A national survey of occupational therapists working with people living with terminal illness: Profile, role, context, professional reasoning and challenges

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No one wants to die. Even people who want to go to heaven don't want to die to get there. And yet death is the destination we all share. No one has ever escaped it. And that is as it should be, because death is very likely the single best invention of life.

STEVE JOBS

(From the Commencement Address at Stamford University, 2005)

This thesis is dedicated to my grandmother, Olive Hardcastle, who despite her long battle with illness, always kept focusing on life.
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Finally, to my mother Glenyce, thank you for giving me the passion to learn and investigate life, as well as always supporting me no matter what life adventure I choose.
Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

..................................................................................

Kathrine Anne Faddy
Table of Contents

Acknowledgements ................................................................................................. i

Statement of Authentication .................................................................................. ii

Table of Contents ................................................................................................... iii

List of Figures ........................................................................................................... x

List of Tables ........................................................................................................... xii

List of Appendices .................................................................................................. xiii

List of Abbreviations ............................................................................................... xiv

Abstract ..................................................................................................................... xv

Chapter 1  Introduction ............................................................................................ 1
  1.1  Introduction ...................................................................................................... 1
  1.2  Context of this study ...................................................................................... 2
  1.3  Statement of the problem .............................................................................. 3
  1.4  Scope and limitations of the study ............................................................... 4
  1.5  Significance of the study .............................................................................. 5
  1.6  Definition of terms ....................................................................................... 7
    1.6.1  Occupational therapy ............................................................................. 7
    1.6.2  Occupational therapist .......................................................................... 7
    1.6.3  Occupation ............................................................................................. 8
    1.6.4  Activity ................................................................................................... 8
    1.6.5  Occupational performance ................................................................. 9
    1.6.6  Occupational engagement ................................................................. 9
    1.6.7  Activities of daily living ...................................................................... 9
    1.6.8  Professional reasoning ......................................................................... 10
    1.6.9  Occupational therapy process ......................................................... 10
    1.6.10  People living with a terminal illness ............................................. 12
    1.6.11  Client .................................................................................................. 13
Chapter 2  Literature Review ................................................................. 18
  2.1  Introduction ................................................................................. 18
  2.2  Terminal diagnoses ..................................................................... 19
      2.2.1  The everyday impact of living with a terminal illness .......... 19
      2.2.2  Illness trajectories ............................................................. 21
      2.2.3  Palliative care .................................................................. 25
      2.2.4  The experience of dying a ‘good death’ ............................ 28
      2.2.5  Place of death .................................................................. 29
      2.2.6  Summary ........................................................................... 30
  2.3  Occupational therapy ................................................................. 31
  2.4  Occupational therapy for people living with a terminal illness ... 31
      2.4.1  Australian occupational therapy demographics................... 31
      2.4.2  The history of the occupational therapy role for people living with a terminal illness 33
      2.4.3  Occupational engagement for people living with terminal illness .... 37
      2.4.4  The occupational therapy process for people living with a terminal illness .... 40
          2.4.4.1  Occupational therapy theoretical frameworks ................ 40
          2.4.4.2  Referral ..................................................................... 41
          2.4.4.3  Assessment .................................................................. 41
          2.4.4.4  Goal setting ............................................................... 43
          2.4.4.5  Intervention .............................................................. 43

1.7  Chapter synopsis and overview of the thesis ............................... 16

1.6.12  Care-giver .................................................................................. 13
1.6.13  Diagnosis ................................................................................... 13
1.6.14  Clinical area ............................................................................... 14
1.6.15  Caseload ..................................................................................... 14
1.6.16  Palliative care ............................................................................ 14
1.6.17  Palliative care approach ............................................................ 14
1.6.18  End-of-life care ......................................................................... 15
1.6.19  Hospice .................................................................................... 15
1.6.20  Dying ......................................................................................... 16
1.6.21  Death ......................................................................................... 16
Chapter 3  Methodology ................................................................. 59

3.1 Introduction ........................................................................... 59

3.2 Research design ..................................................................... 59
  3.2.1 Theoretical Framework ......................................................... 59

3.3 Participants ........................................................................... 60
  3.3.1 Sampling ........................................................................... 60
    3.3.1.1 Purposive sampling ...................................................... 61
    3.3.1.2 Snowball Sampling ..................................................... 62
  3.3.2 Eligibility ........................................................................... 62
  3.3.3 Sample size ....................................................................... 62

3.4 Survey instrument ................................................................... 65
  3.4.1 Survey procedures .............................................................. 65
  3.4.2 Survey development ............................................................ 67
  3.4.3 Pilot testing ....................................................................... 69
  3.4.4 Survey administration ......................................................... 70

3.5 Data collection ....................................................................... 70
  3.5.1 Survey administration ........................................................ 70

3.6 Data analysis ......................................................................... 71
  3.6.1 Mixed methods data analysis ............................................. 71
  3.6.2 Quantitative data analysis ................................................. 72
  3.6.3 Qualitative data analysis .................................................... 72
    3.6.3.1 Stages of qualitative data analysis ............................... 73

3.7 Ethical considerations .......................................................... 74
  3.7.1 Voluntary participation and right to withdraw .................... 75
  3.7.2 Informed consent .............................................................. 75
3.7.3 Data management to ensure confidentiality and anonymity............... 75

3.8 Synopsis ................................................................................................. 75

Chapter 4 The context of Australian occupational therapy practice for people living with a terminal illness ................................................................. 77

4.1 Introduction .................................................................................................. 77

4.2 The Results .................................................................................................. 78

4.3 The Sample .................................................................................................. 78

4.3.1 Sample profile .......................................................................................... 78

4.3.2 Predicted career paths .............................................................................. 81

4.4 Workplaces .................................................................................................. 85

4.5 The Clients ................................................................................................... 86

4.6 Synopsis ....................................................................................................... 90

Chapter 5 Occupational engagement of people living with a terminal illness: Therapists’ perceptions ....................................................................................... 92

5.1 Introduction .................................................................................................. 92

5.2 Perceptions of occupational engagement at the end of life............................... 94

5.2.1 Unique occupations .................................................................................. 94

5.2.2 Meaningful occupations ........................................................................... 95

5.2.3 Therapists’ perceptions of occupational engagement of people living with a terminal illness ................................................................. 95

5.3 “Focusing on life” ......................................................................................... 97

5.3.1 Prioritised engagement .............................................................................. 98

5.3.2 Altered Engagement .................................................................................. 102

5.3.3 Summary of “focusing on life” ................................................................. 104

5.4 “Preparing for death” ................................................................................... 104

5.4.1 Practical preparations ............................................................................... 105

5.4.2 “Facilitating Closure” ............................................................................... 106

5.4.3 Summary of “‘Preparing for death’” ......................................................... 110

5.5 Synopsis ....................................................................................................... 111

Chapter 6 The occupational therapy role and process for people living with a terminal illness ............................................................................................. 112
6.1 Introduction ............................................................................................................. 112
6.2 Results ....................................................................................................................... 113
  6.2.1 Occupational therapy theoretical frameworks ................................................. 113
  6.2.2 Modifying occupational therapy practice for people living with a terminal illness 115
  6.2.3 Referral to occupational therapy ....................................................................... 118
    6.2.3.1 Referral source ....................................................................................... 118
    6.2.3.2 Reason for referral ............................................................................... 119
    6.2.3.3 Referral timeframes and management .................................................. 120
  6.2.4 Assessment of clients living with a terminal illness ......................................... 122
    6.2.4.1 Assessment type .................................................................................. 122
    6.2.4.2 Assessment needs related to end-of-life care ........................................ 125
  6.2.5 Goal setting with people living with a terminal illness .................................... 125
    6.2.5.1 Goals related to “focusing on life” ....................................................... 127
    6.2.5.2 Goals related to prioritised engagement ............................................. 127
    6.2.5.3 Goals related to altered engagement .................................................... 130
  6.2.6 Goals related to “preparing for death” ............................................................ 132
    6.2.6.1 Goals related to practical preparations at the end-of-life ....................... 132
    6.2.6.2 Goals related to facilitating closure ..................................................... 134
  6.2.7 Interventions for clients living with a terminal illness .................................... 135
    6.2.7.1 Outcome measures used with clients living with a terminal illness ....... 141
  6.2.8 Follow-up of clients living with a terminal illness ........................................... 143
6.3 Synopsis ..................................................................................................................... 144

Chapter 7 Challenges to practice, and the educational and supervision needs of therapists working with people living with a terminal illness .................. 145
  7.1 Introduction ............................................................................................................. 145
  7.2 Results ....................................................................................................................... 146
    7.2.1 Challenges and strategies of working with people living with a terminal illness

Chapter 7 Challenges to practice, and the educational and supervision needs of therapists working with people living with a terminal illness .................. 145
  7.1 Introduction ............................................................................................................. 145
  7.2 Results ....................................................................................................................... 146
    7.2.1 Challenges and strategies of working with people living with a terminal illness

  7.2.1.1 Perceived challenges ............................................................................... 146
    7.2.1.2 Service and caseload challenges ......................................................... 147
    7.2.1.3 Intra and interpersonal challenges ....................................................... 149
    7.2.1.4 Role challenges ................................................................................. 149
List of Figures

Figure 1 Illness trajectories for people with chronic disease (Murray & McLoughlin, 2012) ..........22
Figure 2 Ecological Model of Professional Reasoning: Personal and professional lenses shape occupational therapists’ professional reasoning (Schell, 2014)........................................................................52
Figure 3 Ecological Model of Professional Reasoning: Professional reasoning is an ecological process in which the therapist and the client engage in therapy activities in a specific setting. All of these components transact to shape therapist reasoning, resulting actions with the client, and ultimately, therapy outcomes (Schell, 2014).................................................................................................53
Figure 4 Sample working with clients with terminal illness in Australia eligibility.........................64
Figure 5 Survey procedures ...........................................................................................................66
Figure 6 Proportion of therapists employed per state (N=171).........................................................79
Figure 7 Years working with people living with a terminal illness (N=169).................................80
Figure 8 Therapists estimated length of time staying in role (N=132)...........................................83
Figure 9 Clients with a terminal illness as a proportion of therapist caseload (N=144).............87
Figure 10 Therapists’ perceptions of occupational engagement of people living with a terminal illness.........................................................................................................................96
Figure 11 Proportion of therapists using a model of practice or theoretical framework by state (N=60)........................................................................................................................................114
Figure 12 Proportion of referrals received for occupational therapy services (N=144).............119
Figure 13 Percentage of assessments used by therapists with clients and care-givers in the previous week (N=132)........................................................................................................122
Figure 14 Therapists’ primary method of conducting client assessment (N=132)......................123
Figure 15 Frequency of discussions on terminal care needs with clients and care-givers (N=132)125
Figure 16 Coding process and thematic analysis of goals...............................................................127
Figure 17 Proportion of client and care-giver related safety goals (N=41)....................................132
Figure 18 Therapists’ agreement related to meeting the clients’ needs during interventions.......136
Figure 19 Therapists’ agreement related to meeting the care-givers needs during interventions.137
Figure 20 Proportion of the most commonly provided interventions per ADL domain (N=379)....137
Figure 21 Proportion of interventions completed per setting (N=1535).......................................140
Figure 22 Proportion of the intervention type by setting (N=1535)..............................................141
Figure 23 Follow-up of clients and care-givers as part of role (N=128)........................................143
Figure 24 The three categories of perceived challenges to working with people living with a terminal illness (N=508)...........................................................................................................147
Figure 25 Therapists’ feelings of preparedness (N=123)..............................................................153
Figure 26 Therapists’ comfort level when working with people living with a terminal illness.....154
Figure 27 Frequency of therapists’ responses as to the educational setting of occupational therapy topics .................................................................................................................................................................................. 161
Figure 28 Frequency of therapists’ responses as to educational setting of palliative care topics .... 162
Figure 29 Frequency of supervision (N=123) .................................................................................. 163
Figure 30 Therapists level of agreement with supervision statements as a percentage ........... 164
List of Tables

Table 1 Potential Participants (N=156)........................................................................................................61
Table 2 Distribution of therapists work location by state (N=171)..............................................................80
Table 3 Therapists perceptions of working with people living with a terminal illness in the future.82
Table 4 Reasons for continuing to work with people living with a terminal illness (N=75).............84
Table 5 Predicted reason for leaving caseload of working with people living with a terminal illness (N=57)..................................................................................................................85
Table 6 Primary treatment setting (N=144)..................................................................................................86
Table 7 Clinical areas making up therapists’ caseloads (N=540)...............................................................88
Table 8 Diagnosis according to ICD-10 codes...........................................................................................90
Table 9 Therapists’ agreement with statements on modifying practice to work with people living with a terminal illness compared to a non-terminal caseload.................................................116
Table 10 Most frequently reported referral source to occupational therapy services ....................118
Table 11 Top three reasons for referral to occupational therapy services by referral source (N=1462)........................................................................................................................................120
Table 12 Therapists’ level of agreement with referrals practices ............................................................121
Table 13 ADL sub-goals (N=144).................................................................................................................129
Table 14 Frequency of goals relating to the family and/or care-giver (N=104).......................................134
Table 15 Frequency of interventions provided to people living with a terminal illness (N=379) ....138
Table 16 Frequency of intervention completed by therapists working with people living with a terminal illness within the past week (N=1535)...........................................................................139
Table 17 Frequency of outcome measure use by assessment type (N=27)............................................142
Table 18 Percentage of strategies used by therapist to overcome challenges (N=628)....................151
Table 19 Skills, knowledge and qualities required as part of occupational therapy curriculum (n=260)........................................................................................................................................155
Table 20 Perceived areas of competence required to work with people living with a terminal illness (N=316).......................................................................................................................................158
Table 21 Direct supervisor of therapists working with people living with a terminal illness (N=116) ..............................................................................................................................................163
Table 22 Therapists’ demographics and work profiles, and client demographics.........................167
Table 23 Therapists’ perceptions of occupational engagement for people living with a terminal illness ........................................................................................................................................168
Table 24 The occupational therapy process for people living with a terminal illness ....................170
Table 25 The challenges, and education and supervision requirement of working with people living with a terminal illness...........................................................................................................172
## List of Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 1</td>
<td>Peer-reviewed journal article</td>
<td>231</td>
</tr>
<tr>
<td>Appendix 2</td>
<td>Survey instrument</td>
<td>240</td>
</tr>
<tr>
<td>Appendix 3</td>
<td>Introductory recruitment email</td>
<td>276</td>
</tr>
<tr>
<td>Appendix 4</td>
<td>Participant information sheet</td>
<td>278</td>
</tr>
<tr>
<td>Appendix 5</td>
<td>Follow-up reminder email</td>
<td>281</td>
</tr>
<tr>
<td>Appendix 6</td>
<td>University of Western Sydney’s Human Research Ethics Committee approval (H9466)</td>
<td>283</td>
</tr>
<tr>
<td>Appendix 7</td>
<td>Standardised assessment use</td>
<td>285</td>
</tr>
</tbody>
</table>
## List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full text</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>Activity of daily living</td>
</tr>
<tr>
<td>ADLs</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>AKPS</td>
<td>Australian Modified Karnofsky Performance Scale</td>
</tr>
<tr>
<td>BIMS</td>
<td>Brief Interview for Mental Status</td>
</tr>
<tr>
<td>CMOP</td>
<td>The Canadian Model of Occupational Performance</td>
</tr>
<tr>
<td>COPM</td>
<td>Canadian Occupational Therapy Performance Measure</td>
</tr>
<tr>
<td>FIM</td>
<td>Functional Independence Measure</td>
</tr>
<tr>
<td>GAS</td>
<td>Goal Attainment Scale</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental activities of daily living</td>
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<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
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<tr>
<td>MBI</td>
<td>Modified Barthel Index</td>
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<tr>
<td>MMSE</td>
<td>Mini Mental State Exam</td>
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<tr>
<td>MOHO</td>
<td>The Model of Human Occupation</td>
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<tr>
<td>OPMA</td>
<td>The Occupational Performance Model of Australia</td>
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<tr>
<td>OT</td>
<td>Occupational therapy</td>
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<tr>
<td>OTs</td>
<td>Occupational therapists</td>
</tr>
<tr>
<td>PEO</td>
<td>The Person-Environment-Occupation Model</td>
</tr>
<tr>
<td>RUG-ADL</td>
<td>Resource Utilisation Group – Activities of Daily Living Scale</td>
</tr>
<tr>
<td>SAS</td>
<td>Edmonton Symptom Assessment Scale</td>
</tr>
<tr>
<td>VAS</td>
<td>Visual Analogue Scale</td>
</tr>
<tr>
<td>Waterlow</td>
<td>Waterlow Pressure Ulcer Risk Assessment Tool</td>
</tr>
</tbody>
</table>
Abstract

Each year in Australia, over 70,000 people require services and support due to terminal illness. Occupational therapists are part of the multi-disciplinary healthcare team who treat people with a terminal illness in Australia. However, despite occupational therapists playing a central role in this area, research suggests that therapists are challenged in their professional reasoning when adopting a palliative approach, and that they feel unprepared to work with clients who are terminally ill due to the paucity of empirical evidence in this clinical area. This results in therapists identifying that they are unclear on the scope of their role, and what this looks like in various practice contexts.

Therefore the purpose of this study was to gain an in-depth understanding of the scope of the occupational therapy role, the professional reasoning that underpins this role, and the context of Australian occupational therapy practice when working with people living with a terminal illness. In addition, educational preparation for this role, along with the challenges and supervision and support needs while undertaking the role, were examined.

A national online mixed-methods survey, of Australian-based occupational therapists working with people with a terminal illness was completed. This study had an extensive qualitative component, and employed the Ecological Model of Professional Reasoning as its theoretical framework to identify the therapist, client and contextual factors related to working with this client group. This model underpinned all aspects of the study, including the design of the survey. Purposive, snowball sampling techniques led to 171 occupational therapists completing the survey, representing the largest national survey in this clinical area to date. Descriptive data was analysed using SPSS, and qualitative analysis of the findings was completed using grounded theory methods, with the data managed in NVivo.

The survey has provided detailed demographics of a large sample of Australian-based therapists’ work profiles, work settings and client groups served. It has shown that therapists work with these clients, who primarily had oncological diagnoses, across a variety of settings and caseloads, and that people with terminal illnesses are not seen solely within palliative care services.

An understanding of clients’ occupational engagement at the end of life was a key feature underpinning therapists’ professional reasoning. Therapists shared their perspectives on occupational engagement for people living with a terminal illness. They acknowledged the occupations that were unique and meaningful at the end-of-life, namely occupations that focussed on remaining engaged in living despite having a terminal diagnosis, and those that helped clients prepare for death through supportive care and closure. Therapists enabled clients and caregivers to engage in occupations that had this dual focus, and this was further reflected as part of their role in their daily occupational therapy processes. Therapists therefore modified their occupational therapy process to work from a palliative approach to ensure their clients’ needs were met. The goals of the client and caregivers became central to all stages of the process.
Therapists planned on staying in their role into the future, but noted the significant challenges of working with people who are terminally ill. Finding a work/life balance was critical, along with having adequate clinical supervision to guide reasoning and debrief with regards to dealing with death and dying. The majority of therapists reported feeling underprepared to work in this clinical area initially, and were able to identify over 250 core knowledge and skills required for competent practice in this area, with a particular emphasis on advanced communication skills related to working with people who are experiencing grief and bereavement. Therapists emphasised the qualities that they believed were important for development in students and therapists wishing to work with people living with a terminal illness. Therapists reported that more emphasis should be placed on palliative care education at an undergraduate level, with further knowledge being expanded in the workplace.

Therapists in this sample have identified that this area of practice is different to other areas, as therapists face the duality of working with people who are living yet also dying. This meant that professional reasoning had a dual focus, and occupational therapy processes were changed to accommodate a palliative approach. Recognition of the uniqueness of this time of life was a key feature supporting therapists’ clinical decisions. This thesis has made an original contribution to the literature and has shown that further research needs to occur to fully develop this area of practice. There is a need for further development of undergraduate curricula that will ultimately lead to more competent and better prepared therapists, as well as the development of evidence-based guidelines that identifies the scope of the role and the occupational therapy processes used with this client group. Health services now need to respond to the findings on work profiles and client demographics in order to meet the needs of these clients, and further research should be completed into confirming the professional reasoning process of therapists working with people living with a terminal illness.
Chapter 1 Introduction

1.1 Introduction

I have been really lucky in life. I have only had a very limited experience of death and losing people that I love in my personal life, so when I began working with people living with a terminal illness I did not know what to expect. Not only that, I did not feel prepared to work with this client group. I felt that even though I had read about death and dying, I still had a really limited knowledge of what practice could entail.

Even after I began researching the occupational therapy role in this area of practice I still had questions. What was practice meant to look like when your clients are going to die, and they will not improve? What types of conditions would my clients have and how would they present on a functional level? What types of assessments and interventions was I meant to complete with clients living with a terminal illness? How did I set goals with these clients? Could I cope working in an area that was considered to be emotionally challenging? What safe guards could I put in place to prevent myself from burning out?

The longer I worked in an oncology and palliative care setting in a Sydney metropolitan hospital the more I loved working in the area. To me it was a privilege to be allowed into peoples’ lives when they were vulnerable and had just had their worlds turned upside down. However, as my professional reasoning developed, it became evident that clinical practice differed from the limited published literature. For example, the literature discusses the use of occupation as a major focus of interventions with people living with a terminal illness. However, in the setting where I worked, it appeared that the dominance of the medical model had taken the ‘occupation’ out of occupational therapy practice. Instead, the dominant role of the occupational therapist in this area had changed from viewing a client holistically and assisting them to find closure, to a role predominately around equipment prescription. To me, this contradicted what I thought was true about our profession. There had to be more to practice in this clinical area. The only problem was that I was not sure what that might be.
Through my liaisons with other therapists I knew I was not alone in the questions that I was asking, and that I was not the only therapist struggling with the gaps in the evidence base. A clearer role and practice context for occupational therapists working with people living with a terminal illness needed to be established. We needed to understand all of the dimensions to our practice, including why we made the decisions we did.

This thesis outlines my investigation into these very questions. In this study, 171 Australian occupational therapists described their practice with people living with a terminal illness through the completion of an online mixed methods survey that had an extensive qualitative component. At the time of survey, this was the largest study of occupational therapists working with people living with a terminal illness worldwide, and to date remains the largest study of Australian occupational therapists with this cohort. Through this survey therapists were able to anonymously describe their role and the context of their clinical practice, and by doing so gave the professional reasoning behind their responses, and their personal perspectives on working in this area.

### 1.2 Context of this study

Occupational therapists provide unique care to meet the diverse needs of people with terminal illnesses who are nearing the end-of-life (Dawson, 1982). Research has shown that therapists have a dual approach to their role (Bye, 1998). Firstly, therapists work to affirm an individual’s life through continued engagement in meaningful occupations such as spending time with loved ones or engaging in chosen activities. At the same time, therapists assist the person and their loved ones to prepare for death by addressing care giving and support needs, home modifications and equipment, and needs related to life closure and farewells, for example visiting the home for a final time.

However, despite occupational therapists playing a central role with people living with a terminal illness, there is a paucity of empirical evidence to guide daily practice and professional reasoning. The evidence base is lacking in this area of occupational therapy.
when compared to other clinical areas that have large intervention trials to prove their efficacy.

Over the past 30 years approximately 100 articles have been published on occupational therapy practice for people with an oncological or terminal illness, and three key textbooks discuss the occupational therapy role with this client group. The majority of published research investigations have small sample sizes and are descriptive studies, therefore having poor generalisability of findings. The textbooks are predominately based on clinical experience and case studies rather than empirical evidence. Findings from studies in this area conclude that further research needs to occur into understanding: the role of the occupational therapist working with people living with a terminal illness; the educational needs of undergraduate students to prepare them for practice; and the support needs of therapists already working in this field (Keesing & Rosenwax, 2011; Meredith, 2010). There is also a call in this clinical area generally to examine workforce demand given the ageing population and the expected increase in the need for palliative care services (Australian Institute of Health and Welfare, 2010; Murtagh et al., 2014).

1.3 Statement of the problem

Evidence is needed to guide practice, assist with workforce planning, and to develop education and training resources for therapists and students. The scope of the occupational therapy role including the professional reasoning processes used by therapists, and the context of Australian occupational therapy practice working with people living with a terminal illness are unknown. This lack of evidence to guide practice has implications for the care provided to people living with terminal illnesses.

The overall objective of this thesis was to *gain an in-depth understanding of the scope of the occupational therapy role, the professional reasoning that underpins this role, and the context of Australian occupational therapy practice when working with people living with a terminal illness*. The specific aims of this study were:
(i) To understand the workforce context for therapists working with people who are terminally ill in Australia by detailing the demographics of a large sample of occupational therapists, including individual therapist demographics, work context factors and teams, and client base.

(ii) To gain an in-depth understanding of therapists’ perspectives on occupational engagement for people living with a terminal illness;

(iii) To gain an in-depth understanding of the role of the occupational therapist with people living with a terminal illness and the professional reasoning process they follow in their daily practice;

(iv) To gain an in-depth understanding of the challenges, and educational and support needs of occupational therapists who work with people living with a terminal illness.

In order to meet the overall objective, therapists were asked to detail their occupational therapy practice with people living with a terminal illness through the completion of an online mixed-methods survey. The use of mixed methods in the survey design encouraged therapists to provide in-depth information about their practice in open ended questions as well as provide more descriptive data in closed questions. The open-ended questions revealed the professional reasoning process that these therapists used to make decisions in this clinical area. Previous studies in this area had small sample sizes, providing limited context at a state, national and international level. Therefore a large-scale study, which could provide data at a national level, was completed.

1.4 Scope and limitations of the study

Due to the relatively small number of therapists working in this clinical area a national context was chosen over a state context to ensure the largest possible sample size. Therapists who had worked in this practice area within the last three years were included in the study. This timeframe was selected to ensure therapists had currency of practice, and to increase the reliability of their answers when recalling daily practice and clients’ narratives as required for the completion of the survey.
This study was limited to occupational therapists with experience working with people living with a terminal illness. Therefore, all of the findings reported in this thesis are from the occupational therapists’ perspectives. Therapists are in a position of expertise to report what they see in everyday practice with clients, but it needs to be remembered when reviewing the findings, that it is the therapists’ point of view being reported throughout results chapters rather than the clients. For example, when clients’ goals are discussed, it is the occupational therapists’ perspectives on clients’ goals, and the therapists’ answers are based on their clinical experience of the goals that are set by clients. A future study incorporating clients would be required to elicit clients’ points of view. No limitations were placed on the workplace setting or caseload, as it was important to establish all types of occupational therapy practice with this clinical area.

1.5 Significance of the study

Approximately 100,000 people in Australia die an expected death each year (CareSearch, 2011; Palliative Care Australia, 2011). Palliative care is a growing area of practice due to the ageing Australian population and people living longer with chronic or serious health conditions or terminal illnesses. Occupational therapists are skilled in enabling people to adapt to changing functional limitations as they age or face chronic health conditions; however there is only a limited amount of small-scale qualitative research that has been completed with people who are living with a terminal illness. As a result, there is a substantial knowledge gap of what occupational therapy practice for people living with a terminal illness should look like, as well as where the practice takes place, and who the clients are that therapists work with as part of this role.

This study is significant, as it aims to decrease the knowledge gap by establishing the scope of the occupational therapy role, the professional reasoning that underpins this role, and the context of Australian occupational therapy practice when working with people living with a terminal. To understand the context of practice, we must first identify the therapists working with people living with a terminal illness, their workplace contexts, and the clients that they work with. Investigation into these three factors will assist in making informed policy decisions to ensure sufficient and comprehensive
occupational therapy services are provided for people living with a terminal illness in the future, as well as provide a baseline of service for comparison of practice trends in the future.

Limited evidence exists as to how occupational therapists can improve a person’s occupational engagement at the end-of-life (la Cour, Johannessen, & Josephsson, 2009; Vrkljan & Miller-Polgar, 2001) and what therapists’ perceptions are upon diagnosis of a terminal illness. This research will provide new knowledge on therapists’ perceptions of occupational engagement for people living with a terminal illness and provide a framework on occupational engagement for use with this client group.

Research suggests that occupational therapy can enable clients to meet their occupational needs towards the end-of-life (Jeyasingam, Agar, Soares, Plummer, & Currow, 2008; Taylor & Currow, 2003). Yet, there is limited research on what the occupational therapy role entails in modern practice and how therapists practically enable their clients’ occupational engagement. There is also minimal research on the processes that they follow with clients living with a terminal illness. This study will identify and articulate the occupational therapy role and the occupational therapy process for people living with a terminal illness, providing a knowledge base for future research.

Research over the last three decades has shown that occupational therapists working with people living with a terminal illness feel underprepared and ill-educated to work with this client group (Dawson & Barker, 1995; Dawson & Walker, 1998; Meredith, 2010). To date, no research has occurred into therapists needs once working with people living with a terminal illness. Thus, this research has implications for the training, education, and supervision of students and therapists working in this area. This research will identify therapists’ perceptions on their preparation for practice, challenges to working in this clinical area, perceptions of core skills required for competent practice, and identify support needs of therapists working with people living with a terminal illness.
Findings from this study will contribute to a broader and deeper understanding of the scope of the occupational therapy role and the context of Australian occupational therapy practice when working with people living with a terminal illness. This research will inform therapists working in this area on occupational therapy practices and processes, will allow institutions to develop better undergraduate and post-graduate educational resources, and will inform policy development, workforce planning, and clinical guidelines for therapists working with people living with a terminal illness. Additionally, while this research looks at the Australian context, it is expected that the level of detail contained in research findings will allow therapists around the world to compare and contrast findings with their own practice contexts to evaluate the applicability of results.

1.6 Definition of terms

This thesis contains numerous terms that require definition in order to provide context for their use. Key terms that will be further explored within this thesis are now defined.

1.6.1 Occupational therapy

*Occupational therapy* (OT) is founded on the premise that an essential part of being human is the engagement in meaningful and purposeful occupations. The World Federation of Occupational Therapists (2009) defines occupational therapy as “a profession concerned with promoting health and well-being through occupation” (p. 4). The primary goal of occupational therapy is to enable “people to do things that will enhance their ability to participate in their activities of everyday life” despite their illness, injury, disease, disorder, condition, impairment, disability, activity limitation or participation restriction (World Federation of Occupational Therapy, 2009, p. 4).

1.6.2 Occupational therapist

*Occupational therapists* (OTs) are health care professionals who have a degree in occupational therapy. Occupational therapists aim to increase the individual's functional independence and their ability to perform their chosen occupations, roles and relationships (Law, 2002). They do this by addressing a person's occupational
performance deficits area in a variety of contexts in order to support occupational engagement (American Occupational Therapy Association, 2008).

Occupational therapists are also referred to as therapists within the context of this thesis.

1.6.3 Occupation

Occupation forms the central tenant of the occupational therapy profession. Literature suggests that there is not one set definition of occupation used by occupational therapists. Instead occupation has been defined in numerous ways. A common understanding of occupation is that this term pertains to paid employment or work. However, in occupational therapy, occupation extends past this definition to one where occupation is instead thought of as the activities which people engage in their daily lives that bring both purpose and meaning to life (Law, 2002; Molineux, 2009; World Federation of Occupational Therapy, 2009).

Occupations are “viewed as activities that give meaning to the person’s life, contribute to one’s identity, and those to which the individual looks forward to engaging” (McHugh-Pendleton & Schultz-Krohn, 2013, p. 15). Occupations also help an individual to organise their time in terms of life roles, or activities of daily living such as work and productive activities, pleasure, survival, necessity, or personal meaning (American Occupational Therapy Association, 2002; Hinojosa & Kramer, 1997).

1.6.4 Activity

Occupation and activity are often used interchangeably in the occupational therapy literature (American Occupational Therapy Association, 2014). However, within this thesis the term activities will be encompassed by occupations, being differentiated by being goal directed and meaningful, rather than of significant importance to a person’s life like occupations (McHugh-Pendleton & Schultz-Krohn, 2013).
Therefore, activity can be defined as “actions designed and selected to support the development of performance skills and performance patterns to enhance occupational engagement” (American Occupational Therapy Association, 2014).

1.6.5 Occupational performance

*Occupational performance* is the act of performing or completing a selected activity or occupation within a client’s own context and factors. By improving or enabling a client’s occupational performance skills or patterns, clients are better able to engage in their chosen occupations (American Occupational Therapy Association, 2008).

1.6.6 Occupational engagement

*Occupational engagement* recognises the commitment a person makes to their performance in occupations as a result of self-choice, motivation, and meaning (American Occupational Therapy Association, 2002). Occupational engagement can occur objectively through physical participation and ‘doing’, or subjectively by ‘being’ present in an emotional or psychological state. Occupational engagement can be completed individually, or as part of a family or community (Lyons, Orozovic, Davis, & Newman, 2002; Wilcock, 1999).

1.6.7 Activities of daily living

*Activities of daily living*, or *ADLs*, are activities that have to do with taking care of one’s own personal care (McHugh-Pendleton & Schultz-Krohn, 2013). ADLs include activities such as bathing, bowel and bladder management, dressing, eating, feeding, functional mobility, personal hygiene and grooming, sexual activity sleep and rest, and toileting, that are directed towards taking care of one’s own body (American Occupational Therapy Association, 2008).

Instrumental ADLs or IADLs are activities that support one’s daily life and often require more advanced skill levels than general ADLs (Foti, 2013; McHugh-Pendleton & Schultz-Krohn, 2013). IADLs include home management tasks, such as meal
preparation, cleaning, laundry, money management, home maintenance, and care of others and pets, health management and religious observance; as well as community living skills such as driving, shopping and accessing recreation (Foti, 2001; Foti, 2013).

1.6.8 Professional reasoning

Professional reasoning is a context-driven way of thinking and making clinical decisions that guides a therapist’s practice (Higgs, Trede, & Loftus, 2006). Professional reasoning is complex and can be defined as a process in which the therapist through interaction with the client, structures meaning, goals, and health management strategies (Jones & Rivett, 2004). In occupational therapy, therapists help clients to solve problems they have engaging in their daily occupations, which are incurred as a result of varied clinical conditions (Jones & Rivett, 2004). Professional reasoning is a complex process that enables therapists to plan, direct, perform, and reflect on clinical practice (Schell, 2003; Unsworth, 2004).

Professional reasoning is based on a strong discipline specific knowledge base, cognition and reflective inquiry skills that enable therapists to process clinical data, and meta-cognition or reflective self-awareness that allows therapists to identify limitations in their knowledge base and make remedial actions (Jensen, Resnik, & Haddad, 2008). It is a collaborative process where the therapist works with the client and other health professionals to provide a reasoned and specific response that is of best interest to a client and their problem (Jones & Rivett, 2004; Schell & Cervero, 1993).

There are many professional reasoning theories used within occupational therapy, however this thesis will specifically focus on the Ecological Model of Professional Reasoning (Schell & Schell, 2007).

1.6.9 Occupational therapy process

The occupational therapy process helps to guide a therapist’s practice when working with a client regardless of the setting or caseload (College of Occupational Therapists, 2011; World Federation of Occupational Therapy, 2009). This process offers a structure that
therapists can follow when providing occupational therapy services in order to address their clients’ occupational performance issues. There are many published versions of the occupational therapy process, however they mostly follow a similar pathway and all should focus on occupation (Chilsholm & Schell, 2014; McHugh-Pendleton & Schultz-Krohn, 2013). This process helps to structure therapists’ choices from the point of referral through to discharge (Mahaffey, 2009).

The first step in this process involves an established referral pathway and ways to manage referrals (Bennett, 1991). This may include having inclusion and exclusion criteria to ensure that appropriate referrals are received (College of Occupational Therapists, 2011).

Assessment, or information gathering, is the next to occur in this process. Assessment is important as it establishes the client’s occupational profile, including their occupational performance level and their occupational needs (Chilsholm & Schell, 2014). Assessment can occur in person through interview, observation or through a specific standardised assessment and should take into consideration the person, their occupations, and the environment.

Goal setting with the client should then occur as the therapist develops treatment plans and/or recommendations that meet the client’s needs. Goal setting allows for targeted outcomes to be set with the client. Goals can be short-term (i.e. goals achieved in a few days or weeks) or long-term (i.e. goals achieved in the next month or year) (American Occupational Therapy Association, 2008; Chilsholm & Schell, 2014).

Next, the chosen interventions are implemented. Interventions are designed to facilitate the client's performance of everyday tasks and may involve the adaptation of environments in which the person works, lives and socialises. These plans should be completed in collaboration with the client and their care-giver and be based on evidence (Burkhardt et al., 2011; Chilsholm & Schell, 2014). Interventions need to consider the client’s current occupational performance, and predict what goals the client is likely to
achieve. The outcome of interventions should then be measured against the client’s initial occupational performance presentation (Chilsholm & Schell, 2014).

The final step of the process is to evaluate the impact of the intervention to the client and whether it has been effective and met the client’s needs (College of Occupational Therapists, 2011). This form of evaluation is completed through the use of outcome measures. If interventions meet the client’s needs, therapy for that occupational performance issue can be discontinued. Alternatively if the client’s needs have not been met then the target outcomes and goals should be re-evaluated and a new therapeutic route taken (Chilsholm & Schell, 2014).

It is important to note that the steps in the occupational therapy process are not always completed in this order, and at times therapists may complete these steps concurrently, or repeat steps if the client’s occupational performance status changes.

1.6.10 People living with a terminal illness

In 2008, Palliative Care Australia published a glossary of terms. This glossary defines a progressive condition that will result in death as either a *terminal illness* or an *eventually fatal condition*. A terminal illness is defined as a “progressive condition that has no cure” (Palliative Care Australia, 2008a, p. 14). This progressive illness is expected to cause the death of a person within the foreseeable future, regardless of whether the disease is malignant, non-malignant, or due to aging processes (Palliative Care Australia, 2008a). Other terms used interchangeably with terminal illness in Australia, the United Kingdom and the United States of America are: life-limiting illness, terminal condition, and end-of-life.

This thesis will refer to any person who has an incurable progressive condition as having a ‘terminal illness’. Several researchers suggest that people should be supported to continue living while approaching death (Bye, 1998; Jacques & Hasselkus, 2004; World Health Organisation, 2011), therefore people with this type of diagnosis will be regarded as *living with a terminal illness* in this thesis.
1.6.11 Client
For the context of this thesis a client is a person living with a terminal illness seeking the assistance of health care services and professionals, including an occupational therapist.

1.6.12 Care-giver
A care-giver is someone who provides a range of services and offers emotional, social, physical, practical and financial support to another person (Keesing, Rosenwax, & McNamara, 2011; Palliative Care Australia, 2004a). In the case of people living with a terminal illness, family members and friends typically become the person’s care-givers as the transition from living to dying creates a need for increased support.

Changes occur in the family dynamics as previously meaningful life roles and responsibilities are relinquished (Davidson, Dracup, Phillips, Padilla, & Daly, 2007). Responsibilities of a care-giver of a person living with a terminal illness regularly include completing domestic and household tasks, providing assistance with ADLs, giving medications, and providing symptom management for the person living with a terminal illness. These changes result in additional physical, emotional, and financial demands on the caregiver (Boog, 2008; Hale, 2006).

In this thesis the term care-giver refers to the person or people who provide care to the person living with a terminal illness.

1.6.13 Diagnosis
A diagnosis is the name given to an individual illness or condition that a client may present with. A diagnostic group is a way of classifying diseases, including a wide range of signs, symptoms and normal findings, complaints, social circumstances, and external causes of injury or disease. The ICD-10 codes (World Health Organisation, 2010) were used to classify diagnostic groups within this thesis.
1.6.14 Clinical area
A clinical area refers to the diagnostic groupings of clients who are admitted to a health service.

1.6.15 Caseload
A caseload refers to the clients who have been allocated for treatment by a therapist. A caseload may cover many clinical areas.

1.6.16 Palliative care
In the literature, palliative care is often used interchangeably with terminal or end-of-life care. Palliative care is a concept of care, which aims to improve the quality of life for individuals living with and dying from a terminal illness (NSW Health Department, 2001; Saunders, 1995). This care is provided from the time of diagnosis to the end-of-life, including during the bereavement period for significant others. Palliative care is most often delivered via a dedicated palliative care service, such as in a hospice, but can also be provided as part of care in particular settings where people are terminally ill or near death, such as aged care environments (NSW Health, 2007; Palliative Care Australia, 2008b). Palliative care uses a multidimensional approach and involves a range of services and health professionals, including occupational therapists (NSW Health Department, 2001).

1.6.17 Palliative care approach
The World Health Organisation (2011) definition stems from the work of Dame Cicely Saunders and states that a palliative care approach should:

- Provide relief from pain and other distressing symptoms;
- Affirm life and regard dying as a normal process;
- Intend neither to hasten, nor postpone death;
- Integrate the psychological and spiritual aspects of client care;
- Offer a support system to help clients live as actively as possible until death;
• Offer a support system to help the family cope during the client's illness and in their own bereavement;
• Use a team approach to address the needs of clients and their families, including bereavement counselling, if indicated;
• Enhance quality of life;
• Be applicable early in the course of terminal illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and;
• Includes those investigations needed to better understand and manage distressing clinical complications.

1.6.18 End-of-life care

End-of-life care is “a continuum of palliative care and is usually used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours, or less” (Palliative Care Programme Working Group, 2012, p. 3). End-of-life care is sensitive to a person’s belief system, including personal, cultural and spiritual values, beliefs and practices, and includes the provision of support to the family and care-givers up to and including, the bereavement period (Rankin & Gracey, 2008).

1.6.19 Hospice

The term hospice refers to a comprehensive service provided to people living with a terminal illness and may also include day programs and community home visiting teams. Hospice care may “include inpatient medical care, respite care and end-of-life care for people who are unable to die at home” (Palliative Care Australia, 2008a, p. 9).

Occupational therapists working in hospices may directly intervene with a person living with a terminal illness or indirectly with their families or care-givers as educators, trainers or as intermediaries with the aim of improving quality of life for all involved (McHugh-Pendleton & Schultz-Krohn, 2013).
1.6.20 Dying

_Dying_ is a unique process that all people experience, with each encountering this stage of life in their own unique way. Dying occurs when a person advances from a living state, to a state of ceasing to be, ending in death (Palliative Care Australia, 2008a). For some people dying is traumatic and frightening, but for others it is a time of transcendence, insightfulness and peace (Kellehear, 2009).

1.6.21 Death

The point of _death_ occurs when there is “permanent cessation of the critical functions of the organism as a whole” (Bernat, 1998, p. 17), with irreversible loss of the control of respiratory and circulatory systems, homeostatic and neuroendocrine regulation, and consciousness (Bruno, Ledoux, & Laureys, 2009).

1.7 Chapter synopsis and overview of the thesis

This thesis is comprised of nine chapters. This chapter has presented an introduction to the thesis topic and provides an overview of the thesis.

Chapter two is a critical review of the relevant literature on death and dying, palliative care, and occupational therapy for people living with a terminal illness. It also states the research aims, specific research questions, and the theoretical underpinnings that shaped this study.

Chapter three presents and justifies the research design and methods. The participants, instrumentation, and data collection methods and analysis are described. The study delimitations, and ethical considerations are then discussed.

Chapter four is the first of four results chapters and provides a snapshot of the sample, describing the demographics of survey participants, their workplaces, and the clients that they treat. This chapter serves as a detailed understanding of the workforce context of
this Australian occupational therapy sample of therapists working with clients with terminal illness.

Chapter five presents therapists’ perceptions of occupational engagement for people living with a terminal illness. This chapter explores the two themes and four sub-themes on occupational engagement that emerged from the data revealing the unique nature of occupational engagement at the end of life as perceived by therapists.

Chapter six explores the scope of the occupational therapy role by identifying the process that therapists follow when working with people living with a terminal illness. The professional reasoning behind therapists’ choices is a key feature of this chapter.

The final results chapter, chapter seven, ascertains the challenges of working with people living with a terminal illness, as well as therapists’ educational needs, and supervision and support requirements.

Chapter eight summarises the achievement of the research aims and integrates the results into the existing body of knowledge. These key findings are then used to expand on the existing knowledge base for occupational therapy practice in this area.

Chapter nine concludes the thesis by discussing the study strengths and limitations, as well as making recommendations regarding policy, practice, theory, education and future research.

This thesis concludes with references and appendixes.
Chapter 2 Literature Review

2.1 Introduction

People diagnosed with a terminal illness face a difficult road as they begin to understand the reality of living with their illness while at the same time trying to make sense of their impending death. Each client will have different illness trajectories and different needs, which results in them requiring different things from palliative care services at different times. Some researchers have said that there is such a thing as a good death, and this largely involves the person receiving good care, being surrounded by social supports and having the opportunity for planning and closure. Palliative care operates on this mission to support and help people prepare and meet their changing needs while improving quality of life. In Australia this happens in a fairly well co-ordinated way with people living with a terminal illness being able to receive care in whatever setting they choose, whether that is the hospital, hospice, or a community setting such as their own home. Occupational therapists are one of the many health professionals who work with people living with a terminal illness, working across a range of service areas such as in oncology units, palliative care services, and community or aged care settings. It has been reported that occupational therapists as having the unique focus of both enabling clients’ needs to be met through enhancing their ability to complete their daily occupations as well as establishing care and support systems to meet their needs towards the end of life.

This chapter further explores the relevant literature and knowledge pertaining to this study. Firstly, to understand the issues experienced by occupational therapy clients in this clinical area, the experience of living with a terminal illness and the processes of dying are presented. This is followed by an overview of the palliative care approach in general, and then occupational therapy practice for people living with a terminal illness more specifically. The gaps in the literature are identified and the need for this study is argued. The theoretical framework, research aims, and research questions used to guide this study are also discussed.
2.2 Terminal diagnoses

Patterns of death are changing due to an ageing population and a rise in chronic illness worldwide. In the Western world, the way death occurs has changed over the last century from ‘sudden’ deaths, such as infections, accidents, and childbirth, to modern day where most people acquire a serious progressive illness towards the end-of-life and die an ‘expected’ death (Murray & McLoughlin, 2012). These illnesses impact a person’s ability to maintain their usual activities until death.

In 2005 cancer and chronic progressive conditions were responsible for approximately 60% of worldwide deaths (Murray & McLoughlin, 2012). This percentage is set to rise by 2030 when an increase in the number of deaths from organ failure, and physical and cognitive fragility, and cancer, will see the expected annual number of worldwide deaths rise from 58 million to 74 million (Murray & McLoughlin, 2012).

The latest figure released from the Australian Bureau of Statistics of registered deaths in Australia was 140,800 (Australian Bureau of Statistics, 2009). Of these deaths, approximately three quarters were estimated to be expected deaths (Palliative Care Australia, 2011). Expected deaths occur following a chronic disease or lengthy progressive illness where the person has an awareness of the terminal nature of their illness (Palliative Care Australia, 2011; Seale, 2000). In an expected death the person experiences a loss of life roles and an increased dependence on others (Seale, 2000). People who have an expected death have time to plan and prepare for death and are often seen by palliative care teams to enhance and support their dying experience (Ashby, 2009). Those not seen by specialist palliative care teams, may still receive services where health professionals employ a palliative approach to their care in recognition of the unique needs leading up to death.

2.2.1 The everyday impact of living with a terminal illness

Receiving a diagnosis of a terminal illness can lead to major disruptions in the activity patterns in an individual’s life (Bye, Llewellyn, & Christl, 2009; Murray & McLoughlin, 2012). Often the person is left disempowered and the future that they had imagined for
themselves and their family is shattered. Instead they now face a reality full of uncertainty over what will happen, and how life may change.

When faced with the shock of their terminal diagnosis a person might experience negative effects to their physical, emotional, social, intellectual or spiritual self (Buckley, 2009; Murray, Kendall, Boyd, & Sheikh, 2005; Murray & McLoughlin, 2012). Physically, people can react in many ways when they first receive their terminal diagnosis. The physical effects can include: nausea and vomiting, feeling faint or weak legged, having a dry mouth or becoming tachycardic. Emotional responses may include anger, frustration, denial or bargaining, along with feelings of hopelessness, depression and anxiety. People may also be impacted socially when faced with a loss of roles and responsibilities both in their home and work environments. This loss may lead to a person withdrawing from their social circles and isolating themselves. Self-esteem can be impacted through a loss of status in being able to complete their occupational roles, and people can feel alone even if surrounded by social supports such as friends and family. Intellectually, a person’s processing skills may slow, resulting in a decreased ability to recall facts and conversations (Buckley, 2009). Spiritually, people may either lose or strengthen their faith (Rahman, 2000). Loss of spiritual self may result in a loss of control and a lack of purpose and direction. For those whose faith is strengthened, the existential distress can be eased, leading to a greater sense of hope and satisfaction in their life (Chochinov et al., 2005; Rahman, 2000).

