Lowrie, Daniel Leslie (2020) ***An examination of the process of role change at end of life in a contemporary, regional Australian context.*** **PhD Thesis, James Cook University.**

https://doi.org/10.25903/513y%2Dr286

AN EXAMINATION OF THE PROCESS OF ROLE CHANGE AT END OF LIFE IN A CONTEMPORARY, REGIONAL AUSTRALIAN CONTEXT

Thesis submitted by

Daniel Leslie Lowrie BHSc (OT), MSc

A thesis submitted in total fulfilment

of the requirements for the degree of

Doctor of Philosophy

Division of Tropical Health and Medicine

College of Medicine and Dentistry

James Cook University

Townsville, Queensland 4811

Australia

January 2020

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

TABLES

FIGURES

ABSTRACT

Dying roles serve important practical, relational and personal functions. However, little is known regarding the process of role change at end of life and/or the way in which it is experienced and shaped by dying people and members of their inner and outer social networks. This is of concern because dying people, nowadays, often live with an awareness of their dying status for longer than was the case in historical times. The development of an improved understanding of role change at end of life is, therefore, of considerable importance if dying people and their caregivers are to be appropriately supported in managing the challenges and opportunities associated with an elongated dying timeline.

This thesis reports on an Australian, constructivist grounded theory study that examined the process of role change at end of life from the perspectives of dying persons, their caregivers and palliative care professionals. Data were gathered through semi-structured interviews with 13 dying persons, eight caregivers of dying persons and five palliative care professionals. Grounded theory methods were used as a framework for analysing study data, with the lenses of symbolic interactionism (in particular dramaturgy) and narrative inquiry also incorporated, in order to support the examination of role enactment throughout the contemporary drama of dying.

The findings of this study revealed that role transitions at end of life do not happen in a fixed manner; instead, they occur as an oscillating process, whereby dying persons periodically foreground and background their living and dying selfhoods. This process of foregrounding and backgrounding serves a protective function necessary to cope with what can be a lengthy dying trajectory. However, it can also result in role confusion and mismatch among dying persons and members of their social network, which can be distressing for all parties. These mismatches happen when one individual attempts to engage in role relations

that bring to the fore the dying status of the dying person at a time when the other party wants to retain a focus on living. Situations of role mismatch were found to occur most frequently in the middle dramatic unit of the drama of dying, largely due to an overreliance on historical social scripts associated with a shorter dying timeline.

The majority of the middle dramatic unit takes place away from health services and professionals, in dying persons' homes and communities. Consequently, the opportunities and challenges associated with dying role enactment and dying role relations experienced during this time are not well understood by health professionals. Because encounters with health professionals typically draw dying persons towards the projection of their dying selfhood, these same professionals may not understand the importance of the living selfhood to dying persons during this time. This means that health professionals may inadvertently compromise a dying person's efforts at foregrounding his or her living selfhood through recommendations or interventions that bring a focus upon dying.

Based on the findings outlined above, a number of recommendations are proposed concerning adaptations to health service design and delivery that may assist dying persons and their caregivers to manage the challenges and opportunities associated with role change at end of life. These recommendations centre on nurturing conditions that accommodate flexibility and adaptability in role enactment and associated role relations. To be successful in implementing such changes, health professionals need to be mindful of their own influence upon the stage, sets and scripts associated with the drama of dying. Doing so will allow them to modify their approach to care and communication at end of life such that it supports dying persons' evolving preferences.

STATEMENT OF ACCESS

I, the undersigned, the author of this thesis, understand that James Cook University will make this thesis available for use within the University Library and Australian Digital Thesis network for use elsewhere.

I understand that, as an unpublished work, a thesis has significant protection under the Copyright Act and; I do not wish to place any further restriction on access to this work.

2nd January 2020

Signature **Date**

Daniel Lowrie

Name

STATEMENT ON SOURCES

I declare that this thesis is my own work and has not been submitted in any other form for another degree or diploma at any university or other institution of tertiary education. Information derived from the published or unpublished work of others has been acknowledged in the text and a list of references is given.

Note:

Every reasonable effort has been made to gain permission and acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

2nd January 2020

Signature **Date**

Daniel Lowrie

Name

STATEMENT ON ELECTRONIC COPY

I, the undersigned , the author of this work, declare that the electronic copy of this thesis provided to the James Cook University Library is an accurate copy of the print thesis submitted, within the limits of the technology available.

2nd January 2020

Signature **Date**

Daniel Lowrie

Name

COPYRIGHT DECLARATION

I, the undersigned, the author of this work, declare that every reasonable effort has been made to gain permission and acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.

