appendix E) and asked to complete a series of questions including demographic data, service type, hours of work and estimate the proportion of their caseload considered as palliative. The total full time equivalency (FTE) of OTs working in palliative care is represented in Table 3.2.

Table 3.2

Number of OTs identified as working in palliative care in WA in 2009
(N=29)

Location	Number of services	Service Type	Designated palliative beds	Total FTE
East metropolitan	2	Public	15	0.35
North metropolitan	7	Public/Private	28	2.7
West metropolitan	1	Public/Private	10	0.4
South metropolitan	2	Public/Private	N/D	0.8
Peel region	2	Public/Private	7	0.6
All metropolitan (private OTs)	3	Private	N/D	0.5
Rural	12	Public/Private	N/D	0.8

N/D: Not designated as palliative care beds.

3.3.6 DATA ANALYSIS

A frequency count of the number of OTs working in palliative care was determined using the results of the email survey. Using the figures provided in Table 3.2, a simple calculation was made to determine the ratio between the number of OTs providing palliative care in WA and the number of people who died from condition/s considered amenable to palliative care within a one year period. Initially, the number of deaths over a 2.5 year period ($n = 13,453$) was divided by 2.5 to produce a figure of 5,381. This figure was then divided by the total number of OTs (FTE) working with dying people in 2009 ($n = 6.15$) to determine the ratio between these two groups. This figure and discussion regarding the results are presented in Chapter Five, page 82.

3.4 STAGE TWO

3.4.1 OBJECTIVES

1. Determine the met and unmet needs of people during the palliative phase, with particular reference to self-care, environmental contexts and occupational needs for;

a) Primary carers of a family member who had died;

b) The family member who had died (from the perspective of the primary carer).

2. Describe the current philosophies and practices of occupational therapists employed to provide palliative care services in WA with regard to working with people who are dying and their primary carers, from policy, organisational and individual perspectives.

3.4.2 QUALITATIVE METHODOLOGY

Qualitative research methods employ strategies of data collection that involve the gathering and interpretation of words as opposed to numbers (Denzin & Lincoln, 2000; Liamputtong, 2010; Sandelowski, 2000). Qualitative methods are useful to researchers studying human social experiences and behaviours as they allow opportunities to listen and observe the participant in their usual environment in order to understand and interpret the narrative data being collected (Carpenter, 2004). This approach is also useful when a phenomenon is not well researched or understood, by allowing for explanation and interpretation of the data, rather than simple descriptions of the subject matter (Frank & Polkinghorne, 2010).

There are a number of recent studies that examine the dying person's experiences in the period leading up to death as well as the experiences of primary carers, for example, Funk and colleagues (2010) and Stajduhar, Allan, Cohen and Heyland (2008). However, very few of these studies examine the specific needs and wants of these groups of people from an occupational perspective (Keesing, Rosenwax, &

McNamara, 2011). Similarly, the experiences of OTs working in palliative care in WA are relatively under explored and few studies have been published that examine the services provided by OTs in WA (Halkett, Ciccarelli, Keesing, & Auon, 2010). A qualitative approach using grounded theory was chosen in order to explore the experiences of the two participant groups, from their individual viewpoint during the dying person's last year of life.

3.4.3 THEORETICAL PERSPECTIVE- GROUNDED THEORY

Grounded theory was first documented by two sociologists, Barney Glaser and Anselm Strauss in the 1960s and is now used across a range of disciplines to examine social situations and interactions and provides an analysis or 'theory' regarding the phenomena of concern (Glaser & Strauss, 1967; Stanley & Cheek, 2003; Walker & Myrick, 2006). This methodology utilises a variety of data collection methods, including, in-depth interviews, field notes, observations and written reports.

Drawing on the concept of symbolic interactionism, grounded theory assumes that people order and make sense of their world according to their individual needs and experiences. It is assumed therefore, that people sharing a common circumstance will also share some common meanings related to that circumstance. It is this assumption that allows the development of a 'theory' related to the group that is 'grounded' in the data collected (Corbin & Strauss, 2008; Skeat, 2010).

The foundation premises of symbolic interactionism are based on the work of George Herbert Mead (1962) and Herbert Blumer (1969) who postulated that all individuals are socially constructed and people make sense of the world due to the processes of social interaction. Researchers use this premise to investigate how people create meaning during social interaction and how this contributes to the development of self or "identity", and how they interact with others (Annells, 1996). The concept of symbolic interactionism was used to understand and make sense of the participants' dialogue during interviews and to commence the initial formation of themes and codes.

Grounded theory methods of research employ an inductive approach to explain the subject matter; theories about the data are developed from the observations, discussions and dialogue obtained throughout the data collection. This method utilises the practice of 'coding' to interpret and refine the data in order to confirm the developing theory (Liamputtong & Ezzy, 1999; Patton, 2002).

This approach was chosen as a logical basis for identification and interpretation of an individual's experiences with death and dying as each experience is unique to that person. It allowed an understanding of the participants' responses to questions, their use of language and expression and how the experience of death and dying impacted their thoughts, actions and interactions with others. In the context of this study, grounded theory permitted an exploration of the everyday life situations of each participant carer, what do people do each day? What are the processes that cause people to behave in a particular way? What difficulties do they have undertaking activities? How do these difficulties impact their daily routine? Similarly, this approach was used to explore the experiences of OTs working in palliative care. What services do OTs provide? How do OTs decide what services to provide? What models do they use to drive the therapeutic process? What are the difficulties experienced in this area of practice?

3.5 SAMPLING AND RECRUITMENT METHODS

3.5.1 CARERS

Theoretical sampling is a tool used by qualitative researchers that allows decisions regarding the selection of participants and exploration of the data to change throughout the data collection period. As data is collected and analysed, decisions about whom to interview and questions to be asked are based on the emerging themes of the study (Charmaz, 2000; McCann & Clark, 2003). This strategy assists the researcher to develop inductive concepts regarding the phenomena, allowing comparison and contrast between the data collected, leading to the 'theory'.

Theoretical sampling was used to identify carers (as proxies for people who had died) living in metropolitan and rural locations in WA. Advertisements were placed in the newsletters of the following publications:

- Health Advisory Council of WA
- Carers WA
- Country Women's Association of WA
- Regional newspapers including Southern Gazette, Avon Advocate, Collie Mail
- LISA news (newsletter of the Lung Impaired Support Association of WA)
- Local newspapers; Southern Gazette, Canning Times

Additionally, recruitment flyers were provided to contacts at the Cancer Council of WA, West Australian Country Health Service (WACHS), local shopping complexes and libraries. An interview with ABC radio was also completed. Copies of these advertisements can be found in Appendix F.

Sampling was refined and directed as the study progressed and each transcript was analysed to identify potential themes; this assisted with the recruitment of carers who had obtained services, cared for individuals with a non-cancer diagnosis and those living in rural locations. These were important differentiations in the data collection as they lead to further questions; and to determine any differences between participants according to the types of services obtained, the diagnosis of the dying person and where they lived. A summary of participant demographics of this group is found in Chapter Four.

3.5.2 INCLUSION AND EXCLUSION CRITERIA-CARERS

Inclusion criteria stipulated that each participant carer had experienced the death of a person from four months to two years previously or who was currently caring for a person who was determined (by their medical practitioner) to be in their last year of life. Cause of death/diagnosis was due to a condition amenable to palliative care. Despite extensive attempts, no carers were recruited who were currently caring for a person who was dying.

Carers were excluded if the bereavement was less than four months or greater than two years. This time frame was chosen because issues of grief and loss as a result of recent death may create additional stress for the carer, if more recent (Addington-Hall, Fakhoury, & McCarthy, 1998; B. McNamara & Rosenwax, 2007). Two years post death may create issues relating to recall of events. Two carers were excluded using these criteria.

3.5.3 OCCUPATIONAL THERAPISTS

A theoretical sampling technique was also used to identify OTs and OT Heads of Services working in metropolitan and rural locations in WA. Participants were initially recruited from the WA Health Networks data base and the Curtin University School of Occupational Therapy Fieldwork data base, Occupational Therapy Interest Group (Aged Care) and existing fieldwork contacts via email, telephone contact and newsletter advertisements. A summary of participant demographics of this group is found in Chapter Five.

3.5.4 INCLUSION AND EXCLUSION CRITERIA-OTs

OTs were included if they had been registered for at least one year by the Occupational Therapists Registration Board of WA. There were no exclusion criteria as it was recognised that particularly in rural areas, OTs may have worked across a range of service delivery contexts and may not be included in the established palliative care team.

3.6 ETHICS AND INFORMED CONSENT

Ethics approval for the study was obtained on 10/11/2008 by the Human Research Ethics Committee (HREC) of Curtin University and the Department of Health Western Australia (DOHWA) Research Committee on 23/12/2008. Further approval was obtained from the Joondalup Health Campus Research Ethics Committee (JHCHREC) on 20/2/2009 (Appendix G). Each participant was provided with an information sheet outlining the risks and benefits of the study as well as information

regarding access to counselling services, should the interview cause distress (Appendices H and I).

Participants were required to provide written consent for the study and were advised that they may withdraw at any time, should they wish (Appendix J). They were also informed that at no time would they be identifiable to anyone other than the researcher as all names and details were de-identified using synonyms. Embarking on this study raised many questions for the researcher; how to remain objective during the interview process, how to phrase questions so as to avoid undue distress for the participants and manage personal responses to the participants 'stories' and experiences. Participants were advised that they could stop the interview at any time or take a break if needed. They were also informed that counselling was pre-arranged with a bereavement support service if they experienced any further difficulties at a later date (this service was not accessed during the period of the study). Many carers were able to identify natural supports (e.g. family, friends) that they were able to talk with and discuss issues that were raised as part of the interview.

Consideration was also given to the environment with efforts made to minimise distractions and allow sufficient time to complete the interview. Several strategies were utilised to manage these issues including regular debriefing with peers and research supervisors, whereby difficulties relating to the interview process, bracketing and reciprocity were managed. This occurred during regular discussions, listening repeatedly to interviews, reviewing memos and whilst refining codes and themes.

For all interviews, an initial period of rapport building was included, this was based on the premise that all participants were unknown to the researcher and it was felt that providing an opportunity to engage in (non-directed) conversation gave each participant and the interviewer a chance to commence building trust. The subject matter discussed in the interviews was extremely personal, sometimes resulting in emotional distress, crying, pausing and apologies for becoming upset. Using a range of verbal and non-verbal strategies, it was anticipated that each participant felt

comfortable to disclose their experiences and were assured that the information was kept confidential and secure.

3.7 DATA STORAGE

All data obtained as part of the study was stored in accordance with Section 2.6 'Manage storage of research data and records' of the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council, 2007). All raw data (interview transcripts, demographic details, consent forms) collected during the study were kept in a locked filing cabinet in a locked facility at Curtin University for a period of five years.

Electronic data including digital media files were stored on the researchers' computer and this was protected with a password. These digital files will be destroyed at the conclusion of the project.

3.8 DATA COLLECTION

3.8.1 IN-DEPTH INTERVIEWS

In-depth interviews are used throughout qualitative research studies because they provide an extended opportunity for the participant to share ideas, experiences and feelings about a particular subject. The interviewer (researcher) assists with the promotion of dialogue by providing non-verbal cues, active listening and asking open-ended questions in order to facilitate the flow of conversation. The aim of this type of interview is to elicit the individuals' own attitudes, perceptions and opinions about a subject that holds meaning for them and provides individual subjective responses (Serry & Liamputtong, 2010). This approach to interviewing was chosen to ascertain the participants' own unique experiences and reflections regarding their roles as carers or occupational therapists and their individual experiences about death and dying.

3.8.2 INTERVIEW GUIDE

An interview guide was developed following consultation with peers, research supervisors, literature review and reflection on clinical experience. Many qualitative researchers advocate the use of a semi-structured guide as a framework to facilitate extended responses, yet ensure that all the essential issues are raised and discussed (Patton, 2002).

Data were collected from participant carers during the in-depth interview using this semi-structured guide (Appendix K) in order to facilitate extended responses. Interviews were conducted in mutually agreed private locations where interruptions were likely to be minimal. These locations included carers' homes and meeting rooms at health services. One carer was interviewed in the meeting room at a local support centre; another was interviewed in a meeting room at her place of employment. Travel to several rural locations was also completed in order to carry out interviews with four carers and five OTs living in rural towns in WA.

Participant carers were asked to provide basic demographic information. Questions were asked of the carer regarding their own experiences as well as the met and unmet needs of the person for whom they have cared. These questions focused on the self-care, environmental contexts and occupational needs of the individual they cared for during their last year of life. In addition, questions were also asked about the carers' own routine, day to day activities and any changes to their lives as a result of the caring role (Appendix K).

Participant OTs were asked to provide demographic information including length of time practicing as an OT, usual place of work and experience working with people who were dying. Additional questions focused on models and philosophy of practice, types of services provided, what changes (if any) they would suggest to existing palliative care services and their own practice (Appendix L). Each interview, of approximately 60-90 minutes was recorded using a digital recording device and transcribed verbatim, with assistance from a paid transcriber.

Pilot interviews with one (non-participant) carer and one (non-participant) OT were completed in order to identify any difficulties or issues related to the types of interview questions, interviewing style as well as the structure and flow of the interview. Interview guides were modified to reflect this feedback and refine the interview questions.

3.8.3 INTERVIEW PROCESS

Previous clinical experiences were drawn upon in order to prepare for each interview. Reflections on these clinical experiences and the recognition that this area of practice is largely under researched were factors that contributed towards the pursuit of research in this field. Acknowledgement was made that each participant had previously provided an intensive caring role for a person who died, or had provided OT services for a person who died. Each participant had their own 'story', each had positive and negative experiences as a result of their role and consequently each interview was tailored to the individual participant, acknowledging the range of experiences and potential difficulties. Strategies to facilitate discussion included the use of prompting questions, note taking, observation of non-verbal behaviour, open-ended and reflective questioning, and preparation of the environment were all considered in order to elicit comprehensive responses.

3.9 DATA ANALYSIS

3.9.1 CODING

A key principle of grounded theory involves the use of constant comparative analysis. Data collection and analysis occur concurrently, allowing the researcher to compare incidents, identify similarities and patterns in the data and begin to develop categories (Patton, 2002). Each interview was read line by line, several times, in order to understand and make sense of the data. Short phrases, words and key concepts were then clustered into categories with similar ideas.

Initially, 'open' coding involves scrutinising the incidents and dialogue and developing the concepts into categories and sub categories. These categories are given labels and as further data are added to the overall analysis, additional categories are defined.

Following this, a process of 'axial' coding is used to link the categories and subcategories together, allowing the key themes of the research to emerge from the data. Examples of the coding process are outlined in Table 3.3.

Table 3.3

Examples of the coding process

Transcript	Open Code	Axial Code
<p>The self-care thing was really hard to watch... to have to accept help with his self-care because that was part of his dignity ...it wasn't that he couldn't handle us seeing him naked or anything like that it was just like, you know, I can't do this for myself. Because that's the feeling because I can't do anything for myself, I'm hopeless.</p>	<p><u>CARERS</u></p> <p>Hard to accept help, need to keep dignity, helplessness of not being able to do for self</p>	<p>Reduced occupational performance</p>
<p>So he very much wanted to be in control of his faculties and he was fully aware and alert and he was really compromised by the medication. We wanted to advocate for him but it was difficult, feeding that information to the doctor to say 'look the Temazepam's knocked him out, we think it's really not helping' and the doctors come in and said 'look, this is best practice'.</p>	<p>Wanting to feel in control, difficulty explaining needs and wants, wanting to respect patients' wishes</p>	<p>Difficulty with communication amongst key parties, disempowerment as a key party</p>
<p>It was Jane who had actually done the home visits, so we knew where to go for a chair and equipment but I wasn't there to talk with her, then they dropped off the equipment but that was all.</p>	<p>No time with OT, unable to provide sufficient resources</p>	<p>Equipment focus, limited opportunity to focus on occupation</p>
<p>I would have had a couple of nights that I needed some space to sit, twiddle your toes you know something like that so you have to think about how they're going to be able to sustain that.</p>	<p>Difficulty balancing roles as carer, needing respite from carer role</p>	<p>Occupational imbalance</p>

Transcript	Open Code	Axial Code
<u>OTs</u>		
I see a lack of co-ordination of different services so there is lots of that for chronic disease management, which become palliative in the end in the community.	Lack of co-ordination between services	Poor co-ordination
I think we need to be more person centred. I think the palliative care brief is very holistic and takes into account the emotional, spiritual, cultural needs of the person more so than the average medical model.	Value of person centred care versus medical model	Current practices are not person centred
We liaise a lot with (community nursing service) in terms of people going home and us missing them here so we do follow up and provide home visiting services and equipment but more at that sort of level rather than being involved and supporting the families or the person through the occupational issues that they want to address.	Provision of services focuses on equipment and modifications, not related to occupational issues	OT services focus on equipment
What happens is when we see these patients they're usually very ill, almost to the end stage of their life and so it's really it about making their care comfortable, helping their families to try and deal with this person that's very sick in their home situation. So really it's a lot about equipment prescription, organising support or whatever or linking in some services that might not already be there. So our role here tends to be more of an end stage role which is very limiting, that's the unfortunate thing too, that we find we don't get called in early enough.	Limited role due to late referral, equipment and organising support only	Frustrations with current opportunities to work with people with palliative needs

3.9.2 MEMOS

Memos are an important tool used as part of the grounded theory process (Stanley & Cheek, 2003). Memos were used in this study as a method of organising and tracking the data. These were very useful in keeping a systematic record of the data and decisions made during the progress of the study.