As their terminal illness progresses clients have been known to experience uncontrolled and distressing symptoms making symptom control a major concern for clients and their families (CareSearch, 2011; Hardy, Maresco-Pennisi, Gilshenan, & Yates, 2008). Common physical symptoms experienced by nearly all those who are dying include fatigue, weight loss, poor appetite, and a general deterioration in their occupational performance (Ashby, 2009; Georges, Onwuteaka-Philipsen, van der Heide, van der Wal, & van der Maas, 2005; Kealey & McIntyre, 2005). Other known symptoms include pain, nausea and vomiting, dyspnoea, and anxiety (Ashby, 2009). Psychosocial symptoms often display themselves as acopia, unclear consciousness, depressive feelings, problems with accepting dependency, and a feeling of meaningless (Georges et al., 2005).
These symptoms have been shown to impact a person’s ability to complete their activities of daily living (Terry, Olson, Wilss, & Boulton Lewis, 2006).

Having a theoretical understanding of when and how to intervene on a range of conditions is important for a health professional, as prognostic uncertainty can hinder health professionals’, clients’ and family members’ abilities to think and plan ahead (Chochinov et al., 2005). Thus, having knowledge of the stages and illness trajectories of different types of conditions may assist health professionals to employ a palliative approach to care.

### 2.2.2 Illness trajectories

Illness trajectories assist health professionals, such as occupational therapists, to plan and deliver appropriate care in order to optimise a person’s quality of life by incorporating both active and palliative management (Lynn & Adamson, 2003; Murray & McLoughlin, 2012). It should be acknowledged that a person may not always follow their predicted trajectory, and the rate of progression may also vary (Palliative Care Australia, 2011).

There are three distinct illness trajectories that have been identified for people living with a progressive chronic illness that will ultimately end in death (Lynn & Adamson, 2003; Murray & McLoughlin, 2012). These three trajectories were initially proposed by (Higginson & Davies, 2004; Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Murray & Sheikh, 2008) after the examination of a large North American data set of people who had died, and later adapted by Lunney et al. (2003) (Figure 1). More recently, these trajectories have evolved and become more defined after qualitative British studies further investigated clients’ experiences in their last years of life (Murray et al., 2005).
Figure 1: Illness trajectories for people with chronic disease (Murray & McLoughlin, 2012)
**Trajectory 1: Short period of evident decline** involves a fairly predictable decline in physical health over weeks, months, and in some cases years, as is typical in progressive cancer (Murray & McLoughlin, 2012). The majority of weight loss, decline in occupational performance, and a decreased independence with self-care tasks occur in the person’s last few months of life. There is often time to anticipate needs and plan for death, and clients usually receive some form of palliative care (Murray & McLoughlin, 2012). Rapid decline tends to occur in the final weeks and days leading up to death (Lynn & Adamson, 2003). In Australia, approximately twenty percent of clients living with a terminal illness follow this illness trajectory (Palliative Care Australia, 2011).

**Trajectory 2: Long-term limitations with serious episodes** refers to people who have organ system failure that often results in long-term functional limitations (Murray & McLoughlin, 2012). People are usually ill for many months and years but have intermittent severe, acute episodes, and often require hospital admissions during periods of exacerbation (Lynn & Adamson, 2003; Palliative Care Australia, 2011). After admission to hospital most people experience a decrease in their occupational performance of ADLs. The timing of the death is unpredictable, but often occurs post complication or exacerbation of symptoms (Murray & McLoughlin, 2012). Twenty-five percent of the Australian population living with a terminal illness are classified in this trajectory and require ongoing disease management and advanced care planning (Lunney et al., 2003; Murray & McLoughlin, 2012).

**Trajectory 3: prolonged dwindling** generally occurs in people who have managed to escape cancer and organ system failure, and instead are likely to die at an older age. The most common causes of death results from brain failure (e.g. Alzheimer’s or dementia), or generalised fragility of multiple body systems. In Trajectory 3 people tend to have poor baseline cognitive and/or physical function that progressively worsens over time. These kinds of clients may lose weight and have a declining occupational performance status, and ultimately may die from an acute event such as pneumonia, or a fractured neck of femur. In Australia approximately 30% of people living with a terminal illness die from Trajectory 3 each year (Palliative Care Australia, 2011).
The implication of treating people who fit under different illness trajectories is that each trajectory has different care needs that utilise palliative care or other health care services in different ways. For example, clients with non-malignant diagnoses may have more prolonged care needs than someone with cancer. Thus care in a hospice setting is not immediately suitable upon diagnosis as it can be for some forms of cancers. However, regardless of diagnosis and illness trajectory, everyone who is diagnosed with a terminal illness will eventually go through one of four identified phases of dying as they begin to decline.

The four phases leading up to bereavement were developed by the Australian Association for Hospice and Palliative Care in 1993 (Smith, 1993) and further developed in 1996. Each phase provides a clinical indication of the person’s care needs and often correlates with length of survival and helps to predict resource allocation (Eagar, Gordon, Green, & Smith, 2004). Phases do not always occur sequentially, with individual’s changing back and forth between all or some of the phases. The phases include: stable, unstable, deteriorating and terminal (Palliative Care Outcomes Collaboration, 2012).

Stable people have adequate symptom control and have planned further interventions to ensure the maintenance of symptom control and quality of life (Palliative Care Outcomes Collaboration, 2012). Caregiver or family members do not report any issues and all client and caregiver needs are met through their care plan.

A person is considered unstable if they or their caregiver experience new unexpected problems or a rapid increase in the severity of existing problems (Palliative Care Outcomes Collaboration, 2012). These problems require urgent change in their existing care, emergency treatment, or intervention by the multi-disciplinary team (Eagar et al., 2004).

A person enters a phase of deterioration when they have a gradual worsening of existing symptoms or they develop new, but expected problems that are not urgent or require emergency treatment (Palliative Care Outcomes Collaboration, 2012). New care plans
need to be implemented and have close monitoring. Gradually worsening distress, practical or social issues arising from the person’s illness for the caregiver or family requires support and counselling as necessary (Palliative Care Outcomes Collaboration, 2012).

When a person is at the end-of-life, death is imminent in a matter of days, and no acute intervention is planned or required (Palliative Care Outcomes Collaboration, 2012). A person who is in this final phase may be profoundly weak, bed bound, drowsy for extended periods, be disorientated, have a limited attention span, a disinterest in eating or drinking, or have difficulty swallowing. Interventions in this phase aim to increase physical, spiritual and emotional well-being of both the individual and their care giver or family (Palliative Care Outcomes Collaboration, 2012).

During these four phases it is likely that most people will have their care linked to a palliative care service (Palliative Care Outcomes Collaboration, 2012). However those who are not linked to a palliative care specialty are often cared for by others using a palliative approach in facilities such as nursing homes.

### 2.2.3 Palliative care

Palliative care is a medical speciality that focuses on the maintenance of quality of life and effective symptom control for people who are living with a terminal illness. Palliative care was founded by Dame Cicely Saunders at St Christopher’s Hospital in the United Kingdom in the late 1960s (Allen, Chapman, O'Connor, & Francis, 2008; Brooksbank, 2009). Saunders changed the medical perception of dying as being a failure of medical care, to being instead seen as a human event which needed to be viewed holistically (Allen et al., 2008). Her approach focused on pain management to ensure that dying was a comfortable process, while also incorporating spirituality, and a person’s social and emotional contexts in all aspects of care (Allen et al., 2008). This approach gained worldwide acceptance and became known as the modern palliative care movement.
Australia’s palliative care movement began in the mid 1980s using the same philosophical approach as the United Kingdom. Today, Australian palliative care principles involve an active approach to symptom control coupled with a focus on quality of life and care that encompasses the physical, social, emotional, psychological and spiritual dimensions (Brooksbank, 2009).

Referral to palliative care services is an indication that a disease or condition is incurable and that active treatment will cease for the person living with a terminal illness (Boog, 2008; Saunders, 1995). Palliative care in Australia is typically delivered by primary care, or specialist care services (NSW Health, 2007, 2010). Primary care services comprise of the groups of services that follow the person living with a terminal illness along their continuum of care, which begins at the time of initial diagnosis and finishes at the end-of-life, and subsequent bereavement period.

Primary palliative care services consist of an interdisciplinary team who share common goals and collaborate together in the planning and delivery of care for the person living with a terminal condition (NSW Health, 2010; Palliative Care Australia, 2008). Interdisciplinary team members may include: general practitioners, medical or radiation oncologists, surgeons, nurses, allied health professionals, including occupational therapists, pastoral care workers and volunteers (NSW Health, 2007; Palliative Care Australia, 2008). The person with a terminal condition may have pre-existing relationships with the health professionals, or be receiving interventional care in conjunction with more palliative approaches at the time of service delivery (NSW Health, 2010).

Primary care team members’ roles include the provision of “supportive care, including pain and symptom control, social, spiritual and emotional support, education and bereavement risk assessment for clients, caregivers and family members” (NSW Health, 2007, p. 9). The team provides supportive care from initial referral to diagnosis, and through to death and beyond.
Primary care services are supported by specialist palliative care services (NSW Health, 2007). Specialist care services in palliative care consist of interdisciplinary health care professionals whose substantive work is with clients with a terminal condition. These health professionals have recognised skills, knowledge and experience in palliative care (NSW Health, 2010). Specialist services utilise an interdisciplinary approach to complete comprehensive assessment, consultation, and ongoing care. Specialist care provision is typically episodic in nature, occurring when clients have complex care needs or unstable symptoms, and are completed in conjunction with their primary palliative care service (NSW Health, 2007). Care can be provided in a range of settings including community, home, hospitals, aged care homes, hospices, and palliative care units (Palliative Care Australia, 2008b). The place of care is typically dependant on the person or their family’s preference.

In palliative care the person living with a terminal illness and their family are the focus of care (Abu-Saad & Courtens, 2001; NSW Health, 2010). Both the client and their family have access to assessment and interventions from the primary and/or specialist care team, whereby health professionals such as occupational therapists, should aim to meet and respect both parties’ needs where possible.

Palliative care involvement traditionally occurs in trajectory one, predominately for people with cancer. Recently, there has been push for palliative care services to include both clients with cancer and those with non-malignant diagnoses as there is evidence to suggest clients with chronic and progressive conditions experience the same symptoms and severity of symptoms as people with cancer (Edmonds, Karlsen, Khan, & Addington-Hall, 2001; Gill, Gahbauer, Han, & Allore, 2010; Lunney et al., 2003; Mitchell, Johnson, Thomas, & Murray, 2010). Mitchell and colleagues (2006) argue a need for an identification system to be developed that classifies people with palliative care needs, rather than by diagnosis. However regardless of what illness trajectory someone will take, all will experience the process of dying and hope to experience a ‘good death’.
2.2.4 The experience of dying a ‘good death’

Dying is a unique, subjective and personal experience that is influenced by a variety of issues (Boog, 2008; Higginson & Davies, 2004). Regardless of these issues research has shown that people wish to die a ‘good death’ (Kellehear, 2009). A ‘good death’ refers to the process or style of dying that occurs in the lead up to death rather than the particular time point when death occurs (Kaufman, 2000). Notions of a ‘good death’ have been reported in the literature for many years; however it is not always clear what dying a good death involves. This lack of clarity has led people to fear dying from a bad death, more than death itself (Ashby, 2009). A good death has been defined by many attributes.

Kellehear’s (1990) study of 100 people dying from cancer was the first to identify the features that determine a ‘good death’. The five main features of a good death include: (i) an awareness of dying by the individual and their close network; (ii) social adjustments and preparations for death, such as spending time with and entrusting personal affairs to loved ones; (iii) public preparations for death for example making financial, medical and funeral arrangements; (iv) relinquishing roles and responsibilities like work; and (v) finally saying goodbyes both formally and informally (Kellehear, 2009). Consequently, Kellehear’s notions of a ‘good death’ involve the person remaining socially engaged.

Dying a good death has also been shown to include ongoing engagement in meaningful activities and routines. Occupational therapy researchers Payne, Langely-Evans and Hillier (1996), completed semi-structured interviews on perceptions of ‘good’ and ‘bad’ deaths with 18 people living with a terminal illness and 20 staff working in an English hospice. Findings from this study suggest that a person is perceived to die a good death if they remain engaged in meaningful activities and routines; stay pain free; have family involved in care; find closure; reduce stress and anxiety levels; and are enabled to die in a place of their choosing (Payne, Langley-Evans, & Hillier, 1996).

In a later study by Steinhauser et al. (2000) of 340 people who were dying and their families (n=332), physicians (n=361), and other care providers (n=429), a good death was defined to be one in which the client received not only good physical care, but also psychosocial and spiritual care. Good care involved clear decision making, pain and
symptom management, preparation for death, completion, contributing to others, and affirmation of the person as a whole. Both the family and the client also placed emphasis on making contributions such as gift giving, minimising family burden, planning ahead, arranging affairs and saying goodbye. Clients also sought to understand the meaning of their life, aimed to maintain roles for as long as possible, and wished to remain useful in order to maintain dignity.

Emanuel, Bennett, and Richardson (2007) have also proposed three key elements to the dying process that assist in a person dying a good death. Firstly, the practical elements of completing tasks which prepare for death such as leaving a financial legacy, completing end-of-life planning, ensuring there is ongoing caring for dependents, and saying final good-byes to loved ones. Secondly, relational elements which involve: engagement with others; remaining engaged with other roles; passing on a legacy to others; and giving permission for loved ones to keep on living without them. Lastly, the personal elements enables the person to foster growth and complete their life narrative and assist the person to adapt to their changing identity and loss, reach closure, and existential tasks such as questioning their mortality and completing their last rites of passage (Emanuel et al., 2007).

Therefore, whether a person has a good death is determinant not only by the disease progression, but also by the way the person living with a terminal illness and their significant others perceives it. It has also been shown to impact the treating health professionals management of the terminal illness and where the person dies (McKechnie, Macleod, & Keeling, 2007).

2.2.5 Place of death

In Australia, modern death is viewed by society to take place in a hospital once you have reached old age, usually following a progressive, chronic condition (Bruno et al., 2009; McKechnie et al., 2007). However, over the last 100 years there has been a change in how and where people are cared for when they are dying, as well as their place of death (Palliative Care Australia, 2011). The last century saw a shift from people dying at home,
and being cared for and supported by their family, friends or the community, to people
dying in a hospital or institutional setting (Bruno, et al., 2009; Palliative Care Australia,
2011). Approximately 90% of care occurs within the home environment (Hinton, 1994),
and worldwide 50-70% of individuals who are receiving care for a terminal condition
would prefer to continue to stay at home at the end-of-life (Davies, 2004). In Australia
most people living with a terminal illness will spend more time living in the community
and acute hospitals, than they will in hospices or receiving palliative care services (Bruno
et al., 2009).

A systematic review by Gomes and Higginson (2006) found 17 different factors
influenced the place of death for a person, with five major factors determining whether
an individual died at home. These factors were low functional status, preference, use and
intensity of home care, living arrangements and extended family support. People were
11 times more likely to die at home if they were functioning at a higher level. People
who expressed a desire to stay at home during their end-of-life care were up to eight
times more likely to die in their home environment than those who did not state their
wishes. People who had access to formal home health care services and received care on
a frequent basis had a greater chance of dying at home than those without access. People
were also seven times more likely to die at home when surrounded by a close family unit
with the ability to provide care (Gomes & Higginson, 2006).

Nonetheless, while most people say that they wish to die at home, more current
literature suggests that most will ultimately die in an institutional setting such as a
hospital or residential aged care setting (Palliative Care Australia, 2011; Quinn, Hudson,
Ashby, & Thomas, 2008). For instance only 16% of people die at home compared to the
20% who die in hospices, the 10% die in nursing homes, and the 54% who die in
hospitals (Palliative Care Australia, 2011).

2.2.6 Summary

Therefore, research suggests that the diagnosis of a terminal illness will heavily impact on
a person’s life. This impact can be minimised if the person with a terminal illness and
their family receive good care from a palliative care team, and have a social awareness of
dying. During this journey from diagnosis to death it is likely that an occupational
therapist has played a role in assisting the client to die a good death.

### 2.3 Occupational therapy

Occupational therapy is a diverse and multifaceted profession, which promotes health
and participation through people’s engagement in meaningful occupations. Therapists
view people as occupational beings who “need to be enabled to engage in the
occupations of their need and choice, to grow through what they do, and to experience
independence or interdependence, equality, participation, security, health and well-being”
(Wilcock & Townsend, 2008, p. 186).

Everyday occupations, such as getting dressed or making a meal, are used in a
therapeutic manner to assist individuals or groups to participate in their life roles, within
their chosen environment (American Occupational Therapy Association, 2008). People
play many different life roles as part of their daily occupations and these can include
roles such as daughter, worker, or friend. People use each role to help them negotiate
life, often completing an occupational role without knowing it (Dickie, 2009; Emanuel et
al., 2007). As shown previously, people with terminal illness face many changes to their
roles and occupations and require the assistance of occupational therapists.

### 2.4 Occupational therapy for people living with a terminal illness

#### 2.4.1 Australian occupational therapy demographics

There are 13 611 occupational therapists registered as working in Australia today, some
in a role with people who are terminally ill (AHPRA Occupational Therapy Board,
2012). Despite the important role played by occupational therapists in palliative care
teams, there is no current data available that profiles how many therapists are providing
services to people with terminal illness in Australia or worldwide, their personal
demographics such as age or gender, their years of experience and their geographical
location, their type of service provision, for example, in the hospital, hospice, or
community settings, clients’ diagnoses or the caseloads where therapists encounter these clients.

Instead, what exists are limited profiles of therapists working with people living with a terminal illness. The last reported Australian occupational therapy workforce study was over a decade ago and gave negligible demographics for people living with a terminal illness (Australian Institute of Health and Welfare, 2010). This profile looked at the profession as a whole and was obtained through a written survey sent to registered clinicians and OT Australia members, and had 3769 respondents. Palliative care had the lowest level of employment per clinical area, ranking ninth out of nine clinical areas with only 1.6% of respondents working in this area (Australian Institute of Health and Welfare, 2010). The cohort of palliative care clinicians showed a variance in the demographics from the total Australian occupational therapy population (Australian Health and Welfare Institute, 2006). For example, these respondents were slightly older on average (39.8 years), and had a higher proportion of females (94.7%) working with people living with a terminal illness. The palliative care respondents had spent more years working as occupational therapists (Mean 12.7 years) and had more respondents employed in part-time positions (52.8%) than the collective number of respondents did (Australian Institute of Health and Welfare, 2006).

In addition to this workforce profile, there are only three Australian studies that report any form of demographic data on therapists working with people living with a terminal illness (Bye, 1998; Dawson & Barker, 1995; Keesing & Rosenwax, 2011). In all of these studies, each had small sample sizes, were state-based studies, and did not contain similar enough demographic data to allow for comparison, or compilation of data to get a sense of the profile of therapists working with this client group in Australia, or the context of their practice and their clients’ demographics.

While there is only limited knowledge on the workforce profile in this field of occupational therapy, we do know that the role has changed over time to lead to modern occupational therapy practice with this client group.
2.4.2 The history of the occupational therapy role for people living with a terminal illness

The occupational therapy role for people living with a terminal illness has changed over time as practice has evolved in this area. In the 1980s, research and literature first attempted to define the occupational therapy role with people with a life-limiting illness. At this time, authors aimed to tease out what a palliative approach would require for clients who were dying (Cusick, Lawler, & Swain, 1987; Dawson, 1982; Holland & Tigges, 1981; Pizzi, 1983).

Initial occupational therapy literature focused on describing the person’s experience of dying and their unique needs at this time and was predominately based of expert opinion (Flanigan, 1982; Pizzi, 1984a; Pizzi, 1984b). It recognised that some clients preferred to play a passive role, while others wished to remain independent for as long as possible (Flanigan, 1982). Authors such as Pizzi (1984a) argued that by remaining engaged in life, people maintained their quality of life for longer. Through engagement in occupations, people living with a terminal illness were thought to have a greater sense of competence, productivity, and resourcefulness, while feeling mastery over their self, the environment, and the disease process (Pizzi, 1984a).

Dawson (1982) completed the first published qualitative study on occupational therapy practice in Australia with people who were terminally ill. Dawson described the role of the occupational therapist through conducting and analysing seven interviews with both occupational therapists (n=3) and clients with a terminal diagnosis (n=4). She defined the role of the occupational therapist as one which: (i) provided a supportive caring role using therapeutic situations; (ii) assisted clients to remain at home for as long as possible; and (iii) offered practical assistance with any problems arising from an individual’s daily occupations (Dawson, 1982).

In the late 1980s the first occupational therapy textbook relating to the philosophy and treatment of people living with a terminal illness was published in the United States of America (Tigges & Marcil, 1988). Tigges and Marcil (1988) wrote this textbook due to the emerging role for occupational therapists working with people living with a terminal illness.
illness. At the time, this textbook was ground-breaking, as palliative care was in its infancy and education about caring for people living with a terminal illness was not part of occupational therapy curricula. While the intervention processes were descriptive rather than evidence-based, this textbook provided therapists with an understanding of the occupational therapy assessment and intervention processes, and was influential in establishing the occupational therapy role with this client group (Tigges & Marcil, 1988).

The second key textbook on occupational therapy practice in palliative care was published in 1997 in the United Kingdom, and authored by Jill Cooper. This textbook had a strong focus on oncological conditions and provided therapists with both anecdotal and evidence-based intervention strategies, and gave advice on how to deal with dilemmas faced by occupational therapists working in this clinical area (Cooper, 1997). A second edition of the book was published in 2006 and was updated to include more intervention strategies for a larger range of diagnoses than cancer, and a discussion on outcome measures for use with people living with a terminal illness (Cooper, 2006). This textbook continues to play a major role in educating therapists on the core skills required to work in oncology and palliative care.

In the late 1990s, researchers began to tease out the differences experienced by therapists working with people who were terminally ill versus those in other areas of practice. Traditionally, the occupational therapy profession is predominately aligned with a rehabilitative approach that focuses on independence and the restoration of meaningful occupations. In standard practice people get better after their illness or injury and remedial or short-term compensatory techniques or equipment are put in place. In palliative care occupational therapy, clients experience fluctuating changes in their ability to complete their activities of daily living, and deteriorate in function regardless of occupational therapy intervention (Cusick et al., 1987). Therefore, therapists working in palliative care were found to utilise a different framework to traditional occupational therapy practice in order to face the dual reality of treating a client who is not just living, but also dying (Bye, 1998).
A qualitative study by Bye (1998) established that occupational therapists who work with people living with a terminal illness reframe the focus of their daily practice, the occupational therapy process, and the expected outcomes of therapy. Through in-depth interviews and participant observation with 10 Australian occupational therapists working with this client group, Bye (1998) found that occupational therapists conceptually reframe practice and work with clients to ‘affirm their life’ and ‘prepare for death’. For instance, assessments in palliative care displayed distinctive characteristics, with a low-key approach being taken rather than the more traditional formalised or standardised assessments used in other clinical areas. Interventions were client centred, helping the client to build against loss, and enabling their coping abilities through education and functional retraining (Bye, 1998).

Bye (1998) suggested that occupational therapists help a client to achieve a sense of ‘normality’ in an otherwise ‘changed reality’ by empowering them to complete activities in familiar surroundings. Therapists perceived that a person could regain control over both their physical and psychological self through: the involvement in routines and meaningful activities; having a greater sense of control over caregiving; setting goals that were meaningful to the end-of-life and that promoted closure; and achieving desired outcomes through occupational therapy interventions such as equipment prescription, home assessment and returning home to die.

Internationally, position statements and clinical guides have been developed to better establish the scope of the occupational therapy role when working with people living with a terminal illness. In America position statements were developed on “The role of occupational therapy in end-of-life care” (Burkhardt et al., 2011) and “Occupational therapy and hospice” (Trump, Zaboransky, & Siebert, 2005), while Canada produced a position statement on “Occupational therapy and end-of-life care”. The United Kingdom were the first to develop clinical guidances on “Occupational therapy intervention in cancer: Guidance for professionals, managers and decision-makers” (College of Occupational Therapists Specialist Section for HIV/AIDS, 2004). The purpose of these relatively recent position statements was to describe the role of the occupational therapist when working with people living with terminal illnesses. Each of the position statements shared common themes on the role
including occupational therapists: (i) being integral to quality care for people living with a terminal illness; (ii) having an ability to improve quality of life by assisting in pain and symptom control; and (iii) keeping clients engaged in meaningful occupations (Burkhardt et al., 2011; Canadian Association of Occupational Therapists, 2011; College of Occupational Therapists Specialist Section for HIV/AIDS, 2004; Trump et al., 2005). However, the United Kingdom guideline described occupational therapy interventions for people with cancer diagnoses only, rather than looking at a range of life-limiting diagnoses (College of Occupational Therapists Specialist Section for HIV/AIDS, 2004).

More recent research such as the grounded theory study by Keesing and Rosenwax (2011) suggests that within the modern day Australian context, occupational therapists have a more limited perception of their role than what has previously been described in the literature. Instead of focusing on engagement in meaningful occupations, which is central to traditional occupational therapy practice and evident in earlier studies on occupational therapy for people with terminal illness, the 18 therapists in the Bye (1998) study viewed their role as being limited to equipment prescription and home assessments, and discharge planning. This change in practice is thought to be due to the reactive nature of service provision, and a misunderstanding of the scope of the occupational therapy role with people living with a terminal illness by both occupational therapists and their colleagues (Keesing & Rosenwax, 2011).

The literature suggests that initially the scope of the role was much wider than it is today as it was able to incorporate core elements of occupational engagement into practice. The most recent study to delve into occupational therapy practice suggests that in one state in Australia, therapists have significantly reduced their role in comparison with the last three decades of research. This is of concern and points to the need to explore the scope of the occupational therapy role with people living with a terminal illness from a larger context than one small sample from one geographical location. In particular, an empirical understanding of occupational engagement and how occupational therapists facilitate this at the end of life is vital to ensure practice does not become limited to home modification and equipment prescription.
2.4.3 Occupational engagement for people living with terminal illness

As previously discussed, a person living with a terminal illness faces continuing loss as their condition deteriorates. These losses can occur in many facets of a person’s life and impact their ability to continue to engage in their meaningful occupations. In the 1990s occupational therapy literature and research across all areas of practice attempted to explore the meaning and contribution of occupation in people’s lives (Canadian Association of Occupational Therapists, 1997; Law, Steinwender, & Leclair, 1998). This emphasis on occupational engagement in the 1990s was also evident in the occupational therapy research related to people with terminal illness (Bye, 1998; Dawson, 1993; Dawson & Barker, 1995; Hasselkus, 1993; Hasselkus & Dickie, 1994; Penfold, 1996; Söderback & Paulsson, 1997; Thibeault, 1997).

It was argued that through engagement in their typical occupations clients, are able to put their life in order and maintain a sense of normalcy by continuing to participate in their daily routines, despite facing their mortality (Bye, 1998; Tigges & Marcil, 1988). Hasselkus (1993) documented the importance of keeping a person engaged in their daily occupations at the end of their life. This auto-ethnography about caring for her mother, who was dying, shed light onto the need for people to remain engaged in activities that helped to put their “life in order” (Hasselkus, 1993, p. 718). Hasselkus (1993) spoke of the significance of letting the person with a terminal illness choose topics of conversation and how these simple conversations would frequently relate to the meaningful and often routine activities people wished to complete. Hasselkus (1993) argued that this engagement in everyday occupations allowed the opportunity for the person living with a terminal illness to say goodbye and face death.

Facilitating occupational engagement was also deemed an important contribution by therapists working in the hospice setting. Dawson (1993) completed an ethnographic study, which examined the contribution played by occupational therapy groups within an Australian hospice setting. The study found that occupational therapists assisted individuals to retain occupational roles that were perceived as important by the client and the caregiver. Participation in group-activities allowed the clients to reconnect with activities that gave their lives meaning. Dawson (1993) argued that given the limitations
of time, and deteriorating physical ability of the clients, occupational therapists should focus on productivity, ability and wellness, and not on pathology or the life-limiting diagnosis (Dawson, 1993).

This emphasis on the importance of occupational engagement has continued into more current literature. “Occupational deprivation” has been used to recently describe the progressive loss or removal of occupation for people living with a terminal illness as (Keesing & Rosenwax, 2011, p. 335). Occupational deprivation has consequences that can affect a person’s physiological and psychological health (Keesing & Rosenwax, 2011). This is supported by other literature revealing that disengagement in daily routines due to the impact of terminal illness, coupled with an inability to complete meaningful activities, impacts on a person’s sense of self including their body image, senses, valued occupations, future experiences and identity (Lloyd-Williams, Reeve, & Kissane, 2008).

These studies also support findings from numerous qualitative studies which suggest that a lack of engagement in meaningful occupations leads to decreased satisfaction and fulfilment in life for people with advanced cancer, chronic and life-limiting illnesses (Jacques & Hasselkus, 2004; la Cour et al., 2009; la Cour, Josephsson, Tishelman, & Nygard, 2007; Lexell, Lund, & Iwarsson, 2009; Vrkljan & Miller-Polgar, 2001). Jacques and Hasselkus’ (2004) ethnographic study of an American hospice found that occupations assisted people to prepare for death by allowing them to make amends, share their lives and history, and continue to make decisions and exercise control. In addition, la Cour et al.’s (2007) phenomenological study found that creative activity at the end-of-life strengthens connections to life by allowing participants to actively engage in their chosen occupations, and reinforces that they are active and valued people regardless of their diagnosis.

Research also illustrated that while engagement in occupations remains important for people living with a life-limiting illness, the way people conduct their occupations may change (Doble & Santha, 2008; Lyons, Orozovic, Davis, & Newman, 2002). A qualitative study by Lyons et al., (2002), using the Doing-Being-Becoming framework developed by Wilcock (1999), looked at how 23 clients of a hospice day program in
Australia continued to engage in their chosen occupations. Many of the study’s participants had difficulty facing the loss of their daily occupations and struggled with their increasing dependence on others as their illness progressed. However, through participation in the day hospice program, participants were able to maintain a sense of well-being, and decrease feelings of boredom and isolation by ‘doing’ activities. Participants considered that ‘being’ a part of the hospice program by sitting and watching others complete activities was just as important as actually ‘doing’ the activity. Attending the hospice day program gave participants a sense of belonging, enjoyment and support. There was a sense of ‘becoming’ felt by participants who engaged in reflective activities that promoted self-affirmation and a greater insight into themselves as people. Participants gained unexpected new learning experiences by trying new unfamiliar activities that provided a challenge. Lyon’s and colleagues (2002), therefore found that it was vital for people living with terminal illness to continue engaging in their meaningful occupations, as well as new ones, albeit in a hospice context.

Occupational therapy research and literature to date has revealed that people living with a terminal illness strive to continue to remain engaged in occupational activities despite their losses for as long as possible. As a result, authors have argued that people living with a terminal illness should be given the right to choose to participate in life “even in the face of imminent death” (Marcil, 2006, p. 27). Occupational engagement allows people to maintain competence in life tasks, and mastery over self and the environment in their final stages of life and lessens their chance of having unmet occupational needs at the end-of-life (Pizzi, 1984a).

The research on occupational engagement for people living with a terminal illness is limited to small-scale qualitative studies, each looking at occupational engagement from the client’s perspective not the therapists. There is a need for greater understanding of what therapists’ perceive occupational engagement encompasses for people who are terminally ill, and if they believe that there are unique occupations at the end-of-life. Knowledge of therapists’ perceptions would reveal how occupational engagement is facilitated on a day-to-day basis at the end-of-life and the professional reasoning that underpins their work. Therefore it is time for a larger study of everyday occupational
therapy practice to reveal more about therapists’ practices with people living with a terminal illness, and their professional reasoning around this issue.

2.4.4 The occupational therapy process for people living with a terminal illness

To date there is no clear occupational therapy process outlined in the literature for therapists treating people living with a terminal illness. Worldwide only a small number of studies have attempted to describe the occupational therapy role and therapists’ practice with people living with a terminal illness. However, no single study has ever investigated the processes that a therapist follows from the time of their client’s referral through to their discharge when working with this caseload. Instead only partial elements of the occupational therapy process have been described in literature that are either based expert opinion, descriptive reviews, or have small sample sizes.

2.4.4.1 Occupational therapy theoretical frameworks

Prior to commencing the occupational therapy process with a client, therapists should first identify the theoretical base and framework that guides their work (Pizzi, 1983). Theoretical frameworks for practice with people living with a terminal illness are not well documented with only one study describing the benefits of using an occupational therapy framework with this client group (Costa & Othero, 2012). The authors of this review concluded that the Model of Human Occupation (MOHO) can help a person living with a terminal illness to maintain their occupational identity and ascertain their life narrative, all while redefining life roles. The MOHO is also thought to provide a framework for assisting the person to realise their last wishes and enable quality of life (Costa & Othero, 2012). While this article has outlined one framework for use with people living with a terminal illness, it is has not been determined as to whether Australian therapists are using this framework, or if they have preferences towards using other theoretical frameworks.
2.4.4.2 Referral

The first step of the occupational therapy process involves receiving a referral (College of Occupational Therapists, 2011). Two studies have looked at referral as part of practice with people living with a terminal illness. A Swedish study of 102 clients and 11 physicians found that clients were under-referred to occupational therapy despite being assessed as having unmet needs suitable for occupational therapy referral (Söderback, Pettersson, Von Essen, & Stein, 2000). Referrals were most likely to occur if the client was over 66 years of age, in an active phase of their disease, and had less than 6 months left to live. Women were perceived as more likely to need supportive care and advice to complete their everyday occupations, while men required more instructional assistance on how to adapt their occupations to meet their current occupational performance status (Söderback & Paulsson, 1997). An Australian study of 120 clients with cancer also found that clients were not being referred to occupational therapy as often as they should be (Taylor & Currow, 2003). This study showed that at least one in 10 clients should be referred to occupational therapy, with 30% of the clients reporting they had unmet needs in their ability to perform their occupations. Women reported having more unmet needs than males, and older clients had more unmet needs than younger clients (Taylor & Currow, 2003). While these studies’ findings both show that there are limitations with referral to occupational therapy for people living with a terminal illness, they do not state who are the main referrers to occupational therapy, or the reasons for referral.

2.4.4.3 Assessment

Assessment, which is the next stage in the occupational therapy process after a referral (Chilsholm & Schell, 2014), has been documented in three international literature reviews and two Australian studies. The first published paper to report on assessment processes for therapists working with people living with a terminal illness in America was Pizzi (1984a). Pizzi outlined in his review of the literature that assessments should be composed of four areas: identifying the person’s occupational history, ascertaining how the person uses and structures their time in order to make temporal adaptations, establishing their occupational performance status through the completion of ADLs, and determining the person’s bio-medical details, such as their pre-existing conditions and
new symptoms in order to adapt their occupations (Pizzi, 1983). A Canadian opinion piece agreed with these assessment components and concluded that assessment for people living with a terminal illness should contain: an occupational history, temporal adaptation, and assessment of the person’s occupational performance (Llyod, 1989). A literature review published in the mid-1990s found that assessments should include: functional assessment of components of a person’s usual lifestyle, determining the effects of their illness on functional tasks, identifying their rehabilitation priorities and how they spend their day, as well as how the illness has impacted on their ability to complete their ADLs and roles, and any concerns they have with their inability to carry out previously completed ADLs (Penfold, 1996). Bye’s (1998) qualitative study completed with Australian therapists reported that assessments should be viewed as a continual process that reflects the changing nature of the client’s illness. Assessment is also used to identify the client’s problems relating to their deteriorating occupational performance and changing roles, the care-giving and support systems and environment. This study also found that therapists’ focus shifts from assessing the client to assessing the care-giver in the last stages of life (Bye, 1998).

The only study to mention the specific assessments used by therapists with this client group was an Australian study (Taylor & Currow, 2003). Taylor and Currow (2003) aimed to determine what clients would benefit from occupational therapy involvement using four self-reported assessments. This study used the Modified Barthel Index, the Modified Lawton Instrumental Activities of Daily Living, and the Eastern Co-operative Oncology Group (ECOG) and ST-ADL as assessment tools to identify if clients had unmet occupational needs. This study concluded that without the use of screening tools, the needs of a cancer population may go unmet or unrecognised. Thus, the authors recommend the use of a screening tool on referral to measure changes in functional levels and to aid in determining who may benefit from occupational therapy services. (Taylor & Currow, 2003).

Overall, while these studies suggest the assessment domains and specific assessments (standardised and non-standardised) that might be relevant to therapists, an updated exploration into the assessment practices of therapists working with people living with a
terminal illness needs to occur to identify current assessment use and assessment domains being utilised by therapists.

### 2.4.4.4 Goal setting

Once assessments have been completed, goals should be set with clients (Chilsholm & Schell, 2014). Since the inception of palliative care occupational therapy, studies suggest that the overall goal of occupational therapy for people living with a terminal illness is to enable occupational performance or engagement, provide support, find symptomatic relief from pain and suffering, and improve quality of life (American Occupational Therapy Association, 2011; Holland & Tigges, 1981; Keesing & Rosenwax, 2011). Goals tend to be short-term and flexible due to the client’s fluctuating occupational performance status, and set with the client and/or the care-giver (Holland & Tigges, 1981; Llyod, 1989; Svidén, Tham, & Borell, 2010). They aim to assist the person to manage their ADLs, increase their ability to remain in their own home, and to give the person a sense of satisfaction and well-being (Frost, 2001; Schleinich, Warren, Nekolaichuk, Kaasa, & Watanabe, 2008; Söderback et al., 2000). The information on goal setting practices is limited, especially within the Australian context. Further research needs to investigate the types of goals set with this client group, the focus of these goals and their alignment with palliative care aims, and whether interventions target these goals.

### 2.4.4.5 Intervention

Intervention, which is the next step of the process, should ideally focus on meeting a client’s goals (Chilsholm & Schell, 2014). Numerous studies have described the interventions that therapists complete with their clients living with a terminal illness (Armitage & Crowther, 1999; Cooper & Littlechild, 2004; Hoy, Twiggg, & Pearson, 2008; Kealey & McIntyre, 2005; Llyod, 1989; Penfold, 1996; Vockins, 2004). The most commonly cited therapeutic interventions include: addressing occupational performance issues in ADLs, psychosocial issues (including stress and fatigue), exercise programs, positioning and comfort care, splinting, energy conservation and fatigue management, functional mobility, adaptive and assistive equipment, home assessments, and education.
and supportive care for the care-givers and family (Canadian Association of Occupational Therapists, 2011; Cooper, 2006b; Cooper & Littlechild, 2004; Fialka-Moser, Crevenna, Korpan, & Quittan, 2003; Keesing & Rosenwax, 2011; la Cour et al., 2009; Saarik & Hartley, 2010). Yet only a limited number of studies have reported the efficacy of these interventions with people living with a terminal illness (Saarik & Hartley, 2010). Only one of the recent studies has looked at what interventions Australian therapists are completing with this client group. This study by Keesing and Rosenwax (2013) reported that therapists’ interventions are predominately limited to equipment prescription rather than interventions that target a more global enabling of occupational engagement at the end of life. Thus, the current focus of Australian occupational therapy interventions needs to be established.

2.4.4.6 Measuring outcomes

Measuring outcomes, which is the final stage of the occupational therapy process (College of Occupational Therapists, 2011), has been notoriously difficult to determine for occupational therapy practice for people living with a terminal illness (Pearson, Todd, & Futcher, 2007). An Australian study aimed to determine which quality of life tool was appropriate to demonstrate the effectiveness of occupational therapy interventions for this client group. This literature review found 24 assessment tools to meet their criteria; however no one outcome measure was found to be better than another, with most not being sensitive enough to show change. This paper concluded that it may be feasible to use quality of life tools to measure occupational therapy outcomes with these clients; however it may be unrealistic to administer the same pre-and-post assessments depending on the person’s intervention goals (Pearson et al., 2007). This has been the only study on outcome measurement for occupational therapy for people with a terminal illness. While it has reviewed what outcome measures exist for potential use by therapists, it has not identified which outcome measures therapists used as part of their daily practice.

The lack of knowledge on the occupational therapy process for people living with a terminal illness points to the need for further investigation. Investigation into the day-to-
day processes which occupational therapists follow, including their referral practices, assessment use, goal setting practices, interventions, and outcome measurement use needs to occur to better define the occupational therapy role.

2.4.5 Challenges to practice

It has been reported that therapists face many challenges when working with people living with a terminal illness (Cooper, 2006a). These challenges often present, not only because therapists lack an evidence base to their role, but because they are faced with the contradiction of treating clients who are not only living but also dying (Bye, 1998). This contradiction may lead to decreased job satisfaction, as therapists face the challenge of keeping faith in their therapeutic abilities even when their clients may never show any form of tangible functional improvement, or achieve their occupational goals (Bennett, 1991).

Commonly reported challenges for therapists working in this area include, but are not limited to, the following: role ambiguity and having a poor understanding of the occupational therapy role; having a limited evidence base to guide practice; identifying with the client if they are of a similar age or background; communicating with people who are dying and families who are grieving; breaking bad news; time management; lack of supervision; facing constant loss and death; insufficient funding and resources; and finding a spiritual direction to cope with being surrounded by death (Bailey, 1988; Bennett, 1991; Cipriani et al., 2000; Cooper, 2006a; Halkett, Ciccarelli, Keesing, & Aoun, 2010).

To cope with facing the challenges of constant deterioration and loss of life of their clients on a daily basis, the literature reports that therapists employ numerous coping strategies. These coping strategies include: having a belief that a client is no longer suffering and is in peace; debriefing with peers about their experiences; believing that death is a normal part of life; engagement in religious or spiritual beliefs; establishment of clear boundaries, with occasional avoidance and withdrawal from the situation; offering opportunity for sympathy, support and humour to the family as required; and
finally through the completion of self-nurturing activities such as leisure or exercise (Bennett, 1991; Cipriani et al., 2000; Martin & Berchule, 1988; Prochnau, Liu, & Boman, 2003).

Occupational therapists need to experience closure after a client’s passing to ensure they are able to establish and maintain their next therapeutic relationship; a relationship which will also result in loss (Martin & Berchule, 1988). Therapists experience closure differently for each of their clients, with therapists reporting that they often found closure in their own personal time. Reported ways of achieving closure include attending funerals, writing cards, expressing sympathy to clients’ families, lighting candles and keeping journals (Bennett, 1991; Cipriani et al., 2000).

The main literature on therapists’ challenges to practice is over a decade old, with small sample sizes, and there are minimal investigations into the strategies used by therapists to overcome their challenges. An investigation into challenges to practice should occur to illicit whether previous challenges remain in the current health care climate or if they have changed. Strategies should be suggested in order to educate students and therapists on measures they can utilise to prevent burnout.

2.4.6 Occupational therapy education and the need for supervision

The need to better educate clinicians working with people living with a terminal illness has been a topic of discussion in both the occupational therapy literature and the broader multidisciplinary literature for decades. It has been argued that the paucity of evidence regarding the occupational therapy role with people living with a terminal illness has left occupational therapists feeling underprepared to work in this area (Meredith, 2010). If therapists are to meet the occupational needs of their clients at the end-of-life, they must be adequately educated and prepared to work with people living with a terminal illness.

Early research found that there was minimal undergraduate education dedicated to occupational therapy practice with people living with a life-limiting illness (Bennett,
This finding was then supported in a second Australian study by Dawson and Barker (1995) in which 64% of therapists reported they received no formal education in working in a hospice setting or with people with a terminal condition as a student, while 74% of therapists reported they were not offered any specific education once employed in this area.

More recently, attention has been given to the educational and training requirements to prepare therapists for this role (Halkett, Ciccarelli, Keesing, & Aoun, 2010; Hasselkus & Murray, 2007; Jeyasingam, Agar, Soares, Plummer, & Currow, 2008; la Cour et al., 2009; la Cour, Josephsson, & Luborsky, 2005; la Cour et al., 2007; Lexell et al., 2009; Meredith, 2010). Studies suggest that the amount of education required to prepare therapists to work with people living with a terminal illness should be increased (Dawson & Barker, 1995; Halkett et al., 2010; Meredith, 2010). A recent survey completed with 24 therapists in Australia found that feelings of preparedness increased with the length of time therapists worked with this client group, and the more undergraduate training they had received (Meredith, 2010). Only 48.5% of therapists in this study reported they received undergraduate palliative care education, leaving many feeling underprepared to work in the area (Meredith, 2010).

Research has shown that therapists feel that education should cover the diversity and complexity of the clinical area (Halkett et al., 2010; Meredith, 2010). Information should be given on: (i) the occupational therapy role; (ii) communication and counselling skills that focus on grief and bereavement; (iii) the unique focus of service delivery and professional reasoning processes used; (iv) medical and psychological aspects of care; (v) ethical and cultural issues at the end-of-life; and (vi) self care to maintain therapists wellbeing in this demanding role (Bennett, 1991; Cipriani et al., 2000; Dawson & Barker, 1995; Meredith, 2010). Clinical scenarios and exposure to clients with a terminal illness should also be incorporated to enhance learning (Meredith, 2010).

More recently, the Australian Government introduced the Palliative Care Curriculum for Undergraduates (PCC4U) in 2008 to try and close the gap that exists in palliative care education (Palliative Care Curriculum for Undergraduates (PCC4U) Project Team, 2014;
Yates, 2007). PCC4U is a multidisciplinary resource designed to provide integrated palliative care training into all health undergraduate and postgraduate courses in Australia. This program, which aims to increase the skills and confidence levels in the health workforce, gives a generalist overview of the principles of palliative care, how to communicate with people living with a terminal illness, clinical assessment and intervention in palliative care, and how to optimise function for people living with a terminal illness (Palliative Care Curriculum for Undergraduates (PCC4U) Project Team, 2014). While PCC4U provides universities with a generalist tool that can be implemented into curriculum, it does not provide specific information on the occupational therapy role for people living with a terminal illness. It also fails to discuss the assessments and interventions that an occupational therapist could implement with a person living with a terminal illness, or provide useful case studies that a therapist could learn from.

Thus, the current training and education of occupational therapists in this clinical area in Australia is not sufficient. Further investigation is warranted into therapists’ perceptions of their educational needs, the timing of their education in their career, and what areas they should be competent in post-graduation, in order to devise effective training packages at both an undergraduate and post-graduate level.

Supervision is another important element in both continuing professional education and providing the necessary support to therapists working with people living with a terminal illness. Supervision is an expected part of clinical practice in Australia (Occupational Therapy Board of Australia, 2012). Supervision is a process of teaching and learning that enables a therapist “to develop knowledge and competence, assume responsibility for their own practice, and enhance public protection and safety” (Occupational Therapy Board of Australia, 2012, p. 2). Therapists are expected to receive some form of clinical supervision (whether it be direct, indirect, or remote) as part of their daily practice. However there has been no published research into whether therapists working with people living with a terminal illness are receiving appropriate supervision and whether it is meeting their support needs. Awareness of these supervision needs is important for ensuring that therapists are adequately supported, and that they have their professional needs met when working with people living with a terminal illness.


2.5 Gaps in the literature

Many gaps have been identified in the literature regarding occupational therapy practice for people living with a terminal illness. Nationally, there is limited literature addressing the demographics and work profiles of therapists working with people living with a terminal illness. Specifically, holes exist in being able to identify the demographics of therapists and the clients they treat, as existing studies have small sample sizes, lack sufficient detail, or comparable data about therapists and their clients. Therefore, gaps in literature still remain, in particular with regard to: the scope of the occupational therapy role, the professional reasoning that underpins this role, and the context of Australian occupational therapy practice when working with people living with a terminal illness.

This literature review showed that while the occupational therapy role with people living with a terminal illness has evolved over the last 30 years, disparities still exist in what the scope of the role entails as the majority of literature reviewed is based on descriptive reviews or expert opinion, rather than research studies. As there is limited consistency with role definitions and no clear guidelines as to what process therapists should use with their clients, the occupational therapy role with this client group remains unclear. Thus, future research needs to address the literature gap of identifying: an in-depth understanding of the role of the occupational therapist with people living with a terminal illness and the professional reasoning process they follow in their daily practice.