2nd January 2020

Signature **Date**

Daniel Lowrie

Name

STATEMENT OF CONTRIBUTION OF OTHERS

Nature of Assistance	**Contribution**	**Names, Titles and Affiliations of Co-Contributors**
Intellectual support	Supervision	Dr Robin Ray was my principal supervisor at James Cook University. Professor David Plummer was my second supervisor at James Cook University Professor Matthew Yau was my third supervisor at James Cook University.
	Study design and data analysis	My supervisory panel (above) provided guidance and support in relation to study design. My supervisory panel also assisted with data analysis by examining my coding, questioning my assumptions and, when appropriate, offering alternative interpretations for me to consider.
	PhD processes and research methods	My supervisory panel (above) guided me in completing key milestone requirements and advised me, as needed, on research methods. I was also fortunate to be a part of the James Cook University PhD cohort program in which additional education was provided in relation to the above. During my time within the cohort program it was led by: Dr Melissa Crowe (James Cook University) Dr Jenni Judd (James Cook University) Dr David MacLaren (James Cook University)

Nature of Assistance	Contribution	Names, Titles and Affiliations of Co-Contributors
		Dr Diana Mendez (James Cook University)
	Editorial assistance	My supervisory panel (names above) gave critical feedback on both the analysis in and construction of my published and unpublished work in this thesis. My father, Rob Lowrie, provided assistance with proof reading of each chapter of this thesis.
Financial support	James Cook University Higher Degree by Research Grant Funding	I received $3000 of funding through the James Cook University College of Medicine and Dentistry, Competitive Grant Fund. I used this funding to pay for data transcription for some of my research interviews and for my thesis to be professionally formatted.
Transcription support	Transcription of research interviews	Jessie Oldfield professionally transcribed all but three of my research interviews.

STATEMENT OF ETHICS

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council (NHMRC) National statement on ethical conduct in human research 2007. The proposed study received ethics approval from the Human Research Ethics Committees of the Townsville Hospital and Health Service (HREC/14/QTHS/196) and James Cook University (H6101).

2nd January 2020

Signature **Date**

Daniel Lowrie

Name

ACKNOWLEDGEMENTS

I have read that, to complete a PhD, one requires tenacity, patience, wisdom and stamina. Although, for me, these qualities remain very much in development, I am fortunate to have had a PhD supervisory panel who possessed them in spades. To Doctor Robin Ray, Professor David Plummer and Professor Matthew Yau, thank you for your incredible guidance. You have taught me to think more deeply and to theorise more sharply. You have blended constructive criticism and pastoral care, demonstrating a degree of patience that I did not always deserve. Thankyou.

I also owe thanks to all of my family and loved ones, only a few of whom I will be able to mention here. Firstly, special thanks are due to my wife, Irelna, and two children, Cora and Alexander, who have always been there for me but for whom I have not been there enough. I know that, for you, the years I have spent completing this study have come at a cost. I promise from now on to spend more time taking you to the park, pushing you on the swings and being all the things a husband and father should be. To my father, Rob Lowrie, chief proofreader and king of all things grammar. Without you this sentence, let alone this thesis, would make much less sense. To my mother, Deb Lowrie, who, through her actions, has taught me the importance of courage, tenacity and kindness. Given my focus on dying within this research, I would also like to make special mention of the people who matter to me, who have died since I commenced the study. Nana, Uncle Peter, Aunty Merle, Dom Palmer and Dom Sharkey and, importantly, to my little girl, Danika, who never quite made it into the world. You are forever in my thoughts.

To my manager, Associate Professor Trish Wielandt, thank you for doing all you could to provide me with the space and time to construct this thesis. To the Townsville

Hospital and Health Service Palliative Care team, especially Alisha Chand and Ellen O'Connor. Without you, this study would never have been completed. Thank you for your never-ending assistance and for allowing me to discuss and refine my thoughts and ideas with you over many years.

Finally, and most importantly, I owe my deepest thanks to the people who have given their precious time to share their thoughts and stories as part of this research. I know that this was sometimes hard but you did so anyway with the aim of making the experience of dying a little less difficult for the next person. I hope I have done your stories justice.