3.9.3 THEORETICAL SATURATION AND SAMPLE SIZE

It is not usually possible to determine the expected sample size when undertaking a grounded theory study (Corbin & Strauss, 2008). This is because data saturation is only evident when no new categories or themes emerge. The intention of this study was to identify the thoughts and experiences of a range of primary carers and OTs who had experience with death and dying. It is acknowledged that that these experiences are unique, according to a multiplicity of factors and the strategy of theoretical sampling assisted with saturation of the data.

3.10 TRUSTWORTHINESS

Trustworthiness in qualitative research refers to the rigour of the research design and process (Johnson & Turner, 2003). Four key criteria are used to demonstrate trustworthiness in this study; credibility, transferability, dependability and confirmability.

3.10.1 CREDIBILITY

Credibility refers to the 'fit' between what participants verbalise and what the researcher represents as an accurate description of the content (Sandelowski, 1986). Member checking was completed with all participants by providing a transcript of their interview, together with instructions to read carefully and advise the researcher of any errors. Two participants identified errors in the transcripts which were corrected following a further review of each interview (listening to

transcripts again). Preliminary themes of the research were also sent to each participant with instructions to review these and make further comment. These responses were considered as part of the overall development of themes.

3.10.2 TRANSFERABILITY

Qualitative researchers must identify the generalisability of the research to other readers. Can the research be replicated in another setting? Do the findings 'fit' with the readers' own experiences? Could the conclusions be reasonably applied to another setting? According to Koch (1994), the responsibility in answering these questions is required of the reader of the research, however, the author must ensure the context is adequately described in order to provide as much information as possible to ensure that a decision can be made about transferability. A range of factors must be included when considering the transferability of this research to other locations. These include the provision of rural and remote services, models of care, availability of resources and the context of care. Of particular note is the dearth of OTs employed in WA that provide care within community based palliative care services. However, it is felt that the steps in the research process have been described explicitly and within the boundaries of confidentiality and a thorough rationale has been described for decisions made.

3.10.3 DEPENDABILITY

Methods of addressing and ensuring dependability are vital to ensure that the decisions made as part of the research process are rational and clearly documented. This process is known as an 'audit trail' (Ritchie, 2001). This strategy has been implemented from the commencement of the study through to the conclusion with the use of a diary, documentation of meetings with research supervisors and written rationale for the decisions made regarding codes and summaries of interviews.

3.10.4 CONFIRMABILITY

Confirmability is described by Tobin and Begley (2004) as the method by which the research findings can be directly related to the data, rather than simply a reflection of the researchers' own ideas and biases. Several strategies were employed to ensure confirmability of the study. These included discussion and documentation with the research supervisor and peers regarding decisions related to recruitment of participants, interviewing strategies, analysis of transcripts and confirmation of codes and themes. Theoretical sampling throughout the data collection also assisted in the refinement, direction and development of themes throughout the research period.

3.11 LIMITATIONS

Several limitations were acknowledged as part of the study. The number of deaths used to calculate the ratio of OTs providing palliative care services in WA to the number of people who died of conditions amenable to palliative care in WA was taken from a study that utilised data from the period 2000 to 2002. However, this was the most recent population based summary of people who were identified as potentially being able to benefit from palliative care. Additionally, the data set provided limited information about these potential recipients of palliative care and is diagnosis based, rather than based on individual (expressed) needs.

The list of OTs in Western Australia was developed using a brief (non-standardised) tool and relied upon recipients responding with some accuracy regarding their current work. The response rate for the survey was noted to be 14 (from a potential 17 metropolitan-based OTs surveyed). Rural therapists responded at a rate of 9 (from a possible 12 OTs surveyed). It is therefore noted that potentially, there were other therapists in WA providing palliative care services that were not captured in the study sample.

Recruitment of participant carers was also difficult for two main reasons. First, many people find it difficult to discuss their experiences with death and dying and this can be particularly difficult when discussing personal details regarding the care and death of a loved one. Extensive advertising was conducted to overcome this issue. Second, theoretical sampling was required to ensure that participants were recruited on the basis of emerging themes and therefore, recruitment was directed to this end.

A further limitation identified was gender imbalance; many more female carers ($n = 13$) were recruited than male carers ($n = 1$). It was also very difficult to recruit rural carers ($n = 4$ rural, $n = 10$ metropolitan). Therefore, comparisons relating to gender and carers' location were not possible.

Finally, it is also noted that it is very difficult to obtain a true understanding of a dying person's perspectives of their own experiences, as only carers were interviewed (as proxies for the person they cared for). However, several recent studies support the use of carers as reasonable and reliable substitutes for the dying person (Klinkenberg et al., 2003; Kutner, Bryant, Beaty, & Fairclough, 2006).

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4. PUBLICATION ONE

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'Doubly deprived': a post-death qualitative study of primary carers of people who died in Western Australia

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What is known about this topic

- Primary carers are often undervalued for the contributions they make to the care of people who are dying.
- Current research focuses largely on the physical, psychological and emotional demands of being a carer.
- Specialist palliative care community services provide support for people who are dying and their families.

What this paper adds

- The demands placed upon primary carers include a range of occupational difficulties including disengagement and deprivation whilst caring for a person who is dying.
- Being disengaged from previously valued occupations is detrimental to the health and well-being of carers.
- Carers experience a sense of disempowerment during the palliative period when dealing with palliative care services.

Abstract

This paper explores the daily experiences and occupational needs of family carers of people who were dying, with particular reference to their daily routines and ability to undertake other varied activities during the period of care. The impact of the caring experience on these occupations was then examined to determine how, and if, these occupational needs were addressed in the community using potential and available services. An exploratory approach using grounded theory was employed to examine these experiences. Participants were recruited from metropolitan ($n = 10$) and rural ($n = 4$) locations across Western Australia between February and June 2009, using a purposive sampling method. A semi-structured interview guide was developed following consultation with the literature, expert opinion and piloting. Interviews were conducted in participants' homes and questions were asked about their experiences as a carer including routines, engagement in usual activities and the impact of the caring role on their daily life during and after the period of care. Each interview was transcribed verbatim and analysed to determine potential themes. Two important themes were identified: (1) Carers experienced disengagement and deprivation from their usual occupations during and after the period of care; and (2) Participants described significant disempowerment in their role as carer. Carers are 'doubly disadvantaged' as a result of their caring role; they are unable to participate in their usual occupations and they are not recognised for their contributions as carers. Carers experienced disengagement and deprivation from their usual occupations, contributing to physical, psychological and emotional difficulties and this may result in long term consequences for health and well-being. In addition, the current services and support available for carers in the community are deemed inadequate; placing further stress on a health care system which needs to cope with increasing demands as a result of the ageing population in Australia.

Keywords: carers, end of life care, health, occupation, qualitative research

Introduction

Family carers provide a range of unpaid services and offer emotional, social, physical and financial support. 'Caregiver burden' and 'unmet needs' are especially significant for carers of people who are dying (Ferrario *et al.* 2004, Mehta *et al.* 2009, McNamara & Rosenwax 2010). These carers may commit to extended periods of time, often on a full-time basis, and some may have inad-

equate assistance from health services and other formal or informal supports. Carers are impacted by a range of issues including changes in their physical, psychological and emotional health as well as financial, social and life-style adjustments.

In addition, the characteristics of the care-giving situation will mediate the experience: the dying person's disease type and the associated management of symptoms and pain; the intensity of care (full time, part time, occa-

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sional) and the length of time involved with the care; as well as the carers' own experience, coping skills and personal characteristics. Other factors include being prepared for the role, provision of adequate guidance and support, maintenance of other relationships and managing grief and loss (McIlfatrick 2006, Gysels & Higginson 2009, Hughes 2009, Mehta *et al.* 2009).

In contrast, there are many positive aspects associated with caring including family cohesiveness, improved self-efficacy and care-giver personal growth (Mangan *et al.* 2003, Hoppes 2005, Hudson *et al.* 2006, Morasso *et al.* 2008, Wong *et al.* 2009). A study by Hudson (2004) reported the additional benefits of caring for a person who was dying included stronger relationships, being together at home and learning more about how strong they were in managing the situation.

People who are dying and their carers experience the last months of life in a number of different ways. Understanding this variation may lead to a deeper appreciation of what is required to achieve a 'good death' (McNamara 2004). Many health practitioners agree that a 'palliative' approach should be adopted during the period leading up to death to achieve the best possible outcome for those who are dying and their carers (Steinhauser *et al.* 2000, Haras 2008). There is considerable variation in the length of time that people dying of cancer and other chronic conditions experience deteriorating health, but they will usually experience a range of complex symptoms.

The World Health Organisation (2006, p. 1) suggested 'Palliative care improves the quality of life of patients and families who face life threatening illness by providing pain and symptom relief, spiritual and psychological support from diagnosis to the end of life and bereavement'. Although many deaths in developed countries occur in hospital, place of death may also include the family home (McNamara & Rosenwax 2007). The contribution made by unpaid carers in the lead up to a death at home is often underestimated and has been identified as a priority for international research (Stajduhar *et al.* 2010).

While current research in palliative care includes a focus on the physical, psychological and emotional demands of being a carer (Jo *et al.* 2007, Zapart *et al.* 2007, Morasso *et al.* 2008, Thomas *et al.* 2010), there are few studies that explore the potential occupational issues of carers. Proot *et al.* (2003) reported difficulties, including activity restrictions, social deprivation and occupational disruption. Hasselkus & Murray (2007) stated that carers were often viewed as lacking meaningful roles, habits and activities in their lives that were unrelated to their caring responsibilities. Increased caregiving burden was found to be correlated to a decrease in participation in meaningful occupations and activities among carers of people with Alzheimer's disease (Hwang *et al.*

(2009). None of these studies explored the implications for carers when their usual occupations had been disrupted.

The term 'occupation' is often used to refer to a person's employment or work role, however for the purpose of this research 'the term is used more broadly'. Occupational theory has been used to provide an explicit description of the term. The word 'occupations' arguably refers to '[G]roups of activities and tasks of everyday life, named, organised and given value and meaning by individuals and cultures. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity)' (Law *et al.* 2002, p. 34).

In this context, 'caring' could be considered an occupation. The intensive and sometimes unexpected demand of caring may render the caring role as unbalanced occupationally. In such physically and emotionally challenging situations, carers may become overwhelmed by the demands of the caring role and forego other interests to the detriment of their own health and well-being. Little is known about the effects of caring on carers' occupation and health, let alone services and supports that may be needed to assist carers in the community. This is an important concern given a growing body of evidence suggests that engagement in meaningful occupation contributes significantly to one's health and well-being (Whiteford 1997, 2000, 2010, Molineux 2004, Polatajko *et al.* 2007b, Christiansen & Baum 2010).

Aims

This study explored the daily experiences and occupational needs of family carers of people who were dying, with particular reference to the carers' daily routines and their ability to undertake the occupations of self-care, leisure, work and other productive occupations during the period of care. The impact of the caring experience on these occupations was then examined to determine how, and if, these occupational needs were addressed in the community using available services.

Methods

In-depth examination of the occupational needs of carers was based upon the carers' own thoughts as they were expressed in interviews. Interpretations of these experiences and their subjective meanings provided rich information with which to answer the research questions (Denzin 1998, Liamputtong & Ezzy 1999, Walker & Myrick 2006, Liamputtong 2010). A qualitative approach was selected as the preferred method as it provides the

researcher with the opportunity to listen to and observe participants in their usual environments in order to understand the actions, interactions and social processes and make sense of the information provided (Annells 1997a, Strauss & Corbin 1998, Charmaz 2000, Corbin & Strauss 2008, Skeat 2010).

Data were collected through a semi-structured interview with questions based on expert opinion and the literature. Refinement occurred following a pilot with one participant (Patton 2002, Hansen 2006, Serry & Liamputtong 2010). Questions focussed on the carers' experiences with specific questions which focussed on the day to day issues that arose during and following the death of the family member, including those related to the usual occupations of the carer. Each interview, of approximately 60–90 minutes, was conducted face to face by the first author, recorded and transcribed verbatim. Participant details were de-identified using a numeric code. A diary was completed following each interview whereby the researcher documented notes, questions, observations and issues that arose from the interview, assisting in the analysis and development of themes. Demographic data were collected from each carer, including gender and age, relationship to the person who was dying and period of time caring/intensity of caring. Carer provided details on the gender, age and primary diagnosis of the person for who care was provided (Table 1).

Participants

A purposive sampling method was used to identify carers living in metropolitan ($n = 10$) and rural Western Australia ($n = 4$). Advertisements were placed in publications and newsletters in health services, non-government organisations, volunteer agencies and support services. Participants were included if they had cared for an individual who had died in the preceding 2 years of a condition considered amenable to palliative care (Fitzsimmons *et al.* 2007, Gott *et al.* 2008, McNamara & Rosenwax 2010). Participants were excluded if they had experienced bereavement within the previous 4 months. Participants were provided with information outlining the study including purpose, requirements, risks and benefits as well as access to follow-up counselling if required. Participants were provided with opportunity to discuss the study prior to providing informed written consent. Ethical approval was obtained from the Human Research Ethics Committee of Curtin University.

Data analysis

Analysis was ongoing and utilised an inductive approach thereby developing theory from the data

(Denzin 1998). Grounded theory was selected as the preferred method as it requires the researcher to collect and analyse information systematically and develop interpretations which direct further data collection and to assist in developing categories or 'themes' (Charmaz 2000, Corbin & Strauss 2008, Skeat 2010). The researcher listened to the digital recording of each interview and read the transcripts line by line, several times. Content was then listed, grouped and categorised using the constant comparative method to formulate codes and develop categories (Annells 1997b, Strauss & Corbin 1998, Polgar & Thomas 2000, Whalley Hammell 2004).

Trustworthiness

Issues of credibility and confirmability of the research design and analysis were addressed through a process of peer review (Kvale 1996, Liamputtong & Ezzy 1999). Divergent cases were identified and an example of these is included in the findings. Following the initial development of themes from the interview transcripts and diaries, each participant was provided with a summary of the themes and asked for responses/agreement/disagreement and opportunity to add additional information to the results. Themes were further developed to include this feedback.

Methodological limitations

One limitation of the study might be the small sample size, yet saturation of the themes was achieved (Liamputtong 2010). There were also difficulties recruiting carers living in rural communities; however, the themes arising from this sample were consistent with the overall themes of the research. All but one participant was female, so comparison related to gender differences was not possible.

Findings

Two distinct themes emerged from the interviews with the carers. First, they experienced disengagement from their usual daily habits and routines including employment, social activities, hobbies and interests. While this disengagement might be unavoidable as a result of their commitment to caring, it is also a form of occupational deprivation as they were deprived of many occupations that were personally meaningful and contributed to their identity and life satisfaction. Second, carers described significant disempowerment in dealing with, and engaging, health professionals and health services such as specialist palliative care services. Carers felt they were not recognised as 'key parties' in the process

S. Keesing *et al.***Table 1** Characteristics of participants

Participant	Primary diagnosis	Age	Gender	Age of carer	Gender of carer	Relationship	Period of time as carer (months)	Intensity	Bereaved/non-bereaved	Sole/shared/caring
C3	Breast cancer	62	Female	56	Male	Husband	12	Full time	Bereaved	Shared
C4	Bowel cancer	42	Male	71	Female	Mother	6	Full time	Bereaved	Sole
C7	Bowel cancer	63	Male	61	Female	Wife	6	Full time	Bereaved	Sole
C10	Melanoma	70	Male	63	Female	Wife	7	Full time	Bereaved	Sole
C2	Oesophageal cancer	57	Male	51	Female	Partner	8	Full time	Bereaved	Sole
C6	Oesophageal cancer	51	Male	50	Female	Sister	12	Occasional	Bereaved	Sole
C8	Alzheimer's Disease	88	Male	68	Female	Wife	12+	Full time	Bereaved	Sole
C13	Alzheimer's Disease	86	Male	46	Female	Daughter	12+	Part time	Bereaved	Shared
C5	Chronic cardiac disease	76	Male	55	Female	Wife	12+	Full time	Bereaved	Sole
C9	Chronic cardiac disease	71	Male	70	Female	Wife	12+	Full time	Bereaved	Sole
C12	Chronic cardiac disease	76	Female	45	Female	Daughter	12+	Part time	Bereaved	Sole
C14	Chronic renal disease	50	Female	25	Female	Daughter	12+	Occasional	Bereaved	Sole
C1	COPD	91	Male	44	Female	Daughter	9	Part time	Bereaved	Shared
C11	Multiple sclerosis	64	Male	64	Female	Wife	12+	Full time	Bereaved	Sole

and they believed they were deprived of agency and advocacy in the carer role.