The review of the literature did not identify whether Australian therapists are enabling their clients’ to engage in their chosen occupations or their perceptions of occupational engagement at the end of life. The only studies to adequately address occupational engagement for people living with a terminal illness were conducted in Europe. Recent Australian evidence suggests that therapists are prescribing more practical interventions over interventions that encourage occupational engagement. Consequently, the question of to gain an in-depth understanding of therapists’ perspectives on occupational engagement for people living with a terminal illness.
The literature showed that preparing for practice with people living with a life-limiting illness in Australia is difficult at present. The limited knowledge base that therapists work from results in: role ambiguity, blurring of professional boundaries, and burnout. Hence, there is a need to gain an in-depth understanding of the challenges, and the educational and support needs of occupational therapists who work with people living with a terminal illness.

The identified gaps noted above were investigated in this PhD study. A mixed method study, namely a national survey, examined these knowledge gaps with a large sample of therapists. A professional reasoning model underpinned the survey design. The Ecological Model of Professional Reasoning was adopted as the theoretical framework of this study to ensure that the design of the survey captured data from a therapist, client and contextual perspective, which could then be analysed to address the identified knowledge gaps.

2.6 Theoretical framework

Theories guide practice and knowledge in a systematic fashion. A theoretical framework assists therapists and researchers to predict what should occur in practice or research (Hagedorn, 2001). The theoretical framework that provided a lens to shape this research was the Ecological Model of Professional Reasoning. An ecological model is one which considers the transactions that occur between the client, the therapist, and the practice context (Brown, 2014). Ultimately, it is these interlinked transactions that shape occupational performance and therapeutic outcomes (Brown, 2014; Schultz-Krohan & McHugh-Pendleton, 2013). The Ecological Model of Professional Reasoning was first published in 2007 and refined further in 2014. This model describes professional reasoning as a process “directly linked to therapy action, and it is shaped by factors intrinsic to the therapists and client, as well as extrinsic factors in the practice context” (Schell, 2007, p. 419).

The therapist’s professional reasoning is shaped by their personal and professional perspectives (Schell, 2014). It acknowledges that when therapists treat clients, they bring situational knowledge and skills that are grounded in their own personal characteristics,
such as physical capabilities, personality, values and beliefs and their interpretations of their life experiences and world view. These personal factors act as a lens and shape the therapist’s perceptions and interpretations of all life activities. Layered on top of this lens is their professional self, which stems from the therapist’s professional knowledge. This knowledge is acquired through their education, past client experiences, and beliefs about what is important to do in therapy, coupled with their specific skills and therapy routines. In this model, a therapist therefore views therapy situations through both the personal and professional lens. Over time these lenses are thought to merge until they become the customary way that the therapist views the therapy process (Schell, 2014).

The client is viewed as having their own personal characteristics and life experiences, life situation, and occupational performance problems that prompted their need for treatment (Schell, 2014). Clients also have their own theories and expectations for therapy. Together the therapist and the client come together to form a practice context to participate in therapy (Schell, 2014). The personal and professional lenses are visually represented in Figure 2.
The practice context is the setting where the therapist and the client engage in therapy activities. These activities occur over a finite time period and within a set place. However, the practice context is more than the actual location of the activity, and also “includes the physical and social aspects that influence therapy choices” (Schell, 2014, p. 393). The practice context setting is represented in Figure 3 and shapes what therapy
tools are available, and also dictates the time limit of the therapy, the size of the caseload, and whether there is a cost to treatment (Schell, 2014, p. 394).

**Figure 3 Ecological Model of Professional Reasoning: Professional reasoning is an ecological process in which the therapist and the client engage in therapy activities in a specific setting. All of these components transact to shape therapist reasoning, resulting actions with the client, and ultimately, therapy outcomes (Schell, 2014).**
The assumptions of this model were further clarified in a presentation given by Schell (2014b). In this presentation Schell discussed five processes that guide the interactions between the therapists, the client and the practice context as a part of this theory. These are:

1. “Therapy is a co-constructed process between the therapist and the client.
2. Therapy action is a transaction among the therapist, client and the practice context.
3. Many personal and practice context factors influence professional reasoning and the therapy process; some known and some are tacit or unknown.
4. Therapy effectiveness is affected by all of these factors, along with the nature of problem, and the therapy related actions on the part of the client in between sessions.
5. Professional reasoning is thus an ecological process which involves psychological, physiological, sociological and other contextual components” (Shell, 2014, p.19).

Therefore, the Ecological Model of Professional Reasoning outlines that professional reasoning is more than just what occurs in a therapist's mind. It instead involves complex interactions between the therapist, the client and the practice context. This model was used to underpin this study’s aims and research questions, as well as design the national survey, in order to capture all of the elements of occupational therapy practice in a systematic and structured way. Thus, therapists responses to the survey should be viewed as being an ecological process that has resulted from therapeutic interactions between the therapist, client and the practice context.

2.7 Study purpose and research questions

This study’s overall objective was to gain an in-depth understanding of the scope of the occupational therapy role, the professional reasoning that underpins this role, and the context of Australian occupational therapy practice when working with people living with a terminal illness. The four research aims and their research questions are now described:
Chapter 2

Aim 1: To understand the workforce context for therapists working with people who are terminally ill in Australia by detailing the demographics of a large sample of occupational therapists, including individual therapist demographics, work context factors and teams, and their client base.

Aim 1. research questions:

- What are the demographics of therapists working with people living with a terminal illness in Australia?
- What types of workplaces employ therapists to work with people living with a terminal illness?
- What are the demographics of the clients seen by therapists who are living with a terminal illness?
- Do therapists want to remain working with people living with a terminal illness in the future, and what influences this decision?

Aim 2: To gain an in-depth understanding of therapists’ perspectives on occupational engagement for people living with a terminal illness;

Aim 2. research questions:

- What occupations do therapists perceive people engage in once diagnosed with a terminal illness?
- Are there unique or meaningful occupations for people living with a terminal illness, and if so, what are they?
- How do therapists enable occupational engagement for clients living with a terminal illness?
- Do therapists perceive that the occupations a person engages in change as their occupational performance status declines towards the end-of-life, and if so, how?
Aim 3: To gain an in-depth understanding of the role of the occupational therapist with people living with a terminal illness and the professional reasoning process they follow in their daily practice.

Aim 3. research questions:

- What theoretical frameworks are therapists using when working with people living with a terminal illness?
- Do therapists modify or reframe their practice when working with people living with a terminal illness?
- Who are the most common referrers to therapists working with people living with a terminal illness receive referrals?
- What are the reasons for referral to occupational therapy?
- What assessments are completed with people living with a terminal illness, and how do therapists complete these assessments?
- What types of goals are set with people living with a terminal illness?
- What interventions are completed with people living with a terminal illness, and in which setting are they completed?
- What outcome measures are used with people living with a terminal illness?
- Do therapists provide follow-up for people living with a terminal illness?

Aim 4: To gain an in-depth understanding of the challenges, and educational and support needs of occupational therapists who work with people living with a terminal illness.

Aim 4. research questions:

- What are the challenges for therapists working with people living with a terminal illness?
- How do therapists overcome the challenges they face working with people living with a terminal illness?
- Do occupational therapists feel prepared to work with people living with a terminal illness?
• What skills and knowledge are required for competency of practice when working with people living with a terminal illness?
• Are these skills and this knowledge best taught at university, on the job, or as part of a therapists’ continuing professional development?
• Are therapists receiving supervision when working with people living with a terminal illness?
• What are the support needs of occupational therapists working with people living with a terminal illness?

In summary, to answer this broad range of research aims and questions and gain the perspectives of as many therapists as possible, a national online mixed methods survey was designed with a professional reasoning theoretical underpinning.

2.8 Synopsis
This chapter has provided the background to this research by examining current literature on palliative care, and occupational therapy practice for people living with a terminal illness. The aims and research questions, and the theoretical underpinnings of this research have also been presented. The following chapter will discuss the research methodology used in this study.
Peer reviewed outcome arising from this literature review


Please refer to Appendix 1 for a hard copy of the peer-reviewed article.
Chapter 3 Methodology

3.1 Introduction
This study’s objective was to: gain an in-depth understanding of the scope of the occupational therapy role, the professional reasoning that underpins this role, and the context of Australian occupational therapy practice when working with people living with a terminal illness. This chapter will describe the complementary mixed-methods research design used in this study. The survey used for data collection, and the rationale for using a theoretical framework to underpin the survey design and question order is described. The web-based survey instrument, and the sample of occupational therapists recruited to this study are discussed. The mixed method approach used to analyse the data will also be discussed along with the ethical considerations.

3.2 Research design
3.2.1 Theoretical Framework
This study sought to answer many questions about the occupational therapists working with people living with a terminal illness in Australia. Questions existed surrounding the therapists, the clients that they treat, and their work contexts and practices. Therefore, this study needed to identify the therapist, their clients, and the context that they worked within, while describing the professional reasoning processes used when working with their clients. Although other studies had attempted to answer aspects of these questions, it had always been with small sample sizes and through qualitative studies that elicited an in-depth understanding of limited dimensions of the occupational therapy role. Therefore, a challenge of this study was to design a data collection method that could be used on a larger scale, but that would still elicit in-depth responses from the therapists about themselves and their professional reasoning, their client and their practice contexts.

To gain numerous views from a small sub-section of the Australian occupational therapy workforce, a complementary mixed methods survey was chosen. This survey needed a
theoretical basis to guide the structure and design of questions to gain an insight into the therapist, their clients and their workplace and practices. Therefore the survey design, including the question structures, were based on the Ecological Model of Professional Reasoning (Schell, 2007, 2014) as this framework was most suited to understanding the role and context of practice for therapists working with this client group.

This study employed a web-based survey that included both quantitative and qualitative components to elicit responses that would answer the research questions (Johnson & Turner, 2002). This methodology combined quantitative and qualitative methods within a single data collection tool to complement and extend what could be learned from each of the data types separately (Bazeley, 2004; Bazeley, 2012).

### 3.3 Participants

Potential participants were Australian occupational therapists who self-identified as working with clients with a terminal illness. The approximate number of therapists working in this clinical area across Australia at the time of this study was unknown. In 2002-2003, approximately 1.6% of the total population of occupational therapists were working in this area (Australian Institute of Health and Welfare, 2006). Based on this data and recent figures it can be estimated that there are approximately 228 therapists eligible to participate in this study (AHPRA Occupational Therapy Board, 2012).

#### 3.3.1 Sampling

Occupational therapists working with people living with a terminal illness work in a variety of settings, with a varied caseload, and in multidisciplinary teams that are not necessarily labelled ‘palliative care’ or ‘terminal illness’ caseloads. Therefore, potential participants were located using a purposive sample in conjunction with snowball sampling techniques.
3.3.1.1 Purposive sampling

A purposive sampling method, convenience sampling, was used as the study had pre-defined criteria of therapists working in a specific clinical area (Creswell, 2007; Dickerson, 2006; Kemper, Stringfield, & Teddlie, 2006).

Potential participants were initially located through a convenience sample of therapists known through various means to the PhD candidate. These included colleagues from a previous workplace, clinical practice groups, and members of the Occupational Therapy Palliative Care Special Interest Group. Therapists listed on the Occupational Therapy Australia website (Occupational Therapy Australia, 2012) and therapists listed in the National Palliative Care Directory (Palliative Care Australia, 2004b) were also targeted for participation. It is important to note a large proportion of services listed within the Directory did not have occupational therapists working as a part of their service when contacted. However, if the service did contain an occupational therapist, contact was made and the research project explained.

In total, 156 potential participants were sent a direct email containing the participant information sheet and an electronic link to complete the survey. Table 1 lists a breakdown of the potential participants targeted in the convenience sample.

<table>
<thead>
<tr>
<th>Sample</th>
<th>No. of Potential Participants Emailed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational therapists known to the research team</td>
<td>27</td>
</tr>
<tr>
<td>Clinical Network Group</td>
<td>6</td>
</tr>
<tr>
<td>Occupational Therapy Palliative Care Special Interest Group</td>
<td>21</td>
</tr>
<tr>
<td>Occupational Therapy Australia Website</td>
<td>24</td>
</tr>
<tr>
<td>National Palliative Care Directory</td>
<td>78</td>
</tr>
</tbody>
</table>

Table 1 Potential Participants (N=156)

These targeted therapists were then asked to ‘snowball’ or forward this email on to other occupational therapists that they thought may be interested in participating in the study.
3.3.1.2 Snowball Sampling

Snowball sampling was initially developed as a way of studying hidden or sensitive populations, and is used as an informal means of finding hard to reach populations (Biernacki & Waldorf, 1981; Faugier & Sargeant, 1997; Teddlie & Yu, 2008). Snowball sampling was used in conjunction with the convenience sample, as therapists working with people living with a terminal illness tend to be hard to locate as they are often scattered across multiple health care settings and frequently work with clients living with a terminal illness as just one part of their overall caseload.

By using snowball sampling, other therapists that worked with people living with a terminal illness were forwarded information (Faugier & Sargeant, 1997; Kemper et al., 2006). This meant that the number of participating therapists could continue to grow without input from the research team and participants could be found regardless of their geographical location, the percentage of time they spent working in the clinical area, their position title, or setting in which they worked.

3.3.2 Eligibility

To be eligible for participation in this study a potential participant was required to:

1. Be a qualified occupational therapist.
2. Be currently treating clients living with a terminal illness in Australia or have treated clients with a terminal illness within the last three years to ensure recency of practice and the ability to recall daily practice with this caseload.
3. Be willing to complete a web-based survey that would take approximately 30 minutes of their time.

No restrictions were placed on a person’s workplace, caseload or practice setting.

3.3.3 Sample size

Predicting the sample size was difficult due to the unknown number of occupational therapists working with clients with a terminal illness within Australia. An initial target of
50 responses was set. However, this was an arbitrary number that could not be properly estimated as it was unsure how far the recruitment email would spread amongst the potential participants and how many participants could be recruited using the snowball sampling method. It was also impossible to determine a non-response rate, as it is unclear exactly how many therapists eventually received the recruitment email.

During the month of data collection, 186 people attempted to complete the survey. Figure 4 represents the sample’s eligibility and the number of participants who completed each section of the survey.

A sample of 171 (92.4%) eligible respondents completed the first four sections of the survey. These questions sought information to distinguish the eligibility of participants as well as demographic information of the responding therapists. However, 144 (79.1%) of the participants completed the remaining five sections of the survey, which were related to working with people living with a terminal illness, referral to occupational therapy, assessment and intervention practices, and education and supervision requirements for therapists working with this client group.

As one of the aims of this study was to describe the demographics of a large sample of occupational therapists working with people living with a terminal illness, the complete sample of 171 was used for the data analysis in chapter 4. In contrast, it was felt that missing information could possibly skew results in the remaining sections and as a result the total number of respondents decreased to 144 for the remaining results chapters unless stated otherwise.
Figure 4 Sample working with clients with terminal illness in Australia eligibility

Total Eligible Respondents
n=171
Eligibility criteria:
- Were occupational therapists
- Had worked with people living with a terminal illness in Australia in the last three years
- Were willing to complete an internet-based survey

Completed Survey Sections 1-4
n=171
Questions relating to:
- Being an occupational therapist
- Working with terminal illness in Australia
- Currency of practice
- Demographic Information

Completed Survey Sections 5-9
n=144
Questions relating to:
- Working with people living with a terminal illness
- Referral to occupational therapy for people living with a terminal illness
- Occupational therapy assessment
- Occupational therapy interventions
- Education and supervision

Total Survey Respondents
N=186

Ineligible Respondents
n=15
Exclusion reasons:
- Not an occupational therapist (n=2),
- Not working with people living with a terminal illness in Australia within the last three years (n=2),
- Not answering past the first three criteria-based sections (n=8)
- Attempting the survey twice due to reported computer malfunctions (n=3)
3.4 Survey instrument

While typically considered to be quantitative in nature, surveys may also contain open-ended questions that elicit qualitative responses (de Vaus, 2002; Forsyth & Kviz, 2006). This type of complementary mixed-methods was required as both demographics of Australian occupational therapists working with people living with a terminal illness and therapists’ perceptions on their role, including their professional reasoning, were being investigated. A survey was chosen for this study due to its non-experimental research design and ability to gather data regarding the questions under investigation (Creswell, 2003; Forsyth & Kviz, 2006; Polgar & Thomas, 2008). A hard copy of the survey is located in Error! Reference source not found. Completing a web-based questionnaire was also a cost-effective way of reaching large numbers of therapists who could answer the research questions in their own time making it more advantageous than other research methodologies which rely on the researcher’s observations or measurements (Creswell, 2003; Forsyth & Kviz, 2006; Hicks, 2004).

3.4.1 Survey procedures

The processes undertaken from survey design through to the closure of the online survey are described in Figure 5. Each step of this process is now explained in further detail.
Figure 5 Survey procedures

1. Developed survey instrument
2. Created web-based survey template using SurveyMonkey
3. Pilot-tested survey with five occupational therapists
4. Made suggested changes from pilot-testing
5. Created the final version of the survey instrument
7. Emailed participants with an introductory email, participant information sheet, and online survey link on the 2/4/12
8. Emailed participants two weeks later with a follow-up reminder email
9. Closed the survey on the 30th April, 2012
3.4.2 Survey development

As there were no other published surveys to investigate this area of research, a new questionnaire was developed specifically to meet the objectives of this study. As a result the reliability, or the ability of the questionnaire to produce consistent results when given to the same person (de Vaus, 2002; Rudestam & Newton, 2007), is unknown. The validity, or ability of the questionnaire to measure what it says it does (de Vaus, 2002), is also unknown. Therefore, it can only be assumed that the questions were interpreted and answered as they were intended to be by all participants.

The questionnaire commenced with three questions that determined the participant’s eligibility, and consisted of seven sections in total. Section one had two branches: a branch for those who were currently employed, and another for those who had previously worked in this area. Participants were required to complete 52 questions if they were currently working with people living with a terminal illness and 51 questions if they had worked with people living with a terminal illness in the past.

The questionnaire design was underpinned by the Ecological Model of Professional Practice (Schell, 2014). Therefore, the seven different sections of the questionnaire reflected aspects of the Ecological Model of Professional reasoning, namely gathering data about the therapist, the client, and the work context. Specific sections were: (i) demographic information of both the therapist, their workplace, and the clients they treat; (ii) experiences working with people living with a terminal illness, including occupational therapy frameworks, modifying practice, goal setting, challenges and elements of job satisfaction (iii) referral to occupational therapy services; (iv) occupational therapy assessment and outcome measure practices; (v) occupational therapy intervention practices; (vi) occupational needs of people living with a terminal illness; and (vii) and the education and supervision of occupational therapists working with this client group, including challenges and preparation for practice.

The specific web-based layout and design of the question structure was based on recommendations by Portney and Watkins (2009) and SurveyMonkey (2012). The questionnaire layout was uncluttered, used size 12 font, with each section beginning on a
new page. Questions were grouped and categorised in order to create a logical flow that was easy for the participant to follow, for example in the section about occupational therapy role and process, the commonly accepted order of the occupational therapy process was followed. The questionnaire began with general ‘neutral’ questions and finished with more specific questions. Questions were designed to be both closed-ended and open-ended in order to elicit different responses from the participants.

Close-ended questions allowed pre-specification of answers to be collected using various measurement scales (de Vaus, 2002), such as Likert scales, ranking scales, multiple choice questions and attitudinal statements. This type of question format was chosen as it allowed for comparison of therapists’ responses to each other, and to the published literature during analysis by forcing a response from a range of answers (de Vaus, 2002; Polit & Beck, 2010). Respondents were required to answer each closed-ended question prior to moving on to the next question.

Open-ended questions allowed respondents to provide richer insights into the topics being studied as (Polit & Beck, 2010) they were able to answer from their own perspective using their own words (Portney & Watkins, 2009). The structure of the open-ended questions varied, with some questions relating directly to the previous close-ended question, while others were independent of the close-ended question but relating to the section topic. At the end of each section of the questionnaire respondents were given the opportunity to make any other comments on the section topic, or expand on any questions they felt required further explanation in a section of open-text.

A web-based questionnaire was chosen over a traditional mail out questionnaire for this study. Using a web-based questionnaire reduced research costs as there was no postage, printing or travelling costs associated with implementing the survey across a country as geographically sparse as Australia (Baron, Healey, & Ilieva, 2002; Wright, 2005). This web-based medium also gave greater access to therapists who may have been difficult to locate using traditional mail out methods as Australian therapists are often employed in roles across multiple settings and caseloads, as well as, making it easier for therapists to forward the questionnaire on to other occupational therapists working in the area using
snowball sampling. Using a web-based medium also permitted therapists to complete the questionnaire at a time that was convenient to them, whether that be at work or in their personal time (Rudestam & Newton, 2007).

This web-based questionnaire was designed using SurveyMonkey software (SurveyMonkey, 2012). SurveyMonkey allowed the questionnaire to be custom-designed with unlimited questions and a custom URL to be created. SurveyMonkey was chosen for use because of its user-friendly interface and on-line features, such as enhanced security settings and good data exportation options for analysis that were not available from other web-based survey programs. The supervisory team also had previous experience administering surveys using SurveyMonkey, the program did not require installation, and was the most cost effective when compared to other programs.

3.4.3 Pilot testing
A pilot survey was completed in February, 2012, with five occupational therapists who had experience working with this client group to establish the validity of the survey (Creswell, 2003; de Vaus, 2002). These therapists were purposively chosen and know to the researchers through various networks, and had both clinical and academic experience.

Each pilot tester was asked to provide feedback on the length of time it took them to complete the survey, the wording of the questions, their interpretations of each question, the structure and layout of the questions, and the questions relevance to current practice with this caseload.

Several changes were made based on this feedback prior to dissemination to participants. Piloting the survey gave the opportunity to refine and clarify the meaning of questions and change the format and scales used. For example, some questions were reworded to increase clarity, while others were reformatted to likert scales. Finally, new on-line electronic pathways within the questionnaire were fixed when broken electronic links were found.
3.4.4 Survey administration

The survey was self-administered using an electronic link to a web-based program. This electronic link was part of the recruitment email sent to the convenience sample. Therapists agreed to participate in the study if they clicked on to the electronic link embedded in the email. The questionnaire contained three questions to determine eligibility to the study and directed them to the electronic branch of the survey that they would take depending on their working status with people living with a terminal illness. Participants continued through the seven sections of the questionnaire answering a mix of closed and open-ended questions. The time taken for participants to complete the survey ranged from 20 minutes to one-hour-and-20-minutes depending on the therapist’s depth of response to the open-ended questions.

3.5 Data collection

Data collection occurred over a one-month period in April 2012 using the cross-sectional web-based survey to collect data at one point in time.

3.5.1 Survey administration

An introductory email (Appendix 2) was developed which provided the potential participant with details of who was conducting the study, the study’s aims and eligibility requirements, and the participant’s involvement, discussed the benefits and risks of participating in the study. This email also contained the electronic link to the web-based survey and an attached participant information sheet (Appendix 3). This allowed potential participants to make an informed decision to participate in the study.

Contact with potential participants occurred in one of two ways. Occupational therapists known to the PhD candidate were contacted via email. However, potential participants who were located using the Occupational Therapy Australia website or the National Palliative Care Directory were contacted by telephone in order to establish a valid email address. An introductory email was then sent on the same day as the telephone call occurred.
All email contact occurred using Microsoft Outlook with the first initial introductory email being sent to potential participants on the 30\textsuperscript{th} March, 2012. Introductory emails were sent over a period of 14 days as there were over 200 hospices and palliative care services to contact via phone within the Palliative Care Directory and the Occupational Therapy Australia website.

Potential participants were sent a follow-up reminder email (Appendix 4) 14 days after they received their initial email, as research has shown that follow-up emails increase response rates (Deutskens, De Ruyter, Wetzels, & Oosterveld, 2004; Ritter, Lorig, Laurent, & Matthews, 2004). The follow-up reminder email was similar to the introductory email in that it discussed the details of who was conducting the study, the study’s aims and eligibility requirements, outlined participant involvement, and discussed the benefits and risks of participating in the study, except that it also included a closing date for the survey. The email link to the web-based survey remained open for a month, closing on April 30\textsuperscript{th} 2012 after no new responses were generated.

3.6 Data analysis

As both quantitative and qualitative data were collected from this survey, a mixed methods approach was required for analysis.

3.6.1 Mixed methods data analysis

Mixed methods occurs when both quantitative and qualitative data are collected or analysed in a single study with the data being integrated at one or more points in the research process (Creswell, Plano Clark, Gutmann, & Hanson, 2003). This approach allowed both exploratory and confirmatory questions to be addressed through data collection (Teddlie & Tashakkori, 2009). Initially data analysis of the quantitative and qualitative findings occurred separately; however, once both sets of data had been analysed the results were integrated to confirm and strengthen findings (Bazeley, 2012; Creswell & Plano Clark, 2011). The only exception to this mixed methods approach to
analysis was in relation to the findings presented in chapter five, where a qualitative analysis was used to understand therapists’ perceptions on occupational engagement for this client group.

### 3.6.2 Quantitative data analysis

Prior to the quantitative data analysis occurring, the raw data set collected from the questionnaire was converted into numeric value codes (Creswell, 2007) using Microsoft Excel. Missing data was assigned a specific code so that non-responses could be easily identified and not skew results (Forsyth & Kviz, 2006). After the data set was checked for errors it was then exported into SPSS (Version 21) for data analysis (IBM, 2012).

The purpose of this statistical analysis was to obtain descriptions (Teddlie & Tashakkori, 2009) of the demographics of a large sample of therapists, the context of their practice, and the clients they worked with; indications of what therapists felt the occupational therapy role involved with this caseload and the processes they followed; as well as identifying the satisfying and challenging elements of working in this role, and the educational and supervisory needs of therapists.

### 3.6.3 Qualitative data analysis

Open-ended questions were coded using QSR NVivo qualitative analysis software (QSR International, 2010), and analysed using grounded theory techniques. Grounded theory, was developed by Glaser and Strauss as a way of “building theory from data” (Corbin & Strauss, 2008, p. 1) when little is known in an area or about a process (Creswell, 2007; Grbich, 2007). It aims to explain the context of the setting in which interactions take place, be it social, psychological, or structural. In grounded theory the researcher generates a theory, or explanation, of a process, action, or interaction that is formed from the views of the participants (Corbin & Strauss, 2008; Creswell, 2007). Grounded theory analysis can be implemented using one of two approaches(Creswell, 2007); either using systematic procedures as per Strauss and Corbin (2008), or using a constructivist approach, as per Charmaz (2006).
This study used a constructivist approach, which allows us to learn about our world from a different viewpoint. Constructivist grounded theory accepts that the world has multiple realities, and each reality is viewed differently by people, depending on their environment, views and actions (Charmaz, 2006). This interpretive outlook develops theory based on the researcher’s world views and experiences of “embedded, hidden networks, situations, and relationships” (Creswell, 2007, p. 65). It is through these views and experiences that hierarchies of power, communication, and opportunity are made visible (Creswell, 2007). This type of analysis also fits with the theoretical framework chosen for this study, which indicates that the reasoning of therapist was based on their personal and professional experiences.

At times, the qualitative data was also quantified (Bazeley, 2004). This included simple counts of codes, themes or patterns that occurred in the data, and was used to add a different dimension to qualitative by giving frequencies of the response topics (Bazeley, 2004).

The purpose of the qualitative analysis was to gain an understanding of therapists’ perceptions on the context of their role working with people living with a terminal illness. A secondary purpose was to expand on the quantitative findings and to gain an understanding into the professional reasoning processes that therapists used to make decisions when working with people living with a terminal illness.

### 3.6.3.1 Stages of qualitative data analysis

Data analysis occurred in a series of stages and involved coding by asking questions, making comparisons, deriving concepts, and developing terms from the data (Bazeley, 2004). This analysis gave insight into the role of the occupational therapists, together with therapists’ day-to-day work practices and their perceptions on the occupational needs of people who are living with a terminal condition. The four stages of data analysis included: open coding, focused coding, axial coding, and theoretical coding (Charmaz, 2006). Each stage of analysis occurred concurrently, allowing the researcher to move between each stage rather than following a linear process (Charmaz, 2006).
Data analysis began with open coding, where categories were formed about the phenomena by segmenting information (Creswell, 2007). This allowed comparison of data and identification of common problems or themes (Charmaz, 2006). Each category was specified by their properties into subcategories, and then placed on a dimensional continuum (Charmaz, 2006; Creswell, 2007). The second stage of coding was focused coding, whereby the codes were more directed, selective and conceptual than in open coding (Charmaz, 2006). Focused coding used “the most significant and/or frequent earlier codes to sift through the large amounts of data” (p.67) to determine each code’s suitability for use (Charmaz, 2006). The third stage of coding was axial coding, whereby the data was assembled in new ways (Charmaz, 2006; Creswell, 2007). Axial coding identified central phenomenon, explored interrelationships, identified strategies, classified context, and defined the most analytical way to categorise the phenomenon (Charmaz, 2006; Creswell, 2007). The fourth and final stage of coding was theoretical coding (Charmaz, 2006; Creswell, 2007). Theoretical coding allowed for a final relationship between all of the categories to be established, with a central phenomenon being identified and a theory developed (Charmaz, 2006).

While some of the qualitative data was coded using all four stages of analysis, some analysis stopped at the thematic level. The level of analysis was dependent upon what question was being answered. Each of the results chapters outline the method used for data analysis and whether grounded theory analysis or thematic analysis occurred.

### 3.7 Ethical considerations

Ethics approval was obtained from the University of Western Sydney’s Human Research Ethics Committee (H9466) in March 2012, prior to the commencement of the survey distribution (Appendix 5). The research team upheld their ethical responsibilities at all times.
3.7.1 Voluntary participation and right to withdraw

A non-invasive method of recruitment was chosen. Participation was voluntary and participants were aware that they were able to withdraw from the survey at any time during the completion of the survey with no negative consequences. However, as participants’ responses were anonymous survey data could not be removed once it was submitted.

3.7.2 Informed consent

As part of recruitment, participants were sent an email containing summary information about the study and a participant information sheet containing more in-depth information to ensure that they were informed prior to completing the survey. Participants were also informed prior to completing the study in the information sheet, and at the beginning of the survey that there was no consent form and that their consent was implied by their choice to complete the survey.

3.7.3 Data management to ensure confidentiality and anonymity

Data collection was designed to ensure that participants remained anonymous to the researcher. Confidentiality was maintained at all times as all survey data was completed electronically by the participant. The survey was also anonymous and contained no identifying information such as their name or workplace. Data was stored on either a secure server, in password protected files, and locked offices. Data was only accessible to be viewed by the PhD candidate and PhD supervisors.

3.8 Synopsis

A convenience sample of occupational therapists were asked to complete a web-based survey to establish the role and context of occupational therapy practice with people living with a terminal illness in Australia. The survey design in this national survey was underpinned by the Ecological Model of Professional Reasoning (Charmaz, 2006). Participants were then asked to forward, or snowball, the survey on to anyone they felt relevant to participate in the study. The survey was developed specifically for this study.
and created using Survey Monkey software. As the survey contained both open-ended and closed questions, mixed methods data analysis occurred. SPSS was used to manage the descriptive data analysis and NVivo was used for the qualitative data analysis. Data analysis was then integrated to complement and expand on each method’s results.

The following four chapters will present the results for each of the research aims.
Chapter 4  The context of Australian occupational therapy practice for people living with a terminal illness

4.1 Introduction

Occupational therapists have been working with people living with a terminal illness in Australia since the mid 1970s yet little has been reported on the demographics and work profiles of these therapists or on the clients who are referred to occupational therapy services. As outlined in Chapter 2, profiling therapists, their clients and their work contexts will encourage the formation of a professional identity for therapists working in this area of practice, lead to better education of students and therapists, assist in planning of services and resources, as well as giving context for therapists’ professional reasoning.

While national profiles have been completed of the entire occupational therapy workforce both in Australia and internationally, no profiling research has occurred at a national level into the occupational therapy workforce working with people living with a terminal illness. Some small-scale state-based research has been completed looking into occupational therapy practice in this clinical area, but little is known about the demographics and work profiles of the therapists, and the demographics of the people they treat, thus the context of Australian practice remains unclear.

This chapter presents findings in relation to the following research aim: To understand the workforce context for therapists working with people who are terminally ill in Australia by detailing the demographics of a large sample of occupational therapists, including individual therapist demographics, work context factors and teams, and client base.

The research questions addressed in this chapter include:

- What are the demographics of therapists working with people living with a terminal illness in Australia?
• What types of workplaces employ therapists to work with people living with a terminal illness?
• What are the demographics of the clients seen by therapists who are living with a terminal illness?
• Do therapists want to remain working with people living with a terminal illness in the future, and what influences this decision?

Results are based on the quantitative and qualitative findings from the national survey with regards to Section 4: Demographic information and Section 5: Working with people living with a terminal illness. The descriptive quantitative data were analysed using SPSS. The qualitative findings were analysed using grounded theory methods previously described in Chapter Three, and managed using NVivo.

4.2 The Results
The participants who completed this survey account for approximately 1.3% of the registered Australian occupational therapy workforce (Schell, Unsworth, & Schell, 2007). Results profile the 171 occupational therapists who completed the survey and met the inclusion criteria.

4.3 The Sample
Profile demographics include: gender, state and location of employment, educational qualifications, and years working as an occupational therapist and specifically working with the terminally ill, current employment status, predicted career path, and current work role. The workplaces of the participants are described in relation to health sector and treatment setting. A profile of the clients treated by the therapists is also presented.

4.3.1 Sample profile
The majority (n= 159, 93%) of survey participants were female. At the time of the survey 92% (n=157) of the therapists were currently working with people living with a
terminal illness. The remaining 14 therapists were not currently working with this client
group but had done so within the past three years. Most therapists who responded to the
survey were working in New South Wales (n=78), followed by Queensland (n=31) and
Victoria (n=26) (Figure 6).

**Figure 6 Proportion of therapists employed per state (N=171)**

![Proportion of therapists employed per state](image)

Therapists self-nominated their geographical work location as being metropolitan,
regional, rural or remote. Almost half (n=84) of the therapists worked with clients in
metropolitan centres. Forty-three therapists were employed in regional locations, and 40
were employed in rural locations. Only four therapists were employed in remote areas.
The distribution of employment location by state is found in Table 2.

Therapists’ predominately held an undergraduate bachelor degree as their highest
qualification (n=137, 80%), followed by those with a masters degree (n= 18, 11%).
Smaller numbers of therapists held an honours degree (n=9, 5 %), diploma (n=5, 3%),
PhD (n=1, 1%) or postgraduate diploma (n=1, 1%) as their highest qualification.

Therapists reported graduating between 1971 and 2011 (Range 40 years). On average,
therapists’ time since graduation was 12.5 years (SD 9.17, Median 9 years). However,
54% (n=92) of therapists had worked for less than 10 years.
<table>
<thead>
<tr>
<th></th>
<th>Metropolitan</th>
<th>Regional</th>
<th>Rural</th>
<th>Remote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital Territory</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>New South Wales</td>
<td>35</td>
<td>21</td>
<td>22</td>
<td>0</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>South Australia</td>
<td>3</td>
<td>3</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Tasmania</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Queensland</td>
<td>17</td>
<td>8</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Victoria</td>
<td>19</td>
<td>4</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Western Australia</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>84 (49.1%)</strong></td>
<td><strong>43 (25.1%)</strong></td>
<td><strong>40 (23.4%)</strong></td>
<td><strong>4 (2.3%)</strong></td>
</tr>
</tbody>
</table>

*Table 2 Distribution of therapists work location by state (N=171)*

Therapists had worked with people living with a terminal illness anywhere from two months to 25 years (Figure 7). The median time working with this client group was 4.5 years (Mean 6 years, SD 5.2).

*Figure 7 Years working with people living with a terminal illness (N=169)*
The proportion of time post graduation that therapists had spent working with people who are terminally ill was calculated. Therapists had spent on average 50% (SD 26.7) of their time since graduation working with this client group (Range 2% – 100%).

Half of the therapists (n=75, 52%) reported working full time with people living with a terminal illness, while 35% (n=58) worked in part-time positions. Therapists were also employed to work with this client group on an ‘as referred’ (n=10, 7%) or contractual basis (n=7, 5%). Therapists were most likely to be employed in permanent full-time capacity (n=66, 46%) and least likely to be employed to work in a part-time rotational position (n=2, 1%).

Therapists identified their primary position at work when treating people living with a terminal illness. There were fewer therapists in senior clinical positions (37%, n=63) and management positions (3%, n=5), than those in direct clinical positions (60%, n=101). Two therapists answered that they were employed in ‘other’ work positions reporting their work as being consultative (n=1) and project-based (n=1).

### 4.3.2 Predicted career paths

Therapists were asked to report whether they saw themselves working with people living with a terminal illness in the future (Table 3). Response rates varied from 128 to 132, as therapists were able to select as many responses as applied from eight options, while also being given an opportunity to provide ‘other’ responses. The number of responses for each question is provided in Table 3. The majority of therapists reported that they would still be working with people living with a terminal illness in the future when compared to those who did not.
Do you see yourself working with people living with a terminal illness in the future?

<table>
<thead>
<tr>
<th>Response</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, I find the role satisfying (n=132)</td>
<td>72</td>
<td>55</td>
</tr>
<tr>
<td>Yes, but not as my primary caseload (n=129)</td>
<td>52</td>
<td>40</td>
</tr>
<tr>
<td>Yes, but the role needs increased staffing levels (n=130)</td>
<td>46</td>
<td>35</td>
</tr>
<tr>
<td>Yes, but I need more support (n=129)</td>
<td>26</td>
<td>20</td>
</tr>
<tr>
<td>Yes, but with more resources (n=129)</td>
<td>21</td>
<td>16</td>
</tr>
<tr>
<td>No, I do not find the role satisfying (n=128)</td>
<td>16</td>
<td>13</td>
</tr>
<tr>
<td>No, I find it too challenging emotionally (n=128)</td>
<td>16</td>
<td>13</td>
</tr>
<tr>
<td>No, I find it too challenging physically (n=128)</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 3 Therapists perceptions of working with people living with a terminal illness in the future

Six therapists gave additional responses in the ‘other’ category. Four of these therapists identified that they did not want to work with this caseload in the future as they found it to be “emotionally challenging” (n=2), “intense” (n=1) and “too confronting” (n=1). The remaining two therapists reported that they could see themselves working with this caseload in the future if they were better supported through adequate staffing levels, “good team processes”, and had more physical resources.

Figure 8 reports therapists’ estimates of how long they anticipated working with people living with a terminal illness and why. On average therapists planned to stay in the role for a further seven years (Median = 5 years, Mode = 5 years).
Each of the 132 therapists who responded to this question also provided a comment as to why they planned to stay in their current role for their chosen time period. These reasons were categorised. Five reasons emerged from the data as to why therapists wished to continue working with people living with a terminal illness. The five categories included job satisfaction, the diversity of the role, supportive workplaces including “good” teams, family and lifestyle commitments, and because they were “clinical specialists”. The frequency of responses is presented in Table 4.
Chapter 4

Reasons for continuing to work with caseload

<table>
<thead>
<tr>
<th>Reasons for continuing to work with caseload</th>
<th>Examples of comments made by therapists</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Job satisfaction</strong></td>
<td>“I believe that the OT role in this setting is incredibly rewarding and it is a privilege to be able to work with the people and their families to enable them to achieve their goals in the end stages of their lives”</td>
<td>57</td>
<td>76</td>
</tr>
<tr>
<td></td>
<td>“I loved it!! I am working very hard to match my conceptual understanding of the role of occupational therapy in palliative care and putting it authentically into practice. This is very satisfying”</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>“I find satisfaction in being able to respond to and meet clients’ and carers’ needs during the challenging process of dying”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Role diversity</strong></td>
<td>“I get to see a range of conditions”</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>“I enjoy getting to work across a birth to death model”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Supportive Workplace/Good team</strong></td>
<td>“Good team processes are important in keeping perspective and helping me to want to stay in my role”</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>“I work in a supportive, fairly well resourced (comparatively), comprehensive multidisciplinary team”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Family and lifestyle</strong></td>
<td>“My work role suits my family commitments and lifestyle”</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Clinical specialist</strong></td>
<td>“I love the work I do and am a specialist in my field”</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 4 Reasons for continuing to work with people living with a terminal illness (N=75)

Therapists also made predictions as to why they would stop working with people living with a terminal illness. These reasons were categorised and then counted. The reasons for leaving, along with examples of these reasons are presented in Table 5.
### Table 5 Predicted reason for leaving caseload of working with people living with a terminal illness (N=57)

<table>
<thead>
<tr>
<th>Predicted reasons for leaving caseload</th>
<th>Examples of comments made by therapists</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed in a rotational or short-term contract position</td>
<td>“I will rotate as part of my contract to a different area”</td>
<td>20</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>“Contract position end date – I would love to stay longer”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Career change or career progression</td>
<td>“Career progression and specialisation”</td>
<td>10</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>“I would like to progress in my career and I will need to move away from clinical work to do this”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burn out</td>
<td>“I predict emotional burnout if I spend too long in this field”</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>“I think for self-care (of myself). It is important not to get burnt out by staying in the area for too long at any one time”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Split caseloads</td>
<td>“Having a split caseload is hard to manage”</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Retirement</td>
<td>“I will retire in two years”</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Family circumstances</td>
<td>“I want to start a family”</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>“It depends on if my partner gets relocated for his job”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited support</td>
<td>“Poor support and resources for allied health”</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>“I enjoy the work but don’t feel like I can do enough with the limited resources”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal reasons</td>
<td>“It’s personal”</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Poor staffing levels</td>
<td>“If staffing levels increase I would like to stay in this job for the foreseeable future”</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>“My inpatient caseload is too large, I wouldn’t want to stay here long term”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 4.4 Workplaces

The majority of therapists reported working in the public health sector (n=138, 81%), followed by the private health sector (n=18, 11%) and non-government organisations (NGO) (n=6, 4%). Eight therapists (5%) were employed to work across two health sectors.

Table 6 indicates therapists’ primary treatment setting. Therapists indicated the primary place that they treated people living with a terminal illness was within an inpatient
hospital setting (n=51, 35%). Therapists also treated clients in community settings (n=47, 33%), clients’ homes (n=23, 16%), outpatient hospital settings (n=8, 6%), and hospice settings (n=6, 4%). A small number of therapists (n=9, 6%) treated clients across two or more of these clinical settings.

More therapists treated clients within the community (n=70, 49%), i.e. community settings or the client’s home, than within inpatient settings such as hospitals and hospices (n=57, 40%).

<table>
<thead>
<tr>
<th></th>
<th>Inpatient Hospital</th>
<th>Community</th>
<th>Client’s Home</th>
<th>Outpatient</th>
<th>Hospice</th>
<th>Two + Settings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Territory</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New South Wales</td>
<td>22</td>
<td>24</td>
<td>12</td>
<td>4</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>0</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>South Australia</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Tasmania</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Queensland</td>
<td>10</td>
<td>10</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Victoria</td>
<td>10</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Western Australia</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>51 (34.5%)</td>
<td>47 (32.5%)</td>
<td>23 (16%)</td>
<td>8 (5.6%)</td>
<td>6 (4.2%)</td>
<td>9 (6.3%)</td>
</tr>
</tbody>
</table>

*Table 6 Primary treatment setting (N=144)*

### 4.5 The Clients

Therapists indicated in a multiple choice question the proportion of their caseload with a diagnosis of a terminal illness (Figure 9). Half of the therapists (n=72, 50%) had a caseload of up to 25% of clients with a diagnosed terminal illness. More than a quarter of the therapists (n=41, 28%) held caseloads where the majority of clients had a terminal illness (76-100%).
The majority of therapists worked with an adult caseload (n=130, 90%). Less than 10% of therapists were employed to work with children and adolescents (n=5, 4%), or a mixed caseload of adults, children, and adolescents (n=9, 6%).

Therapists were asked to list the diagnostic areas in their caseload from a choice of 10 responses. If the clinical area they worked in was not listed, they were able to list the clinical area in the box marked ‘other’. Therapists (n=144) listed a total of 540 answers to this question, as those who worked across more than one clinical area provided numerous responses, and reported working with people with terminal illness across 22 different clinical areas of practice (Table 7). Over 75% (n= 110) of therapists reported working in more than one clinical area, with the average therapist working in 2.7 (SD 1.65) different clinical areas.
Therapists (n=144) listed their clients’ three most common terminal diagnoses. Four-hundred-and-thirty-two diagnoses were given. These diagnoses were re-classified using World Health Organisation International Classification of Diseases (ICD-10) codes, and then further classified into higher order categories as defined by the ICD-10 (AHPRA Occupational Therapy Board, 2012). The majority of responses could be coded and placed in to one of six categories. However, almost 7% could not be classified due to insufficient information, or the ICD-10 code had less than two responses (i.e. Angleman Syndrome). Therefore a seventh category named ‘Other’ was created. Table 8 presents these results according to ICD-10 categorisation.

<table>
<thead>
<tr>
<th>Clinical area</th>
<th>N=540</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care</td>
<td>111</td>
</tr>
<tr>
<td>Aged Care</td>
<td>87</td>
</tr>
<tr>
<td>Oncology</td>
<td>62</td>
</tr>
<tr>
<td>Neurology</td>
<td>54</td>
</tr>
<tr>
<td>General Medical</td>
<td>52</td>
</tr>
<tr>
<td>Respiratory</td>
<td>43</td>
</tr>
<tr>
<td>Cardiology</td>
<td>37</td>
</tr>
<tr>
<td>Renal</td>
<td>32</td>
</tr>
<tr>
<td>Lymphoedema</td>
<td>31</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>8</td>
</tr>
<tr>
<td>Haematology</td>
<td>5</td>
</tr>
<tr>
<td>Chronic Disease</td>
<td>4</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>3</td>
</tr>
<tr>
<td>Spinal Cord Injury</td>
<td>2</td>
</tr>
<tr>
<td>Paediatrics</td>
<td>2</td>
</tr>
<tr>
<td>Psycho-Geriatrics</td>
<td>2</td>
</tr>
<tr>
<td>Burns and Scar Management</td>
<td>1</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>1</td>
</tr>
<tr>
<td>Mental Health</td>
<td>1</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>1</td>
</tr>
<tr>
<td>Urology</td>
<td>1</td>
</tr>
<tr>
<td>Vascular</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 7 Clinical areas making up therapists’ caseloads (N=540)
<table>
<thead>
<tr>
<th>ICD Code</th>
<th>Diagnoses</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>(C00-D48) Neoplasms</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unspecified cancer</td>
<td>96</td>
</tr>
<tr>
<td></td>
<td>Lung cancer</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>Breast cancer</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Brain cancer</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Bowel cancer</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Metastatic cancer</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Ovarian cancer</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Prostate cancer</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Melanoma</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Leukemia</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Liver cancer</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Lymphoma</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Cervical cancer</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Pancreatic cancer</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Bladder cancer</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Bone cancer</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Multiple myeloma</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Head and Neck cancer</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Renal cancer</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>C00-D48 Total</strong></td>
<td><strong>235 (54.4%)</strong></td>
</tr>
<tr>
<td>G009-G99 Diseases of the nervous system</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Motor Neuron disease</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Multiple Sclerosis</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Muscular Dystrophy</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Parkinson’s disease</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Huntington’s disease</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Machado Joseph disease</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>G00-G99 Total</strong></td>
<td><strong>55 (12.7%)</strong></td>
</tr>
<tr>
<td>J00-J99 Diseases of the respiratory system</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chronic lower respiratory diseases</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>Respiratory failure</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td><strong>J00-J99 Total</strong></td>
<td><strong>53 (12.3%)</strong></td>
</tr>
<tr>
<td>I00-I99 Diseases of the circulatory system</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Heart disease</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Congestive heart failure</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Stroke</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Lymphoedema</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>I00-I99 Total</strong></td>
<td><strong>38 (8.8%)</strong></td>
</tr>
<tr>
<td>N00-N99 Diseases of the genitourinary system</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Renal failure</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td><strong>N00-N99 Total</strong></td>
<td><strong>13 (3.0%)</strong></td>
</tr>
<tr>
<td>ICD Code</td>
<td>Diagnoses</td>
<td>n</td>
</tr>
<tr>
<td>---------------</td>
<td>------------------------------------</td>
<td>----</td>
</tr>
<tr>
<td>F00-F99</td>
<td>Mental and behavioural disorders</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
<td>9</td>
</tr>
<tr>
<td>F00-F99 Total</td>
<td></td>
<td>9  (2.1%)</td>
</tr>
<tr>
<td>B20-B24</td>
<td>Human immunodeficiency virus (HIV) disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>HIV/AIDS</td>
<td>2</td>
</tr>
<tr>
<td>B20-B24 Total</td>
<td></td>
<td>2  (0.5%)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Neurological conditions</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Frail aged</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Haematological conditions</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Batten’s disease</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Chronic conditions</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Multiple medical issues</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Unspecified organ failure</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Angelman’s syndrome</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Burns</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Genetic conditions</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Infections</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Movement disorders</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Paediatric congenital conditions</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Paediatric oncology conditions</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Seizures</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Trauma</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Tray Sach’s Disease</td>
<td>1</td>
</tr>
<tr>
<td>Other Total</td>
<td></td>
<td>27 (6.3%)</td>
</tr>
</tbody>
</table>

*Table 8 Diagnosis according to ICD-10 codes*

### 4.6 Synopsis

Findings from this chapter reveal that Australian occupational therapists that completed this survey and are working with people living with a terminal illness are most likely to be experienced, female therapists working in full time positions. These therapists are most likely to have a direct clinical role with people living with a terminal illness, and work across more than one clinical area.