CHAPTER ONE: INTRODUCTION

In recent years there has been a growth in recognition among Australian health service providers of the importance of quality, person-focused, end-of-life care for dying persons, their families and caregivers (Palliative Care Australia, 2018). However, despite this stated commitment, recent data indicate that fewer than half of dying persons' wishes regarding preferred place of death are successfully met, with as little as 20 percent of Australians dying outside of hospital or residential aged care (Australian Institute of Health and Welfare, 2016). Given the ageing population of Australia, if the current pattern of dying in hospital or residential aged care is not addressed, the cost of end-of-life care will rise rapidly (Australian Institute of Health and Welfare, 2016). Supporting dying persons who express a wish to be at home, to remain there for as long as possible appears, therefore, to have both moral and fiscal merit. However, such decisions place significant pressure upon the informal care networks of dying people with many caregivers reporting feelings of being under-prepared and ill-equipped for the caregiver role (Burns, Quinn, Abernethy, & Currow, 2015). It is, perhaps, because of such concerns that Australian National Palliative Care Standards declared a commitment to supporting family and caregivers of dying people through the provision of appropriate support and guidance about their role (Palliative Care Australia, 2018). Critical to the provision of this support will be an improved understanding of end-of-life role relations between dying people and their family / caregivers and of the experience of role change for both dying persons and the caregivers of dying people.

1.1 PERSONAL AND PROFESSIONAL INTEREST IN RESEARCH AREA

My interest in this area of research came about through my professional experience over many years working as an occupational therapist in palliative care. My role as an occupational therapist in this field involved supporting dying people and their caregivers in acute and hospice settings as well as in their homes. This experience afforded me glimpses into a variety of aspects of the different stages and sets on which the drama of dying unfolds. Palliative care occupational therapists aim to promote quality of life for people with life-limiting conditions by assisting them to maintain participation and engagement in valued occupations (Occupational Therapy Australia, 2015). The concept of occupation, as understood by occupational therapists, relates to the wide variety of activities and tasks associated with everyday living that are given meaning and value by individuals and a culture (Canadian Association of Occupational Therapists, 1997). Occupational therapists, therefore, have a particular interest in what people do (occupations) as well as how, why, where, when and with whom these occupations are undertaken (Christiansen & Townsend, 2010).

Over many years of working in cancer care and palliative care settings, I had observed the gradual loss of independence experienced by dying people in relation to activities that give them a sense of purpose and meaning in their lives. I suspected this loss of independence had a corresponding impact on dying people's sense of identity and satisfaction regarding their valued occupational roles, such as mother, husband and worker. I wondered what this loss of identity would be like and thus set out to examine the experience of role loss at end of life. In hindsight, I recognise this as having been somewhat of a naïve starting point, which I had arrived at by privileging my own professional lens. I had assumed that, as dying persons' functional independence declined, they could only experience role loss and such loss should be avoided whenever possible. This stance elevated the importance of my own professional role in working to maintain the independence of dying people as they neared end of life. Although efforts to promote the independence of dying people are, of course, important, I was only seeing a part of the picture. Fortunately, one of my research supervisors quickly recognised this and suggested that I broaden my thinking to consider the process of role *change* at end of life.

This important recommendation opened the door to a broader, richer examination of the end-of-life experiences of both dying people and those who matter to them. Rather than a narrow focus on gradual deterioration and loss, I found myself challenged to examine the process of dying from a wider variety of scholarly perspectives. Doing so shed light on the numerous tensions within the drama of dying that play out as dying people and those around them attempt to negotiate the various challenges, complexities and, indeed, uncertainties relating to the dying process.

I therefore undertook this research study with the aim of furthering the understanding of role change at end of life, particularly in relation to the contemporary regional Australian context in which I live and work. Social roles, such as dying roles, are important in society in that they help in guiding individuals' behaviour in particular social situations and associated social encounters (Turner, 1990). Dying roles, in particular, serve important practical, relational and personal functions for people nearing end of life as well as for their caregivers, families and friends (Emanuel, Bennett, & Richardson, 2007; Noyes & Clancy, 1977). However, despite the potential value of dying roles, they remain under-researched and poorly understood.

Furthermore, the scenes in which dying roles play out have, themselves, evolved markedly over recent decades, potentially altering the suitability of historically-orientated role expectations. Increased emphasis on autonomy and transparency in health care have meant that dying diagnoses are no longer kept hidden from dying persons, as was the case several decades ago. Moreover, improvements in diagnosis and treatment have contributed to dying persons remaining alive for longer, following the recognition of the dying status (Field & Copp, 1999). Such changes mean that, nowadays, dying persons will often live with a dying diagnosis for substantially longer than they did in historical times. Little is known, however, regarding the way in which dying persons, their caregivers and members of their inner and outer social circles manage the challenges and opportunities associated with this protracted dying timeline. The development of an improved, contemporary evidence base concerning both the experiences associated with transitions into the dying role and the experience of dying role relations will, therefore, be of likely value in promoting quality outcomes at end of life.

1.2 RESEARCH AIMS

I commenced my research with the goal of investigating the experience of, and challenges associated with, both the dying role and dying role relations. In doing so, I hoped to enable improvements in the support and care that can be provided to dying people, as well as to their families and caregivers, in negotiating these complex transitions. I thus set out to examine the process of role change at end of life from the perspectives of dying people, their family / caregivers and health professionals working in palliative care settings. To achieve this, I established the following, broad research questions:

- How does the process of role change unfold over time for dying people and their families / caregivers and how do they manage these changes?
- How do role relations between dying people and their family members / caregivers and the health professionals involved in their care influence the experience of dying?