Ongoing disengagement and resultant occupational deprivation

Carers described being disengaged from their usual daily activities not just during the period of care but sometimes after the death of the family member and on occasion long after the 'typical' bereavement period. Some carers reported having limited participation in paid employment, physical activities, leisure and interest groups and other meaningful pastimes. Caring for a person who is dying meant a constant tension between the person's role as carer and other satisfying roles (including worker, friend, family member or team member). People who are dying have varying unpredictable physical, psychological and emotional needs. Accordingly, carers were in constant demand and opportunities for forward planning and participation in desired occupations such as work, hobbies, going out for a meal, to a movie or shopping were generally not available due to the demands of the caring role.

Most participants reported that caring was always the priority and there was no time or energy to undertake other activities. Many participants were sole carers, giving up paid employment and compromising other activities in order to be available for the person who was dying. These issues were evident during two distinct periods; the palliative phase where the dying person was quickly deteriorating when intense caring was required and during the bereavement period. During the palliative phase carers were unable to take time for themselves and they were under constant pressure to ensure that everything was working well.

I found it hard, I just felt like it was impossible to have my needs met in that situation at all. And I did everything, I had my own career at six in the morning, five in the morning, four in the morning, whatever to try and put my stuff together and still do community stuff which I did a lot of and right now I don't know what I'm doing. (Nellie)

The majority of carers had few supports and often felt that they were responsible for the entire care and comfort of the person they cared for. This meant they had limited choices about their own daily routines; they did not get enough sleep, were exhausted all the time, were unable to carry out their desired occupations and felt guilty when they were able to do something for themselves. Madeleine describes some common difficulties:

You know they totally forget that the carer's probably not getting much sleep. They're having to rush around; they don't get a chance to just go wandering through the shops looking at nothing. They don't get a chance to sit on the dunny and take five minutes and you're on edge all the time. You're constantly listening in; you're constantly watching ...people don't think to ask 'how are you?' So carers have to almost be educated to speak up and say I need help. You know I need a break.

Continued disengagement was evident with carers recognising that the constant demands of caring for the dying person were enormous. Participants described how they struggled to find time and energy to complete tasks that they previously valued and enjoyed- a simple outing or an opportunity to have a break from the emotional demands as a carer was very difficult to justify.

The longer it goes on...you start to struggle a bit because you never get any break from it you know. To have lunch with your daughter or to do something normal that's not

caring, they don't want it every week, but you know that would have been really helpful. (Sarah)

Carers were asked about the changes in their relationship with the dying person from being a husband/wife, daughter/sister or partner to being responsible for the personal care of the person and the other daily tasks of caring. The carer's sense of identity was compromised and often they were the only means of support for the person who was dying. Changes to the dying person's physical capacity, increasing symptoms and pain also meant difficulties maintaining intimate relationships. As a result, carers reported not knowing how to manage loneliness and loss of companionship. They had often given up previous activities, friendships and contacts in order to take up the caring role and had few people to share their personal thoughts with. During and following bereavement most carers reported difficulties returning to their previous routines and stated that the hardest part of being a carer is what happens afterwards. They experienced further disengagement which led to isolation, low motivation and feelings of poor self-worth. The loss of the caring role also left them without habits and routines which became difficult to re-establish.

I call them whacky days, you know I cry or I get upset and I just stay by myself or I sleep. People would try to encourage me, that's the best thing you should be doing is you get straight back into bowls, you should get straight back into everything and I think, excuse me I will in my ability, when I've got to the ability to do that ... (Pam)

Disempowered in the role of carer

Carers reported many difficulties in being recognised as a 'key party' within the system of services for people diagnosed with a terminal illness. They experienced disempowerment caused by a variety of issues relating to the provision of services and support. Many carers expressed feelings of being 'doubly deprived'; not only were they unable to engage in occupations of their own choosing, they were also not recognised as a key contributor to the care and support of the person who was dying. Many believed their role as carer was undervalued by the health services and professionals.

Many carers were not provided with adequate information about potential services that were available to assist them, including home-based hospice services, counselling, respite or nursing care. Carers identified that services for people with palliative needs seemed to be reactive, not proactive and that it would have been helpful to have a plan in place for care. Most agreed that palliative care should be raised with the dying person early in order for them to be fully informed and know

what to expect for the future. This meant that the needs of carers would be recognised and respected and services would be available when needed. This approach represents a cultural change required of both health professionals and the general community. Being fully informed about death and making plans to enable a 'good death' has often been interpreted as simply 'giving up' rather than being fully prepared.

I think they need to know what's ahead for them. I think the specialist has to say that the outlook is grim, so that perhaps then you can make plans while they're alert enough to make them. I think they should be introduced to palliative care before they perhaps even need it, that they should have the nurse visit who could just say look we'll do the admission now and then you can call us in when you need it sort of thing and say what they have to offer. (Lisa)

Many carers reported that communication between the key parties (including carer and patient, doctor, other health professionals) was inconsistent and this led to frustration and the opportunity for referral to palliative care was sometimes missed. Carers were often placed in roles of advocacy and mediation yet they felt they were not considered as an integral part of the care-giving team. The failure of health professionals to consult and consider the opinions of the person who was dying and their carer left carers feeling frustrated and helpless, trying to balance the needs and wants of the person they cared for whilst also considering the advice provided from the 'experts'.

That was a really interesting experience as far as having to advocate for dad and tread the line between the respect that he had for his GP and what we really knew..... So he very much wanted to be in control of his faculties... and alert and that was really compromised by the medication. We wanted to advocate for dad and that was difficult, feeding that information to the doctor to say look the Tem-azepam's knocked him out, we think it's really not helping. (Karen)

There were consistent reports of perceived lack of coordination of services and this was evident for hospital discharge and follow up in the home.

Well as I said ...there's not enough coordination... I didn't have any time before I'd get rushed... with ambulances to the hospitals and I just ended up all over the place and then somewhere else.... There was no coordination. So it's not perfect out there, it could be improved enormously and there needs to be a lot more education I think about carers and making sure that their lives are also sustainable and where they're currently at. (Raelene)

However, one rural carer reported the value of a local support service for people with cancer. This carer was

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able to utilise local resources including hospice, home-based nursing care, financial assistance and a support group for carers. Contact with the service was maintained long after the death of her partner and she continued to attend the support group, which she reported to be a source of great encouragement and empowerment. Similarly, another carer reported that being able to draw upon her own personal and social resources including family and friends was seen as invaluable. It seemed that being able to ask for assistance and take 'time-out' was considered as extremely important to this carer.

Some carers stated that although respite was available, there were mixed feelings about asking for help. They worried that others would look upon this as an indication that they were not coping, when in fact they valued this option because it meant they could take some time out to recharge in order to continue this demanding role and to regain some sense of their own occupational integrity.

Now I know the concern is to a certain degree that they don't want to overload the carer, but I've heard of people who've gone a couple of months and I happen to have gotten talking to them and say you know have you done this... No I didn't know about that. They don't know that they can contact the local council and find out what services are available. (Madeleine)

Many carers felt there was a lack of respect for their opinions (and that of the person who was dying) regarding chosen place for death. These choices were sometimes not respected and services were not engaged in a timely fashion. Carers expressed a sense of helplessness in the decision-making process and this served to undermine the satisfaction of being able to carry out the needs and wishes of the person for whom they cared. Gary describes his frustrations when trying to arrange his wife's discharge from hospital to the family home:

She lost three quality weeks at home... That was very important and that was taken away from her, very unnecessary and that's really my main message and it needs to change you know. ...there are some people that couldn't cope but how do they know whether I can cope or not until you actually do it... No control over anything, being directed as to what to do. (Gary)

Discussion

Disengagement from one's usual tasks was a repetitive theme for the carers due, in part, to the ongoing nature and intensity of caring. Disengagement from daily routines, lack of choice and new roles may contribute to occupational deprivation (Whiteford 2000, Townsend & Wilcock 2004). Occupational deprivation is defined as

'[A] state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the immediate control of the individual' (Whiteford 2000, p. 201). Occupational deprivation has the potential to impact a person's sense of well-being, contribute to social isolation and ongoing physical and mental health issues (Polatajko *et al.* 2007a). Some studies explore the impact of occupational deprivation on particular groups including refugees and prisoners (Molineux & Whiteford 1999, Whiteford 2005). This study suggests a variety of long term effects as a result of this deprivation including lack of access to employment, reduced community participation, and personal and social exclusion.

Occupational deprivation has been found to contribute to physical and psychological health concerns for carers (Ferrario *et al.* 2004, Funk *et al.* 2009). These concerns include depression, anxiety, metabolic disturbances, sleep difficulties, reduced fitness, substance abuse and burnout. The family carers in this study reported similar issues and these problems continued long after the conclusion of the caring period, indicating the intensity of the experience and continued difficulties returning to previous roles and activities. Many were unable to return to paid employment, had trouble resuming friendships, did not know how to re-engage with their previous leisure activities and hobbies and struggled to identify tasks that provided them with a sense of satisfaction. These issues have the potential to create further problems for carers including financial concerns, social isolation and continued disengagement from family, friends and other supports.

Carers reported little assistance was available to overcome the difficulties caused by disengagement and disempowerment. This 'double deprivation' may be due, in part, to the current model of service delivery which focuses on the needs of the person who is dying and often neglects to consider the needs of the carer and other family members (McNamara & Rosenwax 2010). Few carers reported contact with allied health professionals such as social workers, occupational therapists, counsellors or psychologists. The literature provides many examples of the value of these resources (Funk *et al.* 2009, Hasson *et al.* 2010, Kasven-Gonzalez *et al.* 2010), yet many of the carers interviewed were not aware of these professionals or how they may have assisted with their occupational difficulties. Palliative Care Australia states that 'Carers must be recognised as both a key partner in the care team and a recipient of care in accordance with the palliative care service provision model' (Palliative Care Australia, 2010, p. 1) yet in Western Australia many individuals and their carers are not receiving these services (Auon *et al.* 2006, Kristjanson *et al.* 2006, McNamara & Rosenwax 2010).

Implications for health and social supports

Recognition and provision of services targeted at carers during care as well as the bereavement period may assist in achieving previous levels of occupational engagement. Future models of service delivery should be developed in consultation with carers to take into account occupational, social and emotional needs. This approach could utilise existing services (including health, social, vocational, recreational and community resources) to build on the carers' personal supports and networks to enable them to continue or re-engage in valued occupations such as paid employment, sport and hobbies, family and social functions and any other activities that provide them with a sense of identity and purpose.

Without a concentrated focus on the prevention of potential health issues it may be that carers themselves are more likely to become consumers of health services creating a cycle of unsatisfactory outcomes for all stakeholders. Stewart (2003) predicted that in the future, health services will be unable to manage the demands of increasing numbers of consumers of palliative care. An already extended health care system will need to cope with even greater numbers of consumers and the resultant difficulties for carers.

The day to day experiences of carers of people who are dying are impacted by a wide range of factors that are often underestimated by health and social care systems. The carers interviewed in this study reported substantial difficulties maintaining their usual daily occupations. The current health services in Western Australia do not appear to adequately consider the needs of the carer as integral to the overall success of these services. The focus of this paper has been to highlight the disengagement, deprivation and disempowerment of this important group of carers. While some strategies for change have been suggested, further research is needed in order to determine the most effective ways of supporting the needs of people who care for family members who are dying.

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5. PUBLICATION TWO

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Research Article

Is occupation missing from occupational therapy in palliative care?

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Background/aim: The role of occupational therapists in palliative care is largely undocumented in Western Australia (WA). Little is known about the services occupational therapists provide or the needs of people who are dying and their carers in relation to these services. The aims of this study were as follows. First, to determine the number of occupational therapists employed and the range of services they provide in palliative care in WA. Second, with particular reference to self care, leisure, productive roles and occupations, to explore the daily experiences of people who were dying as well as their primary carers to determine the services that might be offered by occupational therapy to this population.

Methods: Semi-structured interviews were used to gather information from carers ($n = 10$ metro, $n = 4$ rural) and occupational therapists ($n = 13$ metro, $n = 5$ rural). Data were analysed qualitatively using grounded theory to develop categories. Themes were defined using the constant comparison method.

Results: Four themes emerged that impacted people who were dying and their carers. These were; ongoing disengagement from usual activities with resultant occupational deprivation; disempowerment of both people who are dying and their carers within palliative care services; 'occupation' not being addressed adequately in palliative care and occupational therapists experience frustration with limited opportunities to contribute to the care of people who are dying.

Conclusions: This paper highlights gaps in service provision in WA to people who are dying and their carers. It provides direction for occupational therapists to offer an occupation-focussed approach to the care of this vulnerable group.

KEY WORDS carers, occupation, palliative care, qualitative research.

Introduction

Recently occupational therapists have been changing practices as a result of re-engagement with the profession's core philosophy – occupation. This is a consequence of an increasing recognition and application of the 'emerging paradigm' of occupation and a shift away from the mechanistic approach of the mid to late 20th century (Kielhofner, 2008; Wilcock, 1999). In Australia there are varying levels of acceptance of this paradigm shift and corresponding changes to practice. Some have found this shift difficult; due in part to the environment and practice context, models of health and social care and lack of scientific evidence for this approach (Blanche & Henny-Kohler, 2000; French, 2001). Other clinicians, researchers and academics have embraced 'occupation' as the core of occupational therapy practice and advocated for a shared philosophy, professional identity, a focus on the occupational nature of humans and use of 'occupation as means and occupation as ends' (Gray, 1998, p. 364). By embracing these shared beliefs, they consider the profession will maintain valued status in future practice (Fortune, 2000).

With this paradigm shift the profession has opportunities to forge new and innovative roles in primary and preventative health care, community rehabilitation, health promotion, emergency medicine, hospital in the home and other areas of practice that offer enhanced roles for occupational therapists. One such developing role for occupational therapists is the care of people who are dying and to that of their families (Pizzi, 2010). Occupational therapists have the knowledge and competencies to assist people to participate in their chosen occupations, within the limits of their illness and to their

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satisfaction, by examining the symptoms caused by illness or disease while determining barriers to self care, leisure and productive roles (Bye, 1998; Cooper, 2006; Ewer-Smith & Patterson, 2002; Pearson & Todd, 2007).

Yet, in the state of Western Australia (WA), little is known about the number of occupational therapists working in palliative care, including the awareness of existing occupational therapy services; types of occupational therapy services provided; potential benefit from these services; and if the role of occupational therapists in the multidisciplinary team is understood. Central to the provision of these services is a palliative approach, providing the best method of care for people who are dying, their carers and their families (World Health Organisation, 2006). The palliative approach relies significantly on carers to provide a range of unpaid services to assist with pain and other symptoms, personal care needs, occupational needs and a range of emotional considerations, including preparation for death.

Palliative care aims to assist people who are dying to achieve a 'good death'. It may be that engagement in occupations of the individual's choice contributes to the achievement of this (McNamara, Rosenwax, Holman & Nightingale, 2004). Yet there has been limited exploration of the value of occupation during the last months of life. Whalley Hammell (2008) described this concept as 'occupational rights' and referred to the rights of all people to engage in meaningful occupations that contribute to their own wellbeing and that of their communities. People, who are dying, and their carers, should be afforded the same rights for occupational engagement and participation as others regardless of the trajectory of illness, their living environment or prognosis.

Occupational therapists have much to offer people who are dying and to their carers (Cooper, 2006). It is necessary for the profession to determine the scope of existing roles for occupational therapists working in palliative care in order to provide appropriate, cost effective and satisfactory services for consumers of these services.

Aims

The aim of the study was to explore the daily experiences and occupational needs of people who were dying and their primary carers during the palliative phase. In addition, the number of occupational therapists working in this field in WA and the range of services provided was also determined.

Methods

The study used mixed methods. Stage 1 consisted of an email survey undertaken over a two-month period in late 2009 to determine the number of occupational therapists providing services to people who were dying in WA. This data was then compared with the total number of occupational therapists working in WA using the most

recent workforce data available (Chief Health Professions Office, 2008). Stage 2 consisted of semi-structured interviews conducted with primary carers and occupational therapists. Carers were asked about the daily routines and occupations of the dying person as well as their own experiences, services they received, the value of these services and recommendations for improved services. The occupational therapists were asked about the provision of services, practice context, opportunities for contact with carers and what modifications would enhance current practice. Prior to stage 2, two pilot interviews informed the data collection; one with a carer and one with an occupational therapist.