Clients are more likely to be treated in a community setting over an inpatient setting. Clients are typically adults, with a diagnosis of cancer, or a neurological condition, and present as part of a palliative care, aged care, or oncology caseload.
Therapists are predominately planning to remain in their role over the coming seven years and reveal they are satisfied in their role due to role diversity, positive team environments, family and lifestyle reasons, and being a clinical specialist. Those planning to leave identify nine reasons for doing so including: being employed in a rotational or contract position, wanting a career change, job burnout, working in split caseloads, retirement, family circumstances, having limited support, and poor staffing levels.

The following chapter delves deeper into how occupational therapists conceptualise their work with clients, specifically detailing therapists’ perceptions on occupational engagement for people with terminal illness.
Chapter 5 Occupational engagement of people living with a terminal illness: Therapists’ perceptions

5.1 Introduction

Occupational engagement has been established as an important concept underpinning occupational therapy practice for people living with a terminal illness (Bye, 1998; Hasselkus, 1993; Tigges & Marcil, 1988). It has been argued that without occupational engagement at the end-of-life, people are at risk of occupational deprivation which negatively affects a person’s sense of health and well-being (Keesing & Rosenwax, 2011). To a minor extent, research has revealed the views of clients’ living with a terminal illness regarding their occupational engagement (la Cour et al., 2009; la Cour, Josephsson, & Luborsky, 2005; la Cour et al., 2007); however therapists’ perceptions regarding occupational engagement at this time of their clients’ lives remains unknown.

This chapter presents findings in relation to the following research aim of: gaining an in-depth understanding of therapists’ perspectives on occupational engagement for people living with a terminal illness.

The research questions addressed in this chapter include:

- What occupations do therapists perceive people engage in once diagnosed with a terminal illness?
- Are there unique or meaningful occupations for people living with a terminal illness, and if so, what are they?
- How do therapists enable occupational engagement for clients living with a terminal illness?
- Do therapists perceive that the occupations a person engages in change as their occupational performance status declines towards the end-of-life, and if so, how?
Results are based on therapists’ responses to two open-ended survey questions, questions 5.12 and 5.13. These two questions from Section 5: Working with people living with a terminal illness specifically targeted qualitative responses on occupational engagement for people living with a terminal illness. Question 5.12 asked therapists, “Are there any unique occupations that people living with a terminal illness need to engage in, in comparison to other client groups. If yes, please list these occupations”. Question 5.13 asked therapists, ‘What have been some of your client’s most meaningful occupations at this time of life? (E.g. Saying goodbye, going places, spending time with family/friends, etc)’.

One-hundred-and-thirty-four therapists responded to each of these two open ended questions. It is important to note that the findings are from the perspective of therapists and not clients. Therapists’ answers are based on their direct experiences of working with clients with terminal illness in their role as occupational therapists. In this role, talking to clients about occupational engagement is a central focus of their work, and assisting clients to engage in chosen occupations is day-to-day practice. Therefore, the following findings are presented from therapists’ points of view, and grounded in the knowledge and experience of their daily practice. These findings do not represent the direct views of clients.

As outlined in Chapter Three, grounded theory qualitative analysis was used to categorise and summarise the responses given by therapists to give the data meaning (Charmaz, 2006). To begin, questions 5.12 and 5.13 were analysed individually. Initially the data for each question was read line-by-line, with each finding being compared to another to identify provisional codes. Codes were then reviewed segment-by-segment with the view of identifying similarities and differences in the data and grouping each code into provisional groups of ‘meaningful occupations’ or ‘unique occupations’. A strong overlap in coded data between each question was noted, as what some therapists considered to be unique to this client group others considered to be meaningful as well as unique. To manage this overlap, codes with the same name in both ‘meaningful occupations’ and ‘unique occupations’ were merged into a third provisional group called ‘meaningful and unique occupations’. Axial coding of the data then occurred. Axial coding allowed for further refinement of the data and provided a framework for identifying the emerging relationships between the overarching categories and sub-categories (Charmaz, 2006).
Where possible the names given to each category and sub-category are the therapists’ words. Using the therapists’ words, or “in vivo codes”, better portrays the therapists’ meaning and context in each category (Charmaz, 2006). In other cases, categories and sub-categories were named to represent the content of the data found in each question. The use of in vivo codes or direct quotes from a respondent is indicated throughout this and other chapters by the use of “double” quotation marks, with category names represented through the use of *italics*.

### 5.2 Perceptions of occupational engagement at the end of life

While each question asked for respondents to provide examples of occupations, therapists listed a mixture of occupations, activities, roles, and tasks as being unique or meaningful at the end-of-life. However, all data was treated equally during analysis as therapists’ perceptions of what was meaningful or unique was more important than whether answers were specifically classified as an occupation, activity, role, or task.

#### 5.2.1 Unique occupations

Over 80% (n=143) of therapists listed unique occupations for people living with a terminal illness, when compared to other client groups. An additional three therapists were unable to address these unique occupations or provide treatment for these unique occupations, as it was not part of their employment funding (n=2) or relevant to their service provision (n=1).

Twenty-five therapists answered “no” to this question, while another three therapists gave a response of a question mark (n=1) or full stop (n=2). These answers were taken as an indication that these 28 therapists did not believe that people living with a terminal illness have unique occupations when compared to other client groups, and were not included in data analysis. However, it could also be an indicator that therapists who answered ‘no’ did not understand the meaning of the questions.
5.2.2 Meaningful occupations

Over 90% (n=160) of therapists gave examples of what they considered to be meaningful occupations for this client group when compared to other client groups. Four therapists reported that their clients living with a terminal illness had meaningful occupations, but did not specifically state what these meaningful occupations were. Another two therapists felt that their clients had meaningful occupations but were unable to work on them due to their service (n=1) and funding (n=1) restrictions.

One therapist answered “no” to this question, while another three therapists gave a response of a question mark (n=2) or full stop (n=1). Two therapists were “unsure” about whether or not this client groups had meaningful occupations. These six answers were taken as indications that these therapists did not believe that people living with a terminal illness had unique occupations when compared to other client groups and as such were not included in the analysis. However, it could also be assumed that therapists who answered ‘no’ did not understand the questions. Five therapists stated “all of your examples” and were also excluded from analysis as specific examples were not provided beyond those given in the question itself.

5.2.3 Therapists’ perceptions of occupational engagement of people living with a terminal illness

In total 580 pieces data were coded during axial coding. This resulted in the creation of two categories and four sub-categories that represent the therapists’ perceptions of occupational engagement of people living with a terminal illness. The categories and sub-categories created from this qualitative analysis are represented visually in Figure 10.
Chapter 5

Figure 10 Therapists’ perceptions of occupational engagement of people living with a terminal illness
Therapists’ views identified a dual focus of occupational engagement that was balanced between “focusing on life” and “preparing for death”. The first category, “focusing on life” has two sub-categories: prioritised engagement and altered engagement. “Focusing on life” centres on therapists’ perceptions of how clients continue to focus on living post diagnosis by remaining engaged in their world, albeit in an altered way. The second category, “preparing for death” has two sub-categories: practical preparations and “facilitating closure”. The category of “preparing for death” reveals therapists’ perceptions of what clients do to practically prepare for death and find closure as their illness progresses.

Both categories were inter-related with clients’ priorities perceived to change from “focusing on life”, to “preparing for death” as their occupational performance level decreased. For example, when a client was well and their disease had not yet affected their functional abilities, therapists perceived that the client was able to focus on living. However as clients’ functional abilities deteriorated and they became more dependent on others, therapists noted that clients were more likely to start “preparing for death”. While some clients were perceived to predominately move from “focusing on life” to “preparing for death”, some clients moved back and forth between the two categories depending on their fluctuating occupational performance status over time.

5.3 “Focusing on life”

This first conceptual category details therapists’ perceptions that clients want to continue “focusing on life”, rather than death, after they are first diagnosed with a terminal illness. By focusing on “the living, rather than the dying part”, therapists viewed that clients were able to stay engaged in, and reprioritise their occupations. “Focusing on life” might involve:

Holding a grandchild. Going to a special beach and putting their feet in the sand. Engaging in a domestic routine (e.g. A mother with her school aged children). Being at home. Spending time with close family and friends. Cooking. Caring for her husband. So, so many things...

Through “focusing on life”, therapists perceived that clients “still felt alive and not like they are waiting to die”. Thus the category of “focusing on life” is comprised of two subcategories: prioritised engagement and altered engagement.
5.3.1 Prioritised engagement

A diagnosis of a terminal illness brings with it a realisation that life is precious. Consequently to continue “focusing on life” rather than death, therapists commented how clients changed their priorities and the focus of their everyday lives. For example, one respondent reported that a client’s “focus often changes from productivity to things of passion ... family, friends, school, etc.” as they become more aware of the temporal aspect of death and the preciousness of remaining engaged in life. One therapist stated:

*I think it is the way that the person prioritises their occupations that is the most unique factor. Goals at this time are more based around leisure, rest and social performance areas as opposed to self-care and productivity domains.*

By reprioritising engagement towards the things that mattered, therapists felt that their clients had a greater sense of control over their disease process and a better quality of life. For example therapists spoke of working with people who “fought for independence until the very end” so that they could continue to “complete their favourite activities”. Therapists felt that by enabling independence, clients were better able to reprioritise the valued roles and occupations they wished to continue to engage in, rather than what others felt they should be doing. Therapists found that reprioritisation occurred based on the client’s occupational performance at that specific time of assessment, and often priorities were readjusted during periods of fluctuations or deterioration. However, remaining engaged in valued roles and occupations enabled clients to “complete the activities that other people take for granted”, maintain routines, and keep a sense of normality despite the fact that their life had taken a new course.

By prioritising routines, therapists enabled clients to continue with “their normal, their habits, and their everydayness” and “manage their regular everyday tasks”. For example, one respondent reported having a client who just wanted to “feel presentable, clean and dignified when friends came to visit”. While for others, “spending time away from the hospital e.g. taking a visit to the beach or to see a pet or to get some fresh air and sunshine” was important. However, according to
Therapists, what was normal for some people living with a terminal illness differed for others. The most common activities identified by therapists that adult clients wished to stay engaged in included: “sitting at the table for meals”, “engaging in family discussions”, “seeing family and friends”, “visiting the cemetery”, “helping with homework”, and “sleeping in the same bed as their partner”.

Therapists reported that their clients highly prioritised maintaining relationships and spending quality time with family, friends and pets due to “the knowledge that time is limited”. Over 130 therapists made reference to their clients wanting to spending time with family and friends, with numerous therapists perceiving that “clients in general prefer to spend their energy/time with family and friends rather than on ADLs”. Therapists believed that these relationships gave clients the motivation to continue to participate in their everyday routines.

Therapists listed numerous everyday occupations that people living with a terminal illness prioritised. One therapist summed this up by saying people wanted “continued participation in life events, leisure activities, school, [and] social outings”. In particular, therapists noted down everyday activities related to social participation with others (n=135). Therapists felt that there was a “big focus on social participation when they [clients] have less physical abilities. Social participation typically involved “spending time with family and friends” in person, by “sitting out of bed for family events”, “having a beer with mates”, “watch[ing] the footy grand final” or by “making phone calls to friends and family when they return home”.

Social participation was not just limited to the client’s home, but to other places in the community such as a “cafe by the beach”, and pubs and clubs, and family and friends' homes. Indigenous clients were reported as needing to “spend time outside, on country. Singing if possible. Dancing if possible. If not, watching others dance/perform in traditional ceremonies where possible”.

Leisure activities were also found to be important, with 49 references to different leisure activities. Leisure activities were varied and ranged from “gardening the roses” to “travelling overseas”, and “going on a cruise with a group of girlfriends”.
Other activities that clients prioritised included “special events” and “bucket list” items. Special events tended to be either a “once off” or annual event such as “attending a daughter’s wedding, having Christmas dinner with the family, or going to the car races”. Therapists reported these special events as being of high priority to clients as they were events “where family will gather” or times that “involve social interaction with others”. Therapists noted that clients’ prioritised events that they felt held special significance such as weddings (n=18), birthdays (n=4), and anniversaries (n=2), or religious holidays such as Christmas or Easter (n=5).

The “bucket list” represented a prioritised list of activities a client wished to take part in before they “kicked the bucket”. Such activities were more specific to the individual and included activities such as “going to the beach one last time”, or “being involved in a gathering/party”. One therapist working in an inpatient unit reflected on helping her client to “achieve something off their bucket list”:

Last week I was asked to help a patient with a bucket list wish which was to feel the sand between her toes and dabble her feet in the water at the beach. We borrowed a beach wheelchair and the physio, myself and the patient’s daughter walked her out into the water and brought her back to the unit complete with sand all over her feet.

Another therapist spoke of assisting a client “with terminal cancer to get married in hospital” before she “passed away the following day”. Therapists felt that engagement in these special events gave clients a sense of “satisfaction”, helped them to “still feel useful”, and reinforced relationship bonds.

Therapists felt that people living with a terminal illness prioritised their continued engagement in valued roles, with clients wanting “to be present within their occupations as a mother, hard worker, sister, grandparent, etc.” Prioritising the completion of everyday home management occupations (n=13), “for example a stay at home mum making lunches for her school aged children”, not only helped a client to focus on living by staying engaged in their normal routines, but also helped clients to “remain engaged in the roles that they feel have defined them”. For example, therapists reported that mothers wished to remain engaged in occupations such as “meal preparation” and “helping with homework” “for as long as possible”, as these
occupations defined their role as a mother and helped them to maintain a sense of normality. One therapist also reported that “younger clients were less likely to want to give up roles that make up their identity, opposed to older clients who are happier to give up their independence”.

Therapists also perceived that clients put less emphasis on remaining engaged in productive tasks, and instead chose to stay in control of “doing the simpler ADLs”. For example, “most of the more complex ADLs like house cleaning and food shopping are no longer achievable for this population, so being able to have control … becomes more important to them”. Prioritising the “simpler ADL” choices “above functional issues” was noted as being at odds with traditional occupational therapy practice, with one therapist even stating, “This usually isn’t an area I would prioritise with my non-terminal clients”. Therefore, therapists recognised that when a client was terminally ill, the clients’ priorities were what mattered.

To understand clients’ priorities for engagement, therapists spoke of the importance of listening to a client’s narrative. For example:

> Originally when I first started to work in palliative care I was very motivated to do therapy with people so they could engage in a meaningful occupation … What I tend to do more now is spend quiet time gathering the person’s narrative and facilitating problem solving to allow people to engage in meaningful occupations in their most natural environment and within the privacy of their normal lives.

By gathering the client’s narrative, therapists felt that they were able to remain client-centred and focused on a client’s priorities. For example, listening to a client’s narrative assisted in the identification of the client’s meaningful activities that they “want[ed] to achieve before death”. Therapists perceived that by listening to the client’s narrative they could better follow their client’s lead as to what occupations should be prioritised.

Priorities not only related to specific activities or occupations, but also included the context or setting. Where possible, therapists felt relationships and occupations should continue to happen in the same environment they always had, to allow clients to stay engaged in their normal routines. For some of the therapists’ clients, routines
involved “be[ing] intimate” and “talk[ing] with their partner in the same bed at night”, while for others it was continuing to meet weekly with their family at their “favourite coffee shop by the beach”. Maintaining the routine of relationships and the environmental context in which they occurred was seen as a way of helping to keep some normalcy in the client’s life. In their own environment, therapists felt that clients “have a sense of control” as the “routines are dictated by the client” rather than by someone else’s schedule. Clients were also perceived to be “surrounded by what is dear to them” (whether that is loved ones, pets or objects) in their home environment. However, therapists also noted it was important to assist clients to continue to “see people and places” in the community. Access assessments were reportedly completed by therapists to community venues such as beaches, coffee shops, halls, churches and sporting facilities to enable clients to engage in their prioritised activities. These visits were thought to enable clients to focus on life through continued community participation in prioritised routines and hobbies with friends and family.

5.3.2 Altered Engagement

As clients’ functional limitations became greater, they become more dependent on others to stay engaged in their everyday activities of daily living. Thus, to continue to focus on life, therapists spoke of the need to alter or modify the way that clients completed their daily occupations. For example,

*It is not that the occupation itself becomes unique, but it may be the way that occupations are done that is unique, based on the person’s abilities and comfort and the level of assistance needed.*

How little an occupation was altered was seen to be dependent on how much assistance a client needed. Some therapists noted that for clients, “part independence can be as valuable as full independence”. Therapists felt that by maintaining partial independence, clients were able to “maintain their dignity”. Therapists saw this as being “especially important in relation to self care tasks” and “transfers and mobility”.

Clients altered engagement in some activities, for example receiving assistance in ADLs, in order to continue to engage normally in other activities of a higher priority. It was
noted by therapists that these clients believed that by keeping some level of independence they were able to “reduce stress” and the “level of burden on their carers”.

Functional ability was not always the most important factor in determining a person’s level of occupational engagement. Instead therapists noted the importance of “being” and wrote about altering the view of what engagement entails at this time of life:

I think at times as OT’s we work with people a lot around the ‘doing’ and the ‘changing’ but not on the ‘being’ (Anne Wilcock’s approach). I think people at the end of their life tend to want to engage in ‘being’, thinking, processing.

Other therapists also noted the importance of clients not having to be actively ‘doing’ things to gain a sense of engagement. Instead clients may engage in an occupation in a small way such as by coming up with the idea, or being present while others physically complete the occupation. This approach also gave “permission” for clients to relinquish their physical independence, yet remain engaged in their chosen occupations.

Therapists reported that clients’ engagement in their routine activities was often altered through the use of equipment. Equipment prescription was important for “positioning” to enhance conversation, enhancing “comfort”, reducing pain and the occurrence of pressure ulcers, and “decreasing isolation”. Equipment was also seen to enhance a person’s participation in community and social occupations. For example, one respondent spoke of a client who attended an African drumming class. Both the drum and the client’s position whilst drumming were modified to allow her to participate and continue socialising with her friends on a weekly basis. Energy conservation strategies in combination with equipment also allowed clients to do more in their daily lives. For example, the provision of a “good pressure care mattress and electric hospital bed” could mean that a client could “be positioned for spending time with people”. Therapists also observed that altering the way occupations were completed through energy conservation strategies and task modification techniques, clients were able to “maintain independence in self-care tasks” and “get more out of what they want to do”.

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Chapter 5
Therapists reported instances where special events were altered in order for clients to be able to continue to focus on life. For example, one therapist spoke of how her client was hoping to get to the Hunter Valley (a wine and cheese region of New South Wales) but physically could not, so her family brought the Hunter Valley to her at the Palliative Care Unit, holding a wine and cheese afternoon. While another therapist recalled how her client’s daughter changed the venue of her wedding to the hospital chapel to allow her bed-bound client (the father) to attend. Altering the place of engagement enabled social participation to occur:

*Instead of socialising with friends at a local club, people want to be able to engage in social activities in their own home i.e. sit out of bed when friends visit.*

Care-givers were also reported by therapists as playing a key role in altering engagement by providing care and support during daily occupations. Education was provided to family and care-givers on “manual handling techniques, and energy conservation/task simplification strategies”. Educating carers was seen to promote ongoing client engagement in valued occupations. Care-giver education was also perceived by therapists as “reducing the feeling of burden that the client often experiences” when receiving help from others.

5.3.3 Summary of “focusing on life”

In summary, therapists identified that their clients chose to focus on life after being diagnosed with a terminal illness. To continue “focusing on life”, clients first needed to establish their priorities for engagement in their occupations. Therapists reported that the identification of these priorities gave their clients a purpose to stay engaged in living. However, as a client’s occupational performance declined in line with advancing illness, therapists looked at ways that clients could continue to stay engaged in life, albeit in an altered fashion.

5.4 “Preparing for death”

As death becomes more imminent and a client’s occupational performance declines, their priorities are perceived to change from “focusing on life” to “preparing for death”. One therapist stated that how people do this:
... will be different for different people i.e. what is important to one may not be important to another, however it includes things like: completion of tasks, having affairs in order such as writing wills and organising finances, or it could be holding a ‘living wake’, or reconciling with their past.

Based on many similar responses, two sub-categories emerged under the “preparing for death” category: practical preparations and “facilitating closure”.

5.4.1 Practical preparations

Therapists reported that people living with a terminal illness prepare for the end-of-life by “address[ing] the practical issues”. Making practical preparations allowed clients living with terminal illnesses to “resolve issues and finish their business”. Practical preparations could be undertaken independently by the client, or with the assistance of others under the client’s instruction. Therapists noted that practical preparations “were very person-orientated” and included “completing tasks to make life easier for families post death” such as organising “financial and legal affairs”, completing “funeral preparations”, “clearing out the home”, and teaching others to take over daily roles and responsibilities.

The types of financial and legal affairs that therapists reported clients prioritised when making practical preparations for the end-of-life were varied. However they included activities such as “writing wills” to ensure that family members had “financial security”, “writing advanced care directives” so that others were aware of their “end-of-life issues”, and organising “guardianship” or “power of attorney” as necessary.

Funeral preparations were another practical issue that therapists assisted clients to undertake. Some therapists reported working with clients who wanted to “select a burial plot”, “write their own eulogy”, and hold a “living wake”. By finalising their own funeral preparations, therapists felt that clients could find “peace before they die” as they knew their wishes would be carried out once they had passed away.

Therapists noted that clients wanted to “clear out the home” prior to death. For example, therapists spoke of arranging day leave for clients from hospice or hospital
for the specific purpose of returning home to “sort through and gift sentimental belongings” to loved ones, and to “tidy up their paperwork and drawers”.

Therapists reported that some clients were concerned about their family’s future once they had died and felt the need to prepare others to continue “caring for those left behind”. For example, therapists spoke of their clients’ need to “prepare partners/siblings for life without them” by “preparing the home and affairs for the partner that is left”, and “educating them on duties they have never done before”.

This need to prepare others for a new role was often precipitated by a decline in a client’s functional ability and their increasing dependence on others. Therapists gave examples of new roles that clients handed on to others. These included organising finances, and completing domestic or parenting tasks. For example, organising finances involved teaching a loved one how to pay bills or how to complete banking tasks. Domestic tasks that needed to be taught to others included taking out the bins, teaching someone how to cook or clean or use particular appliances, while parenting tasks included educating a spouse on a child’s routine, likes and dislikes. Therapists perceived that clients were able to gain “a sense of completion” by making these practical preparations for the end-of-life.

5.4.2 “Facilitating Closure”

“Facilitating closure” was found to be a process of “reflection”, “reconciliation”, and “completion”. Reflection was seen by therapists as an important occupation to facilitate closure for people living with a terminal illness. Reflection was perceived to enable a person to review their life and find closure by reconciling with the past. Closure was also facilitated through a sense of completion of one’s life, which can occur through the achievement of final activities or “striving to complete some tasks they want to achieve before death”, and saying goodbye.

Therapists felt that reflection allowed people to complete a life review by: “reminisc[ing] on life achievements”, identifying “previous meaningful activities”, and determining their “losses and current abilities” in their day-to-day lives. A person’s life achievements were reported by therapists to be reviewed through engagement in meaningful conversation, or through creative expression, such as the
Therapists reported that their clients had meaningful conversations with others as a way of “facilitating closure”. For instance, respondents felt that clients used meaningful conversation as a medium to impart their “wisdom”. This wisdom could come through teaching a loved one a “life lesson” that they wished they had been told. Other therapists noted that their clients had meaningful conversations with others to give a verbal “life review”. A conversation surrounding life review was felt to elicit the person’s wishes and hopes for their family’s future. In this type of conversation, people living with a terminal illness connected with their loved ones through discussion of “love, forgiveness, gratitude and regrets”. Some even “attempted to heal old wounds with family and friends” through this life review. The life review conversation was felt to “acknowledge their place in the world”, thus facilitating a sense of closure.

Writing autobiographies was seen as a way of reflection and a chance to “review their life roles” and any achievements. It also gave the client the opportunity to leave something “concrete and very personal behind”. Therapists felt that this form of reflection helped their clients to “be kinder to themselves” and to focus on “the good that they had done in their life”. By focusing on the positive, therapists thought clients were able to “forgive themselves” for things that may have occurred in the past, and allowed them to come to terms with impending death.

Reflection also gave people living with a terminal illness an opportunity to review their relationships with others and seek reconciliation if required. Therapists felt that clients making preparations for death were more likely to try to reconcile and “heal relationships with certain significant people in their lives” as they had the “knowledge that time is limited”. Through attempting to reconnect with “family and friends that they have fallen out with or not kept in touch with”, clients were thought to reach a place of “self-healing and forgiveness”. For example, this reconnection and “healing of old wounds” allowed people to:

Realise something important in themselves which they can forgive themselves of/ be kinder to themselves / surrender to their situation, but in a profound
and accepting way which is good for their well-being and personal sense of peace.

Ultimately, therapists found that engaging in reflection was an important part of “facilitating closure”.

Completing activities or visiting a place “one last time” also helped clients to facilitate closure. Therapists differentiated these “closure” examples from the earlier examples of people staying engaged in occupations to focus on living, in that “closure” activities or visits were openly acknowledged to be “the last time” a client would ever be able to complete an activity or visit a place, and were often used as an opportunity to say goodbye in some way. For example, most therapists reported that clients wanted to go home one last time if they were expected to die in hospital or hospice care. In such instances, therapists reported organising “day leave home from hospital [for the client] to see their home for the last time” and to “say goodbye”. Other respondents’ spoke of how meaningful it was to their clients to be given the opportunity to farewell their belongings, with one therapist explaining how she enabled a client to return home for a final “play with his model train sets”. Therapists also spoke of helping clients to visit other places that were meaningful “one last time”. Some examples of meaningful places that people wanted to see before they died included “going to the beach one last time”, “redoing past trips” or “enabling them to get into a shed or a particular place on the farm to enjoy the view” for a final time.

As a part of “facilitating closure”, clients were perceived to “seek a sense of completion at the end-of-life with their relationship with others”. An important part of finding closure with relationships was identified as “saying goodbye”. The majority of therapists reported that saying goodbye to people was a unique and important occupation for people at the end-of-life. People were noted as doing this in their own way, with therapists commenting that the way a client said goodbye to a loved one was dependent on the client’s personality, the type of relationship held, and if there were any unresolved relationship issues or estrangement.

Gift giving was the most commonly reported form of saying goodbye (n=23). Therapists reported that clients felt that saying goodbye through a gift was a useful
way of keeping their “memory alive” after they had died. Gift giving could occur in a number of ways, with gifts typically given to close family and friends. Therapists reported that their clients either bought or made gifts, or “gifted sentimental belongings”. For example, therapists spoke of clients “sorting through photos and cherished possessions” with the purpose of “sharing the memories of why they were considered meaningful”. Other clients wanted to make gifts with the loved ones who would receive that actual gift. For example, one therapist reported clients “arranging to have family photos to be done so that children have a reminder of a parent who will die before they are old enough to remember them”. Some of these gifts could occur in the form of “legacies”, such as photo albums or scrapbooks, which could be passed on to future generations.

Saying goodbye in person was the second most popular form of saying goodbye according to therapists (n=20). This type of goodbye involved the person with a terminal illness finding closure by saying a verbal goodbye to their loved ones. Saying goodbye in person could occur face-to-face, via the telephone, or through a video-recorded message. Telephone goodbyes were noted to occur more often if the client had poor functional performance levels, or if they were unable to travel to the person to say goodbye. Video-recorded messages were more often reportedly used when the person living with a terminal illness had young children. For example, one therapist reflected on helping a client to “make a video for an 18 month daughter’s future 21st”. Video messages were made for the “children to see when they were older” with the aim of helping the children to “remember their parent”, and to allow the parent to pass on “future hopes and wishes”.

Saying goodbye through written medium was the third form of saying goodbye reported by therapists (n=16). Clients were encouraged by therapists to find closure through writing letters or cards to their loved ones. One therapist felt that letter writing was a form of “dignity therapy” as it allowed clients to express their feelings, while others reported that letter writing could be used to “resolve issues from the past”. These letters could either be given to the recipient prior to death, or delivered after death had occurred. For example, some therapists reported assisting clients to write letters for future milestone events such as “preparing a letter for a child's school graduation that the client wouldn't live to see”.

109
Several therapists spoke of the importance of saying goodbye to pets ($n=4$). One respondent felt that organising for a pet to visit a care facility was especially important “for the more isolated person, as they (pets) are as important as family”. Another noted how emotionally “moving” it was “having a dog bought onto the ward” so that a client could say goodbye and feel a sense of closure.

Therapist saw that clients having the opportunity to say goodbye was meaningful not only for the person with the terminal illness, but for assisting with their family and friends to find closure as well. For example, one therapist recalled having a client with dementia. In this case “it was very important for the whole family, including children and grandchildren, to be present at home at the time of her death” as it allowed the family to say goodbye and “share key events”, “spend time with each other”, and reflect on the client’s life, with the client, and on their own terms.

Clients were also viewed as “facilitating closure” prior to death by investigating their spiritual self. One therapist reported,

> I do a lot more interventions helping patients explore their meaning of life ... I work much more creatively with patients to help them place themselves in their world.

Therapists felt that this preparation was unique to people living with a terminal illness as attendance at “places of worship” helped clients to “prepare themselves and their loved ones for their death”. Engagement in these spiritual and religious practices was also perceived to aid in emotional “healing and forgiveness”.

### 5.4.3 Summary of “‘preparing for death’”

In summary, people living with a terminal illness are perceived to engage in occupations that help them to start “preparing for death” as their illness advances. Prior to death, clients are seen by therapists to take practical steps to prepare themselves and others for the lead up to their death. To facilitate closure for death therapists identify that they assist a client to complete activities for a final time and say goodbye to loved ones, places and pets.
5.5 Synopsis

Therapists who spend their days working with people with terminal illness have identified their views on occupational engagement at this time of their clients’ lives. Their comments come from their day-to-day experience of assisting clients with the occupational side of life from the time of terminal diagnosis through to death. Therapists’ views identified a dual focus of occupational engagement that was balanced between “focussing on life” and “preparing for death”. The balance between “focussing on life” and “preparing for death” was influenced by changes in occupational performance over time as their health and independence deteriorated leading up to death.

Therapists perceived that despite a terminal diagnosis, clients remained “focusing on life” for as long as possible. They do this through prioritised engagement in their meaningful occupations such as self-care or leisure ADLs, special events, or bucket list items. Altered engagement was required when a client’s occupational performance started to decline and they needed to modify the way they previously completed an occupation, task or activity. Alterations may occur through the use of equipment, energy conservation strategies, task modification or carer education.

As a client neared the end-of-life, they begin “preparing for death” by making practical preparations. Such practical preparations include finalising affairs and making funeral preparations, clearing out their home environment, and teaching others new roles. Clients also needed opportunities that help to facilitate closure. “Facilitating closure” can occur through reflection and reconciliation, saying goodbye, and completing activities one last time.

The subsequent chapter discusses the occupational therapy role for people living with a terminal illness and the processes that therapists follow. As will be seen, the occupational therapy role and processes reported by therapists are closely aligned with their perceptions about clients’ occupational engagement at the end of life.
Chapter 6  The occupational therapy role and process for people living with a terminal illness

6.1 Introduction

The occupational therapy process helps therapists to work with clients to identify and analyse their problems, and to decide on the best possible solutions (Charmaz, 2006). Professional reasoning allows therapists to make systematic decisions and reflect on their practice and to identify if they should change any steps in the occupational therapy process employed.

It is commonly accepted that the occupational therapy process consists of six steps including: referral, assessment, goal setting, interventions, and evaluation. Therefore, this chapter presents findings in relation to: gaining an in-depth understanding of the role of the occupational therapist with people living with a terminal illness and the professional reasoning process they follow in their daily practice.

The research questions addressed in this chapter include:

- What theoretical frameworks are therapists using when working with people living with a terminal illness?
- Do therapists modify or reframe their practice when working with people living with a terminal illness?
- Who are the most common referrers to therapists working with people living with a terminal illness receive referrals?
- What are the reasons for referral to occupational therapy?
- What assessments are completed with people living with a terminal illness, and how do therapists complete these assessments?
- What types of goals are set with people living with a terminal illness?
- What interventions are completed with people living with a terminal illness, and in what setting are they completed?
• What outcome measures are used with people living with a terminal illness?
• Do therapists provide follow-up for people living with a terminal illness?

Results from quantitative and qualitative data analysis from sections five to eight of the national survey are presented. These sections include Section 5: Working with people living with a terminal illness, Section 6: Referral to occupational therapy, Section 7: Occupational therapy assessment and Section 8: Occupational interventions for people living with a terminal illness. The descriptive quantitative data were analysed using SPSS. The qualitative findings were analysed using grounded theory methods previously described in Chapter Three, and managed using NVivo.

Response rates are presented for each analysis. Response rates varied from 121 to 141 depending on the question type. This variation occurred as open-ended qualitative comments sections were optional and not all questions forced the therapist to respond to each individual component question.

6.2 Results

6.2.1 Occupational therapy theoretical frameworks
Sixty (42%) of the 144 therapists reported using a model of practice or theoretical framework to guide their role with people living with a terminal illness. The proportion of therapists in each state who reported using a theoretical framework is presented in Figure 11.
Therapists used eight different models of practice or theoretical frameworks which included: the Occupational Performance Model of Australia (OPMA), the Model of Human Occupation (MOHO), the Canadian Model of Occupational Performance (CMOP), the Person-Environment-Occupation Model (PEO), the bio-psychosocial model, compensatory frameworks, client-centred frameworks, and a combination of models and/or frameworks.

The most frequently reported model of practice was the OPMA (Chapparo & Ranka, 1997) (n=18) which was developed at the University of Sydney and published in its current form in 1997. The majority of OPMA users were employed in New South Wales (n=12). Therapists justified using this model of practice as “it is holistic, and provides a loose structure for considering all areas of clients’ needs while being client centred”. Therapists also reported using the OPMA as “it is the existing departmental framework”, and the model that they “were primarily trained in”.

The MOHO (Kielhofner, 2002) was the second most frequently reported model of practice (n=12). Therapists reported using the MOHO because it was the model they
were “most familiar with” or “trained in”. One therapist reported that the model explored “the motivation and meaning behind client priorities, and also incorporates embodied experience and people with advanced disease have to accommodate to an altered embodiment”.

The CMOP (Townsend et al., 2002) was used by 12 therapists. One therapist stated that it “allows for seeing the person in the different facets of their life with the impact of the environment, person and occupation, but also includes spirituality for this group which is important”.

Eleven therapists reported using a combination of models or theoretical frameworks. A combined approach was used as they reported that they did not “like any particular one”, that it better met their “client’s needs”, or was most “appropriate to clients”.

The PEO model (Law et al., 1996) was used by four of the therapists. The PEO was found to be “simple and quick” and helped therapists to “consider what areas to focus on to promote occupational performance”, especially in the home environment.

### 6.2.2 Modifying occupational therapy practice for people living with a terminal illness

Research suggests that occupational therapists modify their practice when working with people living with a terminal illness (Bye, 1998; Pizzi, 2010; Pizzi & Briggs, 2004). To further explore this finding from previous research studies with small samples of therapists, questions regarding modifying practice were developed based on current literature. Therapists used a four point rating scale of strongly agree, agree, disagree, and strongly disagree to rate their level of agreement with these statements. Therapists’ level of agreement with the statement and the most commonly occurring responses are presented in Table 9.
<table>
<thead>
<tr>
<th>Question</th>
<th>% Agreement</th>
<th>Most common response</th>
</tr>
</thead>
<tbody>
<tr>
<td>My supportive role with care-givers is an important aspect of OT</td>
<td>100</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I see my clients as soon as possible after referral to account for their limited lifespan and possible rapid decline</td>
<td>97.9</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I feel I make a difference as an OT even when the client dies</td>
<td>97.9</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I set goals with clients that meet their wishes</td>
<td>96.5</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I help clients and their families prepare for declining health leading up to death by putting in place care and support needs</td>
<td>95.8</td>
<td>Agree</td>
</tr>
<tr>
<td>I use more temporary home modifications/and or equipment</td>
<td>94.4</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I use more of a family centred approach</td>
<td>93.8</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I help clients to participate in occupations that are meaningful rather than those that emphasise functional performance</td>
<td>93.8</td>
<td>Agree</td>
</tr>
<tr>
<td>I provide more care-giver orientated interventions</td>
<td>93.1</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>I focus more on making the everyday more meaningful</td>
<td>91.7</td>
<td>Agree</td>
</tr>
<tr>
<td>I re-assess my client's needs on a more regular basis to account for rapid changes in functional status</td>
<td>87.5</td>
<td>Agree</td>
</tr>
<tr>
<td>I focus more on the here and now and do not make long term plans</td>
<td>86.8</td>
<td>Agree</td>
</tr>
<tr>
<td>I rarely use standardised assessments or outcome measures</td>
<td>79.2</td>
<td>Agree</td>
</tr>
<tr>
<td>I change how I gather my assessment information, adopting a more low key approach</td>
<td>77.8</td>
<td>Agree</td>
</tr>
<tr>
<td>I change the assessments I get my clients to physically complete</td>
<td>76.4</td>
<td>Agree</td>
</tr>
<tr>
<td>I focus less on independent function</td>
<td>67.4</td>
<td>Agree</td>
</tr>
<tr>
<td>I address the spiritual aspects of my client's lives more often</td>
<td>62.5</td>
<td>Agree</td>
</tr>
<tr>
<td>I address a client's need for closure in preparation for their death</td>
<td>55.6</td>
<td>Agree</td>
</tr>
<tr>
<td>I changed what I view as good OT outcomes</td>
<td>49.3</td>
<td>Disagree</td>
</tr>
</tbody>
</table>

Table 9 Therapists’ agreement with statements on modifying practice to work with people living with a terminal illness compared to a non-terminal caseload

Thirty-nine therapists provided examples of other ways that they modified practice with this client group. Examples included being client centred, and making modifications to their communication style, goal setting and intervention practices. Numerous therapists made comments that reflected that their “practice is more client directed in comparison to other areas”. Therapists felt that they were a “facilitator, rather than the problem solver”. This was viewed positively and resulted in the “the client achieving their priorities for therapy”. Therapists commented on the need to be “flexible” during their consultations and gave examples of this flexibility by “rebook[ing] appointments if it was a bad time” or by changing their treatment plans and “assessments if the client is having an off moment or day”.

116
Therapists modified their communication style when working with people living with a terminal illness by using more narrative techniques and relying more on verbal information from clients to guide practice than in other areas. Therapists spoke of “spending more time” with clients and care-givers, listening to their “goals and needs” to ensure they were correctly understood. By taking this extra time to listen, therapists were able to build “better rapport and trust, which is essential for working with this client group”. Therapists reported they needed to “be aware of the grieving processes and understand that clients and families are often more emotionally vulnerable” than other non-terminal client groups. They responded to this emotional vulnerability by providing “support, reassurance and sometimes incidental counselling” and by becoming more aware of their environmental surroundings and the timing of discussions with this client group, as they were “more sensitive to the stage of grief they’re in”.

Therapists reported that they modified their goal setting practices with this client group, acting “as a facilitator for the clients’ (and) care-givers’ wishes and goals more than non-terminal/palliative patients”. Therapists perceived that they were more likely to set short term goals which help clients “to see what can be done, instead of what is lost”. Therapists reported being “very creative in helping clients to achieve their goals”, even when they are “unrealistic” or “may not always agree with them”. This promoted “greater dignity of risk” and control over their situation.

Interventions were reconceptualised with people living with a terminal illness, changing their focus from “increasing independence” to “optimising function” and “maintaining functional skills”. Therapists reported that their interventions were often “shorter and more frequent”, that their approach was more “predictive and planned for functional deterioration” by “backward grading activities”.

Therapists’ interventions also differed from other clinical areas, for example giving more emotional support than practical support. Therapists noted “providing an ear for listening and a shoulder to cry on” and “time for reflection and talking”. Intervention practices were modified by prescribing equipment rather than permanent home modifications. Therapists were also more likely to recommend
hiring equipment as they were often unable to apply for government-funded equipment due to the shortened life expectancy of this client group. By “taking more risks” in their prescribed interventions with people living with a terminal illness, therapists “focus[ed] less on the traditional ‘safe’ discharge from hospital and more on ensuring that clients and families wishes are accommodated”.

6.2.3 Referral to occupational therapy

Therapists were asked to report on the referral processes for their service. Referral to occupational therapy was analysed according to referral source, reason for referral and referral timeframes.

6.2.3.1 Referral source

A list of 12 medical, nursing, allied health, client and care-giver referral sources was provided for therapists to rate how frequently they received referrals. Therapists rated on a three-point Likert scale whether they received referrals "never, sometimes, or frequently" from these 12 referral sources (Table 10).

<table>
<thead>
<tr>
<th>Referral Source</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Nurse</td>
<td>Frequently</td>
</tr>
<tr>
<td>Inpatient Nurse</td>
<td>Frequently</td>
</tr>
<tr>
<td>Client Self-Referral</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Doctor</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Family/Caregiver</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Social Worker</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Blanket Referral *</td>
<td>Never</td>
</tr>
<tr>
<td>Dietician</td>
<td>Never</td>
</tr>
<tr>
<td>Outpatient Nurse</td>
<td>Never</td>
</tr>
<tr>
<td>Speech/Language Therapist</td>
<td>Never</td>
</tr>
</tbody>
</table>

* A blanket referral occurs when every client admitted to the ward or service is seen by the assigned treating occupational therapist.
Figure 12 indicates the percentage of therapists who reported receiving referrals from each of the sources when the frequency categories of sometimes and frequently were combined. Proportionally when the categories were combined, doctors became the highest referral source, followed equally by other occupational therapists, community nurses and physiotherapists.

**Figure 12 Proportion of referrals received for occupational therapy services (N=144)**

![Bar chart showing referral source percentages]

**6.2.3.2 Reason for referral**

Therapists were asked to choose the primary reason for referral to occupational therapy by referral source. Choices provided were equipment prescription, home assessment and modifications, discharge planning, lymphoedema/oedema management, self-care ADLs, fatigue management, day program, pressure care, domestic ADLs, productivity, leisure or creative activities, and other. Therapists comments reflected that the “primary reasons for referral varied according the client’s need and was not significantly determined by discipline”. The top three reasons that therapists are referred clients with a terminal illness are for equipment
prescription (n=286, 31%), home assessment and modifications (n=221, 24%) and discharge planning (n=175, 19%). A breakdown of each referral source by their top three reasons for referral can be found in Table 11.

<table>
<thead>
<tr>
<th>Referral Source</th>
<th>Reason for referral 1</th>
<th>Reason for referral 2</th>
<th>Reason for referral 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blanket referral</td>
<td>Discharge planning</td>
<td>Home assessment and modification</td>
<td>Equipment prescription</td>
</tr>
<tr>
<td>Care-giver</td>
<td>Equipment prescription</td>
<td>Home assessment and modification</td>
<td>Day program</td>
</tr>
<tr>
<td>Client</td>
<td>Equipment prescription</td>
<td>Home assessment and modification</td>
<td>Discharge planning</td>
</tr>
<tr>
<td>Community nurse</td>
<td>Equipment prescription</td>
<td>Home assessment and modification</td>
<td>Self-care ADLs</td>
</tr>
<tr>
<td>Dietician</td>
<td>Equipment prescription</td>
<td>Home assessment and modification</td>
<td>Fatigue management</td>
</tr>
<tr>
<td>Doctor</td>
<td>Discharge planning</td>
<td>Equipment prescription</td>
<td>Home assessment and modification</td>
</tr>
<tr>
<td>Inpatient nurse</td>
<td>Discharge planning</td>
<td>Equipment prescription</td>
<td>Home assessment and modification</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>Home assessment and modification</td>
<td>Discharge planning</td>
<td>Equipment prescription</td>
</tr>
<tr>
<td>Outpatient nurse</td>
<td>Equipment prescription</td>
<td>Home assessment and modification</td>
<td>Lymphoedema/Oedema management</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>Equipment prescription</td>
<td>Discharge planning</td>
<td>Home assessment and modification</td>
</tr>
<tr>
<td>Social Worker</td>
<td>Discharge planning</td>
<td>Equipment prescription</td>
<td>Home assessment and modification</td>
</tr>
<tr>
<td>Speech and language therapist</td>
<td>Equipment prescription</td>
<td>Discharge planning</td>
<td>Home assessment and modification</td>
</tr>
</tbody>
</table>

Table 11 Top three reasons for referral to occupational therapy services by referral source (N=1462)

6.2.3.3 Referral timeframes and management

Therapists reported that their response to referrals was typically dependent on a “triage” or “eligibility” system that ranked the urgency of the referral to their service, with referrals often prioritised based on a client’s level of deterioration. New referrals were contacted anywhere from the same day of referral to eight weeks post referral depending on this urgency.

Therapists were asked to state their level of agreement on a five point Likert scale to the following statements with respect to their management of referrals. Proportion
of therapist agreement (agree or strongly agree) and the most common responses are presented in Table 12.

<table>
<thead>
<tr>
<th>% Agreement</th>
<th>Most common response</th>
</tr>
</thead>
<tbody>
<tr>
<td>92</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>84</td>
<td>Agree</td>
</tr>
<tr>
<td>80</td>
<td>Agree</td>
</tr>
<tr>
<td>69</td>
<td>Agree</td>
</tr>
<tr>
<td>68</td>
<td>Agree</td>
</tr>
<tr>
<td>57</td>
<td>Agree</td>
</tr>
<tr>
<td>47</td>
<td>Agree</td>
</tr>
<tr>
<td>5</td>
<td>Strongly Disagree</td>
</tr>
</tbody>
</table>

Table 12 Therapists’ level of agreement with referrals practices

Fifty-two therapists provided further comments on their response to referrals. While most therapists agreed that their referrers understood the occupational therapy role with this group, 16 of the 52 therapists reported that their role with this client group was “misunderstood”. These therapists reported that their colleagues have decreased knowledge and poor understanding of the “impact that an occupational therapist can make with a client with a terminal illness”. This resulted in the therapist receiving referrals for “limited interventions such as equipment prescription and discharge planning”.

Therapists’ comments agreed with the statement that “last minute referrals impact what I am able to do with my clients”. The acute care context was noted as being particularly problematic in this area. Therapists perceived that late referrals “can impact on the achievement of client goals”. For example,

In the acute setting the clients are often more unwell than the clients I worked with in the community. We receive referrals when death is more imminent and clients are frequently bed bound with pressure care needs. The clients are no longer able to attend to ADL functions or even active leisure activities… We are jumping straight to the need for large, invasive equipment in the home which can be daunting for care-givers.
6.2.4 Assessment of clients living with a terminal illness

Therapists were asked to write about their assessment practices with people living with a terminal illness. Assessments were viewed as useful to “draw the client’s story out” and “assess rapidly changing situations” that were caused by the client’s functional deterioration. They acknowledged that “not everyone who comes to a palliative care unit is ready to talk about dying or limited life” and this impacted on what assessments they completed and discussions they were able to have with the client or caregiver.