Participants

Purposive sampling was used to recruit participants. Carers (as proxies for people who had died) were recruited using health service newsletters, support groups, volunteer agency flyers and community newspapers. Fourteen bereaving primary carers were recruited (Table 1). Two participants were excluded from the study as they were more likely to have recall bias having been bereaved more than two years. Eighteen occupational therapists were recruited using professional networks (Table 2). All participants were provided with an information sheet outlining details of the study, including access to counselling if required. Participants were de-identified using a numeric code. Written consent was obtained prior to commencement of interviews. Ethical approval was obtained from the Human Research Ethics Committees of Curtin University, Department of Health WA and Joondalup Health Campus.

Data Analyses

Data were analysed using grounded theory which requires the researcher to observe, think and reflect on the information in order to develop content into 'codes' or categories used to explain the information (Denzin & Lincoln, 2000; Skeat, 2010). Each interview, of approximately 60–90 minutes, was transcribed verbatim. The transcript was read several times before listing and categorising the content. The constant comparative method was employed to refine developing themes (Liamputong, 2010) and achieve saturation of the data. Trustworthiness, including confirmability and credibility of the data analysis, was achieved using a process of peer review thus enabling further development of the themes.

Results

The full-time equivalency (FTE) of occupational therapists working in palliative care in WA in 2009 was 6.15. At that time, there were 1609 registered occupational therapists in WA of which 21.9% were not working as occupational therapists in WA. This suggests that 4.9% of the occupational therapy workforce in WA were working with people who were dying.

TABLE 1: Details of participant carers

Details of deceased family member					Details of primary carer					
Participant	Primary diagnosis	Age (years)	Gender	Received occupational therapy	Relationship	Gender	Period of time as carer (months)	Intensity of caring	Bereaved/non-bereaved	Sole/shared caring
C3	Breast cancer	62	Female	Yes	Husband	Male	12	Full-time	Bereaved	Shared
C4	Bowel cancer	42	Male	No	Mother	Female	6	Full-time	Bereaved	Sole
C7	Bowel cancer	63	Male	No	Wife	Female	6	Full-time	Bereaved	Sole
C10	Melanoma	70	Male	No	Wife	Female	7	Full-time	Bereaved	Sole
C2	Oesophageal cancer	57	Male	No	Partner	Female	8	Full-time	Bereaved	Sole
C6	Oesophageal cancer	51	Male	No	Sister	Female	12	Occasional	Bereaved	Sole
C8	Alzheimer's disease	88	Male	Yes	Wife	Female	12+	Full-time	Bereaved	Sole
C13	Alzheimer's disease	86	Male	Yes	Daughter	Female	12+	Part time	Bereaved	Shared
C5	Chronic cardiac disease	76	Male	Yes	Wife	Female	12+	Full-time	Bereaved	Sole
C9	Chronic cardiac disease	71	Male	Yes	Wife	Female	12+	Full-time	Bereaved	Sole
C12	Chronic cardiac disease	76	Female	Yes	Daughter	Female	12+	Part time	Bereaved	Sole
C14	Chronic renal disease	50	Female	Yes	Daughter	Female	12+	Occasional	Bereaved	Sole
C1	COPD	91	Male	Yes	Daughter	Female	9	Part time	Bereaved	Shared
C11	Multiple sclerosis	64	Male	Yes	Wife	Female	12+	Full-time	Bereaved	Sole

Stage 2 generated four primary themes – two from the interviews with carers and two from interviews with occupational therapists.

Theme 1: Ongoing disengagement with resultant occupational deprivation

Dying people experienced significant disruption, disengagement and subsequent occupational deprivation as their usual roles and activities were eroded and death became eminent. Substantial and ongoing readjustment was required to enable them to continue participating in valued occupations such as personal care, recreational pursuits, productive occupations and community activities. However, the focus of health services centred on medical issues such as pain and symptom control with very little consideration given to any other difficulties the person might have been experiencing. Few individuals were aware of the potential services occupational therapists could provide. Those who were referred thought occupational therapists were only involved to 'set up' the bathroom and toilet, ensure access into the home and

provide aids and equipment to assist the dying person. Most carers described the daily personal care routine as exhausting for the person they cared for and assistance would have been welcomed. Additionally, it was a constant struggle to balance care with providing just enough assistance to enable the dying person to preserve dignity, maintain a sense of independence and preserve energy for other desired occupations that they planned to complete each day. Being restricted to the home was also viewed as extremely detrimental for people who were dying.

It meant that he couldn't go and drive to Fremantle and go fishing...You know he was an adventurer...So to be confined to his home was difficult. (Raelene – carer)

The self care thing was really hard...to watch him have to accept help because that was part of his dignity... That's the feeling (he had) because I can't do anything for myself, I'm hopeless. (Karen – carer)

TABLE 2: Details of participant occupational therapists (OTs)

Participant	Service type	Setting	Position	Years experience	Gender	Proportion of caseload considered as palliative (FTE)
OT 1	Aged care facility	Metropolitan	Team Leader	5	Female	Not able to be determined
OT 2	Hospital	Metropolitan	Senior OT	8	Female	0.5
OT 3	Community	Metropolitan	OT	1	Female	Not able to be determined
OT 4	Hospital	Metropolitan	Senior OT	25	Female	0.2
OT 5	Aged care facility	Metropolitan	Senior OT	10	Female	Not able to be determined
OT 6	Hospital	Metropolitan	Senior OT	5	Female	0.15
OT 7	Hospital	Rural	Senior OT	18	Female	0.05
OT 8	Hospital	Rural	Senior OT	16	Female	0.05
OT 9	Hospital	Rural	Senior OT	24	Male	0.05
OT 10	Hospital	Rural	Senior OT	29	Female	0.2
OT 11	Community	Metropolitan	Allied Health leader	13	Female	Not able to be determined
OT 12	Hospital	Rural	OT	1	Female	0.1
OT 13	Hospital	Metropolitan	Senior OT	10	Female	1.0
OT 14	Hospital	Metropolitan	Senior OT	8	Female	0.2
OT 15	Hospital	Metropolitan	OT in Charge	38	Female	0.5
OT 16	Hospital	Metropolitan	OT in Charge	30	Female	0.2
OT 17	Hospital	Metropolitan	OT in Charge	18	Female	1.0
OT 18	Hospital	Metropolitan	OT in Charge	31	Female	0.2

FTE, full-time equivalency.

Carers reported the dying person's need to network with people in similar situations, particularly as the illness often meant isolation from others experiencing similar issues. Yet there were few opportunities to make contact with others in order to share experiences. Lisa describes her husband's experiences during a short hospitalisation.

I think it might have been useful if he had been put in touch with a peer support group ...when he was admitted (to hospital) he'd actually seemed to find it quite helpful to talk to the men in the same ward that go through similar things. So I think if he had, somehow, access to these kinds of services at the beginning that might have been quite good for him. I think he felt he couldn't go to the family. (Lisa - carer)

For the dying person, disruptions in the daily routine, valued occupations and social isolation meant further losses of previous roles, including that of employee, partner, parent and friend; resulting in changes to the persons' sense of identity. Engaging in productive occupations, friendships, intimate relationships and family

were viewed as extremely important, so these changes affected many people. Relinquishing these roles often lead to feelings of inadequacy and dependence and were difficult for the person to accept. One carer describes how the loss of driving affected her husband.

Driving was another big loss. He was a 'blokey' bloke, he liked to get in his car and he loved racing cars and things like that, always watched the racing so that was very difficult, where suddenly I'm the driver.... So I guess my thrust all the time was, despite the level of disability to ensure his independence. (Nellie - carer)

Carers themselves provided many insights into how their lives changed as a result of the caring role, impacting them in varying ways according to need and context. Becoming a carer was a difficult adjustment; they were in constant demand and had an enormous sense of responsibility; often managing care without support from formal or informal services. Many carers were either not aware of palliative care services or these services were involved too late in the disease process. Most carers were

thrust into the caring role with little preparation and were required to carry out a variety of tasks for the person they cared for, including physical assistance for self care, transport, care of the home, medication management, financial and emotional support. Carers were often unable to continue in their desired occupations; giving up employment to care and unable to find time to enjoy their usual hobbies and interests. Caring was a priority, making it hard to balance the demands of the caring role with their own needs. This occupational disengagement was reported during and after the period of care.

And I found it hard, I just felt like it was impossible to have my needs met in that situation at all. And I did everything; I had my own career at six in the morning, five in the morning, four in the morning, whatever to try and put my stuff together and still do community stuff which I did a lot of and right now I don't know what I'm doing. (Nellie – carer)

Carers felt guilty asking for assistance yet felt exhausted due to lack of sleep and fatigue. They described overwhelming loneliness, isolation and did not know how to seek assistance for these difficulties; either before or after the death occurred. Even when services were accessed, little consideration was given to their own occupational needs.

Theme 2: Disempowered within the palliative care system

Carers described the experiences of dealing with health and medical services used by the person who was dying as disempowering. They cited a lack of communication with, and co-ordination between, services. There was little recognition of the dying person, or their family, as central to decision making in the continuum of care. Carers were often relied upon as advocates or mediators for the person who was dying yet their opinions or choices were not respected. Many carers reported having to deal with inconsistencies between the various services; especially when planning for discharge from hospital. As an example, Gary's wife desperately wanted to return home for the last weeks of life but this request was unsupported by the health-care team, resulting in an extended hospital stay. He describes his frustrations as follows:

So you're basically going to have no control. Now she was a highly educated woman, she found that very difficult...Well I just think it's a disgrace to the system because they didn't listen or talk to me properly, they didn't respect Jane's wishes properly. (Gary – carer)

All carers felt that it was important to engage palliative care services early with due consideration given to a planned approach to death. This early engagement rarely

occurred, let alone the planned approach. More often, carers described reaching a crisis point – with hospital admission viewed as the only solution; the pattern of disempowerment continuing through to the ultimate death.

Theme 3: Occupation is not addressed adequately in palliative care

Occupational therapists highlighted a range of issues about working in palliative care. They perceived their role to be 'equipment provider' as referrals were limited to the provision of equipment or home modifications. Coupled with a focus on discharge planning, occupational therapists viewed their role as misunderstood, under resourced and misinterpreted by other health professionals, people who were dying, their carers and the wider community. Referral for occupational therapy in palliative care services seemed reactive and introduced too late; often just one contact was made and this was usually at a point of crisis, when only equipment and discharge planning was requested. The majority of occupational therapy palliative caseloads was part time and required juggling several caseloads with varying success. The occupational therapists felt overwhelmed when asked about their capacity to provide additional services that assisted both the dying person and their carer.

The OT service is very...reactive, just discharge planning, crisis management... rather than going in there and offering stuff on fatigue management, pain management, anxiety management, relaxation. Not doing a lot of that at the moment because there just isn't the capacity to do it. (Jenny – occupational therapist)

While occupational therapists recognised that occupation should always be central to practice, many did not know how to ensure this occurred. As their role was historically 'equipment provider' or 'discharge planner' and referrals were always for these services, they felt unable to change this perception within the team or change the way services were provided. Christie expressed her frustrations with her current role:

Often what matters most to people isn't about getting into the shower or getting on and off the toilet, it's about being able to paint for those last few months of life. It's about being able to communicate with their loved ones. It's about being able to get outside and go to the beach. It's those types of things that medical models just block ...and they're so caught up on safety and protection and I don't think OTs are as caught up on that and it would be so great if we had the time and were brought in to do that role. (Christie – occupational therapist)

The majority of occupational therapy participants were hospital based and it was viewed as being extremely difficult to provide occupation-based services in the hos-

pital setting. They stated it was difficult to follow-up after discharge as there were no occupational therapists employed to specifically provide community-based care to people with palliative needs. The few occupational therapists who were not employed by hospitals were private providers and thus impacted by organisational issues, funding limitations and time constraints. Participants cited a lack of time and pressure to discharge people as very frustrating as it did not allow opportunities to focus on the persons' desired occupations.

The pressure is that you've got fifteen patients on your team you've got to get them out within two days, you haven't got a lot of time to be counselling or do what OTs should be doing. It's about making them feel engaged in their life and making them think about occupation or if there's something they want to do they can. How to feel useful or how to prepare for death or how to plan or what to be remembered for. (Anna – occupational therapist)

Participant occupational therapists concurred with the carers' frustrations, stating that they had limited opportunities to focus on any other concerns for the dying person, due to a lack of time and resources, so other occupational issues including leisure and productivity were not addressed. They recognised that carers also had significant occupational needs but their services were limited by time and resource constraints. Their role with carers was confined to advice regarding equipment and manual handling problems, occupational issues were not considered at all.

We know we can do so much more and we need to be looking at the whole individual... and we don't have the resources to do it so we do the things that will make the difference at the time but I think we're...undervalued, we just can't do it. (Bev – occupational therapist)

Theme 4: Occupational therapists experience frustration with limited opportunities to contribute to the care of people who are dying

Occupational therapists reported that the current system of care does not encourage early and consistent referral for palliative care services, often resulting in poor co-ordination between primary care services, inpatient and outpatient services, community providers, the dying person and their primary carer. However, it was acknowledged, that the contributory factors were considered to be complex. Limited funding and resources, lack of recognition that people with non-malignant illnesses could also benefit from palliative care, unpredictability of terminal disease and the benefits of a multi disciplinary approach were just some issues that respondents raised.

I'm quite often surprised at how long they've been seeing someone who's quite unwell before they come across our books and they're probably the people that need to be aware of engaging their patients and maybe they don't think that the patients are ready to take things on board. But I think they often underestimate people and they also perhaps underestimate what people really need. Yes, you do need to expose people to information; you probably need to do it at a time when they're less stressed. (Hannah – occupational therapist)

Additionally, it was felt that the role of occupational therapy in palliative care is misunderstood; dying people, their carers, some health providers and the wider community did not understand the potential range of services that could be provided. This often meant that occupational therapists continued to receive referrals that were largely focussed on the provision of adaptive equipment and environmental modification. Occupational therapists themselves also found it very difficult to challenge these long-held assumptions and felt that working within the medical model was highly restricting.

I think that we can do so much more and we need to be looking at the whole individual...all those sorts of things and we don't have the resources to do it so we do the things that will make the difference at the time but I think we're undervalued. (Cathy – occupational therapist)

Discussion

Disengagement

Carers described an overwhelming sense of disengagement and disempowerment during the palliative period for the dying person and themselves. Whereas a gradual disengagement from one's usual occupations towards the end of life is expected as a result of terminal disease, there appeared to be little support from the existing health and medical services to support or facilitate the person's desire to continue participating in self care, leisure, hobbies or any productive roles. While pain and symptom control were always a priority, it appeared that few resources were available to support the dying person to continue participating in their usual roles and occupations, albeit within their current capacity. It is within the realm of occupational therapy to provide a much needed focus on occupation and participation as part of their role, yet it appears that there is currently a gap between consumer demand and supply of these services.

Studies exploring disengagement from occupation for people such as prisoners and refugees established significant consequences (Molineux & Whiteford, 1999;

Whiteford, 2005). This study found that people who are dying and their carers fit into this same category. Continued difficulties engaging in productive occupations, accessing the local community and personal and social exclusion were all evident for these individuals. Engagement in occupations of one's own choice contributes to health and wellbeing and when this cannot be achieved, the individual may be considered to experience occupational deprivation (Polatajko *et al.*, 2007).

Occupational Deprivation

Whiteford (2000, p. 201) defined occupational deprivation as 'a state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the immediate control of the individual'. The consequences of occupational deprivation for people who are dying and their carers may include physical and psychological problems including metabolic disturbances, reduced fitness, sleep difficulties, substance abuse, depression, anxiety and burnout (Ferrario, Cardillo, Vicario, Balzarini & Zotti, 2004; Funk, Allan & Stajduhar, 2009). Several carers interviewed in this study reported some of these issues and many described the period following bereavement as especially challenging as they continued to experience many difficulties returning to activities and roles they previously enjoyed. The value of occupation is clearly underestimated for this group of people and they should be provided with the same opportunities and rights for desired occupations and participation as others.

Occupational therapy workforce issues

Occupational therapists are equipped with the skills to facilitate and enable improved outcomes for people who are dying and their carers. Yet, there was very little evidence that the occupational therapists working in this field do so with a focus on occupation. Participant occupational therapists stated that this may be due to a number of factors; misunderstanding of the role of occupational therapy in palliative care, limitations of the medical model, funding constraints and the absence of occupational therapists employed to work in the community with people who have palliative needs. In addition, many of the occupational therapists felt restricted by the pressures of the current health-care system; pressure to discharge, difficulty meeting the demands of the workload and not knowing how to educate other staff, consumers and the wider community about their potential role in palliative care.

Additionally, the study found that only 6.15 (FTE) occupational therapists are employed to work with people who are dying in WA. While this may be attributed to funding and resource constraints, when compared with the potential number of people in WA who died from conditions amenable to palliative care over a one year period (Rosenwax & McNamara, 2006), this represents a ratio of one occupational therapist per 875 people. Com-

pared with labour force statistics from other countries, this ratio is low. In Canada 8–12% of the available occupational therapy workforce is employed in palliative care (Canadian Association of Occupational Therapists, 2005) whereas in Australia, between 2002 and 2003 (the most recent workforce data available) this was just 1.6% (Australian Institute of Health and Welfare, 2006). The low number of occupational therapists employed in palliative care across Australia may contribute, in part, to the limitations expressed by both groups of participants in this study.