Therapists commented that assessment in this area “is usually a combination of asking questions, observation, talking to the care-giver (if present) and information from colleagues” and “focus[es] on the present rather than the remaining days, unless the patient talks in these terms”. The type of assessments completed with clients were “often dependent on the stage of the terminal illness” and as such, needed to be “flexible” and “allow for variation” when compared to their administration with other client groups.

6.2.4.1 Assessment type

Therapists were asked to indicate the types of client assessment they had undertaken in the previous week. Figure 13 presents the percentage of therapists who used each assessment type within the previous week with clients or care-givers.

Figure 13 Percentage of assessments used by therapists with clients and care-givers in the previous week (N=132)
Figure 14 presents therapists’ primary method of assessing their client or the care-giver. Therapists were given the choices of: direct observation, asking the client or care-giver, or liaising with colleagues.

*Figure 14 Therapists’ primary method of conducting client assessment (N=132)*
The use of standardised versus non-standardised assessments was explored. Less than a third (n=37, 28%) of the 132 therapists reported using standardised assessments as part of their practice with most stating that they had “never used a standardised assessment in palliative care type work”. Of those 37 therapists who had used a standardised assessment, 51.4% (n=19) used one standardised assessment, 24.3% (n=9) used two standardised assessments, and 24.3% (n=9) used three standardised assessments as a part of their routine assessment practice. The standardised assessments reported by therapists were categorised into cognitive, ADL, pressure care, fatigue, and assessments that covered more than one assessment domain.

Therapists listed 13 different standardised cognitive assessments, with the most commonly reported being the Mini Mental State Exam (MMSE) (n=11, 16%) (Folstein, Folstein, & McHugh, 1975). Six different standardised assessments which measured ADL function were used, with the Modified Barthel Index (MBI) (n=4, 6%) (Gammage, McMahon, & Shanahan, 1976) being the most commonly used. The most common of the three standardised pressure care assessments reported was the Waterlow Pressure Ulcer Risk Assessment Tool (Waterlow) (n=11, 16%) (Waterlow, 1984). Pain was only measured using the Visual Analogue Scale (VAS) (n=2, 3%) (Huskisson, 1983) while fatigue was only assessed using the Brief Fatigue Inventory (n=1, 1%) (Mendoza et al., 1999). A further breakdown of the standardised assessments used is found in Appendix 6.

The most common reasons for not using standardised assessments were because there were no “tool[s] that showed outcomes relevant for OTs” and the ADL assessments that existed “were not sensitive enough to show small changes in occupational performance”. Therapists instead reported feeling “more confident” using non-standardised measures, such as “observation during meal preparation or self-care assessments” or “asking the care-giver”. They also reported that non-standardised assessments were less likely to “tire clients out than when you put them through formal assessments” and were ultimately “more meaningful to the client”. 
6.2.4.2 Assessment needs related to end-of-life care

Therapists were asked to rate the degree to which they discussed client and caregivers’ needs during end-of-life care prior to completing assessments (Figure 15).

Figure 15 Frequency of discussions on terminal care needs with clients and care-givers (N=132)

6.2.5 Goal setting with people living with a terminal illness

Therapists felt that they needed to be client centred and “find out what is the most important thing for them to be doing at this point in time”. It was important to be aware that “this changes over time depending on whether symptoms are stabilised or whether people deteriorate”, and that “goals are very much set according to individual patient situation”. Therapists noted that their clients’ goals “may not be traditional occupational therapy or medical team goals”, or even “realistic” at times, but were instead based on their meaning and importance to the client. Therefore, therapists felt that the aim of occupational therapy should be to “focus on what the
client really misses doing and what they are desperate to do, but are really struggling with”.

Therapists set goals with people living with a terminal illness that both enabled them to continue “focusing on life” and prepare for death; goals that mirrored therapists perspectives on occupational engagement for clients with terminal illness. These goals aimed to address the client’s needs, and the goal setting process incorporated flexibility and planned for deterioration. For example,

often we talk about the most important plans (at the moment) and a plan A and a plan B. Plan A goals are about exactly what the person wants to do and exactly the way that they want to do it. Plan B is the acknowledgement of a modified version of the same goal. This works well. People work towards their plan A goal, but very often the plan B goal is what is achieved. Since I have been using this approach, I have observed that people transition more smoothly if their situation changes.

Therapists gave examples of the type of goals they set with people living with a terminal illness. One hundred and forty four people listed at least one goal that they set with this client group, with an overall total of 546 goals reported. Each goal was then coded by topic according to the goal content and analysed using thematic analysis. During coding it was found that the goal themes closely aligned with the categories from the earlier analysis of Chapter 5. As such goals are presented in two categories of “focusing on life” and “preparing for death”, and four sub-categories of goals which relate to prioritised engagement and altered engagement, and practical preparations and “facilitating closure”. A diagrammatic representation of this analytical process is presented in Figure 16.
Three quarters of the goals (n=413, 76%) set with people living with a terminal illness were “focusing on life” by either prioritising or altering engagement in meaningful ADLs.

6.2.5.2 Goals related to prioritised engagement

Therapists identified reframing how they set goals related to ADL performance by ensuring that goals emphasised a client’s priorities:

Clients wish to maintain their abilities to participate in daily activities that are most important to them. E.g. To make a cup of tea, or to maintain their sitting tolerance so that they can sit out in the kitchen to talk to their spouse while they are cooking.
In total, 85 therapists listed 144 goals which made reference to prioritising their client’s engagement in life. Such goals related to the completion of desired meaningful activities of daily living. Foti’s (Mendoza et al., 1999) adaptation of American Occupational Therapy Associations ‘Activities in ADL and I-ADL’, which provides a detailed definition of ADLs and IADLs, was used as a classifying framework to categorise meaningful ADLs goals into the domains of functional mobility, self-care, community living skills, home management, and productive tasks. A further category of ADLs (exact tasks not specified) was included as 31 therapists made reference to setting ‘ADL’ goals in their answers, without specifying a specific ADL task. The breakdowns of sub-goals listed by ADL domain in order of frequency are presented in Table 13.

Therapists emphasised the need for their clients to have “continued participation in desired activities” not only in relation to their functional mobility and self-care tasks, but also in terms of their community living skills such as social engagement with friends and family, and accessing the community to complete leisure activities. By attempting to achieve these goals, therapists were “promoting his or her [client’s] self-worth” and assisting them to “maintain dignity”.

It must be noted that goals related to prioritising engagement were closely linked to goals related to altered engagement. For example, to achieve priority engagement in one area, a therapist might need to also have a goal related to altering the task, the environment, or the care methods, so that the priorities could be met. One example of the close link between goals related to priorities and the need to then set goals related to altering engagement was given by a therapist who noted that it was one client’s priority to remain sleeping in the same bed as their spouse. To meet this priority, the bedroom needed to be altered. The next section further examines goals that were set to alter engagement, which in turn support achieving clients’ priorities.
<table>
<thead>
<tr>
<th>ADL domain</th>
<th>Sub-goal</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Functional mobility</strong></td>
<td>Transfers (Chair/Toilet/Shower/Car)</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>Functional ambulation</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Sitting balance</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Bed mobility</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>34 (24%)</td>
</tr>
<tr>
<td><strong>ADLs</strong></td>
<td>ADLs (Exact tasks not specified)</td>
<td>31</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>31 (22%)</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td>Self-care (Exact tasks not specified)</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Toileting</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Showering</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Sleep</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Grooming</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Dressing</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Feeding</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>32 (22%)</td>
</tr>
<tr>
<td><strong>Community living skills</strong></td>
<td>Social participation</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Community access</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Leisure activities (Exact tasks not specified)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Attending appointments</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Transport</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>30 (21%)</td>
</tr>
<tr>
<td><strong>Home management</strong></td>
<td>Home management (Exact tasks not specified)</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Meal preparation</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Cleaning</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>11 (8%)</td>
</tr>
<tr>
<td><strong>Productive tasks</strong></td>
<td>Work</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Play</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>School</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>6 (4%)</td>
</tr>
</tbody>
</table>

*Table 13 ADL sub-goals (N=144)*
6.2.5.3 Goals related to altered engagement

When setting occupational performance based goals, therapists were aware of the client’s fluctuating functional performance levels and the need to alter how the client engaged in their meaningful ADLs. Therapists spoke of helping clients to adapt to their “losses of function”, while trying to maintain their functional performance for “as long as possible”. When this was no longer achievable the notion of “minimal assistance” from a care-giver, or task modification, was introduced to goal statements. For example, one therapist wrote that “often their goals are around participating in meaningful ADLs – so I try to facilitate this through adaptive techniques, and introducing assistance or equipment”.

Therapists set goals to increase a client’s independence or enhance their safety completing a task by altering the environment or the way in which the task was completed. One example included a client,

*being able to spend quality time with their family, i.e. having a wheelchair to go out, or a utility chair to sit in the lounge, a mobile commode so they don’t have to walk to the toilet, and less showers to have energy for being with people, etc.*

Goals were set incorporating equipment prescription to “meet the needs of the client and their family”. For example, “being able to complete self-care occupations independently with equipment/or with minimal assistance”. Goals, which had an element of equipment prescription, were thought to increase their client’s independence and comfort levels, and to decrease pain and fatigue when completing tasks.

Goals related to home modifications and environmental assessments were to allow the client to “continue to engage in their meaningful occupations and life roles”, albeit in an altered way. Goals typically incorporated installation of “hospital beds”, “rails”, “hoists” and “pressure care” to “modify the home environment to meet the client’s needs”. This was also achieved through the installation of “positioning, ramps, and setting up the microenvironment”, such as their bedroom as noted earlier, to enable clients to achieve their goals of “remain[ing] in the same bed as
their partners”, or making alterations to the lounge room to enable “clients to remain socially engaged”.

Twenty therapists reported setting goals around “energy conservation principles”. Energy conservation goals altered the way that a client completed a task and had the aim of “reducing fatigue” and “increasing independence” when a client was completing their ADLs (n=14). Energy conservation principles were also felt to “increase activity tolerance” and “reduce shortness of breath” in clients living with a terminal illness. Therapists also noted that achieving energy conservation goals allowed clients to “redirect their energy to family-orientated activities” or “desired tasks”. This last example again reinforces the close link between goals related to altering engagement that in turn reinforce goals related to clients’ priorities for engagement.

Seven of the therapists’ goals were related to lymphoedema management and enabling prioritised engagement through: improved comfort of the affected limb (n=2); reduction in affected limb size (n=1); improved functional use of the affected limb (n=1); and the prevention of skin breakdown (n=1). Two further goals were set regarding carer support with oedema management.

Therapists viewed safety to be an important part of providing care to people living with a terminal illness. They reported 41 goals (8%) which mentioned either client or care-giver safety in relation to altered engagement in ADLs (Figure 17). Therapists perceived the occupational therapy role to be one that provides “a safe environment [for clients] to participate in their activities of daily living”.

Therapists reported setting goals around client safety (n=21) and carer safety (n=10). Most goals were aimed at increasing client safety whilst completing meaningful ADL tasks. For example, therapists reported goals such as “to enable safe access the shower” and “improve safety and independence with toilet transfers and toileting”. One therapist emphasised safety over independence, stating that occupational therapy goals for clients were “less about independence and more about safety”.

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Chapter 6
6.2.6 Goals related to “preparing for death”

Approximately a quarter of the therapists’ goals were related to assisting clients to prepare for death (n=113, 24%). These goals included practical preparations at the end-of-life and goals which aided in facilitating closure.

6.2.6.1 Goals related to practical preparations at the end-of-life

Therapists set goals with their clients around the “practical issues” and preparations required for end-of-life. Some goals were related to tying up loose ends prior to death, while others related to the practicalities of providing care at the end of life.

Goals included: clearing out their homes, sorting out their wills, finances, and legal affairs, and organising advanced care directives. These practical preparations needed to be done before clients died or became too unwell to do so. Other clients set goals with therapists around organising funeral preparations or wanting to “hold a living wake”. Achievement of these goals relating to the practical issues at the end-of-life were thought to “fill in the gaps” and “make life easier” for clients’ loved ones once
they had passed as they had an opportunity to “tidy up the loose ends” and resolve foreseeable issues.

Therapists noted that it was important to identify where the client wished to spend their last days and where they wished to die. If clients identified wanting to go home, then all the practicalities of arranging the care they needed must be done before the client became too unwell. Therapists identified that they needed to “grasp the window of opportunity” of wellness so that they could “be sent home to die at home as they wished”. Over 15% of therapists also acknowledged that they set goals aiming to keep their clients at home for “as long as possible”, but were aware of the reality that some clients would return to an inpatient setting to die regardless of having done all the preparations required to provide care at home.

Maintaining appropriate pressure care was seen to be an important practical preparation at the end-of-life with 35 therapists reporting pressure care related goals. Therapists set pressure care goals with their clients, which aimed to improve positioning in bed and on chairs (n=7), and skin integrity (n=3). Goals when prescribing pressure care devices, such as cushions (n=2) and mattresses (n=2) were to “maximise comfort when resting in bed” or when sitting, or to “minimise the risk of developing pressure areas”.

Goals were also set around providing practical and emotional support at the end-of-life to clients and their care-givers. Goals were set to “reduce carer burden” through providing the family and care-givers with practical support as required. At times this was completed by therapists setting goals with family and care-givers around seeking respite care or introducing appropriate services, such as “house cleaning, meals and respite” or through education and equipment prescription.

Therapists felt that it was important to “include a family-centred goal which includes the primary care giver”, especially once the client’s functional level had begun to decline in order to provide “support to the carer”. Goals were set predominately around education, support, organising respite care, reducing stress and anxiety and meeting the family and care-givers’ needs (Table 14).
Therapists set goals related to arranging “appropriate service provision” and “putting services in place” prior to a client returning home. Goals were set around family and care-giver education to “prevent injuries”, and increase a care-giver’s independence with “all necessary manual handling and care needs” by educating them on topics such as positioning and equipment use.

<table>
<thead>
<tr>
<th>Goal</th>
<th>Sub-goal focus</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing knowledge of the care-giver</td>
<td>Manual handling and positioning</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Equipment (hoist, pressure care, etc.)</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Non-specific care for the client in the home</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Care in bed</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Carer safety</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Service availability</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Enabling clients to keep their independence</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Home modifications</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Illness progression</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Home exercise program</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Client’s cognition</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>69</td>
</tr>
<tr>
<td>Family-centred goals</td>
<td>Exact goals not specified</td>
<td>13</td>
</tr>
<tr>
<td>Increasing care-giver support</td>
<td></td>
<td>11</td>
</tr>
<tr>
<td>Reducing stress and anxiety</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>Organising respite for the care-giver</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Meeting care-giver needs</td>
<td></td>
<td>2</td>
</tr>
</tbody>
</table>

**Table 14 Frequency of goals relating to the family and/or care-giver (N=104)**

6.2.6.2 **Goals related to facilitating closure**

Therapists reported that clients set goals that “facilitated closure”. One form of closure included goals related to saying goodbye. Clients set goals of saying goodbye to family and friends by writing letters and cards, or creating gifts such as photo albums or autobiographies. Facilitating closure through this type of goal setting was thought to help clients “resolve issues from the past” and create a lasting, “concrete” memory of their existence.
Therapists wrote about the importance of their clients achieving goals such “enabling their clients to see home one more time” or returning home from hospital for extended periods. Therapists who worked “in the inpatient setting” felt that returning home enabled clients to “spend time with family and friends” and “achieve what they would like to achieve while at home” before they died. Returning home often required therapists to set further goals around putting “supports and equipment in place” and this sometimes meant “including more services rather than re-training for self-care”. Therapists felt that the goal of being able to return home gave clients the opportunity to “say goodbye for one last time” to their home and belongings, as well as assisting with “closure”.

Therapists spoke of setting goals that gave emotional support with the aim of allowing the client and/or care-givers the opportunity to “debrief”, “vent” and find closure through therapeutic discussions (n=16). Therapists also set goals, which supported the care-givers’ emotional “needs” for closure, such as being in the same room with the client when they die.

6.2.7 Interventions for clients living with a terminal illness
Questions were asked relating to occupational therapy interventions for people living with a terminal illness. One therapist reported that working with people living with a terminal illness,

is an area of practice where OT interventions can have a huge impact on the client’s/carer’s quality of life leading up to the person’s death and on how well the person dies.

Therapists commented on their intervention practices with people living with a terminal illness. Most comments were positive, but many also felt that occupational therapy practice with this client group “is an undervalued and under resourced area”.

Two main factors impacted on how therapists provided interventions. Firstly, therapists perceived that the amount of client handover given between two services when making a referral impacted the interventions that they initially offered to their
clients. Therapists reported that handover was often “incomplete” between services and typically did not fully address the client’s needs. This incomplete referral often meant that therapists needed to re-ask questions or re-complete assessments that had previously been completed with the client.

Secondly, the client’s level of acceptance with their diagnosis and disease progress was a factor that impacted on therapists’ interventions. Therapists had to be guided by clients’ wishes and their acceptance with their diagnosis when introducing interventions. For example, a therapist stated, “you may not focus on the psychological issues initially as the client doesn’t want to talk about that aspect and purely wants to put functional aspects first”.

Therapists rated how frequently they provided interventions that met different client (Figure 18) and care-giver needs (Figure 19) ranging from always to never on a five-point Likert scale.

![Figure 18 Therapists’ agreement related to meeting the clients’ needs during interventions](image)
Therapists reported that they always addressed their clients’ and care-givers’ physical needs, and almost always addressed their psychosocial and occupational needs. However, spiritual needs were most commonly reported as being addressed on a sometimes basis.

The most common ADL tasks that were the focus of intervention are presented in Figure 20. This question had 379 responses which were then coded using thematic analysis and categorised into one of six domains again using (2001), thereby using the same method as outlined in 6.2.5.2.
A breakdown of the frequency of the focus of interventions provided within each domain is reported in Table 15.

<table>
<thead>
<tr>
<th>Intervention domain</th>
<th>Intervention focus</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Showering</td>
<td></td>
<td>56</td>
</tr>
<tr>
<td>Self-care (Exact tasks not specified)</td>
<td></td>
<td>53</td>
</tr>
<tr>
<td>Toileting</td>
<td></td>
<td>34</td>
</tr>
<tr>
<td>Dressing</td>
<td></td>
<td>30</td>
</tr>
<tr>
<td>Feeding</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Sleep</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td>Grooming</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Continence</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>192 (51%)</td>
</tr>
<tr>
<td><strong>Functional mobility</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional ambulation</td>
<td></td>
<td>74</td>
</tr>
<tr>
<td>Transfers (chair/toilet/shower/car)</td>
<td></td>
<td>43</td>
</tr>
<tr>
<td>Bed mobility</td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>Pressure care</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Sitting balance &amp; positioning</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>140 (37%)</td>
</tr>
<tr>
<td><strong>Community living skills</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community access</td>
<td></td>
<td>10</td>
</tr>
<tr>
<td>Leisure activities (Exact tasks not specified)</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Social participation</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Transport</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>20 (5%)</td>
</tr>
<tr>
<td><strong>Home management</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meal preparation</td>
<td></td>
<td>16</td>
</tr>
<tr>
<td>Home management (Exact Tasks Not Specified)</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>20 (5%)</td>
</tr>
<tr>
<td><strong>Productive tasks</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Play</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>1 (0%)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bed-bound care</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>Home assessment</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Energy conservation</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Mobility &amp; transfers with a care-giver</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td>6 (2%)</td>
</tr>
</tbody>
</table>

*Table 15 Frequency of interventions provided to people living with a terminal illness (N=379)*
Therapists were asked to record from a range of interventions the interventions that they had completed with clients and care-givers. Table 16 presents the frequency of interventions that therapists had completed in the week prior to completing the survey.

<table>
<thead>
<tr>
<th>Intervention</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment prescription</td>
<td>173</td>
</tr>
<tr>
<td>Client education</td>
<td>148</td>
</tr>
<tr>
<td>Care-giver education</td>
<td>139</td>
</tr>
<tr>
<td>Pressure care</td>
<td>124</td>
</tr>
<tr>
<td>Energy conservation</td>
<td>115</td>
</tr>
<tr>
<td>Referral to other health professionals</td>
<td>98</td>
</tr>
<tr>
<td>Discharge planning</td>
<td>97</td>
</tr>
<tr>
<td>Home modifications - temporary</td>
<td>97</td>
</tr>
<tr>
<td>Referral to community supports</td>
<td>78</td>
</tr>
<tr>
<td>Self-care retraining</td>
<td>66</td>
</tr>
<tr>
<td>Home modifications - permanent</td>
<td>60</td>
</tr>
<tr>
<td>Therapeutic conversation</td>
<td>52</td>
</tr>
<tr>
<td>Anxiety and stress management</td>
<td>46</td>
</tr>
<tr>
<td>Pain management</td>
<td>46</td>
</tr>
<tr>
<td>Domestic ADLs retraining</td>
<td>43</td>
</tr>
<tr>
<td>Leisure related</td>
<td>38</td>
</tr>
<tr>
<td>Rehabilitation/Reconditioning activities</td>
<td>37</td>
</tr>
<tr>
<td>Sleep hygiene</td>
<td>26</td>
</tr>
<tr>
<td>Bereavement counselling with care-givers</td>
<td>24</td>
</tr>
<tr>
<td>Group activities</td>
<td>11</td>
</tr>
<tr>
<td>Creative therapies</td>
<td>10</td>
</tr>
<tr>
<td>Workplace interventions</td>
<td>7</td>
</tr>
</tbody>
</table>

*Table 16 Frequency of intervention completed by therapists working with people living with a terminal illness within the past week (N=1535)*

Interventions were most frequently completed within the home environment, opposed to hospital, community health, hospice, or outpatient settings, and least likely to be provided in nursing home settings (Figure 21).
The proportion of intervention type by setting type is broken down in Figure 22. Interventions were divided into three groups: referrals, interventions related to occupational engagement, supportive care interventions and education interventions.

Supportive care and education interventions (n=216) included: anxiety and stress management, bereavement counselling, care-giver and client education, and therapeutic conversations. Interventions related to occupational engagement (n=950) included: discharge planning, domestic ADL retraining, energy conservation, equipment prescription, group activities, home modifications (temporary and permanent), leisure, pain management, pressure care, self-care retraining, sleep hygiene, rehabilitation and reconditioning activities, creative therapies and workplace interventions. Referrals (n=176) were to both community supports and to other health professionals.
6.2.7.1 Outcome measures used with clients living with a terminal illness

Therapists made reference to the lack of outcome measures for use in occupational therapy with this client group. Those that existed were felt to have a strong “medical focus” or only “measure quality-of-life” rather than specific occupational therapy domains. Those that measure functional performance such as the Australian Modified Karnofsky Performance Scale (AKPS) (Abernethy, Shelby-James, Fazekas, Woods, & Currow, 2005) were perceived by therapists as “not being sensitive enough to show small individual changes in occupational performance”.

Seventeen percent (n=23) of 132 therapists reported that they used outcome measures to assess their client’s occupational performance at the end of their intervention. Of those 23 therapists who used outcome measures, 74% (n=17) used one outcome measure, 13% (n=3) used two outcome measures, and another 13% (n=3) used three outcome measures. Therapists reported using a total of 27 outcome measures.
measures with people living with a terminal illness. Out of the 27 outcome measures, therapists listed 14 different tools, with 10 of these tools being standardised measures. These outcome measures were categorised into one of six areas including outcomes that measured changes in ADL function, achievement of individual’s goals, symptom control, cognition, fatigue and oedema and are presented in order of frequency in Table 17.

<table>
<thead>
<tr>
<th>Focus of Outcome Measure</th>
<th>Outcome Measure</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Australian Modified Karnofsky Performance Scale (AKPS) (Fries et al., 1994)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Canadian Occupational Therapy Performance Measure (COPM) (Abernethy, Shelby-James, Fazekas, Woods, &amp; Currow, 2005)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Austoms (Law et al., 1990)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Functional Independence Measure (FIM) (Perry et al., 2004)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Modified Barthel Index (MBI) (Keith, Granger C.V., Hamilton B.B., &amp; F.S., 1987)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>13 (45%)</td>
</tr>
<tr>
<td>Achievement of goals</td>
<td>Recorded achievement of goals</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Goal Attainment Scale (GAS) (Shah, Vanclay, &amp; Cooper, 1989)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>9 (31%)</td>
</tr>
<tr>
<td>Global assessment</td>
<td>Palliative Care Outcomes Collaboration Assessment Tool I (Kiresuk &amp; Sherman, 1968)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Symptom management</td>
<td>Edmonton Symptom Assessment Scale (SAS) (Palliative Care Outcomes Collaboration, 2012)</td>
<td>2 (7%)</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>2 (7%)</td>
</tr>
<tr>
<td>Cognition</td>
<td>Brief Interview for Mental Status (BIMS) (Dudgeon, Harlos, &amp; Clinch, 1999)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Brief Fatigue Inventory (Saliba et al., 2012)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Oedema measurements</td>
<td>Oedema Measurements</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>1 (3%)</td>
</tr>
</tbody>
</table>

Table 17 Frequency of outcome measure use by assessment type (N=27)
6.2.8 Follow-up of clients living with a terminal illness

Some clients required community follow-up post-discharge from inpatient settings to ensure their needs continued to be met. The majority of therapists reported that they were able to provide follow-up for their clients (n=83, 65%) and their care-givers (n=79, 62%) post-discharge as part of their role. A combined follow-up response rate for both clients and care-givers is presented in Figure 23.

Figure 23 Follow-up of clients and care-givers as part of role (N=128)

Therapists reported issues with their current-follow-up processes for their clients and care-givers when they are discharged into the community. For example, therapists reported variances in the time period for which they could provide follow-up care. Some therapists even reported that it is more efficient to discharge a client and await re-referral than to follow-up the same client. Some therapists felt that the follow-up they provided to clients and care-givers was “limited” and “not always in as timely a manner as [they] would like”. The ability to only provide phone follow-up rather than in person was also reported to be an issue.

Five issues shaped follow-up practices. These included: therapists’ “workload”, “the [client’s] need for follow-up”, the type of follow-up required, the distance to see the
client, and “the availability of another OT service” to manage future needs. Funding sources were also seen to impact on client and care-giver follow-up, with references made to specific services, such Department of Veterans Affairs, as not providing funding for follow-up.

6.3 Synopsis

This chapter has reported findings across all stages of the occupational therapy process for people living with a terminal illness, and by doing this has identified the scope of the occupational therapy role. Findings reveal that occupational therapists’ professional reasoning through the occupational therapy process mirrors their perspective on occupational engagement for clients with terminal illness. They reframe the occupational therapy process to assess, set goals and implement interventions to focus on living, as well as preparing for death. Working closely with clients and caregivers is an essential aspect of this process, as is working with other health professionals. The work setting and specific details pertaining to each stage of the occupational therapy process were revealed.

The next chapter presents findings related to challenges to working with people living with a terminal illness, preparation for practice, and the education and support needs of therapists working with this caseload.
Chapter 7 Challenges to practice, and the educational and supervision needs of therapists working with people living with a terminal illness

7.1 Introduction

To meet the needs of clients living with a terminal illness, therapists must be adequately prepared for practice (Mendoza et al., 1999). However, research has found that therapists face challenges, such as role ambiguity and burnout, because they have only received limited education on how to work with this client group (Meredith, 2010). While some studies have explored the challenges and educational requirements of working in this area, most are out of date. Since the initial study by Bennett (1991) was completed, it was important to establish if these challenges and educational requirements have been addressed. Supervision of therapists working with people living with a terminal illness is another important element of postgraduate support and education but has yet to be explored with therapists working with people living with a terminal illness. Therefore, exploration of whether current supervision practices are meeting the needs of therapists was required.

This chapter presents research findings in relation to: gaining an in-depth understanding of the challenges, and educational and support needs of occupational therapists who work with people living with a terminal illness.

The research questions addressed in this chapter include:

- What are the challenges for therapists working with people living with a terminal illness?
- How do therapists overcome the challenges they face working with people living with a terminal illness?
- Do occupational therapists feel prepared to work with people living with a terminal illness?
- What skills and knowledge are required for competency of practice when working with people living with a terminal illness?
• Are these skills and this knowledge best taught at university, on the job, or as part of a therapists’ continuing professional development?
• Are therapists receiving supervision when working with people living with a terminal illness?
• What are the support needs of occupational therapists working with people living with a terminal illness?

The results of this chapter are derived from the survey sections of Section 5: Working with people living with a terminal illness, and Section 9: Education and supervision when working with people living with a terminal illness. Both quantitative and qualitative results from sections five and nine are presented. The descriptive quantitative data were analysed using SPSS. The qualitative findings were analysed using the grounded theory methods previously described in Chapter Three and managed using NVivo.

Response rates are presented for each analysis as they varied from 123 to 141 depending on the question type. Comments sections were also optional and not all questions forced therapists to respond to each individual component question.

7.2 Results

7.2.1 Challenges and strategies of working with people living with a terminal illness

7.2.1.1 Perceived challenges

Therapists were asked to select what they perceived were their main challenges when working with people living with a terminal illness. The challenges they could select from were derived from the literature on job satisfaction and burn out for health care professionals working in this clinical area. More than one challenge could be selected, and they could identify any other challenges they faced that were not listed. Data was grouped into three categories from the 508 examples given in the data: (i) service and caseload demands; (ii) intra and interpersonal challenges; and (iii) role challenges. The frequency of each category is presented in Figure 24.
## 7.2.1.2 Service and caseload challenges

Service and caseload demands involved: juggling multiple caseload demands \( (n=91) \); service being under-resourced \( (n=80) \); service being under-staffed \( (n=66) \); system demands \( (n=11) \); and receiving minimal support from their clinical supervisor \( (n=7) \).

Therapists felt their biggest caseload demand was managing split caseloads, whereby they had to work in more than one clinical area. Therapists felt that their split caseloads impacted client care as they often found it difficult to prioritise clients. Some therapists believed that their non-terminal clients were negatively impacted, as “the palliative clients are all urgent in comparison”. For others in more senior management roles, “juggling the management/clinical split” was a further challenge.

Therapists felt that their services were under-resourced both with material goods and staffing. They reported that equipment availability was often poor and impacted their ability to meet clients’ needs. Therapists were then made to prioritise which client required “major equipment” when equipment supplies were low. Equipment hire was “too expensive”, and there was “insufficient funding for the necessary...”
equipment” to adequately meet the needs of these clients. The time taken to organise the required equipment for their clients was seen to be another challenge, as well as the “slow” waiting time for clients to receive equipment.

Therapists found challenges to service delivery related at times to systems that were in place in the practice context. Therapists perceived that the wards often gave either “late or inappropriate referrals”, or “tried to discharge clients home too early”. They found this challenging as it impacted on the type of care they could give their clients before the client’s passing. For example,

Not receiving referrals in the early stages of disease progression is challenging as it limits the benefit that occupational therapy could have provided to the client and care-givers. Referrals have to focus on functional performance rather than the client’s ability to engage in meaningful activity due to limited time and resources.

The time taken to travel to and from a client’s home was a challenge, with therapists working in larger geographical areas reporting that it impacted their ability to see clients in a timely manner.

Receiving minimal supervision was another challenge of working in this clinical area. Therapists reported that they “don’t have a senior therapist I can call on for expertise”. Therapists that did have supervisors reported that their occupational therapy supervisors frequently had less experience working with people living with a terminal illness than they did, and often lacked an understanding of their role. Some direct supervisors were not occupational therapists. Not having access to a supervisor who could give them discipline specific feedback and support was seen as a negatively which impacted their professional skill development. Another therapist reported having limited support from the service management as their caseload was seen as not belonging to the service setting. This therapist commented that there was “limited support from service management – in their view people living with a terminal illness should not be seen on the transition care program”.
7.2.1.3 Intra and interpersonal challenges

Intra and interpersonal challenges was the second category of challenges. These challenges included: the emotional challenges of working with people who are dying (n=57); working with grieving family members (n=55); and rapport building with people who are going to die (n=17).

Interpersonally, therapists reported that working in this clinical area was emotionally challenging. Therapists identified strategies they used to “prevent burnout” and cope with the “emotional fallout of having my clients die”. Therapists also reported working in the area was particularly challenging if they perceived their “personal and professional boundaries clashing”. This ‘clash’ occurred if the therapists did not set boundaries with their clients, or if the client reminded them of someone in their personal lives.

Poor communication between the client and their family was another challenge. For example one therapist found it difficult to complete discharge planning with clients when “families are unable to care for the client at home, but they don’t want to communicate this to the client”. Therapists also found it challenging to work with clients and families who were in denial of their illness and functional loss, clients who lacked an “understanding or awareness of their prognosis”, or clients where a cultural context influenced the ability to be open about these issues. For example, one therapist summed up that it was a challenge:

*working with families where the nature and the impact of the terminal illness cannot be discussed due to cultural reasons, or simply because of the family’s level of acceptance of what is happening.*

Some therapist reported finding it challenging to build rapport with people who are going to die and their grieving families.

7.2.1.4 Role challenges

The final category to emerge was role challenges. Role challenges included: having their role misunderstood by other health professionals (n=51); having a limited evidence base to support their role (n=41); being unsure of what they can do in their
role (n=21); and the sense that no matter what they do, their clients will not get any better (n=11).

The biggest role challenge perceived by therapists was being misunderstood by other health professionals. Therapists reported that there was a “lack of understanding of the occupational therapy role”. They felt that this particularly impacted upon their interventions. Their colleagues did “not recognise the complexity of discharge planning” or the “breadth of interventions that can usefully be applied”. They also reported receiving inappropriate referrals due to the poor understanding of the scope of the role.

Therapists also felt challenged by the lack of evidence or guidelines for occupational therapy practice in this area. They noted that “this leads to a misunderstanding of the scope of the role”, as it impacted on their daily practice and ability to set goals with this client group. However, they reported that the “evidence base is growing but we just need to know how to access it”, and that they would like to “build a list serve or something similar to post questions, comments and concerns”. Those who had access to journal articles reported different issues: “I have limited time to read the evidence out there re best practice for terminal illness”.

Being “unsure” of what to do in their role was another challenge faced by therapists. They reported being “unsure of [their] role and what they should be doing and focusing on”. For example:

*Often patients are given a vague prognosis so it is hard to know what to realistically put in place in terms of modifications, or knowing how much to encourage patients to be active and what goals to set.*

Therapists also found it challenging that despite occupational therapy intervention, “no matter what I do my client won’t get better”. Some therapists reported a sense of failure when, despite providing therapy, their clients would still eventually die.

### 7.2.1.5 Strategies to overcome perceived challenges

Therapists were asked to choose from a list of options on how they overcame the challenges that they faced. This list was derived from previous research findings.
regarding strategies used by other health professionals. Therapists were able to tick as many choices as relevant, and provide comment regarding other strategies they used to overcome challenges. The percentage of therapists who agreed with each strategy statement is presented in Table 18.

<table>
<thead>
<tr>
<th>Statement</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I debrief with other colleagues</td>
<td>114</td>
<td>79</td>
</tr>
<tr>
<td>I ensure that I have good work/life balance</td>
<td>109</td>
<td>76</td>
</tr>
<tr>
<td>I complete leisure activities</td>
<td>75</td>
<td>52</td>
</tr>
<tr>
<td>I exercise or play sports</td>
<td>68</td>
<td>47</td>
</tr>
<tr>
<td>I seek supervision from my senior</td>
<td>63</td>
<td>44</td>
</tr>
<tr>
<td>I spend time away from the caseload</td>
<td>50</td>
<td>35</td>
</tr>
<tr>
<td>I debrief with personal friends</td>
<td>44</td>
<td>31</td>
</tr>
<tr>
<td>I debrief with my mentor</td>
<td>31</td>
<td>22</td>
</tr>
<tr>
<td>I seek counselling from outside of work sources</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>I attend an OT clinical interest group</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>28</td>
<td>19</td>
</tr>
</tbody>
</table>

**Table 18 Percentage of strategies used by therapist to overcome challenges (N=628)**

When the results were combined therapists were more likely to use strategies that ensured a good work/life balance (n=293, 47%) such as completing leisure activities, participating in exercise or sports, or by spending time away from their caseload, than they were to debrief with others or seek supervision or counselling (n=160, 25%).

Twenty-eight therapists commented on additional strategies used to overcome the challenges that they perceived they faced. These included: completing “rituals”, reflecting, taking leave, and reviewing evidence-based practice.

The main additional strategy was completing “rituals”. Therapists reported completing a variety of rituals such as “lighting candles”, “listening to music”, holding “monthly meetings to remember lives”, “praying” and “attending church”. One therapist wrote about how her specific ritual involved:

...leaving it in the letterbox. For example, I leave any work thoughts in the letterbox when I drive in my driveway at home and don’t think about work at home once I have done this (this has taken years for me to be genuinely able to do this).
Chapter 7

Reflection was an important strategy to overcome the challenges faced working in this area. Therapists reported reflecting in solitude and with others. Solitary reflection allowed therapists to reflect on “interventions as well as personal reflections on my own life and death” and could be done by “taking time out” or through “writing out my own personal reflections”. Reflection could also be completed by reflecting and debriefing informally with friends, family or co-workers. Reflection by debriefing was felt to both “support and distract” the therapist from their challenge.

Reflection allowed therapists to stop and appreciate what they have, and change their frame of mind when working with people living with a terminal illness: “I appreciate what I have now, and know that I will not always have the answers, and this is ok”. Another therapist reported, “I reframe working in palliative care as being very life affirming – I think I practice giving gratitude so much more. I think this helps me personally and professionally”. Therapists “became more aware of the ‘precious’ nature of life” and were more likely to enjoy life “and be thankful when spending time with family and friends”.

Taking leave was another strategy. Therapists spoke about the need to schedule regular breaks at work as well as the need to take regular holidays, “even if they are short breaks”. They perceived that taking regular breaks allowed them to replenish their emotional capacity to cope with their challenges.

Reviewing evidence-based practice could also help to overcome challenges. Reviewing the evidence helped them to improve client outcomes and assisted with their professional reasoning. This knowledge was then used to gain a better understanding of the scope of the occupational therapy role, which lead to therapists “being able to educate others”, and be a “better patient advocate for services and my clients”.

152
7.2.2 Preparation for practice with people living with a terminal illness

7.2.2.1 Feelings of preparedness for practice

Therapists were asked to rate their feelings of preparedness for practice when they first started working with people living with a terminal illness. The results are presented in Figure 25 revealing that the majority of therapists felt only slightly prepared or not at all prepared.

Figure 25 Therapists’ feelings of preparedness (N=123)

Therapists were then asked to report whether their feelings of preparedness changed the longer they worked in the area. Ninety-nine percent of therapists agreed with this statement, with 46% (n=56) strongly agreeing and 65% (n=65) agreeing.

7.2.2.2 Preparation for practice: Undergraduate education

Only 24% (n=29) of therapists felt that that their undergraduate education prepared them to work with people living with a terminal illness. When asked to clarify the reason for their answer, therapists gave varied responses. Therapists who reported feeling prepared stated that they had learnt about palliative care and death and dying as part of their undergraduate curriculum. However, most reported only limited exposure to the topic, and felt that their life experience or practical exposure to the
topic increased their feelings of preparedness. The 76% (n=94) of therapists who did not feel that their undergraduate education prepared them could not recall learning about palliative care at university. Eleven of these 94 therapists reported that they learnt this information “on the job” instead.

Therapists then rated how comfortable they felt with eight statements related to working with people living with a terminal illness. Therapists (n=123) rated their comfort levels from very comfortable to not comfortable at all (Figure 26).

*Figure 26 Therapists’ comfort level when working with people living with a terminal illness*
7.2.3 Perceived educational requirements

7.2.3.1 Skills, knowledge and qualities required for practice

When asked about university preparation, and what skills, knowledge and qualities should be taught to prepare students to work with clients with terminal illness, 119 therapists gave at least one response. The 260 examples given in the responses were coded into four areas of skill, seven areas of knowledge, and five main qualities that occupational therapists should possess or be educated on prior to working with this client group. These skills, knowledge and qualities are presented in Table 19.

<table>
<thead>
<tr>
<th>Skill</th>
<th>Knowledge</th>
<th>Qualities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication (verbal and non-verbal)</td>
<td>Care-givers</td>
<td>Compassionate</td>
</tr>
<tr>
<td>Coping skills</td>
<td>Grief and loss</td>
<td>Empathic</td>
</tr>
<tr>
<td>Counselling skills</td>
<td>How to reframe practice</td>
<td>Flexible</td>
</tr>
<tr>
<td>Goal setting</td>
<td>Occupational engagement for people who are terminally ill</td>
<td>Have insight and self-awareness</td>
</tr>
<tr>
<td></td>
<td>Occupational therapy role</td>
<td>Problem solver</td>
</tr>
<tr>
<td></td>
<td>Palliative care approach</td>
<td>Life experience</td>
</tr>
<tr>
<td></td>
<td>The dying process and end-of-life</td>
<td></td>
</tr>
</tbody>
</table>

Table 19 Skills, knowledge and qualities required as part of occupational therapy curriculum (n=260)

Therapists’ felt that students should receive education on advanced communication skills (n=39), counselling skills (n=28), goal setting (n=10), and coping strategies (n=13). Communication skills training should be provided to students with opportunities to develop their verbal and non-verbal skills such as: active listening, observation skills, how to pick up and respond to emotional cues, the value of supportive pauses and silence, tact, sensitivity towards topics of death and dying, interview skills, rapport building, tone of voice, and how to debrief.

Prior to commencing work with this client group, it was reported that students should receive education on how to counsel people with terminal illness. Specifically, education should include how to provide supportive communication, how to talk about death and dying with clients and families, grief counselling, therapeutic use of self, incidental counselling, and mindfulness.
Therapists felt confident when setting goals with clients who will improve, but needed to realign their goals when first working in this clinical area. Therefore, therapists suggested that students should be educated on “how to set realistic goals when the client’s time frame is unknown” or when they are dying.

General coping strategies and strategies to avoid emotional burn out were also suggested as areas of education for occupational therapy students. Therapists reported wanting to “have strategies in place to deal with [their] own emotions”. They felt new therapists should be taught how to debrief with others about the emotions of continually dealing with death and dying, as well as how to set boundaries with clients with a terminal illness.

There was a need for students to be educated on the occupational therapy role with people living with a terminal illness (n=38), including how to keep these clients engaged in their daily occupations (n=6), and how to reframe practice (n=10). It was seen as important that students be educated on the occupational therapy role and the scope of what they can do in terms of assessment and interventions. Information should be provided on how to “focus more on occupation in order to enable an increased understanding of facilitating leisure and daily occupations”, “spiritual occupations”, and role changes when clients are living with a terminal illness. They also believed it was necessary to be educated on the different forms that occupation can take as a person’s functional status declined. They identified wanting knowledge of “how to work backwards” and “prepare for deteriorating function”. Students “should be taught that this role is different in its approach to any other. It should also be identified that it can be confronting at first”. Therapists felt working in this area required them to reframe their practice “from the ‘rehab’ perspective to knowing that clients are not going to improve”, and that students should understand this re-framing process.

Therapists also reported wanting students to receive more information on palliative care and death and dying (n=55) as part of their undergraduate degree. Understanding of a palliative approach (n=7) and how this approach differs from other areas of practice was vital, as well as the psychology and philosophy behind it.
Knowledge of dying trajectories and common terminal diseases, death and end-of-life care, the medical management of clients who are dying, cultural aspects of death, relevant services, and team roles, were seen as being beneficial prior to commencing in the area.

Knowledge of grief, loss, and bereavement frameworks (n=18) was also perceived as essential knowledge prior to commencing work. Therapists felt an understanding of the grief processes was vital, including how to “work with people who are angry with grief” and “how to deal with the emotional challenges and communicate with the client and carers, particularly during different stages of grief”. Therapists also believed it is important to understand loss, predominantly in relation to role loss, hopes, and family prior to commencing in a role working with people living with a terminal illness.

Therapists felt that students should be educated at university on the care-giver’s role and perspective (n=8) when working with people living with a terminal illness. For example, therapists “need to have an understanding of family dynamics, and how to work from a family-centred care model which looks at the carer’s needs and not just the client’s”. Students also needed better skills in providing education to care-givers.

Personal qualities (n=28) were identified that could be further developed in students. Empathy and compassion were essential to communicate to clients to “support them dying” and comfort their families in their time of loss. Therapists also reported they needed to be “flexible thinkers” and “good problem solvers” in order to “think outside the box” when decision making and providing interventions to this client group. Self-reflection was also vital to developing an understanding of personal ideas and feelings towards death, and to recognise and cope with the emotional impact of having clients die. The possession of life experience was also seen to be an important quality as it was felt to positively impact their personal skill development.

7.2.3.2 Therapists’ perceptions of competent practice

Therapists were asked to comment on the most important skills required for competency by occupational therapists when working with people living with a terminal illness. Data was grouped, with frequencies of each category totalled. Table
20 presents therapists’ perceptions of areas of competence required for practice when working with people living with a terminal illness.

<table>
<thead>
<tr>
<th>Area of Competency</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>General personal skills</td>
<td>126</td>
</tr>
<tr>
<td>Communication and counselling skills</td>
<td>95</td>
</tr>
<tr>
<td>Core occupational therapy skills</td>
<td>74</td>
</tr>
<tr>
<td>Knowledge of terminal diseases, disease progression, symptom management and services</td>
<td>14</td>
</tr>
</tbody>
</table>

Table 20 Perceived areas of competence required to work with people living with a terminal illness (N=316)

Therapists perceived that they needed to have highly developed personal skills (n=126). These skills included: patience and time management, emotional intelligence, an ability to communicate with empathy and compassion, and flexibility. Possession of good time management skills and demonstrating patience were desirable personal skills. Therapists need to be able to complete “efficient and timely assessment and interventions that appreciate the time constraints placed on a client with a terminal illness”. During this process, the skill of working at the client's pace was required to allow clients to make decisions.

Emotional intelligence was seen as “paramount” to working in the area as “this is not an area suited for therapists who need to rescue people or need to be needed”. Being able to demonstrate empathy and compassion during therapy were highly regarded personal skills that therapists felt they should possess. Therapists were thought to need to have a “compassionate and understanding personality” when “dealing with patients and carers”. Therapists also require “empathy and self-management” skills so that they can regulate their own “stress and emotional management”. Self-awareness was another important facet of emotional intelligence. Therapists reported that they needed to “know boundaries and when to let go. We can’t address everything, we still need to remain within the scope of OT”. Having good self-awareness involved having insight and knowledge of “your own attitudes, values and beliefs related to death, dying and spirituality” and “making sure that you are not imposing these on others”. Self-awareness also involved “being able to function autonomously” but knowing when to seek supervision, and debriefing “to avoid burnout”.

158
Chapter 7

Therapists noted needing to have the “ability to be extremely flexible and change plans at the last minute”. Flexibility also involved the “ability to work quickly with altering plans that are dependent on the client’s deterioration”. Therapists needed to have the “ability to reframe practice whereby part independence or the process of moving towards a goal is as valuable as the achievement of the same”. This involves “responsiveness and forward planning” through the prediction of future needs so that therapists can “set appropriate goals and prepare for a decline in functioning”. This means that therapists need to have good activity analysis skills and be able to “grade interventions for clients with terminal illness” rather than saying:

Oh well one day you won’t be able to walk, so we must get you a wheelchair. As clients will not respond positively to that - in fact they will probably never want to see you again.

Therapists also felt they should possess better communication and counselling skills in order to be more effective when providing interventions to this client group (N=95). Therapists perceived communication and counselling skills to incorporate various sub-skills such as “active listening”, “rapport building”, “tact”, “observational skills”, “self awareness”, and “excellent interpersonal skills”. Therapists believed these skills “create empowering relationships with the person and the family rather than them just ‘doing’ occupational therapy”. They were perceived to do this by having “an openness and willingness to hear and prioritise what the client is saying, even about what our OT brains are telling us to do”. When conversing with clients, therapists should be “calm and relaxed” and have “a sense of humour, be happy, friendly, and joyful”. Therapists also need to have a “willingness to ask awkward questions and address uncomfortable topics” and be able to read “between the lines” as to what is not said by clients.

The core occupational therapy skills (n=74) therapists perceived to be competent to work in this clinical area included: “client-centred care and focus”, “patient advocacy”, “setting realistic goals and evaluating regularly”, being proficient at “activity analysis” and “grading activities”, “professional reasoning”, “discharge planning”, and “manual handling”. Therapists required “good basic OT skills with equipment knowledge and the ability to assess modifications needed to the home environment” and “managing at home”. Therapists needed to possess the “ability to
work holistically with both the client and the family”, as well as “being able to assess and treat at both physical and psychosocial levels”. Therapists’ professional reasoning also needed to be at point where they have “the ability to think and reason outside the square for solutions that might be a little quirky” or “which may be needed for a short time only”.

Knowledge of terminal diseases, disease progression, symptom management, and services was essential (n=14). Prior to starting in a role treating people living with terminal illnesses therapists should receive “general education about terminal illness, radiotherapy, chemo, evidence based practice, resources and equipment”. Therapists viewed it as “essential” that they have an “understanding of the impact of the disease process and the impact that is has on occupations” as well as a “foresight of potential issues”, including lymphoedema. Having an “extensive knowledge of care services” that are “available to support the client and their family” was perceived to be important.

### 7.2.3.3 Setting of educational topics

Therapists were asked to report where they believed specific educational topics should be addressed. Therapists were given the choices of university, on the job, or as part of continuing professional development (CPD). While it was intended that therapists only tick one response per question, some therapists provided more than one response to topic areas if they felt that the topic should be taught in more than setting.

Figure 27 presents the response rate and frequency of responses on this issue. Therapists perceived that all of the occupational therapy based educational topics should be covered at university. However, it was perceived that ongoing education should occur through on the job training and CPD topics should also target these topics.
Figure 27 Frequency of therapists’ responses as to the educational setting of occupational therapy topics

Figure 28 presents the response rate, and the frequency of responses as a percentage, as to where therapists perceive generalist palliative care education should be provided.

Therapists reported they felt that the majority of the general palliative care based education topics were best taught within their university education. Service delivery systems for clients with a terminal illness and inter-professional roles at the end-of-life were perceived to be best covered on the job, rather than at university.
Therapists agreed that regardless of the educational topic, they required,

“…more education at university so that OTs don’t think they are working with people who are ‘dying’. This client group is living just as much as someone who has had a fall.”

### 7.2.4 Supervision of therapists working with people living with a terminal illness

Therapists were asked to report on their supervision. Eighty-three percent (n=116) of 140 therapists reported having a direct supervisor. These findings are presented in Table 21.
Table 21 Direct supervisor of therapists working with people living with a terminal illness (N=116)

<table>
<thead>
<tr>
<th>Supervisor</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senior occupational therapist</td>
<td>52  (45%)</td>
</tr>
<tr>
<td>Occupational therapy manager</td>
<td>35  (30%)</td>
</tr>
<tr>
<td>Nursing unit manager</td>
<td>9   (8%)</td>
</tr>
<tr>
<td>Peer</td>
<td>7   (6%)</td>
</tr>
<tr>
<td>Doctor</td>
<td>5   (4%)</td>
</tr>
<tr>
<td>Private mentor</td>
<td>4   (3%)</td>
</tr>
<tr>
<td>Allied health director</td>
<td>3   (3%)</td>
</tr>
<tr>
<td>Occupational therapy director</td>
<td>1   (1%)</td>
</tr>
</tbody>
</table>

Therapists then reported on how often they receive supervision and how often they would like to receive supervision (Figure 29).

Figure 29 Frequency of supervision (N=123)

Each therapist’s response to “how often do you receive supervision” and “how often would you like to receive supervision” was then compared against the other to establish satisfaction levels with their frequency of supervision. Over 70% (n=88) of therapists were satisfied with their frequency of supervision. However, 16% (n=20)
reported that they received less supervision than they would like, while 13% (n=16) reported they received more supervision than they would like.

Therapists were asked to state their level of agreement on a five-point Likert scale ranging from strongly agree to strongly disagree on a range of statements regarding their current supervision. Therapists’ percentage of agreement with each statement and the number of therapists who rated each statement is presented in Figure 30. The majority of therapists were in agreement that their current supervision met their needs, and that they were able to receive supervision and help, and debrief with someone who was knowledgeable in terminal illness. Therapists predominately received informal supervision, rather than set, structured supervision.

**Figure 30 Therapists level of agreement with supervision statements as a percentage**

<table>
<thead>
<tr>
<th>Supervision statements</th>
<th>Agreement</th>
<th>Neutral</th>
<th>Disagreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>My current supervision meets my learning needs (N=122)</td>
<td>61</td>
<td>24</td>
<td>15</td>
</tr>
<tr>
<td>I am able to debrief with my supervisor after challenging situations (N=122)</td>
<td>75</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>I feel my supervisor is knowledgeable in this clinical area (N=123)</td>
<td>58</td>
<td>22</td>
<td>20</td>
</tr>
<tr>
<td>I am able to ask my supervisor for help (N=123)</td>
<td>80</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>I am happy with the amount of supervision I receive (N=123)</td>
<td>73</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>I mainly receive formal supervision (N=121)</td>
<td>25</td>
<td>21</td>
<td>54</td>
</tr>
<tr>
<td>I receive both informal and formal supervision (N=123)</td>
<td>69</td>
<td>10</td>
<td>21</td>
</tr>
</tbody>
</table>

Therapists reported, “Appropriate supervision for staff working in this area is crucial to ensure the continued well being of that staff member”. They also felt that “it is hard to link into a senior with the same level of experience working with these patients”. Therefore therapists perceived it was important to link into “mentors
outside of the organisation” or “clinical interest groups” that are able to provide this supervision, support and opportunity to debrief.

### 7.3 Synopsis

This chapter has identified that the main challenges for occupational therapists working with people living with a terminal illness are service and caseload demands, intra and interpersonal challenges, and role challenges. Strategies such as debriefing and finding a work/life balance were reported as ways to overcome these challenges.

Therapists reported only feeling slightly prepared for practice with this client group, with less than a quarter of therapists reporting that their undergraduate education gave them adequate preparation for practice. Over 250 examples of skills, knowledge and qualities were reported regarding practice with this client group. Skills such as verbal and non-verbal communication skills, coping skills, counselling skills, and goal setting skills were viewed as being important for competent practice. Therapists believed that students should be educated as part of their under-graduate degrees on care-givers, grief and loss, reframing practice, occupational therapy engagement for people living who are dying, the occupational therapy role, palliative care approach, and the dying and end-of-life processes. However, expansion of these education topics was also perceived to be important in post-graduate settings in order to improve therapists knowledge. Therapists also reported specific qualities that were beneficial for working with the terminally ill including: being compassionate, empathetic and flexible, being insightful and having self-awareness, being a problem solver, as well as having life experience.

The majority of therapists had a direct supervisor, who was most likely to be a senior occupational therapist. Overall, therapists reported being happy with their supervision levels, and felt their supervision met their support and learning needs.

The following chapter presents the achievements of the study aims and a discussion of the findings.
Chapter 8  Achievement of study aims and discussion of findings

8.1  Introduction

Using the Ecological Model of Professional Reasoning as the theoretical framework, this PhD has provided an in-depth understanding of the scope of the occupational therapy role, the professional reasoning that underpins this role, and the context of Australian occupational therapy practice when working with people living with a terminal illness. In doing so, this study has filled an important gap in knowledge in occupational therapy practice. To achieve this objective, four individual study aims were developed. Each study aim had its own set of research questions, which were answered in four different results chapters. This chapter presents the answers to each research question, prior to a discussion of the findings.

This chapter employs the Ecological Model of Professional Reasoning as the lens through which results are discussed in relation to the therapist, client and practice context. The wider body of literature is incorporated into this discussion.

8.2  Achievement of study aims

8.2.1  Chapter 4: The context of Australian occupational therapy practice for people living with a terminal illness

The context of Australian occupational therapy practice for people living with a terminal illness was presented in Chapter 4, from a large sample of occupational therapists. Table 22 provides a summary of findings related to each of the research questions, which in turn answered study aim 1, which was to understand the workforce context for therapists working with people who are terminally ill in Australia by detailing the demographics of a large sample of occupational therapists, including individual therapist demographics, work context factors and teams, and client base.
8.2.2 Chapter 5: Occupational engagement of people living with a terminal illness: Therapists perceptions

A conceptual framework on how occupational therapists perceive occupational engagement for people living with a terminal illness was presented in Chapter 5. Table 23 provides a summary of findings related to each of the research questions, which in turn answered study aim 2, which was to gain an in-depth understanding of therapists' perspectives on occupational engagement for people living with a terminal illness.
The occupational therapy process for people living with a terminal illness was covered in Chapter 6. Table 24 provides a summary of findings related to each of the research questions, which in turn answered study aim 3, which was to gain an in-depth
understanding of the role of the occupational therapist with people living with a terminal illness and the professional reasoning process they follow in their daily practice.

<table>
<thead>
<tr>
<th>Question</th>
<th>Summary of Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What theoretical frameworks are therapists using when working with people living with a terminal illness?</strong></td>
<td>Less than half of the surveyed therapists recounted using theoretical frameworks. Eight different theoretical frameworks were reportedly used. These were:</td>
</tr>
<tr>
<td></td>
<td>• Occupational Performance Model of Australia</td>
</tr>
<tr>
<td></td>
<td>• Model of Human Occupation</td>
</tr>
<tr>
<td></td>
<td>• Canadian Model of Occupational Performance</td>
</tr>
<tr>
<td></td>
<td>• Person-Environment-Occupation Model</td>
</tr>
<tr>
<td></td>
<td>• Biopsychosocial Model</td>
</tr>
<tr>
<td></td>
<td>• Compensatory frameworks</td>
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<tr>
<td></td>
<td>• Client-centred framework</td>
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<td></td>
<td>• Combination of frameworks</td>
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<tr>
<td><strong>Do therapists modify their practice when working with people living with a terminal illness?</strong></td>
<td>Yes, therapists agree they modify practice when working with this client group. Specifically, therapists decreased their referral waiting times, changed their assessment approach (including type and delivery), set shorter-term goals, and changed intervention practices by providing more emotional support than in non-palliative clinical areas. Therapists also reported changing their communication style by using more narrative techniques and client self-report than direct observation of task performance. However, just under half of therapists reported that they did not modify what they considered good client outcomes for people living with a terminal illness when compared to non-palliative practice.</td>
</tr>
<tr>
<td><strong>Who are the most common referrers to therapists working with people living with a terminal illness?</strong></td>
<td>Therapists most frequently received referrals from community and inpatient nurses, but proportionately received the most referrals from doctors.</td>
</tr>
<tr>
<td><strong>What are the reasons therapists receive referrals?</strong></td>
<td>Referrals were most likely to be received for equipment prescription, home assessment and modification, and discharge planning, but most therapists were able to complete their own assessments to determine additional needs post referral.</td>
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<tr>
<td><strong>What assessments are completed with people living with a terminal illness, and where are they completed?</strong></td>
<td>The top five assessments completed with this client group related to:</td>
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<tr>
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<td>1. Equipment needs</td>
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<td>2. Home environment</td>
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<td>3. Self-care ADLs</td>
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<td>4. Pressure Care</td>
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<td>5. Transfers</td>
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<td>Assessment choices tended to not be standardised, and instead therapists were most likely to complete their assessments through direct observation of the activity, followed by asking questions of the client or the care-giver.</td>
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<tr>
<td><strong>What types of goals are set with people living with a terminal illness?</strong></td>
<td>More client goals were set “focusing on life” than “preparing for death”. Goals which prioritised engagement in occupations of living related to:</td>
</tr>
<tr>
<td></td>
<td>• ADL (functional mobility, self-care, community living skills, home management, productive tasks)</td>
</tr>
<tr>
<td></td>
<td>• Safety (home, ADLs, transfers, access, community, ambulation)</td>
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Goals which helped to alter a client’s engagement so they could remain engaged with life related to:
- Equipment prescription
- Home modifications/Environmental assessments
- Fatigue management and energy conservation

Goals which enabled practical preparations for death related to:
- Clearing out their home
- Sorting out legal affairs (wills, finances, Advanced Care Directives)
- Funeral preparations
- Remaining at home
- Pressure care
- Provision of practical and emotional support
- Care-giver role

Goals which helped to facilitate life closure related to:
- Saying goodbye to loved ones, possessions or pets
- Creating gifts or a legacy for loved ones
- Returning home
- Pressure care
- Provision of practical and emotional support

What interventions are completed with people living with a terminal illness, and where are they completed?

Intervention programs were designed to be client-centred and were most likely to focus on the client or care-giver’s physical needs. The most common interventions provided to this client group in order of frequency were related to: (i) self-care, (ii) functional mobility, (iii) community living skills, (iv) home management; (v) other (bed-bound care, home assessment, energy conservation, mobility and transfers with a care-giver), and (vi) productive tasks.

Overall, therapists were most likely to provide practical and physical interventions over supportive care and education, or referrals to others.

Most interventions were completed in the home environment, followed by the hospital setting.

What outcome measures are used with people living with a terminal illness?

Less than 20% of therapists used a form of outcome measurement. The most common outcome measures used were:
- ADL (RUG-ADL)
- Goal setting (Recording achievement of goals)
- Symptom management (SAS)
- Cognition (BIMS)
- Fatigue (Brief Fatigue Inventory)
- Oedema (Oedema measurements)

Do therapists provide follow-up for people living with a terminal illness?

Yes, the majority of therapists were able to provide follow-up to their clients, or alternatively they could refer on to other services for follow-up.

Table 24 The occupational therapy process for people living with a terminal illness

8.2.4 Chapter 7: Challenges to practice, and the educational and supervision needs of therapists working with people living with a terminal illness

Therapists’ perceptions of what were the main challenges to occupational therapy practice with this client group, and the educational and supervisory needs of
therapists working in this area was presented in Chapter 7. Table 25 provides a summary of findings related to each of the research questions, which in turn answered study aim 4, which was to gain an in-depth understanding of the challenges, and educational and support needs of occupational therapists who work with people living with a terminal illness.

<table>
<thead>
<tr>
<th>Question</th>
<th>Summary of Result</th>
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| **What are the challenges for therapists working with people living with a terminal illness?** | Therapists perceived their main challenges were:  
1. Service and caseload challenges  
2. Role challenges  
3. Intra and interpersonal challenges |
| **How do therapists overcome the challenges they face working with people living with a terminal illness?** | Therapists overcame their challenges by implementing the strategies of:  
- Debriefing (with colleagues, friends, mentor, or external counselling)  
- Improving work/life balance (sport and exercise, leisure activities, spending time away from caseload)  
- Completing rituals (lighting candles, writing a card)  
- Being appreciative of all they have  
- Reflection  
- Reviewing the evidence base to see how they could improve client outcomes and clinical reasoning |
| **Do therapists feel prepared to work with people living with a terminal illness?** | Over 75% of surveyed therapists believed their undergraduate education did not adequately prepare them for practice with people living with a terminal illness, with therapists only feeling slightly prepared to work in this clinical area. However, 99% of therapists agreed that they felt more prepared the longer that they worked in the area.  
When working with people with a terminal illness therapists felt least comfortable when:  
- Completing a home visit  
- Prescribing aids and equipment  
- Working with a person with a terminal illness in general  
- Completing assessments, and  
- Talking about dying with clients’ families |
| **What skills and knowledge are required for competency of practice when working with people living with a terminal illness?** | Therapists believed that undergraduate students should be competent in the skills of:  
- Communication (verbal and non-verbal)  
- Coping skills  
- Counselling skills  
- Goal setting  
They should also have knowledge of:  
- The care-giver’s role  
- Grief and loss  
- How to reframe practice to suit people with terminal illness  
- Occupational engagement for people who are dying  
- The occupational therapy role in this clinical area  
- A palliative approach to care  
- The dying process and end-of-life |
Additionally, competent therapist should possess the following qualities:

- Compassion
- Empathy
- Flexibility
- Insight and self-awareness
- Problem solving skills

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<th>Are these skills and this knowledge best taught at university, on the job, or as part of a therapist’s continuing professional development?</th>
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<tr>
<td>Therapists believed that the majority of occupational therapy based skills and knowledge should be taught at university. However, this information should also be provided on the job, and as part of continuing professional development. Generalist palliative care education was also thought to be best provided at university, except for service delivery systems and inter-professional roles which should be learnt on the job.</td>
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<tr>
<th>Are therapists receiving supervision when working with people living with a terminal illness?</th>
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<tr>
<td>Yes, therapists were receiving supervision and the majority of therapists felt that their current supervision level met their needs. Supervision most frequently occurred on a monthly basis, and was most likely to occur with the therapist’s senior occupational therapist, or their occupational therapy manager.</td>
</tr>
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<tr>
<th>What are the support needs of therapists working with people living with a terminal illness?</th>
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<tr>
<td>Therapists believed that it was important that their supervisor was knowledgeable in the clinical area, able to provide practical assistance, and offer opportunities for debriefing</td>
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Table 25 The challenges, and education and supervision requirement of working with people living with a terminal illness

8.3 Discussion of findings

This study was the first of its kind to explore occupational therapy practice for people living with a terminal illness on a national scale. By using the Ecological Model of Clinical Reasoning as both the theoretical framework and as a guide for the survey development, this study was able to gain insight into: (i) the ecological processes that therapists follow when working with people living with a terminal illness; (ii) the clients factors when living with a terminal illness; and (iii) the impact of therapists’ practice contexts on their professional reasoning. Professional reasoning is seen as a complex transaction that involves the therapist and their personal and professional worldviews, the client and their worldviews, and the practice context that therapy is completed within, as well as the activity that is being completed (Schell et al., 2007). Thus, this discussion will review the literature in regards to the therapists’ professional self and personal lens, the client’s personal worldviews, and the factors that influence the practice context.
In order to properly explore the findings of the research it was imperative to construct the discussion around the assumptions of the Ecological Model of Professional Reasoning and to integrate study findings into this body of literature as well as the wider body of literature and research on occupational therapy practice for people with terminal illness.

### 8.3.1 The therapist

Lee and Miller (2003) suggested that occupational therapists consider a range of information when making clinical decisions such as their own personal values, knowledge and experiences. Similarly, it is indicated in the Ecological Model of Professional Reasoning that a therapist’s professional reasoning is affected by the way that they view the world both personally and professionally (Schell, 2014). In this model a therapist’s personal lens is shaped by the therapist’s perceptions and understanding of all life events. The therapist’s professional self is then overlapped on their personal self and includes all their professional knowledge from their education, experiences from former clients, beliefs about therapy practices, and specific skills and knowledge for use in the practice context. These two selves of the therapist then act together to respond to the client’s problems and contextual demands of practice (Schell, 2014).

#### 8.3.1.1 Personal lens

Early literature suggests that therapists working with people living with a terminal illness enter into the therapeutic relationship with their own beliefs, morals, values, and concepts regarding death and dying (Martin & Berchule, 1988). Therapists in this study commented on a number of personal factors that affected their clinical reasoning when working with this unique client group. These personal factors included: life experience; flexibility; emotional intelligence; and burnout and stress.

Therapists saw life experience as a positive factor that helped to prepare them for practice, and reflect on past experiences. Life experience was also felt to assist therapists with their skill development. While life experience has not been well explored in the published literature on palliative care, studies looking at clinical
reasoning in other area of practice, such as upper limb hypertonicity (Lee & Miller, 2003), and paediatric practice (Copley, Turpin, & King, 2010) have found that therapists use life experience to enhance their decision-making and therapeutic relationship with clients. This study therefore adds new knowledge to the existing literature on the importance of life experience when working as an occupational therapist.

While emotional intelligence involves having an understanding and awareness of one’s own emotions (McKenna & Mellson, 2013), and can be an issue in any clinical area, it is particularly important when working with clients who are at their end-of-life. Therapists in this study reported that it was important to have an understanding of their personal emotions and attitudes towards death and dying if they wanted to be successful practicing in this clinical area. Occupational therapy research completed in other areas of practice suggest that therapists with advanced emotional intelligence cope better with workplace stressors, remain in practice longer, and increase opportunities of practice experience, than those with lower levels of emotional intelligence (Chaffey, Unsworth, & Fossey, 2012; McKenna & Mellson, 2013). This notion is also supported in the wider social work and nursing literature. For example Howe (2008) advises social workers to have insight into their own, and other’s emotional responses in order to effectively communicate and empathise with their clients, as well as regulate the affective states of all involved. While in the emergency department Bailey, Murphy, and Porock (2011) found that nurses who heavily invest in the nurse-client relationship with a client who is dying, are better able to develop their emotional intelligence and manage their emotions related to death and dying.

Working with people living with a terminal illness can be emotionally challenging and has been known to cause high levels of burnout and stress (Martins Pereira, Fonseca, & Sofia Carvalho, 2011). In this present study some therapists felt working with people living with a terminal illness was confronting, and that they were at risk of emotional burnout if they stayed in the role. Pizzi (1983) and Bye (1998) suggests that working with people with a terminal illness can be confronting because occupational therapists are traditionally aligned with helping someone to get better. Thus, therapists often feel a sense of failure working in palliative care, as their clients will always deteriorate regardless of the interventions provided. This sense of failure
has been shown to impact a therapist’s personal and professional sense of self and present a multitude of challenges ultimately resulting in decreased job satisfaction (Pizzi, 1984). In addition, Bye (1998) found that therapists worked hard to reconceptualise their contribution to still feel that they made a difference in clients’ lives despite the final outcome of death.

In this current study, therapists displayed an insight into the factors that caused them stress and were able to articulate their stress management strategies. Such strategies included: debriefing with colleagues and maintaining a good work life balance. The strategies implemented by therapists in this study improved their work/life balance and enabled them to reflect on their practice in order to seek closure. The strategies discussed by therapists in this study matches previous research that suggests that debriefing and maintaining a good work/life balance significantly reduces burnout and increases job satisfaction and retention (Cipriani et al., 2000; Prochnau et al., 2003). Thus, therapists in this study appeared to be utilising good stress management techniques when working with people living with a terminal illness.

### 8.3.1.2 Professional self: Practice theories and knowledge

The professional self was driven by practice theories and knowledge that related to client-centred practice, the occupational therapy process, and prior education.

#### 8.3.1.2.1 Therapists collaborate with the client and their family when providing care

A therapist’s professional self was underpinned by their belief that using a client-centred approach enhanced outcomes for people living with a terminal illness. Client-centred care has been defined as individualistic care that is respectful and responsive to the client’s needs, preferences, and values (Institute of Medicine, 2001). Client-centred care is derived from relationships between the client and the health professional, and by extension the client’s family members (Epstein, Fiscella, Lesser, & Stange, 2010). Prior research with clients with terminal illness suggests that practicing from a client-centred approach assists clients to build against loss, and enhances their ability to cope with their situation (Bye, 1998). Identifying a client’s narrative was one of the central ways that therapists believed they were client-
centred. It was through this narrative that therapists were able to identify their clients’ meaningful occupations, plus the goals they wished to achieve prior to death. Therapists also described how meeting a client’s needs prior to death provided them with a strong external motivation to ensure that their practice centred on the client. Literature suggests that using a narrative approach allows a therapeutic relationship between the client and the therapist to build, as “the therapist is attempting to understand the unique lived experience of a client through the articulation of their story” (Hassellung, 1993, p. 720). Additionally, Rahman (2000) found that by “tuning in” and listening to the client and their family’s narrative therapists are able to determine what is most important (p. 810). Therefore, as dying is a unique experience (Panagiotis, 2013), it appears that the therapists use of narrative reasoning enhanced both their sense of client-centredness and their ability to select interventions that focused on clients’ goals rather than their own agendas.

While family-centred practice is part of the palliative care ethos, it is not typical practice in most adult caseloads even through it has been shown to improve client outcomes by increasing: information sharing of diagnosis and trajectory, collaboration and joint goal setting, and ensuring that both the client and their family’s needs of are met (Kuo et al., 2012). Therapists in this study spoke of extending client-centred practice to include family-centred care, especially once the client’s occupational performance began to decline and the client began to require assistance. By ensuring their therapeutic relationships included both the client and family and caregivers, therapists were able to include the relevant people during decision-making and goal setting processes once the client began to require assistance (either physical or from equipment or aids). Findings suggest that therapists in this study had the same perceptions as found in previous literature: using a client-centred approach that encompassed the family, enhanced clients’ outcomes and better meets the client and care-givers needs.

8.3.1.2.2 A flexible occupational therapy process

In this caseload, therapists are faced with a disease trajectory where people will either rapidly decline, have periods of exacerbation, or slowly decline until the point of death. As a result therapists reported that they needed to be responsive to change,
and skilled in thinking on their feet, as well as having alternative plans in place. In other words therapists were required to take a flexible approach to care in case the client was not well enough for the planned assessment or intervention on a particular day due to the dynamic nature of their disease progression. Previous research supports the need for therapists to be flexible when working with people living with a terminal illness (Bye, 1998; Keesing & Rosenwax, 2011, 2013). For this flexibility to occur seamlessly in practice, therapists needed to employ conditional reasoning, and this is evident in the results of this study as well as earlier research. Conditional reasoning allows therapists to flexibly respond to a client’s changing condition (Schell, 2014), while also helping the client to reconstruct a new reality in the face of their deteriorating condition (Keesing & Rosenwax, 2011).

An unexpected finding in this study was how therapists shaped their therapeutic interventions on their perceptions of what was the right thing to do in terms of client and care-giver safety. Although safety has previously been reported as a phenomena of complex discharge planning in occupational therapy literature (Jensen et al., 2008; Schell, 2014), it has only received limited attention in the occupational therapy and palliative care literature. Bye (1998) found that therapists perceived providing “supported and safe care” as a positive outcome of occupational therapy interventions, especially for clients who were living and being cared for in the home environment (p.14). A safe environment was perceived to be one where clients had a sense of security, knowledge of alternative supports, and clients and care-givers were empowered through education (Bye, 1998). This notion of safety draws on a therapist’s ethical reasoning. Ethical reasoning often presents itself when the therapists is trying to determine the right course of therapeutic action, but faces competing principles, risks and benefits (Schell, 2014). In this study the main ethical dilemmas revolved around client and carer safety and choosing the allocation of resources for clients. Therapists needed to be aware as to whether their ethical dilemmas impacts on their decision-making processes. For example, some therapists in this study reported that their goals and recommendations were based on their safety concerns for the client and care-giver, and they saw a greater importance in providing a safe environment for clients to perform their activities of daily living in, over maintaining the client’s occupational engagement. While it is agreed that safety and risks should be considered, it is questionable whether it should be the major
determinate of an intervention choice, especially if therapists are truly advocating for a collaborative client-centred approach to practice, and respecting their dignity of choice as suggested by Moats (2007).

There is limited evidence to suggest how therapists should react to working with clients' with an unknown length of mortality. Routledge and Arndt (2005) suggest that temporal adaptation begins the moment that a client knows they are facing death, and results in changes to the way the client will organise their life roles and occupations. In this study, therapists reported an awareness of being time limited because of the client’s terminal diagnosis and felt that this temporality impacted their occupational therapy practice and decision-making in a unique way. These therapists reported an awareness that time was precious, and as a result, it changed the occupations that their clients wished to engage in. Larson (2004) describes this type of interruption to time “temporal rupture”, whereby events that restructure a person’s life, such as a terminal illness, change the everyday notions of time and unsettle their typical routines of everyday life (p.27).

In this present study, therapists’ goals were set around occupational performance regardless of the predicted time before the client’s death. However, a decline in the client’s occupational performance status often led to a desire to help clients achieve their goals, albeit in an alternative manner to what was originally planned. Research on clients’ perspectives of temporal awareness when facing mortality suggests that people prefer to be distracted, choosing to engage in meaningful occupations that give them a sense of value (Pizzi & Briggs, 2004). Therefore, this present study has revealed that therapists are in sync with clients needs by facilitating occupational engagement.

8.3.1.2.3 Education and training impacts therapists’ perceptions of their professional self

In this study, therapists’ professional knowledge was hugely impacted by the amount of education they had received. This study highlighted the failure of current Australian occupational therapy undergraduate curricula to adequately prepare therapists for practice with people living with a terminal illness. This intrinsic feeling
of not being prepared has major implications on the way that therapists viewed themselves and on their professional self-confidence. In this current study over 75% of therapists stated that their undergraduate education did not meet their needs to work confidently and competently with this client group. This is exemplified by therapists’ reports of not feeling comfortable completing home assessments or prescribing aids and equipment for people living with a terminal illness, yet these two factors are the most commonly reported reasons for referral.

These study findings also support previous studies into therapists’ training and education needs which have revealed that the occupational therapy undergraduate programs were not equipping therapists with the skills and knowledge to adequately prepare them for practice with people living with a terminal illness (Dawson & Barker, 1995; Meredith, 2010). While specific time spent on palliative care education at university was not the focus of this study, the majority of therapists reported they felt unprepared for practice with this client group upon graduation and this was due to the limited amounts of time on palliative care content in their undergraduate degrees. This is inline with research completed in Canada where occupational therapy graduates did not feel clinically competent in regards to their general knowledge and skills, and their ability to provide interventions (Hodgetts, Hollis, Triska, Dennis, & et al., 2007). This lack of preparedness for practice lasted for approximately six months to two years post graduation in these cohorts of new graduates (Hodgetts et al., 2007). More positively however, this sample of therapists reported that the longer that they spent working with people living with a terminal illness and the more exposure to working with clients who were dying they received, the more prepared they feel to work in the area. Consequently, it could be hypothesised that clinical exposure or simulation should be included when providing education and training to therapists to enhance feelings of preparedness working with people living with a terminal illness.

8.3.1.3 Professional self: Professional experience and skills

A therapists’ professional self and skill development when working with people living with a terminal illness was influenced by past clinical experiences, their and professional knowledge. This prior experience led therapists to alter the occupational
therapy process to meet the needs of people towards the end-of-life, as well as their practice of therapeutic use of self.

8.3.1.3.1 Therapists alter their therapeutic interactions and therapy processes

As part of their traditional practice, occupational therapists typically work from a rehabilitation framework, whereby a client's occupational performance status should improve (World Federation of Occupational Therapy, 2009). However, as noted previously, for therapists working with people living with a terminal illness this is not the case. This study and others have revealed that therapists instead face a dual reality of life and death and reconceptualise and reframe their practice (Bye, 1998; Keesing & Rosenwax, 2011; Pizzi, 2010). This present study has elucidated what this reframing of practice entails in terms of implementing the occupational therapy problem solving process with clients with terminal illness, and how essential therapists' communication skills are to this process.

Therapists in this sample discussed how their ability to communicate with their client and construct their interventions was based on their perceptions of the client's level of acceptance of their prognosis, and their understanding that their illness would ultimately result in death. Therapeutic conversation was part of their intervention process working with people living with a terminal illness and death was openly discussed. Therapists reported taking the time to really listen to clients and their families and caregivers in order to be better meet their needs and build stronger rapport. Therapists believed that laying the foundations for good communication enhanced their ability to provide emotional support to both the client and the caregiver as a client’s disease progressed and they faced the reality of death. The majority of therapists stated that they were comfortable discussing death and dying with the client and their families, albeit depending on their client’s level of acceptance or denial of their prognosis. Therapists perceived that talking about death positively assisted them to meet the needs of their client and their families as they prepared for death. This new knowledge contradicts previous studies on medical staff and students working with clients with terminal illness. For example, research investigating the communication skills of doctors and medical students working with clients with a terminal illness has found that they fail to acknowledge that their
clients are dying which has led to negative client outcomes, such as poor coordination of care, late hospice admissions, poor pain management and higher rates of emotional distress (Anderson, Kools, & Lyndon, 2013; Goldsmith, Wittenberg-Lyles, Shaunfield, & Sanchez-Reilly, 2011).

Triaging referrals is typically geared for an acute population, rather than for those clients with complex needs such as people living with a terminal illness (Worth et al., 2006). Therapists in this study reported how they changed referral practices by prioritising based on a client’s level of deterioration, rather than when they received the referral as they would in non-palliative caseloads. While there is limited evidence to support any triaging approach to management of referrals for people living with a terminal illness, prioritising referrals based on client deterioration appears to suggest that therapists use diagnostic reasoning as a method of prioritisation. This finding adds to the occupational therapy evidence base by suggesting that therapists use diagnostic reasoning to hypothesise what occupational performance problems the client might be facing, what factors may be contributing to the decline, and how each problem may present itself (Jones, Jensen, & Edwards, 2010), thereby using this knowledge to determine which client should receive a prioritised response.

Therapists reported varying their assessment practices when working with people living with a terminal illness in comparison to working with non-palliative clients. Therapists spoke of the need to be flexible during assessments due to a client’s fluctuating health status. They were less likely to use standardised measures, instead using non-standardised assessments such as interviewing clients and caregivers, using direct observation of activities, and liaising with other health professionals. This finding is similar to Bye’s (1998) study with a small group of therapists (n=10) which found that therapists complete assessments using a variety of means and adopt a low key approach of interviewing and observation. This present study is able to add details to this earlier finding to more comprehensively understand why therapists adopt such an approach. Therapists felt that standardised measures were not sensitive enough to show change, or considered relevant to occupational therapy practice, as most measures used with clients who are terminally ill focus on overall quality of life rather than occupational performance or engagement. The barriers to standardised assessment use and outcome measurement listed by therapists in this
study are congruent with findings from a systematic review which investigated the barriers and facilitators to routine outcome measurement by allied health professionals (Duncan & Murray, 2012). Duncan and Murray (2012) found that therapists were less likely to use a standardised assessment to measure outcomes if they could not see the relevance to practice, or if they felt they were not going to benefit the client in anyway.

This study has provided insight into the goal setting practices of therapists working with people living with a terminal illness and shown the uniqueness of goals setting in this area and how it differs to non palliative clinical areas. Therapists see goal setting as a way to ensure clients’ wishes remain the focus of therapy. This finding is in contrast to a recent systematic review of client-centred goals in rehabilitation settings which found that goal setting was rarely adopted as part of practice (Rosewilliam, Roskell, & Pandyan, 2011). Whereas, this study found that the majority of occupational therapists working with people living with a terminal illness set goals as part of daily practice. These goals were oriented to ensure clients could engage in desired occupations. For instance, therapists set achievable short-term goals that were suited to the client’s occupational performance at that particular time-point. In conjunction, an alternative goal was also set in case of deterioration or fluctuation in the client’s occupational performance. Findings also suggest that therapists went against their own therapeutic agenda at times by helping clients to achieve goals that they did not believe were realistic. These findings on goal setting build on previous occupational therapy research into palliative care goal setting which also suggests that goal setting needs to be client-centred, and be based on the every day activities, saying goodbye, going home (Bye, 1998; Jacques & Hasselkus, 2004). Therefore, this study has extended earlier research on goal setting with this client group, finding that therapist modify their goal setting practices to take on a ‘facilitator’ role with clients and their caregivers, considering all goals worthy of an attempt, given the preciousness of time.

When working with people living with a terminal illness, the dual focus on occupations that enhance life, and occupations that prepare for death, uniquely shapes therapists’ intervention decisions. By keeping clients’ needs and wishes at the forefront of therapy, therapists in this study found that their interventions naturally
became based around occupational engagement. This finding is different to Keesing and Rosenwax’s (2011) study. While therapists in the Keesing and Rosenwax study acknowledged the importance of occupational engagement, the historical nature of their services meant that they were unable to broaden their scope of practice from equipment prescription to enable performance of activities of daily living to enhancing occupational engagement more broadly (Keesing & Rosenwax, 2011; Rosewilliam et al., 2011). In this present study, therapists used their clinical reasoning to justify further occupation-based interventions, regardless if they received a referral for equipment prescription or discharge planning. Consequently, this sample of therapists implied that they were strong advocates for occupation-based interventions for people living with a terminal illness, and it was this advocacy, along with reframing practice, that helped to define who they were as therapists.

### 8.3.1.3.2 A co-constructed therapeutic relationship with a dual focus

Schell (2014b) describes ‘co-construction’ as a collaborative process where therapeutic decisions are made by the therapist in consultation with the client. The findings from this study have revealed therapists’ perspectives on how they co-construct therapy with clients to manage the dual reality of clients staying engaged in life, while preparing for their inevitable decline and eventual death. Therapists in this sample stated that the co-construction of therapy could not ignore the fact that the client’s death was impending. Therefore, clients engaged in activities that were “focusing on life”, while also “preparing for death”. Early occupational therapy literature has also discussed this dual reality of having clients who are both living and dying, and the contradiction therapists can experience in this area (Bennett, 1991; Bye, 1998; Flanigan, 1982; Hasselkus, 1993; Marcil, 2006; Tigges & Marcil, 1988); however, only two studies report on this concept in depth.

Hasselkus (1993) stated that therapists may view death as a negative experience, and that they may only value roles which support continued life in order to receive job satisfaction. To overcome these feelings of dissatisfaction, Hasselkus (2003) suggests that occupational therapists “must live with the contradictions of providing comfort and enhancing life while also recognising and supporting the approaching death” (p. 448). In other words, therapists must work in collaboration with their client to ensure
that they can participate in their chosen occupations for as long as possible, while also being cognisant of their client’s declining occupational performance, as therapists in this present study did.

Bye’s (1998) study also reported on the contradiction of operating under the assumptions of a traditional occupational therapy rehabilitative framework when working with people who are both living and dying. Bye’s study found that to cope with the contradiction of life and death, therapists reconstructed, or reframed, their clinical reasoning to ensure they focused on enabling a client to affirm their life and prepare for death (Bye, 1998).

This dual focus has also continued to be supported in the wider body of palliative care literature and research on death and dying. Researchers and commentators suggest that dying a good death can only occur if there is a dual focus to care. Kelleher’s (1990) research with people who were dying showed that preparations for death occurred by making both social adjustments and public preparations for death. By being given the opportunity to spend time with others and entrust personal affairs to others, as well as make financial, medical and funeral arrangements participants were perceived to die a ‘good death’ (1993, p. 448). This was then followed up by Steinhauer et al’s (2000) study on clients with a terminal illness and their families. This study found that by planning ahead, contributing to others, and arranging their personal affairs people were able to prepare for death but more importantly, were perceived to keep their dignity in the process (Kellehear, 1990).

Consequently, findings from the current study build on earlier research findings with smaller samples of occupational therapists, and the wider palliative care literature to confirm that therapists require a dual focus when working with people with a terminal illness. This dual focus underpins the co-construction of therapy with clients who are terminally ill.

8.3.1.3.3 Therapeutic use of self

Therapeutic use of self has previously been defined as a “practitioner’s planned use of his or her personality, insights, perceptions and judgements as part of the
therapeutic process” (Punwar & Peloquin, 2000, p. 285). Therapists in this study best described their therapeutic use of self when talking about their communication practices and rapport building with both the client and the care-giver. This finding fits with previous research by Holmqvist, Holmefur, and Ivarsson (2013) and Taylor, Lee, Kielhofner, and Ketkar (2009). Holmqvist et al.’s (2013) survey research found therapeutic use of self to be a critical element of professional reasoning, and used it as a means to encourage occupational engagement and drive intuitive practices with their clients. While a Delphi study with therapists working with people with a cognitive deficit by Taylor et al.’s (2009) saw therapeutic use of self as a way of being able to use their own personal characteristics, such as their communication skills and empathy, to enable a client to reach their goals and empower their own rehabilitation. Thus, this study has expanded previous research on therapeutic use of self, and has added new insights into therapeutic use of self with people living with a terminal illness.

8.3.1.4 A summary of therapist factors impacting professional reasoning

Therapists face numerous personal and professional factors which influence their professional reasoning when working with people living with a terminal illness. In sum, this study has identified and described how therapists use their narrative and interactive reasoning with clients living with a terminal illness, as well as how they co-construct therapy to ensure clients’ wishes are met, and families and caregivers are supported, during the dual reality of living with and dying from a terminal illness. Findings revealed that therapists are cognisant of their approach to care and reconceptualise occupational therapy practice to incorporate elements of focusing on life and preparations for death. Therapists recognised the need to shift their focus over time, and gradually increasing the involvement of clients’ families and caregivers as clients functionally declined.

8.3.2 The client

The Ecological Model of Professional Reasoning sees the client as a valuable part of the ecological process (Schell, 2014). This model suggests that the client views the therapy process through his or her own personal lens, and that this lens is shaped by the person’s life experiences, characteristics and personal beliefs, and the
occupational performance problems that bought them to therapy (Schell, 2014). However, as this study did not survey or interview people living with a terminal illness, it is impossible to identify clients’ life experiences or characteristics. Thus, assumptions made clients’ personal beliefs and occupations have been made from the therapists’ responses to the survey.

8.3.2.1 A client’s personal beliefs impact therapy

This study has shown that therapists consider their client’s wishes when prescribing therapy. Therapists could help clients remain engaged in occupations that focussed on living and prepared for dying. Numerous articles describe the benefits of clients living with a terminal illness remaining engaged in chosen occupations (la Cour et al., 2009; la Cour et al., 2005; Pizzi, 1983). Therapists in this study perceived that by facilitating clients to prioritise the occupations they wished to remain engaged in, they were encouraging occupational engagement in light of death. Prioritisation of occupations often resulted in the formation of a ‘bucket list’ that then directed the therapeutic processes that occurred between the client and the therapist. This finding adds greater dimensions to earlier research by Bye (1998) and Jacques and Hasselkus (2004). In Bye’s (1998) study, prioritising engagement and engaging in everyday routines was termed “normality with a changed reality”, while Jacques and Hasselkus (2004) noted that “continuing life” was one of the four domains of the dying experience (p.52).

Clients were able to direct therapy and positively impact their therapeutic outcomes by discussing what roles and occupations were meaningful to them, and subsequently re-prioritising occupations based on what was important for them to remain engaged in. Through their narrative, clients were able to direct the focus of their interventions in one of two ways: maintaining occupations that promoted normalcy and kept the focus on living, or occupations that facilitated preparations for death. Thus, successful outcomes were dependent on the therapist’s ability to collect the client’s narrative and remain client-centred when goal setting and designing interventions. This finding fits with studies that have been completed on clients’ needs, which advocate for open discussion with the client so that their fears about their functional decline and their inability to complete their ADLs can be addressed (Bentley, Hussain, Maddocks, & Wilcock, 2012; Harrison, Young, Price, Butow, & Solomon,
Therapists reported that clients and care-givers interacted differently in relation to occupational engagement depending on their level of acceptance of their diagnosis. For example, therapists reported interventions such as discharge planning or talking about place of death was easier if the client and care-givers had an awareness of their terminal illness. This finding strengthens Kellehear’s (1990) and Steinhauser et al’s (2000) studies that argue to die a good death, the client and their family need to have a social awareness of the dying process in order to make decisions.

8.3.2.2 A client’s occupational engagement changes once diagnosed with a terminal illness

This present study found that therapists perceived that their clients wanted to remain engaged in occupations but that they had to alter their engagement in occupations as their condition progressed. Altered engagement not only changed the way that clients completed their occupations, but also led to clients changing how they interacted with their environment and caregivers. Bye (1998) noted the importance of continued engagement, when she highlighted that “client control” could be regained through the involvement in “routines, activities, privacy, goals, treatment and decision-making processes” (p.13). These perceptions match Wilcock’s Doing-Being-Becoming approach in which she suggests that being able to participate through either ‘doing’ an activity, ‘being’ present for the activity completion, or ‘becoming’ a part of the activity through reflective activities, is just as important to a client as being able to complete the whole activity independently (Wilcock, 1999). These findings are also congruent with more recent occupational therapy studies, such as Sviden et al’s (2010) grounded theory study which had a theme of “striving for continued involvement in everyday life through the performance of activities” after diagnosis of a terminal illness (p.349). Sviden (2010) determined that being able to continue to stay engaged in everyday life, in new or existing roles, produced a sense of satisfaction for clients, as long as they adjusted their expectations as their occupational performance declined.
Therapists in this present study also perceived that once a person with a terminal illness began to decline functionally, they consequently started preparing for death. Through these activities therapists perceived that their clients were given the opportunity to: finalise their affairs; say goodbye; prepare others for new roles; reflect on, and affirm their life; and most importantly have the opportunity to return home if desired. These same findings have been highlighted in prior research, and the larger sample in this present study confirms findings found in smaller research samples.

For example, Bye’s (1998) study, identified that therapists helped clients to find closure through going home for a final time, taking part in an activity one last time, and making gifts for loved ones prior to death. In Jacques and Hasselkus’ (2010) study which aimed to understand the meaning of occupation surrounding death and dying, preparatory occupations gave clients a final chance to make amends, share their lives and history, and to make decisions and exercise control. Similarly, Rahman’s (2000) study found that therapists use occupations, such as completing life reviews or letters and reconnecting with past relationships, as a part of their therapy to work towards death with their clients’. Thus, this present study confirms previous research that occupations related to preparing for death and finding closure are important as they enable people a final chance to reconcile with others, share their lives and history, contribute to others, affirm their life, make decisions and exercise control.

Two interlinked client factors related to therapeutic outcomes for the client were the length of time the client had until they died, and the onset of decline in their occupational performance. Time is important as it assists us to structure the things we want to do and gives meaning to it (Hagedorn, 2001). In this study, time impacted on the occupations that a client chose to engage in, with therapists perceiving clients to prioritise what they wanted to either achieve or see before dying. Consequently, a person’s remaining days were restructured to complete chosen occupations off their ‘bucket list’. The importance of this temporal element is not matched in the literature, nor is it highlighted strongly in the Ecological Model of Professional Reasoning. While the Ecological Model of Professional Reasoning makes reference to time, it defines time as being “finite”, referencing it more as part
of the time and place that therapy occurs (Schell, 2014, p. 394), than as an element that overshadows a therapist’s reasoning and client choices due to the enormity of a terminal diagnosis. Consequently, this study has added a new depth to the meaning of time in the Ecological Model of Professional Reasoning.

The achievement of client outcomes was further impacted by the extent of their functional deterioration at that particular time point. Therapists perceived that the greater occupational performance level that somebody had, and the more time until death, the more likely they were to prioritise the occupations that they wished to continue, in the hope to maintain normalcy. In contrast, clients who had a lower occupational performance status, and less time prior to death, were more likely to make practical preparations for death and attempt to find closure. Literature suggests that when occupational engagement is limited, clients have poorer outcomes both physically and psychologically (Cheville, 2001; Kealey & McIntyre, 2005; Keesing & Rosenwax, 2011). For instance, these studies have shown that clients feel powerless and helpless, have a lack of control and choice, and an overall poorer quality of life when they are unable to engage in their chosen occupations (Cheville, 2001; Kealey & McIntyre, 2005; Keesing & Rosenwax, 2011). Thus, clients were often dependent on their therapists to ensure that they were able to continue to engage in their occupations in an altered manner because of their limited time and decreased occupational performance status.

### 8.3.2.3 A summary of client factors impacting the ecological processes of professional reasoning

Several client factors impacted on the therapist’s professional reasoning when working with people living with a terminal illness. In particular, a client’s personal beliefs were seen to influence the interventions selected for therapy and the types of conversations held with the client and their respective care-giver. The timing of, and the extent that occupations were altered, were also dependent on client factors and whether they were “focusing on life”, or beginning to prepare for death.
8.3.3 The practice context

The practice context has shaped the way occupational therapists think about occupational engagement for years. Schell (2014) takes this further and argues that therapists’ clinical reasoning is also impacted by the extrinsic factors of the practice context. The Model of Ecological Professional Reasoning states that the practice context is “where the therapist and the client meet to engage in therapy” (Schell, 2014, p. 394). The practice context includes the setting that it occurs in, as well as the social and physical aspects, such as the rules and expectations or the physical location, that turn guide therapeutic decisions (Schell, 2014).

8.3.3.1 A varied practice setting that impacts intervention

Therapists work with people living with a terminal illness within varied practice setting, that each have differing demands. The practice setting is often determined by the clients’ occupational performance status, rather than the intervention selected.

There is very limited literature to support a therapist’s choice of practice setting for people living with a terminal illness in both the occupational therapy and wider palliative care literature. A large number of therapists in this study worked in non-community based settings such as hospitals and hospices, and were most likely to complete interventions within the home environment. This finding is important, as statistics show that the majority of people living with a terminal illness die in a hospital setting opposed to the home environment (Australian Institute of Health and Welfare, 2014).