Disempowerment

Carers were overwhelmed by the responsibilities of caring for the person who was dying; they were not aware of existing palliative care services or how these services, including occupational therapists, might be used to assist them. This disempowerment is easily addressed by an improved focus on people who are dying and their carers as 'key stakeholders' in the palliative care continuum. Using a 'person-centred' approach, occupational therapists are able to facilitate this, by providing education, advocacy, problem solving and case management skills as part of their services as well as concentrating on the core philosophy – occupation. These occupational therapists are able to assess and explore an individual's occupational performance during the last year of life in order to provide assistance with tasks and roles that are considered valuable to them in order to achieve a 'good death'. They are integral in providing assistance to carers to meet their own occupational needs during and after the palliative period. Occupational therapists must find suitable ways to influence and inform funding bodies, policy, service providers and other health professionals in order to provide improved services to people who are dying and their carers.

Methodological limitations

There were difficulties recruiting rural and male participants; however, the information obtained from these smaller groups was consistent with the overall themes of the research.

Conclusion

While occupational therapy services for palliative care potentially fit into the emerging paradigm, in WA the majority of these occupational therapy services still fit within the mechanistic paradigm, with some variation due to health-care setting, model of service delivery, organisational and policy considerations, access to specialist services and the experience and skills of individual occupational therapists. The study results indicate that the occupational needs of people at the end of life as well as their carers are currently not being met. Few occupational therapists are employed to provide services in palliative care and even then these services were limited

to equipment provision and discharge planning. Perceived barriers to increased employment of occupational therapists included funding, resource limitations and lack of knowledge about the role of occupational therapists by health professionals, people who are dying, carers and the wider community. Little evidence was provided of any occupation-based practice. Further research is needed to investigate the developing roles for occupational therapists in palliative care and the effectiveness of occupation – focussed practice during the last year of life.

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6. DISCUSSION

6.1 INTRODUCTION

In the 21st century it is expected that occupational therapy will continue to grow and practices will diversify in response to the multitude of factors impacting the world's population. Changes to patterns of disease, the environment and availability of resources are all expected to influence the health, wellness and lifestyles of people living in different communities across the world. The profession's ability to respond to these changes will dictate the areas of OT practice in the future. Research into current and emerging practice areas enables OTs to develop and validate roles in the many areas of service delivery.

This research investigated existing OT services and identified the occupational needs for people who are dying and their primary carers in WA. The research determined that comparatively few OTs are currently employed to provide palliative care services in WA. The study also identified four significant themes following interviews with carers of dying people and OTs currently providing services to this group of consumers. Dying people and carers experienced disengagement from meaningful occupations as well as disempowerment when engaging with service providers. Occupational therapists described frustrations with the lack of opportunity to contribute to services for dying people and their carers and occupational difficulties were not adequately addressed in palliative care.

Discussion will proceed on these research findings specific to the dying person, their primary carer, OTs and their employing organisations, and the influence of current policies and models of care on the delivery of palliative care services. Recommendations for further research are discussed.

6.2 IMPLICATIONS FOR DYING PEOPLE AND THEIR CARERS

DISENGAGEMENT

The carers who participated in this study provided a wealth of information and insight into the daily life of the dying person and their own lives during the palliative period. They reported that it was essential for the dying person to maintain a regular daily routine, contribute to their own personal care tasks, undertake regular hobbies and interests and participate in productive occupations within the limits of their illness and for as long as possible. These occupations assisted the person to experience a sense of personal achievement and well-being, provided social opportunities with their family, friends and local community and contributed towards a 'quality' end of life. While death is always the eventual outcome for a person with a terminal disease, it is the quality of the individual's life during the palliative phase that enables the dying person to have their needs met as well as delivering satisfactory outcomes for the primary carer (Jo, Brazil, Lohfeld, & Willison, 2007; Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003; Randall Curtis, Engelberg, Wenrich, & Au, 2005).

However, pain and symptoms associated with their illness often means that these occupational goals are very difficult to achieve. It seems that services, when engaged, concentrate primarily on medication, pain relief and physical assistance for the personal care of the dying person. Understandably, a focus on pain and symptom management is essential due to the nature of the terminal illness. However, additional support is not offered to enable the dying person to engage in many of their desired and meaningful occupations often resulting in boredom, frustration, reduced occupational performance and disengagement from significant others, usual environments and their local communities.

The primary carers interviewed in this study were impacted by a loss of engagement in their own usual occupations, citing numerous difficulties maintaining and balancing their dual roles as both an individual and that of carer for a person who is dying. Carers are expected to provide intensive and ongoing

care for the dying person, often with little or no assistance, and with little consideration of their personal needs. There are few opportunities or time to enjoy hobbies, interests, maintain paid employment, socialise with friends, take a holiday or get enough sleep. These activities provide routine as well as feelings of increased personal satisfaction. Caring for a person who is dying is a highly complex and demanding task; carers are often required to be available on a twenty four hour per day basis which forces them to relinquish many previous, precious roles and responsibilities. However, several carers also reported little acknowledgement for their significant contribution to the care of the dying person, thus prompting the concept of 'double deprivation'. Not only are carers deprived of their usual roles and contributions as individuals, but also deprived of recognition for the substantial contributions they make to the lives of dying people. This concept of double deprivation is explored in depth, in Chapter Four.

For carers, disengagement and deprivation may also contribute to significant problems with their physical and psychological health including disruption to sleep, changes in metabolism, anxiety, depression, burnout and substance abuse (Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004; Funk, Allan, & Stajduhar, 2009). Participant carers identify some of these difficulties as a result of the demands placed upon them as a carer of a person with palliative needs. In the longer term, carers also reported a range of difficulties returning to their previous occupations following bereavement such as resuming paid and volunteer employment, social and leisure opportunities and sustaining valued friendships. These activities also assist carers to maintain a sense of contribution, self-worth and personal fulfilment.

There is minimal published research available that studies the impact of this occupational disengagement for carers of dying people. However, Hasselkus and Murray (2007), Hwang and colleagues (2009) and Proot et al. (2003) provide supporting evidence of the impact of this phenomenon on carers who provide long term assistance to people with Alzheimer's disease. These carers all experience activity restrictions, social deprivation and a lack of meaningful roles and habits as a result of the caring role. It can be postulated, therefore, that the carers in this study

may also experience similar difficulties as a result of the intensive and unremitting nature of their caring responsibilities.

There are significant consequences for individuals who experience prolonged disengagement from their usual daily activities and roles and this may contribute to further difficulties including occupational deprivation. The effects of occupational deprivation on other (marginalised) groups of people have been studied elsewhere. The findings include a negative impact on ones' sense of well-being, as well as physical and mental health difficulties and reduced community participation (Stadnyk, Townsend, & Wilcock, 2010; Thibeault, 2002). There are various contributory factors to explain these findings and the personal experience of occupational deprivation is not unique to carers. Molineux and Whiteford (1999), Whiteford (2005; 2010) and Wilcock and Townsend (2000) have provided various examples of people who experience occupational deprivation including individuals impacted by geographical isolation, adverse employment conditions, sex-role stereotyping, prisoners and refugees.

Polatajko et al. (2007) concluded that occupational deprivation may result in enduring consequences, including changes to physical and mental health, social isolation and the resultant negative impact on one's sense of well-being. Further research is required to explore the impact of disengagement and deprivation for dying people and their carers in order to improve and direct supports accordingly. The impact of occupational deprivation for people who are dying and their carers is discussed in Chapter Five.

Participant carers experiencing these difficulties stated that they were not acknowledged by existing services nor does there appear to be adequate assistance to help them manage these problems in the short or longer term. Most palliative care services in WA are hospital based, where the social and occupational needs of dying people and their carers are not a high priority. These contributory factors may assist to explain some of the difficulties currently experienced by consumers in this care context.

DISEMPOWERMENT

The current system of palliative care in WA is based on the medical model. Decisions about type of care, place of care and specific strategies for pain and symptom management are largely directed by the health care team, which primarily consists of medical and nursing staff. While some of the physical care needs including pain and symptom management are met, carers state that often neither they nor the dying person are considered as central to decision-making when choices are made about care. Referral for palliative care services often does not occur or occurs too late in the disease process, making it very difficult to plan and co-ordinate care. This often results in a crisis for the dying person, their carer and family, with a resultant presentation at the emergency department of the hospital. Choices about place of care and place of death are often not respected, because the carer's skills and capacity to look after the dying person are underestimated. The expressed wish of dying at home often does not occur, with carers reporting great sadness and disappointment with this outcome.

The participant carers of this study reported that their role was largely unrecognised. According to Palliative Care Australia "Carers must be recognised as both a key partner in the care team and a recipient of care in accordance with the palliative care service provision model" (Palliative Care Australia, 2010, p. 1). Organisations that provide palliative care need to embrace the importance of being 'family centred' with the delivery of these services. Dying people, their carers and families must be considered as key stakeholders in the continuum of care with assistance by the health care team to make decisions affecting this care (Grande et al., 2009; Linderholm & Friedrichsen, 2010; Mehta, Cohen, & Chan, 2009; Morris & Thomas, 2001). Many carers reported poor communication and co-ordination between themselves and palliative care services resulting in frustration, feelings of disempowerment and overall dissatisfaction with the health services that provide care to the dying person.

The majority of dying people and their carers did not receive services from allied health professionals as part of their care. Few were aware of the role of these

professionals specific to the palliative care team and most did not understand the role of the occupational therapist in palliative care. Many dying people did not receive OT, but for those who did, the service primarily focused on discharge planning from hospital, home modifications and provision of assistive equipment and aids for their home such as hospital beds, shower chairs, toilet raisers and pressure care devices. There were minimal opportunities for follow up visits from the occupational therapist. For those people who died at home, OT was not offered as part of the community (public) palliative care service. While some people and their carers were able to obtain private OT services in their home, the focus of these services remained primarily on equipment provision and home modifications.

6.3 IMPLICATIONS FOR OCCUPATIONAL THERAPISTS

LACK OF OCCUPATIONAL FOCUS IN PALLIATIVE CARE

Occupational therapists are highly skilled professionals who assist people to engage in their chosen occupations within the limits of illness. Achieving goals around ones' self-care, leisure and productivity are all important domains of the occupational therapist. However, this research indicates that within the context of palliative care in WA, the role of the occupational therapist is misunderstood, undervalued and often absent from the interdisciplinary team. Results of the survey completed in late 2009 indicated that there were very few OTs working in palliative care in WA. Of the 6.15 full time equivalent OTs working in WA, the majority worked in hospital services, where, according to the participant OTs, there was minimal opportunity to provide a comprehensive and occupation-focused service.

The OTs interviewed in this research expressed dissatisfaction with the current model of care as it directed their services towards discharge planning and the provision of equipment and home modifications. This resulted in restrictions regarding the provision of a holistic approach to dying people. The limitations of the practice context, available resources and personal ideologies prevented them from

providing additional interventions such as pain and stress management, strategies for managing breathlessness and fatigue, positioning for comfort and activity, and the provision of assistance/education to carers.

When combined with the existing roles of environmental modifications, and provision of equipment, the use of these interventions complements the existing services provided by other members of the team and assists the dying person to remain engaged in their chosen occupations with a possible higher level of choice. What does the person enjoy doing each day? What gives them satisfaction and a sense of personal achievement within the limits of their illness? What are their goals and desires as they reach the end of life? These questions create opportunities for OTs to assist dying people and their carers to meet their goals of occupational engagement.

Participant OTs questioned their role in the palliative care service stating that they are restricted in providing an occupation-focused service. Many stated that this was unsatisfactory from their own professional, philosophical and ethical viewpoint. Few opportunities were provided to dying people and their carers that enabled engagement in occupations that were considered important to them. Many OTs working in the palliative care system practiced according to a 'mechanistic' paradigm with little evidence of engagement in the contemporary or 'emerging' paradigm of occupation (Kielhofner, 2008; Wilcock, 1999).

According to some OT literature, the profession continues to experience difficulties identifying a core philosophy from which to base occupational therapy practice (Fortune, 2000; Gray, 1998; Wilcock, 1999, 2001). For the individual OTs interviewed in this study, many recognised this as a potential problem, yet few were able to suggest solutions; it was a result of factors beyond their influence, such as working in a hospital, and there was little they could do to change their practices. They were not prepared to challenge the pre-existing, and long-held, view of the OT role in palliative care in WA. Despite recent moves from within the profession to ensure OTs practice with 'occupation' as the central focus, it appears

that in this area of service delivery there are numerous policy, organisational and individual barriers that prevent the provision of an occupation driven service.

FRUSTRATION WITH LACK OF OPPORTUNITY TO CONTRIBUTE

Occupational therapists reported frustration regarding their perceived and actual roles within palliative care services. Contributory factors included resource constraints, insufficient time available to work with individuals and a narrowly defined role in service delivery which concentrates on discharge planning and equipment prescription rather than providing a more holistic approach. Existing organisations in WA are not currently prepared to create further opportunities for OTs to work in additional acute and community settings.

Occupational therapists stated that there were few opportunities for on-going education and professional development at an undergraduate and postgraduate level in the field of palliative care. This contributed to feelings of being under prepared and ill-equipped to work in this area. This also resulted in a lack of promotion of the broader OT role; that of enabling people to engage in meaningful occupation. Within their current professional capacity, many OTs experienced difficulty supporting the dying person to achieve this occupational aim. A lack of published evidence to support the potential role was also viewed as a barrier to OT practice.

The OTs identified in this study were employed in hospital and residential aged care settings and, except for private practitioners, there were no positions based in the community. Having identified the significant gap of no community-based OTs employed to provide services to dying people and their carers in the palliative period, and the paucity of OTs in palliative care generally, it is important to understand the implications for future service delivery.

6.4 IMPLICATIONS FOR SERVICE DELIVERY

The implications for service delivery are considerable for both consumers and providers of palliative care services in WA. It is estimated that by 2016, the demand

for palliative care services will far outweigh the availability of these services (Department of Health Western Australia, 2008). Consequently, existing and proposed policies must inform both models of service delivery and organisational strategies for all palliative care services. As detailed by the participant carers and OTs, this research identified many gaps in existing services. These disparities must be addressed at a policy, organisational and individual level in order that improvements are made to meet the needs of dying people and their carers in the future.

The Australian Government in 2010 endorsed the National Palliative Care Strategy (NPCS) as the preferred guide to policy development and service delivery for palliative care in Australia. The strategy targets four key areas which seek to direct the delivery of palliative care services in Australian states and territories. These are as follows:

1. Awareness and understanding: To significantly improve the appreciation of dying and death as a normal part of the life continuum. To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to palliative care services;
2. Appropriateness and effectiveness: Appropriate and effective palliative care is available to all Australians based on need;
3. Leadership and governance: To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches; and
4. Capacity and capability: To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care. (Australian Government Department of Health and Ageing, 2011).

While this strategy aims to provide a comprehensive approach to the delivery of palliative care services to individuals living in Australia it is imperative that organisations and individuals that deliver these services continue to provide feedback about the implementation of the strategy. Data were collected for this

study in 2009, so it is not possible to comment on the effectiveness of the NPCS for dying people and their carers in WA. However, the participant carers in this study reported that existing referral pathways and systems within palliative care services and organisations did not appear to meet the expressed needs of dying people and themselves. Clearly the problem of access and referral for palliative care services, including OT, creates a fundamental block and one that needs to be addressed as a priority.

In addition to this strategy, Palliative Care Australia, in 2005, also identified the 'Standards for Providing Quality Palliative Care for all Australians'. Thirteen standards are detailed with a recommendation to accrediting bodies to assess palliative care services based on these standards. The standards are consistent with the NPCS but also recognise the importance of access and referral to holistic and highly co-ordinated care; collaboration and communication with the dying person, their carers and families; and specific reference to supporting the health workforce in this field. In WA, palliative care services are structured according to the 'Palliative Model of Care' (Department of Health Western Australia, 2008). This model recommends the involvement of allied health professionals at all levels of palliative care in both hospital and community based services, yet the results of this research indicate that very few OTs are currently employed in palliative care in WA.

According to international literature and Palliative Care Australia, allied health professionals perform essential roles in the interdisciplinary model of palliative care (Berry & Kuebler, 2002; Cooper, 2006b; George, 2000; Palliative Care Australia, 2011). These health professionals, including OTs, assist to maximise the dying persons' physical, psychological, social and spiritual potential as well as support carers throughout the palliative period. Increasingly, individuals are choosing their place of care and place of death to be at home or hospice with the support of specialist palliative care services (Gomes & Higginson, 2008; Higginson & Sen-Gupta, 2000; McNamara & Rosenwax, 2010; Thomas, Morris, & Clark, 2004). Occupational Therapists are recognised as invaluable resources to assist in meeting

the needs of people who die at home (Cooper, 2006a; Egan, 2003; Kealey & McIntyre, 2005; National End of Life Care Programme, 2010).