However, this study showed that therapists were able to work with their clients in hospital settings and follow them up in the community as required. This meant that while most therapists were employed to work in hospital settings, therapists also worked with their clients in community contexts rather than just inpatient facilities. Only one study could be located that looked at the effectiveness of completing occupational therapy practice within the community with clients living with a terminal illness (Kealey & McIntyre, 2005). This Irish study found that these services were invaluable to the client and the care-giver, especially in the areas of equipment provision and occupational adaptation (Kealey & McIntyre, 2005). However, these
results are from a small sample, and the study was completed in a different country limiting the generalisability of this study to the Australian context. In addition, it is hard to acknowledge the effectiveness of community-based interventions without considering the cost of such interventions. For example, Hoy et al. (2008) established that home assessments were the most time consuming intervention that a therapist working in oncology or palliative care could complete. Therapists in this Australian study took on average anywhere from 3.31 to 5.59 hours to complete the preparation for the home assessment, travel to and from, time spent in the home environment, and any follow-up or documentation that was required (Hoy et al., 2008). These findings have highlighted that working with clients in the community is common practice. However, further investigation is warranted into the effectiveness of occupational therapy interventions in the home environment for this client group, and the real cost-benefit to the client and the care-giver.

Interestingly though, this current study showed that the practice context did not dramatically change the types of interventions that were completed with clients living with a terminal illness. For example, approximately a quarter of therapists provided supportive care and education interventions, and 60% of therapists provided clients with interventions that related to occupational engagement, in both hospital and community settings. While there are limited intervention studies that have been completed with this client group, the majority of intervention studies have considered hospital-based settings rather than in the community (College of Occupational Therapists Specialist Section for HIV/AIDS Oncology Palliative Care and Education, 2004; Cooper & Littlechild, 2004; Dawson, 1993; Romsaas & Rosa, 1985; Vockins, 2004). Thus, this finding could assume that therapists in this study met client’s needs, by focusing on their goals as opposed to worrying about practice setting restraints.

Instead, this current study found that the choice of practice setting and interventions completed was often linked to a client’s occupational performance status. Therefore, it was more likely to be the person living with a terminal illness who influenced the choice of practice setting, than the therapist. Therapists in this study reported that as a client’s health declined, they prioritised remaining at home over going to hospital, which ultimately led to therapists spending more time in the community with the
client than in hospital settings. This finding fits with the literature that suggests that people not only wish to remain at home to die, but that home is the place where they receive the majority of their care (Davies, 2004; Hinton, 1994).

### 8.3.3.2 Mixed caseloads and multi-disciplinary teams negatively affected a therapists professional reasoning

Working as part of a mixed caseload, and within multidisciplinary teams, was found to negatively affect a therapist’s professional reasoning, and impact their clinical decision-making.

On average therapists in this study worked with more than one caseload, with this impacting on their clinical decisions and prioritisation of their client demands. Ethically, therapists felt compelled to prioritise clients living with a terminal illness, but still had responsibilities to meet the demands of their other part of caseload. This ethical dilemma is not new for therapists working in palliative care (Bennett, 1991), and has previously been shown to account for poor retention and cause stress and burnout in the workforce in the both the occupational therapy and wider literature.

Therapists in this study worked as part of multi-disciplinary teams involving a range of health professionals from different disciplines, and as part of specialist and generalist services. While this study saw multidisciplinary teams to be a positive aspect of working with this client group, such as providing support and a way of helping to keep the job in perspective numerous therapists also reported barriers.

Previous qualitative research completed in Western Australia with 10 occupational therapists and 10 other health professionals suggests that the majority of health professionals have an inadequate understanding of the occupational therapy role with this client group (Bennett, 1991; Halkett et al., 2010; Keesing & Rosenwax, 2011). Participants in Halkett et al.’s (2011) study reported that they could not see how a referral to occupational therapy would assist in improving client care. Of those participants who acknowledged the contribution of occupational therapy to client care, most perceived the scope of the role as being related to home visits prior to discharge or equipment provision (Keesing & Rosenwax, 2011). In 2011, a study of 18 Western Australian occupational therapists found that therapists perceived the
scope of their role to be limited to being an ‘equipment prescriber’ or discharge planner (Halkett et al., 2010). Participants perceived that the limited reasons for referrals, combined with a misunderstanding of their role, diminished their ability to focus on meaningful occupational engagement (Keesing & Rosenwax, 2011). Halket et al.’s (2010) research suggests that therapists’ roles are misunderstood in palliative care due to the lack of specificity between the referral reason and the client’s actual needs.

A third of therapists in this current study reported that their referral sources had a poor understanding of the occupational therapy role with this client group, with just over half of the therapists reporting that these referrals were representative of clients’ needs. This is in line with previous research that implies multidisciplinary teams can have a negative impact on the therapist (Bassett & Lloyd, 2001; Martins Pereira et al., 2011; Painter, Akroyd, Elliot, & Adams, 2003; Rogers & Dodson, 1988; Scanlan & Still, 2013). Thus, this study provides an expansion on current knowledge by stating the benefits and barriers to working as part of a multidisciplinary team when treating people living with a terminal illness.

8.3.3.3 Resource allocation and equipment supplies impact therapeutic decisions when treating people living with a terminal illness

Resource allocation and the availability of equipment impacted on a therapist’s professional reasoning and decision-making. Resource allocation impacted therapists’ decision-making when working with people living with a terminal illness. Low levels of staffing, caseload limitations, funding limitations that impacted therapy, and working across split caseloads impacted on their level of job satisfaction. These factors impacted on therapists’ sense of achievement, which in turn influenced the amount of time that therapists wanted to remain working with people living with a terminal illness. Keesing and Rosenwax (2011) argue that therapists who have a lack or resources, or are not able to provide the amount of care they perceive the client warrants, are at risk of job dissatisfaction as their personal values are not being met by the contextual demands of their service.

Equipment prescription was perceived to be an important part of the occupational therapy role. Therapists reported that prescribing equipment enabled clients to alter
their engagement in their meaningful occupations. Therapists also discussed how they tended to prescribe more temporary modifications over permanent modifications due to the client’s impending death. This finding supports Bye’s (1998) research showing therapists tended to provide temporary equipment to clients who were dying. In addition, this present study also found that therapists were ineligible to apply for funding on their clients’ behalf to some government-funded organisations due to a client’s terminal diagnosis. These contextual demands appeared to influence therapists reasoning, revealing their pragmatic reasoning, which took into consideration the realities of their service delivery. For example, therapists had to determine who would pay for the recommended equipment or modifications and whether this was possible, or which client should be prioritised to receive a piece of equipment that was in short supply. Therapists then faced further ethical reasoning dilemmas as to whether these subsequent recommendations were the most appropriate to meet the client’s needs or if they were only chosen due the cost or availability of an item.

8.3.3.4 A summary of practice context factors impacting professional reasoning

Several factors impacted the way in which a therapist interacted within their practice context. These factors included: the practice setting and whether or not it met the client’s occupational needs, social aspects of multidisciplinary teams and working in more than one caseload, as well as the lack or abundance of physical resources provided. The factors could have a positive or negative effect on therapeutic outcomes, and the therapists desire to stay in their current position.

8.4 Synopsis

This PhD aimed to gain an in-depth understanding of the scope of the occupational therapy role, the clinical reasoning that underpins this role, and the context of Australian occupational therapy practice when working with people living with a terminal illness, and did so by answering four overarching study aims. The first section of this chapter demonstrated the achievement of these study aims through a summary of the findings. This chapter then discussed the study findings in relation to both the occupational therapy and
wider palliative care literature, with reference to the theoretical framework that guided this study.

Findings from this study have strengthened the existing occupational therapy evidence base in many ways. These include providing current knowledge: on the personal factors that shape a therapist’s worldview and their subsequent reasoning, the dual focus of practice, and the occupational therapy process, including confirming barriers to the practice context. Especially highlighted, were therapists perceptions of the importance of occupational engagement for people living with a terminal illness, and the need for client-centred practice.

In addition this study has provided new perspectives on occupational therapy practice for people living with a terminal illness. It has demonstrated the importance of conditional reasoning and its impact on flexibility during the occupational therapy process and the need for good communication skills. This study has also added new depth to the temporal aspect of working with people with limited mortality, and has identified the practice setting context for Australian therapists.

Ultimately this research has contributed new knowledge on the scope of the occupational therapy role for people living with a terminal illness, including the ecological process that therapists use to inform their professional reasoning, as well as defining the context of Australian occupational therapy practice.

The following chapter concludes this thesis and discusses the study’s strengths and limitations, and implications and recommendations for practice, policy, theory, education and research.
Chapter 9 Thesis conclusions

9.1 Introduction

While the evidence base has been slowly evolving over the last three decades, understanding the scope of the occupational therapy role and the context of practice of therapists working with people living with a terminal illness has been difficult. There are still many unknowns, and with a limited evidence base to guide practice, therapists to continue feel underprepared to practice with this group.

To describe the occupational therapy role and the context of Australian occupational therapy practice for people living with a terminal illness, this study needed to explore the gaps in the literature, and identify current service provision. A mixed methods study with a large qualitative focus was employed to identify and describe:

- the context of Australian practice,
- therapists’ perceptions of occupational engagement for this client group,
- the occupational therapy process including therapists’ clinical reasoning,
- the current challenges to practice, and the educational and supervisory needs of therapists.

This study has shown that occupational therapy practice for people living with a terminal illness is an ecological process that is dependent upon the therapists ability to reframe their practice to use a palliative approach and their views on death and dying. In conjunction with this, this process is affected by the client and their personal views on occupational engagement and their acceptance with death and dying; as well as the contextual demands of the practice context which was originally designed to make a person better not allow them to die.

The strengths and limitations of this study are presented in this concluding chapter, along with implications and recommendations for clinical practice, education, policy, theory, and future research.
9.2 Study strengths

This study has several strengths that require reflection including: the use of a mixed methodology, the introduction of a professional reasoning framework, sample size, in-depth knowledge of the occupational therapy process for people living with a terminal illness, and identification of the education and support needs of therapists.

The use of a mixed methodology enhanced the findings of this research. Therapists were able to provide quantitative answers as part of the survey, but then justify their responses through the extensive qualitative nature of the survey design. By allowing both quantitative and qualitative responses, therapists were able to expand on their quantitative selection. Therapists who participated in this study provided extensive qualitative responses that gave depth to their qualitative answers, and as a result provided their clinical reasoning behind each selection.

This is the first study to illustrate how the Ecological Model of Clinical Reasoning can be applied to people living with a terminal illness. The Ecological Model of Clinical Reasoning was used as a lens to frame the survey design, the analysis of the results, and a discussion of the findings. As a result, the ecological processes of professional reasoning resulting from interactions between the therapists, the clients living with a terminal illness, and the practice context, have now been defined.

An additional strength of this study is its sample size. At the time of completion of study no other Australian or international study had explored occupational therapy practice for people living with a terminal illness at a national level. Not only was this study the first of its kind, but it exceeded all expectations for response rate, with 1.3% of occupational therapists working nationally completing this study. Thus demonstrating the need for such a study to be completed. The latest statistics available on this workforce are from the 2006 labour force survey (Moore, Cruickshank, & Haas, 2006). If these statistics are still accurate, this equates to 81% of Australian occupational therapists working in this clinical area responding to this survey.

This study has also provided in-depth knowledge of the occupational therapy process for people living with a terminal illness. While some smaller studies previously
suggested that therapists modified practice for this client group, this study reveals an in-depth picture of the occupational therapy processes that therapists working with people living with a terminal illness followed. The findings of this study will help to reduce the ambiguity that exists around the occupational therapy role with people with a terminal illness as it has identified occupational therapy frameworks, goals, assessments, intervention practices and outcomes with this client group.

Identification of the education and support needs of therapists was another achievement of this study. It is hoped that the results of this study will aid in the development of future occupational therapy curriculum and start to address the feelings of unpreparedness reported in this, and previous studies. These findings will also allow targeted education courses for therapists working with people living with a terminal illness to be developed, and address areas of knowledge deficits described by therapists in this study.

9.3 Study Limitations

The study limitations are related to aspects of the sampling and survey design.

9.3.1.1 Sampling Limitations

This study used a non-probability sampling method of convenience combined with snowball sampling. This type of sampling design relies on subjective judgments of the research team and the targeted participants about who should and should not be included as part of the study (AHPRA Occupational Therapy Board, 2012). This approach is thought to result in an non-representative sample of participants and has implications for the generalisation of findings (Australian Institute of Health and Welfare, 2006). However, at the time of this study no sampling frame could be established in order to generate a random sample. National registration of occupational therapists had not occurred leaving no way of being able to identify or contact every occupational therapist working in the country. Therefore, as this study required a specific subgroup of the occupational therapy population that are hard to locate due to working in mixed caseloads and non-palliative care specific roles, a non-probability sampling method was considered the most efficient and effective way of locating occupational therapists of interest (Forsyth & Kviz, 2006).
method then allowed occupational therapists working in the area to identify others working with terminal illness that were not known to the PhD candidate nor able to be located through systematic analysis of likely work sites. No attempt has been made to generalise findings and all results are presented as being specific to the sample and the practice contexts in which the therapists perform their roles.

Another recruitment strategy used was to directly contact known palliative care services through the National Palliative Care Directory (Couper & Bosnjak, 2010; Forsyth & Kviz, 2006). While this was successful, a barrier occurred when some sites asked for the submission of a local hospital ethics application prior to letting their staff complete the survey. Any setting with multiple sites which requested an in-house ethics application was excluded from being contacted further as the survey had already been approved through the UWS ethics committee and was deemed non-coercive in nature. Therapists working in such sites may have become aware of the study through other professional channels and complete the survey in their own time. Indeed, given the large sample size, it is likely that therapists did so.

Participation bias was another limitation that may have occurred with the sampling methodology. It is hard to identify if participants had specific motives for answering the survey as this study was non-coercive, and there were no rewards for participating in the survey except for personal satisfaction of sharing their expertise and opinion on practice in this area (Couper & Bosnjak, 2010). Considerations should be made when making inferences from the results as people who self select may show a response bias due to their vested interest in the topic (Palliative Care Australia, 2008a). Given that this was a mixed methodology, and participants with a rich experience of the phenomenon under study were the ideal participants, this response bias is less of an issue (Couper & Bosnjak, 2010).

9.3.1.2 Survey Design Limitations

While using an online web-based survey had many advantages, it also had some limitations requiring consideration. For example, to complete the survey, participants required knowledge on the use of a computer, access to a computer, email facilities, and the internet (Portney & Watkins, 2009). While this may have proved a limitation a decade ago (Couper & Bosnjak, 2010), most people now have basic computer
literacy skills and access to a computer or mobile device with internet access at work and/or home making online survey administration a more feasible choice of survey design (Forsyth & Kviz, 2006).

The purchase of web-based survey software could also be considered a limitation of selecting online administration of a survey. However, when compared to postage and printing costs of a traditional survey, a web-based program was the more economical choice, and was better suited to allow for ‘snowballing’ during recruitment.

While, participation was limited to those occupational therapists who had an email address and internet access due to the web-based survey design, participants were given the option of having a hard copy of the survey posted to them if required. However, no participants requested this offer and all participants completed the survey on-line.

On-line survey administration makes it difficult for the participant to clarify the meaning of questions or any issues they may have during completion of the survey when compared to face-to-face or telephone interviews (de Vaus, 2002). This lack of ability to clarify questions or issues may have increased non-response rates, misinterpretation of questions or lead to participants giving false responses (Couper & Bosnjak, 2010). However, all clarity issues discovered during the pilot-testing phase were rectified prior to the final survey going live to participants to minimise problems in this area.

Some minor limitations may have occurred due to technical difficulties caused by on-line administration (Forsyth & Kviz, 2006). For example some health services had browsers that limited the web-sites participants could access while at work or impose time limits for computer use, meaning that some participants may have been unable to open or complete the survey on work computers. Again, with the good response rate, it is likely that therapists encountering such issues were able to overcome these to have their say.

This survey was developed specifically for this research and this cohort of occupational therapists. As such no psychometric properties of the survey tool, such
as face validity or reliability were known. This may have influenced the understanding and interpretation of some of the questions that could not be picked up by the small number of pilot testers. In retrospect, greater consistency may have occurred if further definitions or examples were given in some of the survey questions. Additional questions such as knowing the therapist’s age may have also been beneficial when making comparisons to the literature.

9.4 Implications and recommendations

The findings from this research have implications and recommendations for practice, policy, theory, education, and future research. Each of these implications and recommendations will now be discussed.

9.4.1 Implications and recommendations for practice

This is the first large-scale national occupational therapy study to identify the types of clients therapists treat when working with people living with a terminal illness. A detailed understanding of patient diagnoses enables therapists to target their learning around identified medical conditions and the associated disease trajectories, and to better meet their clients’ needs. For example, within this sample of therapists there was almost an even split between malignant and non-malignant diseases, suggesting that therapists need to have an understanding of disease trajectories and outcomes for a wide range of clients, not just those with cancer.

In addition, this study revealed that therapists working with people living with a terminal illness are hard to find, as they are not always working in palliative care role. This study provided an understanding into the therapists themselves, as well as their workplace contexts. This knowledge may aid in future planning of services. For instance knowledge of locations of current services enables health administrators to look at future need and areas of growth, and will help with future service planning and resource allocation to different states and geographical areas.

This study has identified therapists’ perceptions on the uniqueness of occupational engagement for people living with a terminal illness. It has provided a conceptual framework to guide therapists working with people with a terminal illness and has
identified that therapists perceive that their clients with a terminal illness want to continue focusing on life, whilst preparing for death. How and when clients started preparing for death was perceived to be linked to their occupational performance status, as well as their life expectancy. These finding have major implications for practice and builds upon what is already known. To begin, this framework can assist therapists to acknowledge the contradiction of life and death and gain an understanding that their client’s needs and occupations will change the closer that they are to death. Secondly, these finding can enable therapists to have an understanding of the types of occupations they can focus their practice on while working with clients, rather than limiting themselves to the role of equipment prescriber that has been previously identified in a recent Australian study (Keesing & Rosenwax, 2011).

Research has previously shown that barriers to occupational therapy service provision include an inconsistent understanding of the contribution that occupational therapy can make to people living with a terminal illness, and that there is insufficient promotion of the contribution that occupational therapists can make (Halkett et al., 2010; Keesing & Rosenwax, 2011). This study has provided a deeper understanding of the occupational therapy processes followed by therapists when working with people living with a terminal illness. Therapists can use the information gained in this study to guide their practice with this client group. Therefore, dissemination of this study’s findings should occur to both therapists and their colleagues with the aim of reducing role ambiguity and reinforcing the contribution that occupational therapists can make to a person’s care when they are living with a terminal illness.

This study found that a large number of therapists are working in split caseloads when working with people living with a terminal illness. Thus, this study can assist senior clinicians to support staff who are working from a rehabilitative framework in one aspect of their work, to shift focus and work from a palliative care approach in their other role. It is believed that therapists who receive this education and support would be more likely to reframe their practice and acknowledge that positive client outcomes can still occur, even though the client will eventually die.
One of the purposes of clinical supervision is to increase the professional confidence of therapists (Holland, Middleton, & Uys, 2012). Thus, it is recommended that all therapists receive supervision regardless of caseload or clinical setting in order to promote confidence in their ability to provide care to people who are living, but also dying. Supervision should address the therapist’s needs, and ideally be provided by a clinical senior, or mentor with more experience working with people with a terminal illness. The role of the supervisor should enable the therapist to debrief after challenging situations, meet their learning needs and provide assistance where required. The supervisor should take into consideration the therapist’s skill and knowledge level, the client’s personal perspective and experience, as well as the setting context when providing supervision (Schell, 2014). It is also recommended that a mentoring programme be established to support therapists working in this area who do not have access to a supervisor with clinical experience working with people living with a terminal illness.

### 9.4.2 Implications and recommendations for policy

This study has implications for health policy. By gaining therapists’ perceptions on their role, this study has shown that therapists perceive that they have a unique role to play with people living with a terminal illness. These therapists identified that their role was not limited to an inpatient one, but that they could also play a major role in the care of people living with a terminal illness in community and home environments. While occupational therapists are encouraged to be included in specialist teams (Palliative Care Australia, 2011), this study has shown that therapists play a role in helping someone to remain engaged in their occupations, which is perceived to increase feelings of normalcy, as well as prepare for death, find closure, and die in their chosen environment. Therefore, the findings of this study can be used to educate policy makers on the occupational therapy role with this client group, and to better advocate for the need for the inclusion of occupational therapists in every palliative care team.

This study has shown therapists’ perceptions of the differences that they can make to a person towards the end-of-life, especially within the home environment. Thus, the 70% of people living with a terminal illness who wish to die at home, may be better enabled and equipped to do through the inclusion of therapists in palliative care.
teams. Ultimately, while funding to palliative care teams would need to increase to fund the extra staffing, it is hypothesised that there would be an overall reduction in care costs if the number of people who died at home increased from 16% to the estimated 50-70% of people who wished to pass away at home (Palliative Care Australia, 2011).

9.4.3 Implications and recommendations for theory

This study has been shaped by the Ecological Model of Professional Reasoning and its assumptions, and has been the first to apply this framework to understanding professional reasoning with clients living with a terminal illness. The findings from this study have deepened the understanding of the application of this model to a unique client base where clients are living, yet also dying.

Therapists in this study used ecological processes when working with people living with a terminal illness. For example, therapists described not only the skills and abilities that they perceived were required to practice in this context, but also highlighted the need to consider the client’s declining abilities and wishes in light of their terminal illness, as well as the contextual demands of their practice setting.

When discussing their therapeutic processes, therapists realised that they needed to take a holistic approach to caring for the client and their care-givers, due to the unique reality of working with someone who is living, but also dying. Therapists perceived that the types of occupations that a client wanted to engage in, and the place they were conducted in, were related to their occupational performance status and the amount of time until death. Thus, the ecological processes in this caseload are driven by time restraints because of the client’s terminal illness.

Through the analysis of the findings, therapists in this study showed that they had a different understanding of time than what the Ecological Model of Professional Reasoning currently assumes. Time, and the sense that it was a finite and precious resource for clients, was a major factor that guided these therapists’ professional reasoning. For instance, therapists were cognisant of the time that a client had left, and how time, along with occupational performance, impacted on the selection and
completion of goals and interventions. This may mean that different occupations get prioritised over others.

The context in which they complete these occupations often changes from the community to the home environment as the client’s occupational performance starts to decline from independent to dependent. At this point therapy stops occurring in the hospital setting and is more likely to occur in the home, creating a new environment for the therapist and the client to collaborate in.

This study also demonstrated that occupational therapy practice for people living with a terminal illness is an ecological process that is carried out in unique ways due to the unusual contradictions found when treating a person towards the end-of-life. Hence, this study has provided a new insight into the application of the Ecological Model of Professional Reasoning to a specific clinical area.

This research has also contributed to the theory base by establishing a framework of therapists’ perceptions on occupational engagement for people living with a terminal illness. This framework can be used to guide therapists in enabling clients to identify occupations that either focus on living or making preparations for death. In addition, this study has also expanded current knowledge of the occupational therapy process for people living with a terminal illness. This study has shown that therapists working in this area complete an occupational therapy process the same as they would in non-palliative areas of practice however this process is reframed to assist the therapists to cope with treating a client who is concurrently living and actively dying. Thus, this study builds on previous theories that occupational therapists reframe their practice in this clinical area, as well as providing fresh insight into what therapists actually do in day-to-day practice with this client group.

### 9.4.4 Implications and recommendations for education

The findings from this study can have a substantial impact on the education of both students and therapists working with people living with a terminal illness. This is the first national study to be completed with therapists working with this client group, and gives a good insight into the educational needs of therapists working with people living with a terminal illness.
Findings support the need to expand current undergraduate curriculum to include more information on the occupational therapy role for people living with a terminal illness, and generalist palliative care. Results reveal a clear list of topics that should be covered as part of under-graduate studies. Thus, in order to provide knowledge of working with people living with a terminal illness to all occupational therapists it is recommended that the findings from this survey be disseminated and used within university curriculums. Curriculum should focus on educating students on the scope of the occupational therapy role and context of their practice, as well as including the specific knowledge and skills suggested by therapists in this study for competent practice. It is hoped that increasing a therapist’s knowledge and skill base would result in an increased sense of professional identity, less role ambiguity, and greater feelings of preparedness when working with people with a terminal illness.

Additionally, results reveal that therapists have identified the need for the implementation of specialist postgraduate education, and on the job training on these topics with the aim of increasing therapists’ level of preparedness for practice and defining the occupational therapy role. The findings from this study have highlighted that a number of therapists commented on the lack of specific education for occupational therapists working with people living with a terminal illness. While PCC4U was designed to improve education to a multidisciplinary audience, it lacks specific occupational therapy related educational material (Palliative Care Curriculum for Undergraduates (PCC4U) Project Team, 2014). To improve feelings of preparedness and increase retention of therapists in this area, there needs to be improvements made to continuing the professional development of therapists working in palliative care or caseloads with a large proportion of clients living with a terminal illness. This is especially important for therapists who work alone, or do not have the support of a larger multidisciplinary palliative care team. Therefore, it is recommended that an educational package be developed and implemented with occupational therapists that work with people living with a terminal illness, incorporating information on occupational therapy theoretical frameworks, methods of modifying practice and processes to be in line with palliative care approaches. In the past, distance education has been suggested as a feasible option for flexible learning (Dawson & Walker, 1998) however therapists in this study reported a need
for simulated learning and hands-on experience, thus face-to-face postgraduate workshops should also be considered.

Finally, Holland et al (2012) argue that developing and fostering professional confidence should be nurtured and valued to the same extent as professional competence, as the former underpins the latter, and both are linked to professional identity. Professional identity has been shown to increase when theory and practice are integrated (Ikiugu et al., 2011). Therefore it is important that students and therapists alike, are not only educated about working with people living with a terminal illness, but also given clinical exposure prior to working in the area. The majority of therapists reported that they learnt the role on the job. Ideally, students should know more about the role prior to commencing work and given the opportunity to experience working with people with a terminal illness during clinical practicums or placements. However, as it is not realistic to expect that every student would receive a clinical placement working with this group, the implementation of simulated learning is also suggested. Simulation is thought to provide students with clinical exposure required to increase competence in practice, and is seen to be an emerging adjunct to traditional teaching methods (Bradley, Whittington, & Mottram, 2013).

### 9.4.5 Recommendations for future research

The findings of this research have created several topics that should be further investigated as part of future research to deepen the understanding of the occupational therapy role for people living with a terminal illness. While, the therapists’ perspectives are now known, in general future research should also include client perspectives. Topics for future research include:

*Client perceptions on the occupational therapy role:* It is recommended that further research be completed with clients with a terminal illness into whether their perceptions match therapists’ perceptions of occupational engagement. While existing research suggests that these perceptions of focusing on life and preparing for death are correct, a qualitative study examining this issue in people living with a terminal illness is suggested to truly understand clients’ thoughts on requiring a dual focus to care and ongoing occupational engagement.
Efficacy studies: This study has identified common interventions that are completed by occupational therapists with people living with a terminal illness; however very few of these interventions have been tested for their efficacy with this client group. Therefore, it is recommended that research be conducted into the effectiveness of occupational therapy interventions for people living with a terminal illness. The outcomes from these intervention trials could then be used to enhance evidence-based guidelines for this area of practice.

Evidence-based guidelines: Evidence-based guidelines are useful documents for therapists to have to guide their practice and highlight the best current best practice. Now that the scope of practice is defined, research should be conducted into the development of evidence-based guidelines for therapists working with people living with a terminal illness. The development and introduction of these guidelines would see occupational therapists delivering best practice, based on current evidence, to their clients and set out clear professional boundaries on what the occupational therapy role is, and its effectiveness with people living with a terminal illness.

Outcome Measurement: Evaluating the work that therapists do is important. The lack of outcome measures for this client group has been argued as posing a threat to therapists' professional and personal confidence (Bennett, 1991; Pearson et al., 2007). While in the past there has been attempts to identify a quality of life outcome measure for occupational therapy use with this client group (Pearson et al., 2007), it is suggested that further research is completed in looking at a specific occupational therapy outcome measurement for people living with a terminal illness. This research should entail the development of a holistic outcome measure that assesses a client’s occupational performance and symptom control, achievement of client-led goals, and the identification of spiritual and psychosocial needs (Stiel, 2012).

Educational Packages: It is recommended that an occupational therapy specific education package be developed to complement the PCC4U multidisciplinary content that currently exists. However, any educational packages that are developed as a result of these research findings should be evaluated for their effectiveness, as it is important that the education package meets the needs of the participants. Hence,
it is recommended that two educational packages be developed: one for therapists and one for students, as each group will have its own distinct learning needs.

9.5 Conclusion

This study has shown that there is a growing role for occupational therapists working with people with terminal illness. It is estimated that this role will only continue to increase due the ageing Australian society and the fact that people are living longer with terminal illnesses due to medical advances (Stiel, 2012). The findings from this study established a profile of occupational therapists working with people living with a terminal illness, and of the clients that they treat. Therapists’ perceptions of occupational engagement for this client group were examined. The theoretical frameworks used, and the occupational therapy processes for people living with a terminal illness that are followed were established. The challenges to working in this area were identified, along with therapists’ education and supervision requirements. In summary, this thesis is an original contribution to occupational therapy knowledge and practice for people living with terminal illness. This study has shown that therapists working with people living with a terminal illness follow an ecological process, which involves interactions between the therapist, and the client, in a time sensitive, occupation-focussed manner, across diverse practice contexts.
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Appendices

Appendix 1 Peer-reviewed journal article
Appendices

Critical review

Occupational therapy for people living with a life-limiting illness: a thematic review

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Key words:
Palliative care, practice, education.

Introduction: Little is known about occupational therapy practice for people with a life-limiting illness. This paper aims to review the available occupational therapy literature in order to develop a greater understanding of the role and practice trends of occupational therapists working in this area.

Methods: A systematic search of literature published from 1975–2013 was conducted. Three hundred and fifty-five pieces of literature were located and screened for inclusion using a three-stage process. All literature that met the inclusion criteria was then analysed thematically.

Findings: An in-depth review of 52 articles, three position statements, two key occupational texts, and one clinical guideline identified three themes in the literature. These themes comprised: (i) reframing practice: defining a palliative approach in occupational therapy; (ii) continuing occupational engagement despite loss; and (iii) preparing for practice when your client is dying: educational requirements of occupational therapists.

Conclusion: Occupational therapy has an important role to play in the care of people with a life-limiting illness. However, knowledge gaps remain concerning the scope of the role and how best to engage clients in meaningful occupations at the end of life. Further education is required at the undergraduate level and for clinicians working in this area.

Introduction

People living with a life-limiting illness have a ‘progressive condition that has no cure’ (Palliative Care Australia [PCA] 2008, p.4). Regardless of diagnosis, the life-limiting illness is expected to cause the death of the person within the foreseeable future (PCA 2008). Common illnesses that can limit life expectancy include both malignant and non-malignant diagnoses, such as heart and circulatory disease, cancer, and respiratory, renal, and neurological diseases (Roog 2008, PCA 2011).

After receiving a life-limiting diagnosis, the person is forced to face their mortality and deal with complex personal, social, and emotional issues, as well as changes to their physical health in the period leading up to their death (Broom and Cavenagh 2011, Davies 2004, Georges et al 2005, Terry et al 2006). Often, clients will require specialist palliative care services to help them meet their needs as they near the end of life. Palliative care focuses on maintaining quality of life and effective symptom control for people who are living with, and dying from, a life-limiting illness (PCA 2008). End-of-life care, meanwhile, is ‘a continuum of palliative care and is usually used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours, or less’ (Palliative Care Programme Working Group 2012). It is at this point that the person becomes ‘terminal’ (CareSearch 2011).

Referral to palliative care services has been shown to make a difference in meeting the needs of people and their caregivers at this time of life. Literature suggests that people living with a life-limiting illness and their caregivers...
who receive either a late, crisis, or a total non-referral to palliative care services, including occupational therapy, have a poorer quality of life and higher unmet occupational needs than those who receive a referral (Keessing and Rosenwax 2011, Soderback and Paulson 1997). Clients’ unmet needs (and those of their caregivers) typically occur in the areas of stair mobility, transfers, showering, everyday mobility, domestic tasks, work, driving, and engagement in leisure activities (Jayasingam et al 2008, Taylor and Currow 2003). Those whose needs remain unmet often experience role loss and disengagement in their meaningful occupations (Keessing and Rosenwax 2011, la Cour et al 2007, Lyons et al 2002).

Occupational therapy is an important service for people with a life-limiting illness as it can assist people to stay engaged in their meaningful occupations. Traditionally, occupational therapy is aligned with rehabilitation, and centres on independence and the restoration of meaningful occupations. In standard practice, people improve after their illness or injury, and remedial or short-term compensatory techniques or equipment prescription is implemented. However, people with a life-limiting illness experience fluctuations in their ability to complete the activities of daily living, and deteriorate in functional ability regardless of occupational therapy intervention (Cooper 2006). Therefore, a different approach to occupational therapy practice is required to help a person continue to live until they die (Bye 1988).

While research into the occupational therapy role in this area has grown since initial work by Dawson (1982), Gammage et al (1976), Holland and Tiggas (1981), and Pizzi (1984a, 1984b), knowledge gaps remain. Over 30 years of practice, only a small number of studies have investigated occupational therapy practice for people living with a life-limiting illness. Those that exist are predominately low-level descriptive studies or small-scale qualitative studies. This lack of a clear knowledge base makes it difficult for clinicians to determine not only the scope of their practice, but also the educational training and clinical skills required to work in this area.

The purpose of this paper is to present a thematic analysis of the published occupational therapy palliative care and end-of-life literature, to provide a greater understanding of the scope of occupational therapy practice with people who have a life-limiting illness, identify practice issues, and highlight the themes evident in the occupational therapy literature. Knowledge gaps in practice are highlighted, and future research directions are suggested.

Method

A systematic literature search was undertaken to identify the literature pertinent to occupational therapy practice and palliative care. Databases including Medline, PubMed, CINAHL, ProQuest, The Cochrane Library, Ovid, Clinical Evidence, Science Direct, and Google Scholar were searched to obtain an overview of the literature. Manual searches of reference lists, hard-copy journals, and key occupational therapy texts were also completed.

Due to a lack of uniform terminology in the literature, multiple key words were searched in various combinations. These included: occupational therapy; terminal; terminal illness; life threatening illness; palliative; palliative care; hospice; death; dying; role; practice; occupation; assessment; treatment; intervention; clinical reasoning; education; and theory. Key words were chosen based on the Palliative and end of life care: glossary of terms (PCA 2008). Each search strategy was limited to sources published in English and publication dates ranging from January 1973—April 2013. No restrictions were placed on: (i) the stage of life-limiting diagnosis; (ii) the age of the participant/s; (iii) the clinical practice setting; or (iv) the research methodology. These criteria were chosen both to encompass the historical development of the occupational therapy role with people with a life-limiting illness and to identify current practice issues, trends, and evidence.

Literature screening and inclusion criteria

The initial literature search, using a combination of key words, resulted in the selection of 355 pieces of literature for further review. Screening of these 355 pieces of literature occurred using a three-stage process. Stage one involved determining the relevance of the article or key text based on the title. This resulted in the selection of 118 articles, three position statements, two key occupational therapy texts, and one clinical guidance statement. From the 118 articles, 97 were selected during stage two for review of their abstract, based on their title and relevance to occupational therapy practice for people living with a life-limiting illness. In stage three, all items were read and reviewed in depth for their relevance to occupational therapy practice for people living with a life-limiting illness. Following this full-text review, 52 articles, three position statements, two key texts, and one clinical guideline were selected for thematic analysis.

Thematic analysis

Thematic analysis was the chosen method for this review as it provided a systematic way of organizing, analysing, and describing the dataset (Braun and Clarke 2006). Braun and Clarke describe six key phases of thematic analysis, with each phase used to find ‘repeated patterns of meaning’ (Braun and Clarke 2006, p13). The six phases involve: (i) familiarizing yourself with the data; (ii) generating initial codes; (iii) searching for themes; (iv) reviewing themes; (v) defining and naming themes; and finally (vi) producing the final analysis in a scholarly form (Braun and Clarke 2006). To ensure this thematic analysis occurred in a systematic manner, each of the six steps was duly completed. A thorough review of all included literature was carried out to ensure familiarization with the content, and summary documents were generated for each. Each summary document was then manually coded using descriptive codes. NVivo was used to store and organize the data and coding. Emerging themes were identified from the codes, and a final name was then given to each theme. Final themes and their included codes were then member-checked by the second author.
Findings

The 58 pieces of literature included in the review for thematic analysis contained a range of research methodologies and participant diagnoses. The literature was published over a 36-year period from 1975 to 2012, with almost half having been published within the last decade. The thematic analysis identified three themes in the occupational therapy literature for people living with a life-limiting illness. These themes comprised: (i) reframing practice: defining a palliative approach in occupational therapy; (ii) continuing occupational engagement despite loss; and (iii) preparing for practice when your client is dying: educational requirements of occupational therapists.

Reframing practice: defining a palliative approach in occupational therapy

The occupational therapy role in palliative care is less defined than in other areas of clinical practice, leaving clinicians unsure of the scope of their role in this clinical area. Historically, the scope of this role has changed as practice has evolved. Research and literature first attempted to define the occupational therapy role with people with a life-limiting illness in the 1980s (Cusick et al 1987, Dawson 1982; Holland and Tigges 1981, Pizzi 1984a, Pizzi 1984b). Authors aimed to tease out what a palliative approach would be for occupational therapy clients who were dying.

At this time, occupational therapy literature focused on describing the person’s experience of dying and their unique needs at this time (Flanagan 1982, Pizzi 1984a, Pizzi 1984b). It recognized that some clients preferred to play a passive role, while others wished to remain independent for as long as possible (Flanagan 1982). Authors such as Pizzi (1984a) argued that by remaining engaged in life, people maintained their quality of life for longer. Through engagement in occupations people living with a life-limiting illness were thought to have a greater sense of competence, productivity, and resourcefulness, while feeling mastery over themselves, the environment, and the disease process (Pizzi 1984a).

In 1982 Dawson completed the first study on occupational therapy practice with people who were terminally ill. Dawson established the role of the occupational therapist by conducting and analysing seven interviews with both occupational therapists (n = 3) and clients with a terminal diagnosis (n = 4). She defined the role of the occupational therapist as one which: (i) provided a supportive, caring role using therapeutic situations; (ii) assisted clients to remain at home for as long as possible; and (iii) offered practical assistance with any problems arising from an individual’s daily occupations (Dawson 1982).

In the late 1980s, Tigges and Marcell wrote the first occupational therapy textbook relating to the philosophy and treatment of people living with a life-limiting illness, responding to the emerging role for occupational therapists working with such clients (Tigges and Marcell 1988). This textbook was ground-breaking, as palliative care was in its infancy and education about caring for people living with a life-limiting illness was not part of occupational therapy curricula. While the intervention processes were descriptive rather than evidence-based, this textbook provided clinicians with an understanding of the occupational therapy assessment and intervention processes, and was influential in establishing the occupational therapy role with this client group (Tigges and Marcell 1988).

The second key textbook on occupational therapy practice in palliative care was published in 1997, authored by Jill Cooper. This textbook had a strong focus on oncological conditions; it provided clinicians with both anecdotal and evidence-based intervention strategies and gave advice on how to deal with the dilemmas faced by occupational therapists working in this clinical area (Cooper 1997). A second edition of the book, published in 2006, was updated to include intervention strategies for a larger range of diagnoses, and a discussion on outcome measures for use with people living with a life-limiting illness (Cooper 2006). This textbook continues to play a major role in educating clinicians on the core skills required to work in oncology and palliative care.

In the late 1990s research examined how clinicians alter practice to reflect the needs of someone with a terminal illness. A qualitative study by Bye (1998) established that occupational therapists who work with people living with a life-limiting illness reframe the focus of their daily practice, the occupational therapy process, and the expected outcomes of therapy. Through in-depth interviews and participant observation with ten Australian occupational therapists working with this client group, Bye (1998) found that occupational therapists conceptually reframe practice and work with clients to ‘affirm their life’ and ‘prepare for death’. For instance, assessments in palliative care displayed distinctive characteristics, with a low-key approach being taken rather than the more traditional formalized or standardized assessments used in other clinical areas. Interventions were client-centred, helping the client to build against loss, and facilitating their coping abilities through education and functional retraining (Bye 1998).

Bye (1998) suggested that occupational therapists help clients to achieve a sense of ‘normality’ in an otherwise ‘changed reality’ by empowering them to complete activities in familiar surroundings. Clinicians perceived that a person could regain control over both their physical and psychological self through involvement in routines and meaningful activities, having a greater sense of control over caregiving, setting goals that were meaningful to the end of life and that promoted closure, and achieving desired outcomes through occupational therapy interventions, such as equipment prescription, home assessment, and returning home to die.

Since the inception of palliative care occupational therapy, studies have suggested that occupational therapy supports people living with a life-limiting illness to find symptomatic relief from pain and suffering and improves quality of life (Burkhart et al 2011, Holland and Tigges 1981, Keeling and Rosenwax 2011). More recent research, such as the grounded theory study by Keeling and Rosenwax (2011), suggests that within the modern Australian context, occupational therapists have a more limited perception of their role. Instead of
focusing on engagement in meaningful occupations, which is central to traditional occupational therapy practice, clinicians viewed their role as being limited to issuing equipment and home-modification prescriptions and undertaking discharge planning. This change in practice when therapists switch to palliative care contexts is thought to reflect both the reactive nature of service provision and a misunderstanding of the scope of the occupational therapy role in palliative care (Keesing and Rosenwax 2011).

To try to better establish the scope of the role of occupational therapy with people living with a life-limiting illness, position statements and clinical guidelines have been developed: in the United States (US), these have included The role of occupational therapy in end-of-life care (Burkhart et al 2011) and Occupational therapy and hospice (Trump et al 2005); in Canada, Occupational therapy and end-of-life care; and in the United Kingdom (UK), Occupational therapy intervention in cancer: guidance for professionals, managers and decision-makers (College of Occupational Therapists Specialist Section [COT-SS] HIV/AIDS 2004). The purpose of these relatively recent position statements is to describe the role and processes of the occupational therapist when working with people living with life-limiting illnesses. Each of the position statements shares common themes on the role of the occupational therapist for people living with a life-limiting illness. Commonalities included the idea that occupational therapists: (i) are integral to quality care for people living with a life-limiting illness; (ii) have an ability to improve quality of life by assisting in pain and symptom control; and (iii) can keep clients engaged in meaningful occupations (Burkhart et al 2011, Canadian Association of Occupational Therapists [CAOT] 2011, COT-SS HIV/AIDS 2004, Trump et al 2005). However, the CAOT guidance describes occupational therapy interventions for people with cancer diagnoses only, rather than looking at a range of life-limiting diagnoses (COT-SS HIV/AIDS 2004).

Over the last three decades, occupational therapists have refined their practice when working with people living with a life-limiting illness. This has resulted in numerous attempts to redefine the occupational therapy role with this client group, along with the definitions used to describe practice at palliative and end-of-life stages of care. However, further clarification of the occupational therapy role for people living with a life-limiting illness needs to occur, as confusion still remains as to the scope of occupational therapy practice in this clinical area.

Continuing occupational engagement despite loss
A person living with a life-limiting illness faces continuing loss as their condition deteriorates. This loss can occur in many facets of a person’s life. In the 1990s, occupational therapy literature and research across all areas of practice attempted to explore the meaning and contribution of occupation in people’s lives (CAOT 1997, Law et al 1998). This emphasis in the 1990s on occupational engagement was also evident in the occupational therapy research related to people with a life-limiting illness (Bye 1998, Dawson 1993, Dawson and Barker 1995, Hasselkus 1993, Hasselkus and Dickie 1994, Penfold 1996, Soderback and Paulsson, 1997, Thibeault 1997). It was argued that through engagement in their typical occupations, clients are able to put their lives in order and maintain a sense of normality by continuing to participate in their daily routines (Bye 1998, Tigges and Marcil 1988). Hasselkus (1993) showed clinicians the importance of keeping a person engaged in their daily occupations at the end of life in an auto-ethnography about caring for her mother who was dying, which shed light on the need for people to remain engaged in activities that helped to put their ‘life in order’ (Hasselkus 1993, pt18). Hasselkus (1993) spoke of the significance of letting the person with a life-limiting illness choose topics of conversation and described how these simple conversations would frequently relate to the meaningful and often routine activities people wished to complete. Hasselkus (1993) argued that this engagement in everyday occupations allowed the opportunity for the person living with a life-limiting illness to say goodbye and face death.

Facilitating occupational engagement was also deemed an important contribution by clinicians working in the hospice setting. For example, Dawson (1993) completed an ethnographic study which examined the contribution played by occupational therapy groups within a hospice setting. The study found that occupational therapists assisted individuals to attain occupational roles that were perceived as important by the client and the caregiver. Participation in group activities allowed the clients to reconnect with activities that gave their lives meaning. Dawson (1993) argued that, given the limitations of time and the deteriorating physical ability of the clients, occupational therapists should focus on productivity, ability, and wellness, and not on pathology or the life-limiting diagnosis (Dawson 1993).

This emphasis on the importance of occupational engagement has continued into more current literature. A recent study termed the progressive loss or removal of occupation for people with a life-limiting illness as ‘occupational deprivation’ (Keesing and Rosenwax 2011, p335). This occupational deprivation has consequences that can affect a person’s physiological and psychological health (Keesing and Rosenwax 2011). This finding is supported by other literature, revealing that disengagement in daily routines due to the impact of life-limiting illness, coupled with an inability to complete meaningful activities, impacts upon a person’s sense of self, including their body image, senses, valued occupations, future experiences, and identity (Lloyd-Williams et al 2008).

These studies also support findings from numerous qualitative studies that suggest a lack of engagement in meaningful occupations leads to decreased satisfaction and fulfillment in life for people with advanced cancer and chronic and life-limiting illnesses (Jacques and Hasselkus 2004, la Cour et al 2007, la Cour et al 2009, Lexell et al 2009, Vikljan et al 2001). For example, Jacques and Hasselkus’s (2004) ethnographic study of a hospice found that occupations assisted people to prepare for death by allowing them to make amends, share their lives and history, and continue to
Occupational for people living with a life-limiting illness: a thematic review

make decisions and exercise control. In addition, la Cour et al’s (2007) phenomenological study found that creative activity at the end of life strengthens connections to life by allowing participants to actively engage in their chosen occupations, and reinforces the fact that they are active and valued people regardless of their diagnosis.

Research has also illustrated that, while engagement in occupations remains important for people living with a life-limiting illness, the way in which people conduct their occupations may change (Lyons et al 2002). A qualitative study by Lyons et al (2002) looked at how clients of a hospice day programme continued to engage in their chosen occupations using the Doing–Being–Becoming framework developed by Wilcock (1999). Many of the study's participants had difficulty facing the loss of their daily occupations and struggled with their increasing dependence on others as their illness progressed. However, through participation in the day hospice program, participants were able to maintain a sense of well-being and decrease feelings of boredom and isolation by ‘doing’ activities. Participants considered that ‘being’ a part of the hospice programme by sitting and watching others complete activities was just as important as actually doing the activity. Attending the hospice day programme gave participants a sense of belonging, enjoyment, and support. There was a sense of ‘becoming’ felt by participants who engaged in reflective activities that promoted self-affirmation and a greater insight into themselves as people. Participants gained unexpected new learning experiences by trying unfamiliar activities that provided a challenge. Lyons et al (2002), therefore, found that it was vital for people living with life-limiting illnesses to continue engaging in their meaningful occupations, as well as new ones, albeit in a hospice context.

It can be seen, therefore, that people living with a life-limiting illness strive to remain engaged in occupational activities despite their losses for as long as possible. Clients’ occupational engagement in meaningful activities can be enhanced where clinicians engage in active listening during conversations; run both individual and group sessions focused on productive ability, wellness, and reflection, rather than diagnosis, to help the person prepare for death; and facilitate control by enabling client participation, regardless of the capacity in which they perform that task.

Preparing for practice when your client is dying: educational requirements of occupational therapists working with people living with a life-limiting illness

Occupational therapists need to be adequately educated and prepared to work with people living with a life-limiting illness if they are to meet the occupational needs of their clients at the end of life. It has been argued that the paucity of evidence regarding the occupational therapy role with people living with a life-limiting illness has left occupational therapists feeling underprepared to work in this area (Meredith 2010). Recently, however, attention has been given to the educational and training requirements needed to prepare clinicians for this role (Halkett et al 2010, Hassellius and Murray 2007, Jayasingam et al 2008, la Cour et al 2005, la Cour et al 2007, la Cour et al 2009, Lexell et al 2009, Meredith 2010).