Australians live in an ageing society where it is anticipated that there will be increased demand for palliative care services. The age of primary caregivers will also increase (Davies & Higginson, 2004; Stewart, 2003). Changes to desired place of care, place of death and demographics are likely to affect existing and proposed services with a resultant impact on all levels of service delivery in WA.

While dedicated OT positions exist in specialist oncology and inpatient palliative care services, a gap in OT services is evident for individuals who remain at home throughout the palliative period or who choose to die at home. Participant OTs reported that the poor timing of referrals and demands of time and limited resources sometimes meant that the OT was involved late in the disease process or not at all. Provision of OT services for the dying person, once discharged from hospital, was minimal and often provided by another OT as part of the 'home visiting' team. This generalist approach contrasts with models of service delivery in many other countries including the UK, Canada, USA, and some states of Australia where community based OTs are employed to provide specialist palliative care services in the clients' own home or hospice setting (Frost, 2001; Kealey & McIntyre, 2005; Lyons, 2002; Pickens, O'Reilly, & Sharp, 2010). While a rationalisation of resources is required to meet health budget demands, in WA there has not been a corresponding organisational shift to create sufficient OT positions to meet the demands of dying people and to ensure adequate access to OTs in both the acute and community care contexts.

From an organisational perspective, it is essential to ensure that the managers of OT services within hospital and community palliative care organisations translate the intentions of policy towards increasing the number and availability of OTs for people with palliative needs. Presentations provided by OT staff to a range of health professionals may assist to increase others' understanding of their current and potential roles in the palliative care team. In addition, following recruitment of

these staff it is incumbent on organisations to provide suitable education, training and support for these professionals to undertake their roles.

Participant OTs reported that they must take responsibility for the education of the wider community about their role, and the contributions they can make, with regard to the care of dying people, their carers and families. This can be achieved by continued research and publication in OT and non-OT journals, increased participation at relevant conferences and representation at organisations that contribute to policy development including Palliative Care Australia and the various consumer groups including the Health Consumers Council of WA and Carers WA. Occupational Therapy Australia Limited (OTAL) may also contribute to the dissemination of information with the publication of a position statement that advocates for employment of OTs in palliative care settings.

Occupational Therapy special interest groups, non-government organisations and voluntary bodies are stakeholders that can also be utilised to further develop the community's knowledge about OT in this area. These agencies provide an opportunity to disseminate information to consumers and the public about the role of OT in this area of service delivery. Occupational therapists must also acknowledge their professional responsibilities to the palliative care field by delivering services that are supported with recent and valid research as well as undertaking relevant professional development activities.

6.5 RECOMMENDATIONS FOR FURTHER RESEARCH

This research raises further questions regarding the contributions made by OTs to the care of dying people. Of particular interest are the contributions of OTs employed across a range of different care contexts; the dying person's home, residential aged care services, hospice and hospital. How might these contributions be evaluated? For existing services, what generic or unique tools are being used within the different care contexts? What differences in practice exist between OTs working in rural and metropolitan services? Further research is essential to determine if additional and diversified roles for OTs in palliative care services in WA

may assist to meet the occupational needs of people who are dying and their carers in the future.

6.6 SUMMARY AND CONCLUSION

This research identified and explored the many difficulties experienced by people who are dying and their carers, including disengagement and deprivation from their usual occupations during the period of care, and for carers, sometimes long after the bereavement period. Carers expressed their frustration with attempts to engage timely and suitable services for the dying person and strived for recognition as a key stakeholder in the continuum of care. Occupational therapists possess an ideal set of professional skills that contribute a unique role within the interdisciplinary team of palliative care. This role includes assistance for the management of pain and other symptoms, provision of equipment, positioning for comfort and activity, management of stress, breathlessness and fatigue, and environmental modifications in order to facilitate and participate in desired and meaningful occupations.

Occupational therapists work with dying people and their carers to prevent further problems including disengagement from usual roles and activities during the palliative period, potentially contributing to occupational deprivation; this is not currently a recognised role within the current services. Existing policies and standards purport to include allied health professionals as part of the model of care. This research has determined that in WA, few OTs are employed to deliver palliative care services and the role of the OT is largely unrecognised and undervalued.

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7. APPENDICES

Appendix A – Evidence of peer review

18-Mar-2011

Dear Ms. Keesing:

Many thanks for resubmitting your manuscript entitled "‘Doubly deprived’: a post-death qualitative study of primary carers of people who died in Western Australia.". I am now pleased to accept the paper for publication in the journal of Health & Social Care in the Community. The comments of the reviewer(s) who reviewed your manuscript are included at the foot of this letter.

I attach a copyright form for you to sign and would be grateful if you could return to me either by fax on +44 (0)161 306 7867 or scan and email to hscj.journal@manchester.ac.uk.

Sincerely,
Prof. Karen Luker
Editor, Health & Social Care in the Community

Associate Editor Comments to Author:

Associate Editor
Comments to the Author:
(There are no comments.)

Reviewer(s)' Comments to Author:

Appendix B – Evidence of peer review

11-Jul-2011

Dear Ms. Keesing:

It is a pleasure to accept your manuscript entitled "Is occupation missing from occupational therapy in palliative care?" in its current form for publication in the Australian Occupational Therapy Journal.

If you have not done so already, you will need to provide a signed copy of the (ELF/CTA) to the editorial office at your earliest convenience. Please note we are unable to publish your contribution without completion of this form. We can accept this form by post or fax, or as an electronic scanned version which can be emailed. The editorial office contact details are provided below.

Thank you for your fine contribution. On behalf of the Editors of the Australian Occupational Therapy Journal, we look forward to your continued contributions to the Journal.

Yours sincerely
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Appendix C – Copyright declaration

Sharon Keesing

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> will of course forward the appropriate letter and include a statement to
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>
> Sincerely
>
> Sharon
>
> Sharon Keesing
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Appendix C – Copyright declaration

Sharon Keesing

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Sharon

Sharon Keesing

Appendix D – Additional publication

Research Article

Occupational therapy in palliative care: Is it under-utilised in Western Australia?

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Aim: To explore potential barriers to occupational therapy in palliative care in Western Australia, as perceived by occupational therapists and other health professionals.

Method: A qualitative research methodology was used. Semi-structured interviews were conducted with 10 occupational therapists and 10 health professionals (including a physiotherapist, a social worker, medical registrars and clinical nurses). Interviews were transcribed verbatim and analysed using content analysis.

Results: The four main themes identified were: inconsistent understanding of the contribution that occupational therapists can make to palliative care, insufficient promotion of the potential contribution of occupational therapy, insufficient funding, and limited research on the role of occupational therapy in palliative care.

Conclusion: This study provides an understanding of the barriers that have limited occupational therapists' involvement in providing palliative care in Western Australia.

KEY WORDS barriers, occupational therapy, palliative care, qualitative research.

Introduction

Palliative care is defined as 'improving the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psy-

chosocial support from diagnosis to the end of life and bereavement' (World Health Organisation, 2006). Although palliative care is traditionally associated with oncology, the philosophy of palliative care applies to all patients facing terminal illness (Prochnau, Liu & Boman, 2003). Recent international studies indicate that many life-limiting and chronic conditions may be amenable to palliative care (Addington-Hall *et al.*, 1998; Ahmed *et al.*, 2004; Potter, Hami, Bryan & Quigley, 2003). Stewart (2003) predicted that because of the ageing population in Australia, the increasing demand on palliation services for those with non-malignant disease will outweigh the availability of these services.

In Western Australia, palliative care services provide assistance to terminally ill patients and their families through hospital consultancy services, hospice, palliative care units, residential aged care facilities and community nursing and hospice care resources (Department of Health, 2008; Rosenwax, McNamara, Blackmore & Holman, 2005). In most instances, a palliative approach to care can be provided in the community supported by knowledgeable health professionals. The community is the preferred place of care for most patients, and admission to a specialised palliative care inpatient facility may only occur during brief episodes of care (Aoun & Kristjanson, 2005). However, every year approximately 6000 Western Australians die as a result of illnesses that are potentially amenable to palliative care (McNamara, Rosenwax, Holman & Nightingale, 2004). A national inquiry into the social impact of caring for terminally ill people called for 'improved access to allied health services in provision of care in the home to palliative/terminal patients' (Aoun, 2004).

A strong multidisciplinary approach is central to the effective delivery of palliative care (Eva, 2006). Although palliative care outcomes should reflect the contributions of the palliative care team as a whole, occupational therapists have a unique and valuable contribution to make to the team by focussing on the functional implications that symptoms present. Occupational therapy explores how symptoms impact on the individual and their family, in

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particular, how the symptoms prevent individuals from participating in activities and roles that are important to them (Cooper, 2006). Furthermore, occupational therapists specialise in the management of fatigue, breathlessness, anxiety and depression, pressure care and in promoting participation in daily occupations through provision of assistive devices, and task and environmental modification (Cooper). By considering options available to remediate or compensate for symptoms, occupational therapists can facilitate improved functional performance in occupations that the terminally ill individual identifies as necessary or desirable (Ewer-Smith & Patterson, 2002; Jacques & Hasselkus, 2004; Rahman, 2000).

The involvement of occupational therapists in multidisciplinary palliative care teams in Western countries has been documented in the literature (Finlay, 2001; Flanagan, 1982; Folts, Tigges & Weisman, 1986; Frost, 2001; Lyons, Orozovic, Davis & Newman, 2002; McMichael, 1991; Pizzi, 1984); however, in Australia, there are few occupational therapists employed in palliative care. In 2003, approximately 1.6% of the occupational therapy workforce were employed in this field, compared with 27.9% of occupational therapists employed in rehabilitation (Australian Institute of Health and Welfare, 2006). This translates to 0.2 full-time employed (FTE) occupational therapists designated to provide palliative care services to 6.7 beds (Palliative Care Australia, 2003). This compares unfavourably with labour force statistics from other countries, including Canada, where between 8% and 12% of the occupational therapist workforce were

working in palliative care (Canadian Association of Occupational Therapists, 2005). The reasons for the low representation of occupational therapists in palliative care services in Australia are unknown.

There is a paucity of literature exploring the barriers to occupational therapy involvement in palliative care; however, prior studies have discussed the lack of understanding of the role of occupational therapists in palliative care (Dawson & Barker, 1995; Marcil, 2006) and occupational therapists' uneasiness with working in palliative care (Bye, 1998; Cooper, 2006). Furthermore, there is limited research identifying the benefits of occupational therapy services in palliative care (Norris, 1999; Prochnau *et al.*, 2003) and funding restrictions (Kealey & McIntyre, 2005; Rahman, 2000). The current study investigates the reasons for the limited numbers of occupational therapists working in palliative care in Western Australia, from the perspectives of palliative care occupational therapists and health professionals.

Methods

Study design

A qualitative study was conducted using in-depth, semi-structured interviews to identify the perceived barriers to occupational therapists working in palliative care.

Participants

Occupational therapists ($n = 10$) and health professionals ($n = 10$) involved in palliative care in Western Australia

Interview guide
<ul style="list-style-type: none"> • What is your understanding of palliative care? How would you define palliative care? • What do you consider the role and duties of an occupational therapist to be in a palliative care setting? • What are your typical duties include in this palliative care ward? • What are the primary forms of interventions used within the palliative care setting? • How might these duties differ from other professions? • Is there anything else which you believe occupational therapists can potentially contribute to the area of palliative care? How would this benefit the clients and other health professionals? • How do you feel clients perceive the work by occupational therapists in palliative care? Do they see the worth of occupational therapy? • What motivated you to work in palliative care? • There are currently a small number of occupational therapists working in the area of palliative care. Why do you believe this is so? • What level of influence does funding have on the presence of occupational therapists in palliative care? How is funding sourced to facilitate occupational therapists services, is this an issue in regards to limited occupational therapists involvement in palliative care? • What do you think could be added to the undergraduate course of occupational therapy to better prepare students to work in the field of palliative care? • If you have previously worked in palliative care, what were your reasons for leaving the field?

FIGURE 1: Guiding questions for interviews.

were recruited via convenience sampling. Potential participants were contacted via telephone or email to request their participation. The participants were provided with an information sheet explaining the study requirements, risks and benefits, and asked to provide written informed consent prior to data collection. This study was approved by the Human Research Ethics Committee of Curtin University of Technology (RD-09-08).

Procedure

Interviews were conducted in a mutually convenient location and were typically of one hour duration. Guiding questions used in the interviews focussed on the perceived role of occupational therapists in palliative care, and potential barriers to occupational therapists working in this field (see Fig. 1).

Interviews were tailored according to each participant's occupation and years of experience in palliative care. All interviews were audio-recorded and transcribed verbatim. All participants' names were removed from the data, and the initials OT and HP and a numerical code were assigned to occupational therapy and health professional participants prior to data analysis.

Data analysis

Transcripts were imported into QSR N7 and read line by line by the researchers to determine themes. Researcher triangulation was used to improve credibility of the find-

ings. Identified categories and themes demonstrated redundancy and were supported by the data. Issues of trustworthiness of the data analysis process were addressed using the following methods: audit trail, peer debriefing and use of multiple analysis teams to re-read and verify coding of datasets.

Results

The median age of occupational therapist participants was 33.5 years (min = 23 and max = 58 years) and the median years of experience working with patients requiring palliative care was 2.25 years (min = 0.5 and max = 13 years). The median age of health professionals was 48 years (min = 31 and max = 56 years) and the median years of experience working in palliative care was 11 years (min = 2 and max = 20 years). The disciplines of these health professionals varied, with the majority being nurses (six), two medical registrars, one social worker and one physiotherapist. Of all participants, 40% worked in a community setting. A description of the characteristics of participating health professionals and occupational therapists working or researching in the field of palliative care is presented in Tables 1 and 2, respectively.

Four themes that present as barriers to occupational therapy involvement in palliative care emerged from the data.

TABLE 1: Demographics of occupational therapy participants

	Age (years)	Involvement in palliative care	Years experience in palliative care
OT01	52	Palliative care researcher	8
OT02	28	Occupational therapy manager in a public hospital and occupational therapist in palliative care and oncology	2
OT03	29	Senior occupational therapist in a private hospital	1
OT04	25	Senior occupational therapist in a public hospital oncology department	1
OT05	58	Academic in an occupational therapy education programme; occupational therapist working with elderly patients in residential care	10
OT06	44	Academic and researcher in an occupational therapy education programme	2.5
OT07	23	Occupational therapist in a private hospital oncology ward; coordination with Silver Chain services	2
OT08	54	Coordinator of occupational therapy in a public hospital	10
OT09	38	Senior occupational therapist in an oncology ward and deputy head of a public hospital. Membership to a loss and grief committee	13
OT10	23	Occupational therapist in a regional public hospital and health facility	0.5
	Median = 33.5 years old		Median = 2.25 years

TABLE 2: Demographics of health profession participants

	Age (years)	Involvement in palliative care	Years experience in palliative care
HP01	31	Palliative care training registrar at a public hospital	2
HP02	46	Nurse manager in the palliative care unit of a public hospital	10
HP03	52	Social worker in a private community hospice	6
HP04	52	Registered nurse attached to a palliative care unit	3
HP05	43	Clinical nurse in a private community hospice	19
HP06	55	Clinical nurse in a private community hospice	20
HP07	56	Clinical nurse and nurse coordinator	20
HP08	n/a	Physiotherapist in the oncology ward of a public hospital	12
HP09	48	Clinical nurse consultant at a public hospital and a community nursing service	15
HP10	35	Palliative care registrar at a public hospital	5
	Median = 48 years old		Median = 11 years

n/a, not applicable.

Inconsistent understanding of the contribution that occupational therapists can make to palliative care

The majority of health professionals reported that they had an inadequate understanding of occupational therapy practice. For example, one stated:

We, as your colleagues, don't know what you do, or don't think about what you can do, and I think it's maybe not even a lack of knowledge ... it's a lack of thinking of it. (HP07)

Furthermore, health professionals believed that their palliative care patients were not referred for occupational therapy services because they did not understand how referral for occupational therapy would assist in improving the care provided to patients.

Among health professionals who identified that occupational therapists could contribute to the palliative care team, the perceived scope of services that occupational therapists could provide was often limited to conducting home visits prior to discharge from hospital, shower assessments and provision of aids and equipment in the patient's home to assist the patient in the completion of self-care activities of daily living. The following exemplar demonstrates this lack of knowledge:

They assess what the patient might require when they go home. They can do home visits ... and organise all their equipment to be put in place. I suppose at one time people used to think [OTs] just did art and craft, but that's not so now ... it's more than that. (HP05)

Within this view of the potential contribution of occupational therapy in palliative care, it was suggested by

some health professionals that occupational therapy services were unrecognised because these tasks were often provided by other health professionals. For example:

The social worker does all the equipment things and the other occupational therapist roles are distributed between other staff. The nurses do all of the shower assessments. I suppose [OTs could do] activities as well, but then we have an activity person here who does that side of it. (HP06)

Occupational therapists confirmed that they felt their potential role and contribution to the palliative care team were poorly understood by other palliative care health professionals.