Early research found that a clinician’s life experiences and professional training were typically inadequate preparation for facing not only mortality on a daily basis, but the unique dilemmas of working with people living with a life-limiting illness (Bennett 1991). During the 1980s and 1990s, researchers reported that there was minimal undergraduate education dedicated to occupational therapy practice with people living with a life-limiting illness (Bennett 1991). At this time in Australia, 64% of clinicians reported they had received no formal education in working in a hospice setting or with people with a life-limiting condition as a student, while 74% of clinicians reported they were not offered any specific education once employed in a position in this area (Dawson and Barker 1995).

Studies continue to suggest that the amount of education required to prepare clinicians to work with people living with a life-limiting illness should be increased (Dawson and Barker 1995, Halkett et al 2010, Meredith 2010). A recent survey completed with 24 clinicians in Australia found that feelings of preparedness increased amongst clinicians with the length of time that they worked with this client group and with the amount of relevant undergraduate training they had received (Meredith 2010). Only 48.3% of clinicians reported that they had received undergraduate palliative care education, with many feeling underprepared to work in the area (Meredith 2010).

Research has shown that clinicians feel that education should reflect the diversity and complexity of the area (Halkett et al 2010, Meredith 2010). Information should be given on: (i) the occupational therapy role; (ii) communication and counselling skills that focus on grief and bereavement; (iii) the unique focus of service delivery and clinical reasoning processes used; (iv) medical and psychological aspects of care; (v) ethical and cultural issues at the end of life; and (vi) self-care, to maintain clinicians’ wellbeing in this demanding role (Bennett 1991, Cipriani et al 2000, Dawson and Barker 1995, Meredith 2010). Clinical scenarios and exposure to clients with a life-limiting illness should also be incorporated to enhance learning (Meredith 2010).

Consequently, preparing for practice with people living with a life-limiting illness is difficult at present. Educational changes need to be made to undergraduate curricula to enhance clinical exposure and learning in this area. More postgraduate courses that involve clinical scenarios, face-to-face contact with clients, and educational sessions on topics ranging from the occupational therapy role to communication, disease trajectory, and self-care strategies to avoid burnout should be introduced.

Discussion and implications

While there have been several decades of research into the role of occupational therapy with people who have a life-limiting illness, most studies have been either descriptive, quantitative
studies or small-scale qualitative studies conducted in the 1980s and 1990s, with only a few recent investigations into current practice. The focus of the research has evolved from primarily investigating the occupational therapy role with people with a life-limiting illness, to take on a greater emphasis on symptom control and psychosocial care. Varied definitions of palliative care terminology and the limited research into this clinical area have left therapists confused about their scope of practice. The three themes identified in this review reveal that occupational therapists who work with people living with a life-limiting illness reframe their practice, continue to engage their clients in occupational activities despite their loss, and need further preparation for practice with this client group.

Reframing practice with people who have a life-limiting illness has enhanced the role that occupational therapists play with people living with a life-limiting illness. However, the exact scope of this role has not been clearly defined in the research to date. For instance, there is limited research regarding the specific occupational needs addressed by clinicians when working with clients, and the interventions lack research on effectiveness. This has resulted in both occupational therapists and other health professionals having an inconsistent understanding of the total contribution that occupational therapy can make to someone who is living with a life-limiting illness (Hallett et al 2010). Further research should be conducted on how occupational therapists define their role when working with people living with a life-limiting illness, and what they perceive the scope of their role with this client group to be.

At a more detailed level, only a few studies over the past 30 years have explored the day-to-day work profile of occupational therapists working with people with a life-limiting illness (Dawson 1982, Hallett et al 2010). The modes of service delivery, referral pathways, and the diagnostic groups being treated by occupational therapists working with people with a life-limiting illness are unknown in most countries. This knowledge is required to inform the establishment or maintenance of service provision, and to ascertain appropriate educational and training resources for students and therapists entering this field.

The idea of continuing occupational engagement despite the client’s loss began in the 1990s as a push toward understanding the occupational engagement of people with a life-limiting illness. Through a solid, qualitative evidence-based research has established that people living with a life-limiting illness should remain engaged in their occupational tasks to meet their daily needs. This engagement assists people with a life-limiting illness to maintain a sense of competence and mastery over self and the environment in their final stages of life. The challenge that presents itself to clinicians is ensuring that occupation remains the focus of interventions (Keeging and Rosenwax 2011). Exactly how clinicians do this remains unknown. Future research should investigate occupational therapists’ perceptions regarding the occupations which people with a life-limiting illness want to engage in, and how, as clinicians, they enable this engagement to occur.

The current education of occupational therapists not prepare clinicians for practice with people living a life-limiting illness. Occupational therapists need a understanding of what their day-to-day practice with with a life-limiting illness should involve. To date, no position statements for this practice area exist only UK, Canada, and the USA. Evidence-based clinical gui are yet to be developed worldwide. This means that limited information available to inform clinicians of ment and intervention choices for people whose cot will deteriorate rather than improve. A clearer understand ing of the scope of assessment and treatment practice the reasons why and where these practices would be mented, is required to reduce the current ambiguity of rounds occupational therapy practice with this client. Once a clear scope of practice has been identified, the profile needs to be disseminated to undergradua graduate occupational therapists with the aim of ign preparedness for working with people with a life-li illness. Once educated, clinicians need to take more responsibility to promote their role to multidisciplinary team bers, with the aim of reducing the existing role am and current blurring of professional boundaries (l et al 2010, Keeging and Rosenwax 2011).

Therefore, further research should be conducted how occupational therapists define their role when w with people living with a life-limiting illness; (ii) occup therapists’ perceptions of their roles in the complex working with people living with a life-limiting illness; (iii) occupational therapists’ perceptions of the occup in which clients with a life-limiting illness want to and how, as clinicians, they enable this engagement to. Finally, more evidence-based studies investigating o tional therapy practice for people living with a life-li illness are needed.

Conclusion

In summary, occupational therapists’ role with people with a life-limiting illness has evolved over the las decades to become one that involves reframing pract keeping clients engaged in occupational activities despi loss. Clinicians need to receive better preparation to wo this client group through increased educational opport at both the undergraduate and postgraduate levels. This has highlighted the need for future research to be con into better defining the occupational therapy role a scope of practice for people living with a life-limiting as well as investigating occupations in which people with a life-limiting illness wish to engage, from both a d client perspective.

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Research ethics: Ethical approval was not required for this study.

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Appendices

Occupational therapy for people living with a life-limiting illness: a thematic review

Key findings
- Clinicians need better role definition to reduce the ambiguity about the scope of practice.
- Clinicians require more education on life-limiting illness and refocusing practice at undergraduate and postgraduate levels.

What the study has added
This study has provided a thematic analysis of the evidence surrounding the occupational therapy role for people living with a life-limiting illness.

References
Appendices

Kathrine Hammill, Rosalind Bye, and C


Appendix 2 Survey instrument
1. Occupational therapy for people with a terminal illness

Occupational therapists play a unique role treating people with a terminal illness. People living with a terminal illness have an incurable, progressive condition. These people are expected to die within the foreseeable future regardless of whether their diagnosis is malignant, non-malignant, or due to the ageing process.

This survey is targeting occupational therapists who are currently working, or have worked with people with a terminal illness in Australia in the last three years.

Please be aware that by completing this survey you are consenting to the research team using the information you provide.

1. Are you an occupational therapist?

☐ Yes

☐ No
2.

1. Have you worked with people with a terminal illness within Australia in the last three years?
   - [ ] Yes
   - [ ] No
Appendices

3.

1. I currently work with people with a terminal illness as part of my caseload.
   - [ ] Yes
   - [ ] No
4. Demographic information

1. I am:
   - Male
   - Female

2. In what year did you graduate?

3. What is your highest level of education obtained?
   - Diploma
   - Degree
   - Honours
   - Masters
   - PhD
   - Other (please specify)

4. In which state or territory are you employed?
   - Australian Capital Territory
   - New South Wales
   - Northern Territory
   - South Australia
   - Tasmania
   - Queensland
   - Victoria
   - Western Australia

5. Is your primary work area:
   - Metropolitan
   - Regional
   - Rural
   - Remote
   - Other (please specify)

6. What is your primary work role when working with people who are terminally ill?
   - Clinician
   - Senior Clinician
   - Manager
   - Other (please specify)
7. In which health sector do you work?

- Private
- Public
- NGO (Non Government Organisation)
- Other (Please Specify)

8. How long have you worked with people with a terminal illness?

Years

Months
5. Working with people living with a terminal illness

1. In what capacity are you employed to work with people with a terminal illness?
   - Permanent (Full Time)
   - Permanent (Part Time)
   - Rotational (Full Time)
   - Rotational (Part Time)
   - Other (Please Specify)

2. I primarily work with:
   - Adults
   - Children and Adolescents
   - Adults and Children and Adolescents

3. Please indicate your primary work setting where you treat clients with a terminal illness.
   - Community
   - Home
   - Hospice
   - Inpatient
   - Outpatient
   - Other (please specify)

4. What clinical areas are involved in your caseload? (Tick all that apply)
   - Palliative Care
   - Oncology
   - HIV/AIDS
   - Lymphoedema
   - Neurology
   - Other (please specify)
5. What proportion of your clients would have a diagnosis of a terminal illness?
- [ ] 0-25%
- [ ] 26-50%
- [ ] 51-75%
- [ ] 76-100%

6. What are the three most common terminal illnesses you treat in your caseload?

1. 
2. 
3. 

7. Do you see yourself working with people with a terminal illness in the future? (Tick all that apply)
- [ ] Yes, I find the role satisfying.
- [ ] Yes, but I need more support.
- [ ] Yes, but the role needs increased staffing levels.
- [ ] Yes, but not as my primary caseload.
- [ ] Yes, but with more resources.
- [ ] No, I do not find the role satisfying.
- [ ] No, I find it too challenging emotionally.
- [ ] No, I find it too challenging physically.
- [ ] Other (please specify) 

8. How long do you plan on staying in the role and why?

<table>
<thead>
<tr>
<th>Length of time (in years)</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

9. Do you use an occupational therapy model of practice (eg. Canadian Measure of Occupational Performance, Model of Human Occupation, Occupational Performance Model of Australia, etc) or a theoretical framework to guide your role with this client group?
- [ ] No
- [ ] Yes (please list the model/framework used and why you have selected this approach)
10. Research suggests that occupational therapists modify their practice when working with people with a terminal illness. Please rate your level agreement with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I see my clients with terminal illness as soon as possible after referral to account for their limited lifespan and possible rapid decline.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I change how I gather my assessment information, adopting a more low key approach with people with terminal illness.</td>
<td></td>
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</tr>
<tr>
<td>I rarely use standardised assessments or outcome measures with clients with terminal illness.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I change what assessments I get my clients with terminal illness to physically complete.</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>I reassess my clients needs on a more regular basis to account for rapid changes in functional status of people with terminal illness.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I set goals with clients with terminal illness that meet their wishes.</td>
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</tr>
<tr>
<td>I use a more family centred approach when working with clients with terminal illness.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I provide more caregiver oriented interventions with clients with terminal illness.</td>
<td></td>
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</tr>
<tr>
<td>My supportive role with caregivers is an important aspect of occupational therapy with clients with terminal illness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I use temporary home modifications and/or equipment when working with clients with terminal illness.</td>
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<td></td>
</tr>
<tr>
<td>I address the spiritual aspects of my clients’ lives more often when they have terminal illness.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I address a client’s need for closure in preparation for their death.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I help clients with a terminal illness to participate in occupations that are meaningful rather than those that emphasise functional performance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I focus more on making the everyday more meaningful for clients with a terminal illness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I focus more on the here and now and do not make long-term plans with clients with terminal illness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I help clients and their families prepare for declining health leading up to death by putting in place care and support needs.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I focus less on independent function for clients with terminal illness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I change what I view as good occupational therapy outcomes for clients with terminal illness.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I make a difference as an occupational therapist even when the client dies.</td>
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</tr>
</tbody>
</table>

Please list any other examples of how you modify practice when working with clients with terminal illness:

11. Give examples of the main goals you set with your clients with a terminal illness.
12. Are there any unique occupations that people with a terminal illness need to engage in, in comparison to other client groups? If yes, please list these occupations.

13. What have been some of your client’s most meaningful occupations at this time of life? (eg. saying goodbye, going places, spending time with family/friends etc)

14. What is the most satisfying element you have found when working with people with a terminal illness?

15. What are the main challenges you face in your role? (Tick all that apply)
   - Working with people who are dying is emotionally challenging for me.
   - Building rapport with people who are going to die.
   - Working with grieving family members.
   - No matter what I do my client won’t get better.
   - Being unsure of what I can do in my role.
   - Service is understaffed.
   - Service is under-resourced.
   - Juggling multiple caseload demands.
   - Receiving minimal support from my senior clinician.
   - Limited evidence-base to support my practice.
   - Role being misunderstood by other health professionals.
   - Role being misunderstood by other occupational therapists.
   - Other (please specify)
16. How do you overcome the challenges that you face? (Tick all that apply)

- I ensure I have good work/life balance.
- I exercise or play sports.
- I complete leisure activities.
- I seek supervision from my mentor.
- I seek support from my colleagues.
- I seek feedback from personal friends.
- I spend time away from the caseload.
- I seek counselling and support at work.
- I seek counselling from outside work sources.
- I attend an occupational therapy interest group.

Other (please specify):

17. Rate your level of agreement with how other occupational therapy colleagues perceive your role with this client group.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My role is valued by other occupational therapists.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most occupational therapists are scared of working in the clinical area.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is a role most occupational therapists want to do.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My role is misunderstood by other occupational therapists.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>It is not seen as being as important as other occupational therapy areas of practice.</td>
<td></td>
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</tr>
</tbody>
</table>
### 6. Referral to occupational therapy for clients with a terminal illness

#### 1. Who refers clients with a terminal illness to your service?

<table>
<thead>
<tr>
<th>Frequency of Referral</th>
<th>Primary Reason for Referral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td></td>
</tr>
<tr>
<td>Inpatient Nurse</td>
<td></td>
</tr>
<tr>
<td>Outpatient Nurse</td>
<td></td>
</tr>
<tr>
<td>Community Nurse</td>
<td></td>
</tr>
<tr>
<td>Dietitian</td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
</tr>
<tr>
<td>Client Self-Referral</td>
<td></td>
</tr>
<tr>
<td>Family/Caregiver</td>
<td></td>
</tr>
<tr>
<td>Speech/Language Therapist</td>
<td></td>
</tr>
<tr>
<td>Blanket Referral</td>
<td></td>
</tr>
</tbody>
</table>

#### 2. In the past month, within what timeframe did you typically respond to referrals?

- [ ] Same day
- [ ] 1 day
- [ ] 2 days
- [ ] 3 days
- [ ] 1 week
- [ ] 2 weeks
- [ ] Other (please specify)

#### 3. Reflecting on your current practice with people with a terminal illness, please rate your level of agreement with the following statements:

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can only see the client for what they have been referred for.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Once referred, I complete my own assessments to determine what the client needs.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>The referrals I receive represent the client’s needs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My referrals understand the occupational therapy role within this client group.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I receive referrals that let me address a client’s occupational therapy needs to my satisfaction.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I receive referrals that let me address a client’s equipment needs to my satisfaction.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staffing levels allow me to respond within a timely manner to address clients’ needs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I receive last minute referrals which impacts what I am able to do with my clients.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. Do you have any further comments regarding how you receive or respond to referrals for people with a terminal illness?
### 7. Occupational therapy assessment for people with a terminal illness

1. When planning which assessments to complete with your clients with a terminal illness, do you discuss: (Tick all that apply)

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>The client’s wishes.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The client’s care and support needs.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The caregiver’s ability to provide supportive care.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Where the client would prefer to die.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How the client would like to spend their remaining days.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The client’s goals for care.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The caregiver’s goals for care.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Over the last week, which assessments did you complete with your clients? (Tick all that apply)

<table>
<thead>
<tr>
<th>Assessment completed</th>
<th>Primary method of assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Assessment</td>
<td></td>
</tr>
<tr>
<td>Cognitive Assessment</td>
<td></td>
</tr>
<tr>
<td>Domestic ADL’s</td>
<td></td>
</tr>
<tr>
<td>Equipment Needs</td>
<td></td>
</tr>
<tr>
<td>Fatigue and Energy Level Assessment</td>
<td></td>
</tr>
<tr>
<td>Home Assessment</td>
<td></td>
</tr>
<tr>
<td>Leisure</td>
<td></td>
</tr>
<tr>
<td>Pressure Care</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
</tr>
<tr>
<td>Self Care ADL’s</td>
<td></td>
</tr>
<tr>
<td>Sleep</td>
<td></td>
</tr>
<tr>
<td>Stress and Coping Assessment</td>
<td></td>
</tr>
<tr>
<td>Transfers</td>
<td></td>
</tr>
<tr>
<td>Wheelchair Prescription</td>
<td></td>
</tr>
<tr>
<td>Workplace Assessment</td>
<td></td>
</tr>
</tbody>
</table>

3. Were any of the completed assessments standardised?

- [ ] No
- [ ] Yes (please name standardised assessments used)


4. Do you use any outcome measures to assess your client’s occupational performance?

☐ No

☐ Yes (please name any outcome measures used)

5. Do you have any further comments regarding occupational therapy assessments with people who have a terminal illness?

[Blank space]
## 8. Occupational therapy interventions for people with a terminal illness

1. List the three most common ADL tasks (e.g. dressing, cooking, mobility) that you provide an intervention for with this client group.

   1. 
   2. 
   3. 

2. In the last week, what interventions did you provide and where did you provide them? (Tick all that apply)

<table>
<thead>
<tr>
<th>Anxiety and Stress Management</th>
<th>Home</th>
<th>Hospital</th>
<th>Hospice</th>
<th>Nursing Home</th>
<th>Community</th>
<th>Outpatient</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bereavement Counselling</td>
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<td>Care Education</td>
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<tr>
<td>Client Education</td>
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<tr>
<td>Creative Therapies</td>
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<tr>
<td>Discharge Planning</td>
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<tr>
<td>Domestic ADL's Retaining</td>
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<td>Energy Conservation</td>
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<tr>
<td>Equipment Prescription</td>
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<tr>
<td>Group Activities</td>
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<tr>
<td>Home Modifications - Temporary</td>
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<tr>
<td>Home Modifications - Permanent</td>
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<tr>
<td>Leisure Related</td>
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<tr>
<td>Pain Management</td>
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<tr>
<td>Pressure Care</td>
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<tr>
<td>Referral to Community Supports</td>
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<tr>
<td>Referral to other Health Professionals</td>
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<tr>
<td>Self Care Retraining</td>
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<tr>
<td>Sleep Hygiene</td>
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<tr>
<td>Therapeutic Conversation</td>
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<td></td>
</tr>
<tr>
<td>Rehabilitation/Reconditioning Activities</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Workplace Interventions</td>
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</tr>
</tbody>
</table>
3. Think about the way that you complete your interventions. Rate how frequently you provide interventions that focus on:

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Almost Always</th>
<th>Sometimes</th>
<th>Almost Never</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your client's physical needs.</td>
<td></td>
<td></td>
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<tr>
<td>Your client's psychosocial needs.</td>
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<tr>
<td>Your client's occupational needs.</td>
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<tr>
<td>Your client's spiritual needs.</td>
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<tr>
<td>A carer's physical needs.</td>
<td></td>
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<tr>
<td>A carer's psychosocial needs.</td>
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<tr>
<td>A carer's occupational needs.</td>
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</tr>
<tr>
<td>A carer's spiritual needs.</td>
<td></td>
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</tr>
</tbody>
</table>

4. Are you able to provide follow-up for your clients within your role?
   - Yes
   - No, but I am able to refer to another occupational therapy service for follow-up
   - No (please state why not)

5. Are you able to provide follow-up for the client’s caregiver within your role?
   - Yes
   - No, but I am able to refer to another occupational therapy service for follow-up
   - No (please state why not)

6. Do you have any further comments regarding occupational therapy interventions with people who have a terminal illness?
9. Education and Supervision when working with people with a terminal illness

1. When I first started working with people with a terminal illness I felt:
   - Very Prepared
   - Moderately Prepared
   - Slightly Prepared
   - Not At All Prepared

2. I feel more prepared to work with people with a terminal illness the longer I work in the area.
   - Strongly Agree
   - Agree
   - Disagree
   - Strongly Disagree

3. At University, what skills, knowledge or qualities should be taught to help prepare someone to first work in the clinical area?

4. Rate how comfortable you feel with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Very Comfortable</th>
<th>Comfortable</th>
<th>Not Comfortable At All</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am comfortable working with a person with a terminal illness.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I am comfortable working with the family of a person with a terminal illness.</td>
<td></td>
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<tr>
<td>I am comfortable assessing a person with a terminal illness.</td>
<td></td>
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<tr>
<td>I am comfortable prescribing aids and equipment for a person with a terminal illness.</td>
<td></td>
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</tr>
<tr>
<td>I am comfortable completing a home visit with a person with a terminal illness.</td>
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</tr>
<tr>
<td>I am comfortable grading my interventions to enable a person with a terminal illness.</td>
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</tr>
<tr>
<td>I am comfortable talking about dying with a person with a terminal illness.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am comfortable talking about dying with the families of clients with a terminal illness.</td>
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</tr>
</tbody>
</table>

5. Do you feel that your undergraduate education prepared you to work with people with a terminal illness?
   - Yes (please give rationale why)
   - No (please give rationale why)

6. What do you think are the most important skills required by occupational therapists to work with people with a terminal illness?
7. From your experience, where do you feel the following educational topics would be best covered?

<table>
<thead>
<tr>
<th>Topic</th>
<th>At University</th>
<th>On the job</th>
<th>Continuing professional development</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational therapy assessments for clients with a terminal illness.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapy interventions for clients with a terminal illness.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Communication skills related to clients with a terminal illness.</td>
<td></td>
<td></td>
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<tr>
<td>Medical aspects of dying.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service delivery systems for clients with a terminal illness, eg. hospital wards, palliative care unit, hospice, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical reasoning related to clients with a terminal illness.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Occupational therapy role in end-of-life care.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological aspects of death and dying.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-care for occupational therapists.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethical and cultural concerns at the end-of-life.</td>
<td></td>
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<td></td>
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<tr>
<td>Inter-professional roles at the end-of-life.</td>
<td></td>
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</tr>
</tbody>
</table>

8. Who supervises your role with people with a terminal illness? (Tick all that apply)

- [ ] I do not receive supervision
- [ ] Senior Occupational Therapist
- [ ] Occupational Therapy Manager
- [ ] Doctor
- [ ] Nursing Unit Manager
- [ ] Allied Health Director
- [ ] Other (please specify)

9. On average, how often do you receive supervision?

- [ ] Never
- [ ] Once per week
- [ ] Once per fortnight
- [ ] Once per month
- [ ] Once per year
- [ ] Other (please specify)
10. How often would you like to receive supervision?
- Never
- Once per week
- Once per fortnight
- Once per month
- Once per year
- Other (please specify)

11. Please state your level of agreement with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I receive both informal and formal supervision.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I mainly receive formal supervision.</td>
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<tr>
<td>I am happy with the amount of supervision I receive.</td>
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<tr>
<td>I am able to ask my supervisor for help.</td>
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<tr>
<td>I feel my supervisor is knowledgeable in this clinical area.</td>
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<tr>
<td>I am able to debrief with my supervisor after challenging situations.</td>
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</tr>
<tr>
<td>My current supervision meets my learning needs.</td>
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</tbody>
</table>

12. Do you have any further comments regarding educational or supervisory requirements for occupational therapists working with people who have a terminal illness?
10. Demographic Information

1. I am:
   - Male
   - Female

2. In what year did you graduate?

3. What is your highest level of education obtained?
   - Diploma
   - Degree
   - Honours
   - Masters
   - PhD
   - Other (please specify)

4. In which state or territory were you employed when you worked with people with a terminal illness?
   - Australian Capital Territory
   - New South Wales
   - Northern Territory
   - South Australia
   - Tasmania
   - Queensland
   - Victoria
   - Western Australia

5. Was your work area:
   - Metropolitan
   - Regional
   - Rural
   - Remote
   - Other (please specify)
6. What was your primary work role when you worked with people with a terminal illness?
- Clinician
- Senior Clinician
- Manager
- Other (please specify)

7. In what health sector did you work?
- Private
- Public
- NGO (National Government Organisation)
- Other (Please Specify)

8. What is your current work role?
- Clinician
- Senior Clinician
- Manager
- Academic
- Researcher
- Other (please specify)
### 11. Working with people with a terminal illness

1. **In what capacity were you employed to work with people with a terminal illness?**
   - [ ] Permanent (Full Time)
   - [ ] Permanent (Part Time)
   - [ ] Rotational (Full Time)
   - [ ] Rotational (Part Time)
   - [ ] Other (Please Specify):
     
2. **I primarily worked with:**
   - [ ] Adults
   - [ ] Children and Adolescents
   - [ ] Adults and Children and Adolescents

3. **Please indicate your primary work setting where you treated clients with a terminal illness.**
   - [ ] Community
   - [ ] Home
   - [ ] Hospice
   - [ ] Inpatient
   - [ ] Outpatient
   - [ ] Other (please specify):

4. **What clinical areas were involved in your caseload?**
   - [ ] Palliative Care
   - [ ] Oncology
   - [ ] HIV/AIDS
   - [ ] Lymphoma
   - [ ] Neurology
   - [ ] Other (please specify):
   - [ ] Cardiology
   - [ ] Aged Care
   - [ ] General Medical
   - [ ] Renal
   - [ ] Respiratory
5. What proportion of your clients had a terminal illness?
- 0-25%
- 26-50%
- 51-75%
- 76-100%

6. What were the three most common diagnoses you treated?
1. 
2. 
3. 

7. I left the clinical area because: (Tick all that apply)
- I did not like it.
- I did not feel supported.
- I was in a rotational position.
- I did not have the skills.
- There was inadequate occupational therapy staffing.
- I was under-resourced.
- Other (please specify) 

8. How long did you work with people with a terminal illness?
- Years
- Months

9. Did you use an occupational therapy model of practice (e.g. Canadian Measure of Occupational Performance, Model of Human Occupation, Occupational Performance Model of Australia, etc) or a theoretical framework to guide your role with this client group?
- No
- Yes (please list the model/framework used and why you have selected this approach)
10. Research suggests that occupational therapists modify their practice when working with people with a terminal illness. Please rate your level agreement with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I saw my clients with terminal illness as soon as possible after referral to account for their limited lifespan and possible rapid decline.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I changed how I gathered my assessment information, adopting a more low key approach with people with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I rarely used standardized assessments or outcome measures with clients with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I changed what assessments I got my clients with terminal illness to physically complete.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I re-assessed my clients needs on a more regular basis to account for the rapid changes in functional status of people with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I set goals with clients with terminal illness that met their wishes.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I used a more family-centred approach when working with clients with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I provided more caregiver oriented interventions with clients with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>My supportive role with caregivers was an important aspect of occupational therapy with clients with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I used temporary home modifications and/or equipment when working with clients with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I addressed the spiritual aspects of my clients’ lives more often when they have terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I addressed a client’s need for closure in preparation for their death.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I helped clients with a terminal illness to participate in occupations that were meaningful rather than those that emphasised functional performance.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I focused more on making the everyday more meaningful for clients with a terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I focused more on the here and now and do not make long-term plans with clients with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I helped clients and their families prepare for declining health leading up to death by putting in place care and support needs.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I focused less on independent function for clients with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I changed what I viewed as good occupational therapy outcomes for clients with terminal illness.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I felt I made a difference as an occupational therapist even when the client died.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Please list any other examples of how you modify practice when working with clients with terminal illness:

11. Give examples of the main goals you set with your clients with a terminal illness.
16. How did you overcome the challenges that you faced? (Tick all that applied)

- I ensured I had a good work-life balance.
- I exercised or play sports.
- I completed leisure activities.
- I sought supervision from my senior.
- I discussed with my mentor.
- I discussed with other colleagues.
- I discussed with personal friends.
- I spent time away from the caseload.
- I sought counselling at work.
- I sought counselling from outside work sources.
- I attended an occupational therapy interest group.
- Other (please specify)

17. Rate your level of agreement with how other occupational therapy colleagues perceived your role with this client group:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My role was valued by other occupational therapists</td>
<td></td>
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<td></td>
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<tr>
<td>Most occupational therapists were scared of working in the clinical area</td>
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<tr>
<td>It is a role most occupational therapists wanted to do</td>
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<tr>
<td>My role was misunderstood by other occupational therapists</td>
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<td></td>
</tr>
<tr>
<td>It was not seen as being as important as other occupational therapies</td>
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</tbody>
</table>
### 12. Referral to occupational therapy for people with a terminal illness

#### 1. Who referred clients with a terminal illness to your service and why?

<table>
<thead>
<tr>
<th></th>
<th>Yes/No</th>
<th>Primary reason for referral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inpatient Nurse</td>
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<tr>
<td>Outpatient Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietitian</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
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<tr>
<td>Client Self-referral</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech/Language Therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blanket Referral</td>
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<td></td>
</tr>
</tbody>
</table>

#### 2. In what timeframe did you typically respond to referrals?

- [ ] Same day
- [ ] 1 day
- [ ] 2 days
- [ ] 3 days
- [ ] 1 week

Other (please specify)

#### 3. Reflecting on your practice with people with a terminal illness, please rate your level of agreement with the following statements:

- [ ] Strongly Disagree
- [ ] Disagree
- [ ] Agree
- [ ] Strongly Agree

I could only see a client for what they have been referred for.

Once referred, I completed my own assessments and then determined what the client needed.

The referrals I received represented the client's needs.

My referrals understood the occupational therapy role with this client group.

I received referrals that allowed me to address clients occupational therapy needs to my satisfaction.

I received timely referrals that allowed me to address clients' equipment needs to my satisfaction.

Staffing levels allowed me to respond within a timely manner to address clients' needs.

I received last minute referrals which impacted on what I was able to do with clients.
4. Do you have any further comments regarding how you received or responded to referrals for people with a terminal illness?
13. Occupational therapy assessment of people with a terminal illness

1. When planning you occupational therapy assessments with your clients with a terminal illness, did you discuss? (Tick all that apply)

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>The client’s wishes</td>
<td></td>
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<tr>
<td>The client’s care and support needs</td>
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<tr>
<td>The caregiver’s ability to provide supportive care</td>
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<tr>
<td>Where the client would prefer to die.</td>
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<tr>
<td>How the client would like to spend their remaining days.</td>
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<tr>
<td>The client’s goals for care.</td>
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<tr>
<td>The care/giver’s goals for care.</td>
<td></td>
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</tbody>
</table>

2. Which assessments did you routinely complete with your clients? (Answer 'Yes' to all that apply)

<table>
<thead>
<tr>
<th>Assessment Name</th>
<th>Assessment completed</th>
<th>Primary method of assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Assessment</td>
<td></td>
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<tr>
<td>Cognitive Assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domestic ADL’s</td>
<td></td>
<td></td>
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<tr>
<td>Equipment Needs</td>
<td></td>
<td></td>
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<tr>
<td>Fatigue and Energy Level Assessment</td>
<td></td>
<td></td>
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<tr>
<td>Home Assessment</td>
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<tr>
<td>Leisure</td>
<td></td>
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<tr>
<td>Pressure Care</td>
<td></td>
<td></td>
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<tr>
<td>Pain</td>
<td></td>
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<tr>
<td>Self Care ADL’s</td>
<td></td>
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<tr>
<td>Sleep</td>
<td></td>
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<tr>
<td>Stress and Coping Assessment</td>
<td></td>
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<tr>
<td>Transfers</td>
<td></td>
<td></td>
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<tr>
<td>Wheelchair Prescription</td>
<td></td>
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<tr>
<td>Workplace Assessment</td>
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</tr>
</tbody>
</table>

3. Were any of the completed assessments standardised?

- [ ] No
- [ ] Yes (please name standardised assessments used)

[Blank space for comments]
Appendices

4. Did you use any outcome measures to assess your client's occupational performance?
   - [ ] No
   - [ ] Yes (please specify any outcome measures used)

5. Do you have any further comments regarding occupational therapy assessments with people who have a terminal illness?
14. Occupational therapy interventions for people with a terminal illness

1. List the three most common ADL tasks (e.g. dressing, cooking, mobility) that you provided an intervention for with these clients.
   1. 
   2. 
   3. 

2. What interventions did you routinely provide and where did you provide them? (Tick all that apply)

<table>
<thead>
<tr>
<th></th>
<th>Home</th>
<th>Hospital</th>
<th>Hospice</th>
<th>Nursing Home</th>
<th>Community</th>
<th>Outpatient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety Management</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Bereavement Counselling</td>
<td></td>
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<tr>
<td>Care Education</td>
<td></td>
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<tr>
<td>Client Education</td>
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<tr>
<td>Discharge Planning</td>
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<tr>
<td>Domestic ADL's Retraining</td>
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<td></td>
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<tr>
<td>Energy Conservation</td>
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<tr>
<td>Equipment Prescription</td>
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<td></td>
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<tr>
<td>Group Activities</td>
<td></td>
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<td></td>
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<tr>
<td>Home Modifications - Temporary</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Home Modifications - Permanent</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Leisure Related</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Pressure Care</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Self Care Retraining</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Sleep Hygiene</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress Management &amp; Coping Skills</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rehabilitation/Reconditioning Activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workplace Interventions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments


3. Rate how frequently you provided interventions that focused on:

<table>
<thead>
<tr>
<th></th>
<th>Always</th>
<th>Almost Always</th>
<th>Sometimes</th>
<th>Almost Never</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your client's physical needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your client's psychosocial needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your client's occupational needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your client's spiritual needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A carer's physical needs</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>A carer's psychosocial needs</td>
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<td></td>
<td></td>
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<tr>
<td>A carer's occupational needs</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>A carer's spiritual needs</td>
<td></td>
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</tbody>
</table>

4. Could you provide follow-up for your clients within your role?
   - Yes
   - No, but I could refer to another occupational therapy service for follow-up
   - No (please state why not)

5. Could you provide follow-up for the client's caregiver within your role?
   - Yes
   - No, but I was able to refer to another occupational therapy service for follow-up
   - No (please state why not)

6. Do you have any further comments regarding occupational therapy interventions with people who have a terminal illness?
   - [Blank]
15. Education and Supervision when working with people with a terminal illness

1. When I first started working with people with a terminal illness I felt:
   - Very Prepared
   - Moderately Prepared
   - Slightly Prepared
   - Not At All Prepared

2. I felt more prepared to work with people with a terminal illness the longer I worked in the area.
   - Strongly Agree
   - Agree
   - Disagree
   - Strongly Disagree

3. At University, what skills, knowledge or qualities should be taught to help prepare someone to first work in the clinical area?

4. Rate how comfortable you felt with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Very Comfortable</th>
<th>Comfortable</th>
<th>Not Comfortable At All</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was comfortable working with a person with a terminal illness.</td>
<td></td>
<td></td>
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<tr>
<td>I was comfortable working with the family of a person with a terminal illness.</td>
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<tr>
<td>I was comfortable assessing a person with a terminal illness.</td>
<td></td>
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<tr>
<td>I was comfortable prescribing aids and equipment for a person with a terminal illness.</td>
<td></td>
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<tr>
<td>I was comfortable completing a home visit with a person with a terminal illness.</td>
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<tr>
<td>I was comfortable grading my interventions to enable a person with a terminal illness.</td>
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<tr>
<td>I was comfortable talking about dying with a person with a terminal illness.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>I was comfortable talking about dying with the families of clients with a terminal illness.</td>
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</tbody>
</table>

5. Do you feel that your undergraduate education prepared you to work with people with a terminal illness?
   - Yes (please specify how) 
   - No (please specify how)

6. What do you think are the most important skills required by occupational therapists’ to work with people with a terminal illness?
7. From your experience, where do you feel the following educational topics would be best covered?

<table>
<thead>
<tr>
<th>Topic</th>
<th>At University</th>
<th>On the job</th>
<th>Continuing professional development</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational therapy assessments for clients with a terminal illness.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapy interventions for clients with a terminal illness.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Communication skills related to clients with a terminal illness.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical aspects of dying.</td>
<td></td>
<td></td>
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<tr>
<td>Service delivery systems for clients with a terminal illness, e.g., hospice wards, palliative care units, hospice, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical reasoning related to clients with a terminal illness.</td>
<td></td>
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<tr>
<td>Occupational therapy role in end-of-life care.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Psychological aspects of death and dying.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Palliative care for occupational therapists.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Ethical and cultural concerns at the end-of-life.</td>
<td></td>
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<tr>
<td>Inter-professional roles at the end-of-life.</td>
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</tbody>
</table>

8. Who supervised your role with people with a terminal illness? (Tick all that apply)

- [ ] I did not receive supervision
- [ ] Senior Occupational Therapist
- [ ] Occupational Therapy Manager
- [ ] Doctor
- [ ] Nursing Unit Manager
- [ ] Allied Health Director
- [ ] Other (please specify) [ ]

9. On average, how often did you receive supervision?

- [ ] Never
- [ ] Once per week
- [ ] Once per fortnight
- [ ] Once per month
- [ ] Once per year
- [ ] Other (please specify) [ ]
10. How often would you have liked supervision?

- Never
- Once per week
- Once per fortnight
- Once per month
- Once per year
- Other (please specify)

11. Please state your level of agreement with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I received both informal and formal supervision.</td>
<td></td>
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<tr>
<td>I received mainly formal supervision.</td>
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<tr>
<td>I was happy with the amount of supervision I received.</td>
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<tr>
<td>I was able to ask for help from my supervisor.</td>
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<tr>
<td>I felt my supervisor was knowledgeable in this clinical area.</td>
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<tr>
<td>I was able to debrief with my supervisor after challenging situations.</td>
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<tr>
<td>My supervision met my learning needs.</td>
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</table>

12. Do you have any further comments regarding educational or supervisory requirements for occupational therapists working with people who have a terminal illness?
16. Thank You

Thank you for taking your time to complete this survey. Your responses are greatly appreciated.

We know that finding people who work in this clinical area are hard to locate, so please forward the email containing the study information to anyone else who may be interested in completing this survey.

As part of Phase Two of this study we are planning to interview a number of occupational therapists regarding their role working with people with a terminal illness, including gaining their perspective on the occupational needs of this client group.

1. If you would like further information regarding participation in Phase 2 of the study please enter your email address below. (Please note: Entering your email address will not affect your anonymity with your survey responses)
Appendix 3 Introductory recruitment email
Do you currently work with, or have you worked as an occupational therapist in the past three years with people living with a terminal illness in Australia?

If so, then you are invited to participate in a research project entitled “The scope and dimensions of Australian occupational therapy practice for people living with a terminal illness”. This project is being carried out by occupational therapist and PhD candidate, Katie Faddy. Katie is being supervised by Dr Rosalind Bye and Dr Catherine Cook, from the School of Science and Health, at the University of Western Sydney.

WHAT IS A TERMINAL ILLNESS?
People living with a terminal illness have an incurable progressive condition, which regardless of their diagnosis is expected to cause the death of a person within the foreseeable future. The disease may be malignant, non malignant, or due to aging processes.

WHAT IS THE PURPOSE OF THE STUDY AND WHAT DOES IT INVOLVE?
Participation will include the completion of an anonymous online survey, which will focus on identifying the day-to-day work practice profile of occupational therapists working with people with a terminal illness. Questions in the survey will relate to:

• Your role with people living with a terminal illness;
• The assessment and treatment processes you use; and
• The educational requirements of occupational therapists’ working with this client group.

This study is will take approximately 30 minutes of your time. Further information for this study is attached and can be found on the Participant Information Sheet.

Please note that completing and returning the questionnaire represents your consent to take part in the study. Once you have submitted your survey you will be unable to withdraw your data from the study.

HOW DO I PARTICIPATE?
If you are interested in participating in this study please use the following link to go directly to the online questionnaire:
https://www.surveymonkey.com/s/otforpeoplewithaterminalillness

This study is using a snowball sampling method. Please forward this email and the attachments to other occupational therapists working with people with a terminal illness in Australia who may be eligible. If you have any questions regarding this study, please contact Katie via email on k.faddy@uws.edu.au.

Thank you for your time,
Katie Faddy
PhD Candidate

School of Science and Health
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P +61 2 414 972 383
F +61 2 4620 3792
E k.faddy@uws.edu.au
Appendix 4  Participant information sheet
PARTICIPANT INFORMATION SHEET

Project title: The Scope and Dimensions of Australian Occupational Therapy Practice for People Living with a Terminal Illness

Who is carrying out the study?
You are invited to participate in a study conducted by Katie Faddy, an occupational therapist and PhD Candidate at the School of Science and Health at University of Western Sydney. This study is being supervised by Dr Rosalind Bye and Dr Catherine Cook. This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is H9466.

What is the study about?
The purpose is to investigate the occupational therapy role working with people living with a terminal illness. In particular, we are interested in determining the day-to-day work practices of Australian therapists. To our knowledge, this is the first national study into this issue.

What does the study involve?
We are asking therapists who currently work, or have worked in Australia within the last three years with people living with a terminal illness as part of their caseload, to voluntarily take part in an anonymous survey. The survey can be completed online at https://www.surveymonkey.com/s/otforpeoplewithaterminalillness or you can request that a hard copy be sent to you.

Survey questions involve giving demographic information and your thoughts on the occupational therapy role with people with a terminal illness. Questions relate to referral sources, assessment and intervention practices, as well as educational requirements.

Please note: Completing this survey implies your Consent for this study.

How much time will the study take?
It is estimated that the survey will take approximately 20-30 minutes.

Will the study benefit me?
The study aims to further professional knowledge about providing care for people living with a terminal illness. Sharing your experience and ideas will help to identify the critical practice issues associated with working with this client group. However, the results may not directly benefit you.

Will the study have any risks?
There are no known risks to sharing your professional knowledge. We will endeavour to make the interviews as relaxed as possible so you can freely share your views in confidence.
How is the study being paid for?
This study is being sponsored by an Australian Postgraduate Award, received from School of Science and Health at the University of Western Sydney.

Will anyone else know the results? How will results be disseminated?
All aspects of the study will be confidential and only the researchers will have access to important information on individual participants.

The findings from this research will be disseminated as a PhD thesis. De-identified results from this study on the group data will be published in peer-reviewed journals and results presented at relevant conferences.

Can I withdraw from the study?
Participation is entirely voluntary: you are not obliged to participate and – if you do participate – you can withdraw at any time without giving any reason and without any consequences. Your participation will not impact on any future relationship with the occupational therapy program at the University of Western Sydney.

Can I tell other people about the study?
Yes, you can tell other people about the study by providing them with Katie Faddy’s contact details. They can contact Katie to discuss their participation in the research project and to obtain an information sheet.

What if I require further information?
When you have read this information, Katie Faddy can discuss it further with you and answer any questions you may have. If you would like to know more information at any stage, please feel free to contact Katie by email or phone (see details below).

What if I have a complaint?
If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

With thanks,

Katie Faddy

PhD Candidate
School of Science and Health
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Locked Bag 1797| Penrith South
NSW 1797
P +61 2 414 972 383
F +61 2 4620 3792
E k.faddy@uws.edu.au
Appendix 5 Follow-up reminder email
Recently you received an email regarding survey research being conducted by Katie Faddy at the University of Western Sydney into the occupational therapy role for people with a terminal illness.

We have had a great response so far, and wish to sincerely thank all of the therapists who have supported this research not only by taking the time to complete the survey, but by forwarding the email onto their colleagues.

For those who haven’t had a chance to complete the survey as yet and would still like to participate, the survey will remain open until 5pm Monday, April 30th 2012.

As a reminder the survey is targeting occupational therapists that currently work with, or have worked with people living with a terminal illness in Australia in the past three years. The survey is focusing on identifying the day-to-day work practice profile of occupational therapists working with people with a terminal illness and asks questions relating to:

- Your role with people living with a terminal illness;
- The assessment and treatment processes you use; and
- The educational requirements of occupational therapists working with this client group.

Further information can be found in the attached participant information sheet.

To complete the survey, which will take approximately 30 minutes of your time, please click on the following link:

https://www.surveymonkey.com/s/otforpeoplewithterminalillness

It would be appreciated if those who forwarded this email on initially, could forward this reminder on to the same people.

If you have any questions regarding this study, please contact Katie via phone (0414 972 383) or email (k.faddy@uws.edu.au).

Thank you for your time,

Katie Faddy

School of Science and Health
THE UNIVERSITY OF WESTERN SYDNEY
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NSW 1797
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F +61 2 4620 3792
E k.faddy@uws.edu.au
Appendix 6 University of Western Sydney’s Human Research Ethics Committee approval (H9466)
21 March 2012

Ms Rosalind Bye,
School of Biomedical and Health Sciences

Dear Rosalind,

I wish to formally advise you that the Human Research Ethics Committee has approved your research proposal H9466 “The scope of dimensions of Australian occupational therapy practice with people and a terminal illness”, until 1 April 2014 with the provision of a progress report annually and a final report on completion.

Please quote the project number and title as indicated above on all correspondence related to this project.

This protocol covers the following researchers:
Rosalind Bye, Catherine Cook, Kathrine Faddy.

Yours sincerely

Dr Anne Abraham
Chair, UWS Human Research Ethics Committee
Appendix 7 Standardised assessment use
## Domain

**Outcome Measure**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Outcome Measure</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL</td>
<td>Modified Barthel Index (MBI) (Palliative Care Curriculum for Undergraduates (PCC4U) Project Team, 2014; Yates, 2007)</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Functional Independence Measure (FIM) (Shah et al., 1989)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Resource Utilisation Group – Activities of Daily Living Scale (RUG-ADL) (Abernethy et al., 2005)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Bruininks-Oseretsky Test of Motor Proficiency 2nd Edition (BOT-2) (Keith et al., 1987)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>10</strong> (14%)</td>
</tr>
<tr>
<td>Cognition</td>
<td>Mini Mental State Exam (MMSE) (Fries et al., 1994)</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Rowland Universal Dementia Assessment Scale (RUDAS) (Bruininks &amp; Bruininks, 2005)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Cognistat (Folstein et al., 1975)</td>
<td>5</td>
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<tr>
<td></td>
<td>Addenbrookes Cognitive Examination - Revised (ACE-R) (Storey, 2004)</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Montreal Cognitive Assessment (MoCA) (Kiernan, Mueller, Langston, &amp; Van Dyke, 1987)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Neuropsychiatry Unit Cognitive Assessment Tool (NUCOT) (Mioshi, Dawson, Mitchell, Arnold, &amp; Hodges, 2006)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Brief Interview for Mental Status (BIMS) (Nasreddine et al., 2005)</td>
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<td></td>
<td>Behavioural Assessment of the Dysexecutive Syndrome (BADS) (Walterfang, Velakoulis, Gibbs, &amp; Lloyd, 2003)</td>
<td>1</td>
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<td></td>
<td>Modified Mini Mental State Test (3MS) (Saliba et al., 2012)</td>
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<tr>
<td></td>
<td>Confusion Assessment Method (CAM) (Wilson, Evans, Alderman, Burgess, &amp; Emslie, 1997)</td>
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<tr>
<td></td>
<td>Loewenstein Occupational Therapy Cognitive Assessment (LOTCA) (Teng &amp; Chui, 1987)</td>
<td>1</td>
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<tr>
<td></td>
<td>Mental Status Questionnaire (MSQ) (Inouye et al., 1990)</td>
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<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>37</strong> (54%)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Brief Fatigue Inventory (Itzkovich, Elazar, Averbuch, &amp; Levinshtain, 2000)</td>
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<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>1</strong> (1%)</td>
</tr>
<tr>
<td>Pressure care</td>
<td>Waterlow Pressure Ulcer Risk Assessment Tool (Waterlow) (Wilson &amp; Brass, 1973)</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Braden Pressure Care Scale (Mendoza et al., 1999)</td>
<td>4</td>
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<tr>
<td></td>
<td>Pressure Care Mapping (Waterlow, 1984)</td>
<td>2</td>
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<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>17</strong> (25%)</td>
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<tr>
<td>More than one domain</td>
<td>Visual Analogue Scale (Bergstrom, Braden, Laguza, &amp; Holman, 1987)</td>
<td>2</td>
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<tr>
<td></td>
<td>Assessment of Motor and Processing Skills (AMPS) (Stinson, Porter-Armstrong, &amp; Eakin, 2003)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>4</strong> (6%)</td>
</tr>
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