I think the role of OTs is really misunderstood by a lot of people. People don't know what OTs do ... they think we just shove in rails, give them an over-toilet frame, and if we can't give them a piece of equipment to help, then we are not involved. (OT10)

Inadequate understanding of occupational therapy and subsequent referral of palliative care patients for occupational therapy services were seen to be of concern, especially in rural areas of Western Australia.

In the rural and remote communities they're just not set up to provide PC services. I think in a lot of cases oncologists and specialists don't always refer for palliative care. A lot of the times in the community people aren't made aware of PC services, and therefore they don't ask for them or they don't receive them. Some people slip through the gaps, especially those who don't have cancer. (OT06)

Although participating health professionals were unable to identify the roles of occupational therapists in palliative care, some health professionals acknowledged occupational therapy's potential for contributing to the quality of life of the patient:

My understanding is that one of the underlying philosophies for OT is really to try and maximise function across many domains for an individual ... that sort of meaningful function for an individual ... assisting people to do what's important for them in their life. (HP10)

It's all about quality of life isn't it? With the time you've got left. So even if it was something as simple as that person still wanting to, you know, put cream on their face or something every morning ... then that's their goal. (HP05)

When asked what they considered the roles and duties of an occupational therapist on the palliative care team would be, these health professionals included stress management, relaxation training, supporting other team members in providing emotional support to the terminally ill patients and their family and assisting the patient with alternative communication methods, including keeping a journal.

Occupational therapists believed they had more to offer to terminally ill patients and their families than conducting home assessments for the purpose of providing aids and equipment. Rather, they saw that their potential role was to improve the patients' quality of life, by facilitating engagement in occupations that were meaningful to the patient.

I probably look at my role more as providing quality of life and dignity to patients rather than trying to promote independence and rehabilitation ... with a focus on doing what they want to do. (OT02)

I think we have a lot to offer in terms of making the person comfortable, so pain management in terms of postural seating and positioning. Making human contact ... it's one of the challenges, particularly for people with dementia ... in the final stages where it is hard for them to communicate with us ... I think we make a conscious effort to actually connect with the person at whatever level they can and use all the senses, as well as do the technical stuff and positioning and equipment. (OT05)

Insufficient promotion of the potential contribution of occupational therapists in palliative care

Data analysis identified that occupational therapists do not promote their roles and sufficiently educate other health professionals about the potential contribution they can make to palliative care. One health professional offered:

I think you have to get out there and sell yourselves. So ... do presentations, go over to a palliative care unit like at [public hospital] and say this is what we can do and please think about us and what we can offer as your patients go through and you are assessing what their needs are. (HP07)

Occupational therapists agreed that they need to communicate more to their colleagues about the contribution they can make to the field of palliative care.

A lot of it comes back to ... who makes the referrals and that's the medical staff, so we need to make sure that they are aware of what we can do as well. I think once that starts to change and I can see some change is happening now, then maybe there will be a spin off effect where the people that write the policies and hand out the money will say "hey, maybe it will be better to get ... you know ... an OT and a physio working on the PC team for [community nursing service]", and you know when that day comes, that will be fantastic, because that's ... that's the obvious way to get us working out in the community as part of that traditional PC team. (OT06)

I think it's about putting OT's in positions where they can do more than just the biomechanical [aspects] or the discharge planning, so you can be an OT; but I would also take responsibility as an individual OT to inform and to share and educate those around us what are our capacities in what we do and advocate for funding ... (OT09)

One possible explanation for why occupational therapists do not promote their role well came from graduate occupational therapists who expressed concerns about their lack of adequate exposure to palliative care during their tertiary education.

I can't remember covering palliative care at all when I was at university. (OT02)

Palliative care was only touched on briefly at University [sic]. (OT04)

Insufficient funding for timely occupational therapy involvement in palliative care

All participating occupational therapists and several health professionals identified that occupational therapists should be involved in providing care as soon as possible after diagnosis, and then at frequent intervals throughout the period of care.

When a patient is diagnosed they receive treatment but there is no reason they can't also begin palliative care. Like an introduction to PC. Then when curative treatment is no longer possible, then palliative care

is stepped up. But this doesn't mean they still can't receive treatment. So the treatment will vary in length. So OT may only come in for one visit, but in fact there needs to be multiple visits. (OT01)

OT needs to become involved earlier in the palliative care, rather than later. Simply because whatever you are trying to establish, might not be established because the disease is progressing very quickly. (IIP05)

Participants stated that insufficient funding within the current health care and political environments placed occupational therapy services as a low priority. Participants reported that they believed palliative care services were not always a priority:

I think OTs have a lot to contribute to the area of palliative care, but unfortunately we just don't have the funding to do it. I don't know if a lot of people see the need for OT in palliative care. When you have a small number of FTE in any department, and you've got patients who are needing to go home and lead independent lives, I think a lot of people tend to fund the resources into that. It's high patient turn over in those areas. Palliative care is not a lucrative business. I don't know if there have been studies done to support or refute that. (OT02)

There are lots of other options in the community, like hospice, where I can see there is a role for OT; but again it does boil down to where is the money coming from, who is paying for it. If we can start to let people know that we have a role to contribute then, then we can say perhaps you'd be better off putting your money into an OT rather than another nurse. We can actually make a difference or we can put a different perspective on the team. (OT06)

The provision of basic services such as access and safety in and around the home was perceived to be the most important aspect of the occupational therapist role. Furthermore, with limited available funding for palliative care services, other health professionals were seen to be able to provide these basic services to the patient and the family.

It is a matter of not having that service per se, also having the resources too, we haven't had the resources to broaden our role there either. (OT08)

Limited research on the role of occupational therapists in palliative care

Participants reported that there is a need for more research into occupational therapy in palliative care to contribute to an evidence base for practice. It was

suggested that the paucity of published research about the role, contribution and benefits of occupational therapy in palliative care contributes to the limited opportunities provided for occupational therapists:

You don't start with the funding; you start with the evidence ... because if you have got evidence and strong enough evidence, then you can change funding. (OT01)

I think the research needs to happen. I think that the research needs to sort of be incorporated into the way the model of palliative care service delivery in Western Australia is changing. So it understands more about the role of the allied health professional. (OT06)

I think that if GPs and specialists, especially oncologists, could get to see the potential role for an OT, then they would probably invite them more often to be involved, and so ... there is a potential role even in the private system where we have OTs who provide equipment and modifications to people in their home to be involved at that level as well in palliative care. I mean it stems right back to the whole education process of ... educating residents and registrars ... (OT01)

Discussion

Four themes that present as barriers to occupational therapists' involvement in palliative care in Western Australia emerged from the data. First, an inconsistent understanding of the unique contribution of occupational therapists to the palliative care team among the general community, palliative care health professionals and some occupational therapists may result in under-referral of terminally ill patients for occupational therapy services. This is of concern given that working in an interdisciplinary team has long been integral to the philosophy of palliative care and caring for the 'whole' person (Crawford & Price, 2003). Our data demonstrated that although all health professionals agreed that occupational therapists could contribute to the field of palliative care, there were differences in health professionals' and occupational therapists' knowledge and opinions of the roles that occupational therapists could play. Occupational therapists provided more detailed explanations of the possible roles that they could play within palliative care. These roles were consistent with the occupational therapist philosophy, which involves taking a 'doing' philosophy and focussing on the interaction between person, environment and occupation (Law, Baum & Dunn, 2001).

Wee *et al.* (2001) highlighted that professional groups develop their own identities and stereotype those of other professionals. This stereotyping of occupational therapists as simply 'providers of equipment in the home' was evident in the current study and that by others (Atwal,

2002). Health professionals indicated that these types of tasks were often completed by other members of the palliative care team. However, as the occupational therapist participants suggested, their role in the palliative care team would extend beyond these tasks and focus on assessing patients' symptoms and needs and improving their overall functional performance.

Nevertheless, health professionals' understanding of the role of occupational therapists can be changed to facilitate their further involvement in the palliative care team. In 2000, research from the United States demonstrated that when occupational therapists were more integrated into a hospice team, there was greater awareness of the role of occupational therapy by the team members, and a subsequent increase in referrals for occupational therapy services (Rahman, 2000). In the United Kingdom, the establishment of the Gold Standards Framework for community palliative care has helped to facilitate an established role for occupational therapists working as part of a multidisciplinary team (National Gold Standards Framework Centre, 2009). According to Cooper (2006), providers of palliative and oncological services in the United Kingdom are employing more occupational therapists in the community as more individuals seek support to die in their own homes. To increase occupational therapists' involvement in palliative care in Australia, similar standards need to be established and health-care professionals need to work together as an interdisciplinary team.

Evidence from the current study suggests that occupational therapists do not sufficiently communicate their role and contribution to the palliative care team and to their patients. Role ambiguity and confusion among interdisciplinary teams, and the importance of clear communication among the team and with patients have been identified by others (Atwal, 2002; Crawford & Price, 2003), to solve problems and ensure that the best care available is provided by appropriate health professionals. At present, palliative care does not have a clear presence in the professional profile of the Western Australian Occupational Therapists' Association, and there is no special interest group or strategy for the promotion of occupational therapists working in palliative care. This insufficient promotion and marketing contributes to the reduced awareness of the potential contribution of occupational therapists in palliative care.

Second, limited exposure to palliative care within occupational therapy education has resulted in occupational therapy graduates in Western Australia being unsure of the contribution of occupational therapy to palliative care. In past years, the occupational therapy curriculum in Western Australia has not clearly articulated the scope of occupational therapy practice in palliative care. Although the knowledge and professional skills required by an occupational therapist to work in palliative care are addressed throughout the course, no emphasis has been given on the application of these professional skills in an

'end of life' context. In response to this issue, the occupational therapy curriculum at Curtin University of Technology has been adapted to better articulate to students their potential role in palliative care settings. Students now spend up to 12 hours in directed learning activities that focus on palliative care and the role of the occupational therapists in treatment planning. An occupational therapist working in palliative care at the children's hospital shares with students about the provision of occupational therapy services as part of the palliative care team, including maintaining participation in meaningful activities, finishing 'unfinished' business, living with hope, relationships with siblings and parents and grieving. Final year students can nominate to complete a fieldwork placement in palliative care, and honours students are invited to participate in palliative care research programmes within the school. These changes are preliminary steps to improve occupational therapy students' understanding of their potential role in palliative care.

In addition to educating occupational therapy students, it would also be beneficial to educate health professionals about the role of occupational therapy in palliative care. This study demonstrated that occupational therapists and other health professionals had different knowledge and opinions about the roles of occupational therapists in palliative care. An inter-professional educational model of health-care education would improve the opportunity for medical, nursing and allied health professionals to better understand the value and contribution that occupational therapists and each of the other professionals bring to the palliative care team (Wee *et al.*, 2001), so as to optimise the services offered to the patient and their family.

Third, insufficient government funding for specialist palliative care services, including occupational therapy, may limit the involvement of occupational therapists. Other health professionals on the palliative care team are often required to substitute the occupational therapist's role. 'Traditional' occupational therapy services such as provision of equipment and discharge planning are frequently carried out by other team members and may lead to suboptimal outcomes. Occupational therapy focusses on maintaining individuals' participation in important life roles and quality of life, and providing assistive equipment is only one means to facilitate this participation. Without the necessary training, it is not appropriate for nurses or other allied health professionals to take on this role, just as it is inappropriate for an occupational therapist to administer pain medication to terminally ill patients (Marcil, 2006). Available funding prioritises hospital, medical and nursing services with limited resources available for allied health services. Consequently, occupational therapy is often not introduced in the early stages of palliative care, which limits the planning of future services based on anticipated needs; rather, occupational therapy is often called on to manage crises as they arise, and usually to address issues of access and

self-care function in and around the home. The opportunity for the patients and their family to have their needs fully met is compromised.

Finally, limited scientific research and publication about the role and effectiveness of occupational therapy in palliative care have contributed to the perpetuation of the three aforementioned barriers. Further research is needed to determine the effectiveness of occupational therapy interventions in improving patient function, comfort, occupational performance and quality of life, thereby substantiating the continuing role of occupational therapists in palliative care in Western Australia. Recommended future research includes investigating the met and unmet needs of patients and their carers who consume palliative care services in Western Australia. Research findings should be communicated by occupational therapists working in palliative care to members of the interdisciplinary palliative care team, especially those responsible for referral of patients for services. Provision of sound evidence and the communication of this will influence the development of policy and procedures and determine the future practice opportunities for occupational therapy in palliative care in Western Australia.

Methodological limitations

The opinions of palliative care service users were not sought in this study, which may have limited the breadth of data obtained, wherein the consumer perspective is lacking. The use of convenience sampling may have resulted in a homogenous sample that may not represent all occupational therapists and health professionals' views of occupational therapy in palliative care in Western Australia. However, inclusion of two participant groups enabled data saturation and a greater understanding of the potential barriers limiting occupational therapy involvement in palliative care.

Conclusion

This study provides an understanding of the barriers that have limited occupational therapists' involvement in providing palliative care in Western Australia. It is evident that occupational therapists have a valuable contribution to make; however, changes need to be made to current practice, educational curriculum and funding models to facilitate their active involvement in the palliative care team. Further research is required to demonstrate the varying roles that occupational therapists can take in palliative care.

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Appendix E – Email survey

Sharon Keesing

Subject: FW: OTs in palliative care study-confidential

From: Sharon Keesing [<mailto:S.Keesing@exchange.curtin.edu.au>]

Sent: Tuesday, 6 October 2009 16:18

To:

Subject: OTs in palliative care study-confidential

Dear

As you may know, I have been working on my Masters by research (An investigation of occupational therapy services for people who are dying in Western Australia) and it has been great to talk to many Occupational Therapists about their experiences.

I have found many interesting things during the study including just how few OTs are employed to work in palliative care in WA. I have also interviewed many carers and they have reported there are many gaps in the overall care provided to their family members. My research (and other studies) has found that OTs have many skills to help meet some of these needs.

I am hoping that the results of my study will contribute towards improved services for the dying and their carers. I believe the demand on these services will increase due to the ageing population in Australia, prevalence of cancer, cardiovascular disease, chronic diseases and other non-malignant diseases and the demand on occupational therapy services is likely to increase.

I am at the stage now where I would really value your contribution to the study as a provider of these services in Perth. As I have been unable to obtain this information from all the sources I have approached (including the Registration Board) I would really benefit from your approximation of the OT FTE devoted to the care of the dying/palliative care, either in hospital situations or in the homes of clients.

Of course, this information would be treated confidentially, de-identified and would greatly assist me to provide an estimate of how many OTs are working in this area in W.A. I hope to match the data with the potential number of clients who could benefit from OT services.

Any assistance you can provide would be greatly appreciated.

This study has received ethical approval from Curtin University of Technology, Department of Health WA and Ramsay Health Care. Please let me know if you have any questions about the study.

Sincere thanks

Sharon

Sharon Keesing

Lecturer | School of Occupational Therapy and Social Work | Faculty of Health Sciences | Curtin University of Technology | GPO Box U1987 Perth | Western Australia | Telephone + 61 8 9266 3630 | Facsimile | + 61 8 9266 3636 | Email S.Keesing@curtin.edu.au

CRICOS Provider Code 00301J Perth 02637B Sydney

Vision: An international leader shaping the future through our graduates and research and positioned among the top 20 universities in Asia by 2020

Appendix F – Advertisements



WANTED

CARERS

SHARE YOUR EXPERIENCES AND HAVE YOUR SAY
TO IMPROVE CRITICAL SERVICES
FOR PEOPLE IN NEED.

Are you a person who has cared for someone in the past two years who has died? We would like to interview you to hear about your experiences and to gain valuable insight into services and resources that you believe could have been improved for the person you cared for.

The study aims to assist carers by identifying areas of need to improve support and resources in the future.

A one hour private interview will be conducted at a time and place that is convenient to you.

For more information or to volunteer to participate please
contact the researcher:

SHARON KEESING, Occupational Therapy, Curtin University
9266 3630 | S.Keesing@curtin.edu.au



This study is approved by the Human Research Ethics Committee at Curtin University of Technology and the Department of Health WA Ethics Committee.

Appendix F - Advertisements

MEDIA RELEASE



Tel: (08) 9266 1930, 0401 103 877; Fax: (08) 9266 2266; Email: k.mcgregor@curtin.edu.au Web: www.curtin.edu.au

March 2009
C/09

Volunteers wanted for carers study

Curtin University of Technology researchers are looking for volunteers for a study focusing on improving support and resources for carers.

They would like to interview people who have cared for someone in the past two years who is now deceased.

The study aims to determine what support services and resources carers are currently using and what can be improved.

Participants will be asked to undertake a one-hour private interview.

For more information contact Sharon Keesing, Department of Occupational Therapy, on (08) 9266 3630 or s.keesing@curtin.edu.au

Ends

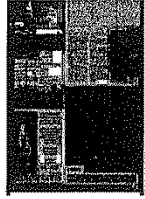
Contact: Sharon Keesing, Department of Occupational Therapy, Curtin, 08 9266 3630, s.keesing@curtin.edu.au or Katie McGregor, Acting Public Relations Coordinator, Curtin, 08 9266 1930, 0401 103 877, k.mcgregor@curtin.edu.au

Looking for expert comment? Visit Curtin's On-line Directory of Experts at <http://experts.curtin.edu.au>

CRICOS provider code: 00301J

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Appendix F – Media Release



Canning Community

07/04/2009

Page: 14

General News

Region: Perth

Circulation: 34994

Type: Suburban

Size: 97.12 sq.cms

-T-----

Help for carers

CARERS provide an important service but often have not got the help they need, a situation Curtin University researcher Sharon Keesing wants to do something about.

Ms Keesing hopes to improve on the level of support currently available and develop a new model for carers as part of her studies at the School of Occupational Therapy.

"I want to ask carers what their needs are, and whether these are being met," she said.

"I've found that often the

services available to them and the people they treat are very limited.

"For conditions other than cancer, people often find themselves neglected in terms of the different kinds of support they can access. Resources are there, but not at the right time."

Ms Keesing said her research highlighted the increasing importance of occupational therapists as a resource that carers can turn to.

"The impetus behind it indicates the emerging role of occu-

pational therapy around the world," she said.

"Doctors and nurses have an established role, but allied health professionals don't, so it's often difficult for carers to anticipate the kind of help they can access through these people."

Ms Keesing began her research last December, and she is calling on carers to come forward for interviews – people who have cared for someone in the past who are now deceased.

Contact her on 9360 3630, or S.Keesing@curtin.edu.au.

Appendix G – Ethics approval



Government of Western Australia
Department of Health

HUMAN RESEARCH ETHICS COMMITTEE (DOHWA HREC) AHEC EC00422

Postal Address:
Executive Officer
DOHWA HREC
1st Floor 'C' Block
189 Royal Street
EAST PERTH WA 6004

ph: (08) 9222 4278
fax: (08) 9222 4236
e-mail: HREC@health.wa.gov.au
<http://www.health.wa.gov.au/healthdata/hrec/index.cfm>

Professor Lorna Rosenwax
Head of School of Occupational Therapy & Social Work
Curtin University of Technology
GPO Box U1987
PERTH WA 6845

Dear Prof Rosenwax

RE: **Project # 2008/23**
An Investigation of Occupational Therapy Services for People Who Are Dying in Western Australia

Date of commencement:	01/02/2008
Date of completion:	01/12/2010
Research Team:	Prof Lorna Rosenwax, Ms Sharon Keesing, Ms Heather Freegard
Data linkage required:	Yes
Datasets to be accessed:	Mortality Register, HMDS, Cancer Registry
Date of next review:	10/09/2009
Ethics approval validity:	10/09/2012 (4years)

Following our letter dated 15/09/08, I am pleased to advise that the Committee has granted ethical approval for this project.

This letter constitutes Ethics Approval only; you will not receive the data requested for your project until approval for the release of these data is signed by the Department of Health WA Director General's delegate.

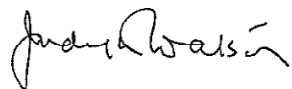
This approval is subject to your continued compliance with the following conditions:

- DOHWA HREC holds the Principal Investigator responsible for the ethical conduct of the project and the security of the personal health information therefore he/she must -
 1. Report anything which might warrant review of ethical approval of the project in the specified format including:
 - Any serious or unexpected adverse events.
 - Unforeseen events that might affect the continued ethical acceptability of the project.
 - Submit for approval any changes or amendments to the research protocol, including methodology, data required, duration of the project and any changes to the approved data storage arrangements.
 2. Advise if the project is discontinued or withdrawn before the expected date of completion and give reasons for this action.
 3. Provide an annual progress report to the HREC and a final report at the completion of the project.
 4. Advise any changes of personnel in the research team, and provide a DOHWA Confidentiality Agreement/Confidentiality Acknowledgement form for any addition to the research team.

Please find enclosed a copy of the completed Confidentiality Agreement/s, signed by the authorised DOH WA officer.

We wish you well with your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Judyth Watson', written in a cursive style.

Dr Judyth Watson
Chair
Department of Health WA Human Research Ethics Committee

23 December 2008

Appendix G- Ethics approval

memorandum

To	Sharon Keesing, Occupational Therapy
From	A/Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval HR 122/2008
Date	10 November 2008
Copy	Professor Lorna Rosenwax Occupational Therapy Graduate Studies Officer, Faculty of Health Sciences

Curtin 
University of Technology

Office of Research and Development

Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Committee (HREC) for the project titled "An investigation of occupational therapy services for people who are dying in Western Australia.". Your application has been reviewed by the HREC and is approved.

- You are authorised to commence your research as stated in your proposal.
- The approval number for your project is HR 122/2008. Please quote this number in any future correspondence.
- Approval of this project is for a period of twelve months 07-10-2008 to 07-10-2009 To renew this approval a completed Form B (attached) must be submitted before the expiry date 07-10-2009
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Divisional Graduate Studies Committee.
- The following standard statement **must** be included in the information sheet to participants:
This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 122/2008). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:

When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,



A/Professor Stephan Millett
Chair Human Research Ethics Committee



Appendix G – Ethics approval

JOONDALUP
HEALTH CAMPUS

13 March 2009

Ms Sharon Keesing
PO Box U1987
PERTH WA 6845

Joondalup Hospital Pty Ltd trading as
Joondalup Health Campus
ABN 61 106 723 193
Cnr Grand Blvd & Shenton Ave
Joondalup WA 6027
PO Box 242
Joondalup WA 6919
Telephone: 08 9400 9400
Facsimile: 08 9400 9055
Web: www.ramsayhealth.com.au

Dear Ms Keesing

RE: An investigation of occupational therapy services for people who are dying in Western Australia (ref 0905)

The Human Research Ethics Committee of Joondalup Health Campus is pleased to notify you that your proposal to undertake research on this campus has been approved, including endorsement from the Hospital Executive. As the Committee is bound by NHMRC Guidelines, the following conditions apply:

- That the Committee be notified immediately of any substantial changes in the design, methodology, time line or intended subjects of the project,
- That the Committee be notified immediately of any unforeseen complications of the project,
- That the Committee be notified if the project does not commence within six months of approval,
- That the Committee receive annual/final reports on the study (you will receive a pro forma from the Committee in twelve months), and
- That the Committee be informed of any other matters which arise during the course of the project which may have ethical implications.

Your approval is initially for four years; after this period you may be asked to re-apply. You are also required to notify the Committee promptly of any changes in your contact details.

Our best wishes for a successful implementation of your research project.

Yours sincerely



Ann Y Hammer
Executive Officer, JHC HREC

www.ramsayhealth.com.au

RAMSAY
HEALTH CARE

Appendix H – Information sheet for carers



PARTICIPANT INFORMATION FORM- CARERS

An investigation of occupational therapy services for people who are dying in Western Australia

Introduction

I invite you to participate in a new research project that examines some of the current issues for people who are dying in Western Australia. The study is being conducted by a Researcher who is an Occupational Therapist and is working towards a Master of Science degree at Curtin University of Technology. The study has been approved by the Human Research and Ethics committee (HREC) at Curtin University of Technology.

Please read through the following information which will explain what the study is about and how you will participate.

Purpose of the study

You have been asked to participate in this study because you have had experience in caring for a person who has died. In Western Australia, there is very little information available about the impact of these experiences. One of the aims of the study is to determine what you consider to be the met and unmet needs of the person you have cared for as well as your own needs.

Occupational therapists will then be interviewed to determine what and how services could potentially be provided for people who are dying.

What the study will involve

The study involves your agreement to be interviewed by the Researcher. The interview will be conducted at a mutually agreed location (your own home if preferred) and will last approximately one hour. The interview will be tape recorded and then typed word for word (transcript). You may refuse to answer any of the questions, take a break or terminate the interview if you do not feel comfortable. A copy of the interview transcript will be forwarded to you for checking and corrections made if necessary.

Confidentiality

All information provided to the Researcher will be considered confidential. The interview transcript will be saved on to a computer using only a number code and your name will not be recorded. This information will be protected by password, known only to the Researcher. The original tape will be destroyed. All other information including research reports and documents will be stored in a locked filing cabinet in the Researcher's office at Curtin University of Technology.

Benefits

Your responses will assist individuals in the future who may be caring for people who are dying as well as occupational therapists working in this area.

Discomfort and Risk

The interview questions will focus on your experiences when you cared for a person who died. These questions may trigger emotions such as sadness and grief relating to your experiences. If the interview questions cause distress, the interview can be terminated and resumed at another time or you may withdraw from the study entirely. Should you require any further assistance or support a referral can be made to the Silver Chain bereavement and counselling service.

Voluntary participation and withdrawal

Your participation in this study is voluntary and you may withdraw for any reason at any time.

Questions or concerns

If you have any questions or concerns about the study, please do not hesitate to contact the Researcher. You may also contact the Secretary of the Human Research Ethics committee at Curtin University, on 92662784 or hrec@curtin.edu.au.

Sharon Keesing
Researcher
Ph: (08) 9266 3630
Email: S.Keesing@curtin.edu.au

Professor Lorna Rosenwax
Research Supervisor
Ph: (08) 9266 3604
Email: L.Rosenwax@curtin.edu.au

Heather Freegard
Co-Supervisor
Ph: (08) 9266 3635
Email: H.Freegard@curtin.edu.au

This study has been approved by the Human Research and Ethics committee at Curtin University. If required, you may verify this approval by contacting the committee Secretary, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845, telephone 9266 2784 or hrec@curtin.edu.au.

Appendix I – Information sheet for OTs



PARTICIPANT INFORMATION FORM- OCCUPATIONAL THERAPISTS

An investigation of occupational therapy services for people who are dying in Western Australia

Introduction

I invite you to participate in a new research project that examines some of the current issues for people who are dying in Western Australia. The study is being conducted by a Researcher who is an Occupational Therapist and is working towards a Master of Science degree at Curtin University of Technology. The study has been approved by the Human Research and Ethics committee (HREC) at Curtin University of Technology and the Department of Health W.A. Ethics committee.

Please read through the following information which will explain what the study is about and how you will participate.

Purpose of the study

You have been asked to participate in this study because you are an experienced occupational therapist. One of the aims of the study is to determine what you consider to be the current and 'ideal' practices of occupational therapists working with people who are dying. Another objective of the study is to interview carers about their experiences of caring for people who are dying. A model of 'best practice' will be proposed at the completion of the study.

What the study will involve

The study involves your agreement to be interviewed by the Researcher. Permission from your Employer will be sought in order to participate in the interview. The interview will be conducted at a mutually agreed location (your work place if preferred) and will last approximately one hour. The interview will be tape recorded and then typed word for word as a transcript. You may refuse to answer any of the questions, take a break or terminate the interview if you do not feel comfortable. A copy of the interview transcript will be forwarded to you for checking and corrections made if necessary.

Confidentiality

All information provided to the Researcher will be considered confidential. The interview transcript will be saved on to a computer using only a number code and your name will not be recorded. This information will be protected by password, known only to the Researcher. The original tape will be destroyed. All other information including research reports and documents will be stored in a locked filing cabinet in the Researcher's office at Curtin University of Technology.

Benefits

Your responses will assist individuals in the future who may be caring for people who are dying as well as occupational therapists working in this area. Other benefits include support for a multi-disciplinary approach to the care of people who are dying, curriculum development and identification of further OT intervention in this area.

Discomfort and Risk

The interview questions will focus on your opinions and experiences as an occupational therapist. It is not anticipated that these questions will create any difficulties, however if this occurs you may terminate the interview, resume at another time or withdraw from the study completely.

Voluntary participation and withdrawal

Your participation in this study is voluntary and you may withdraw for any reason at any time.

Questions or concerns

If you have any questions or concerns about the study, please do not hesitate to contact the Researcher.

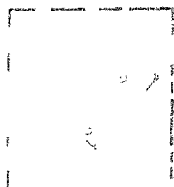
Sharon Keesing
Researcher
Ph: (08) 9266 3630
Email: S.Keesing@curtin.edu.au

Professor Lorna Rosenwax
Research Supervisor
Ph: (08) 9266 3604
Email: L.Rosenwax@curtin.edu.au

Heather Freegard
Co-Supervisor
Ph: (08) 9266 3635
Email: H.Freegard@curtin.edu.au

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 122/2008). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Ethics Committee, c/o Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Appendix J – Consent form



CONSENT FORM

An investigation of occupational therapy services for people who are dying in Western Australia

Participants' Name _____

1. I am voluntarily taking part in this research project which has been described to me in detail by the Researcher
2. I am over 18 years of age.
3. I have been provided with a thorough explanation of the nature and purpose of the study. I understand the procedures involved and what is expected of me.
4. I have been provided with the opportunity to ask questions and these have been answered satisfactorily.
5. I give my permission for de-identified information and results to be used in the research report and research documents.
6. I understand that I am able to withdraw from the study at any time.
7. I understand that confidentiality of my details and responses will be maintained at all times.
8. I have read and been given a copy of this consent form and information sheet.

Signature of Participant

Signed _____

Date _____

Signature of Researcher

Signed _____

Date _____

Should you have any questions, please contact:

Sharon Keesing
Primary Researcher
Curtin University of Technology
Ph: 9266 3630
Email: S.Keesing@curtin.edu.au

Professor Lorna Rosenwax
Project Supervisor
Curtin University of Technology
9266 3604
Email: L.Rosenwax@curtin.edu.au

Appendix K – Interview guide (carers)

Questions for carers- July 23, 2008

- 1) Can you tell me about your (husband, wife, partner), your life together?
- 2) Can you tell me what your (husband, wife's, partners) diagnosis was?
- 3) Did they have any other medical issues to deal with (co-morbidities)?
- 4) When did the diagnosis occur?
- 5) Can you tell me about how the news impacted on your life?
- 6) Tell me about your (husband's, wife's, partner's) routine at the time of the diagnosis?
- 7) And around 6 months before they died?
- 8) Was your dad and your family actually told that he would die as a result of the condition?
- 9) And a few weeks before they died?
- 10) Can you describe any difficulties you had, personally during the last 6 months before they died?
- 11) And the few weeks before they died?
- 12) What do you think made it difficult for your (husband, wife, partner) to carry out their normal routine during those periods?
- 13) What services were you able to access during this time, and did you access these? What were they?
- 14) What people were available to you and your (husband, wife, partner) if you needed them?
- 15) Did you and your (husband, wife, partner) have access to anyone for psychological/emotional support, who was that person?
- 16) Who seemed to take care of co-ordinating the services during that time, eg your specialist, GP etc?
- 17) How effective was that for you?
- 18) Did your (husband, wife, partner) maintain any of their usual routines during the last few months- such as exercise, hobbies, social occasions?
- 19) Were there any particular things that didn't work well at that time?
- 20) Why do you think they didn't work?
- 21) Did you have assistance from an allied health provider such as an OT or physiotherapist?
- 22) Did you receive any assistance for equipment or modifications to your home?
- 23) Were there any areas that you felt needed to be improved?
 - pain and symptom control
 - care of the person; physical assistance, moving around, showering, toileting, dressing, eating and positioning
 - conserving their energy, managing breathlessness
 - managing stress
 - leisure, hobbies, usual activities
 - social opportunities- visits, using the phone, email, writing letters
 - psychological and emotional support
 - spirituality
- 24) What would be your suggestions about changing the way your dad was cared for in order to improve the situation for others?

Appendix L – Interview guide (OTs)

Question list- OTs

Can you just confirm some details:

Name	Age	Location	FTE	Registration	Year of graduation	Title @organisation

Can you tell me about your work experiences since graduation?

Have you worked overseas or interstate at all- where and when?

Can you give me some information about the unit that you work in, how it operates?

Can you tell me about the range of diagnoses are that you manage?

Is your caseload hospital based or in the clients homes?

Can you tell me about some of the positive and negative experiences you've had working in this area?

Do you experience any frustrations or difficulties about working in this area?

What has been the main role as an OT working with these people?

Can you tell me about the different services that have been provided whether they've been in patients or at home?

Have you much involvement with the carers of these patients when you've visited them at home?

What sort of involvement have you had with the families?

What do you think are the main difficulties or problems experienced by these people?

What would you say is your OT philosophy or model of care when working with the dying?

If you had access to sufficient resources, how would you like to support people who are dying? So in an ideal world what could be provided?

Do you feel that OTs are able to offer additional specific services to people who are dying? What might these services be?

How could you facilitate this with your current workload?

Would you say that there are any organisational issues or barriers for OTs working with people in this area?

Do you think you could promote additional roles for the OT working in this area?

How would you do this?

Do you have anything you would like to share with me?

Sharon Keesing

6/06/2011

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