- What factors influence the way in which dying roles are enacted in contemporary regional Australia and how do these factors affect end-of-life experiences?

1.3 LOCAL CONTEXT OF DEATH AND DYING

I completed the study presented in this thesis within the Townsville Hospital and Health Service area in Northern Queensland, Australia. The region served by the Townsville Hospital and Health Service spans approximately 148,000 square kilometers and comprises a resident population of 238,614 people, many of whom live in rural communities (Townsville Hospital and Health Service, 2018). Approximately 7.9 percent of this population identify as Aboriginal and/or Torres Strait Islander and 26.3 percent had one or both parents born overseas, most commonly in England, New Zealand, Italy, Scotland or The Philippines (Australian Bureau of Statistics, 2018). The Townsville Hospital and Health Service offers specialist palliative care inpatient and outreach services for people with life-limiting illness. The service is recognised as a level 5/6 Clinical Services Capability Framework (CSCF) Specialist Palliative Care provider with a multidisciplinary team including dedicated medical, nursing, social work and allied health staff (Queensland Health, 2017).

1.4 DEFINITION OF KEY CONCEPTS AND INFLUENCE ON STUDY SCOPE AND FOCUS

1.4.1 Definition of dying as applied to this study

As will be outlined in detail in Chapter Two of this thesis, considerable conjecture exists in relation to the question of when an individual might be regarded as dying. For the purpose of my research I have examined dying predominantly in terms of illness-related dying and, in particular, among individuals who were aware of their dying status. Given the potentially sensitive nature of the topic of death and dying, ethical approval for this study was granted with the provision that interviews with dying people and/or their caregivers could be undertaken only with individuals who had been formally told of a dying diagnosis by a medical professional. Although these conditions were very important for protecting the wellbeing of participants in the study, they also contributed to a narrowing of the scope of my research to a focus on the types of dying most easily recognised and diagnosed by doctors.

To some extent, this narrowing of scope meant that I was no longer able to explore the experience of what Kellehear (2009, p. 13) describes as “disenfranchised dying” which refers to the forms of dying not well recognised by medical, political and international authorities. Although some study participants did share stories relating to non-illness-related dying (such as death due to old age or suicide), the thoughts that they offered came from their perspectives as individuals describing other people’s dying, rather than from their own, personal dying experience. As a result, the voices of people dying because of old age, dementia or poverty or those who experience a very rapid and unexpected death do not form part of this study.

1.4.2 Roles and role change

Roles are described by Turner (1990, p. 87) as a comprehensive pattern of behaviour and attitudes for coping with a recurrent set of social situations. Social roles function as a guide to assist people in negotiating particular social situations and encounters (Goffman, 1959). Social roles, as performed by different individuals, are usually recognisable and, hence, act as a criterion for identifying and categorising people within groups, organisations and society (Turner, 1990). In addition to this, social roles play a key function in shaping an individual’s sense of personal identity. As such, they form a point of interface between the individual and society (Lynch, 2007). It is important to note that roles are relational in nature. This means that changes to the role status of one individual will have a corresponding impact on role relations and, consequently, on role enactment with those with whom they interact (Mead, 1934; 1972). Therefore, entry into the dying role for a dying person will also influence both the roles of, and role relations with, members of their social circle. Taking this into account, my research has examined the experience of role change from the perspectives of dying people as well as their family and/or caregivers.

Role change refers to the process through which an individual relinquishes a particular role status in order for it to be replaced with a new role status and associated social identity (Turner, 1990). Across the course of their lifespans, individuals will transition into and out of a variety of roles. Role transitions frequently accompany key life milestones such as puberty, coming of age, marriage or retirement. Entry into the dying role represents one of life's final and most important transitions, with the dying role serving practical, relational and personal functions (Emanuel et al., 2007). However, the value placed by both individuals and broader society on the living selfhood can complicate the enactment of dying roles. It is, therefore, the experience of, and challenges associated with, the transition into the dying role that form the focus of this research study.

1.5 SELECTING A RESEARCH METHODOLOGY TO EXAMINE THE PROCESS OF ROLE CHANGE AT END OF LIFE

While the experiences of role enactment and role change at end of life have deeply personal meanings for individuals, they are also shaped by the social, cultural and temporal context in which people live (Belgrave & Charmaz, 2014). Therefore, to achieve my research goal of examining the process of role change at end of life I needed a research methodology that would not only foster a rich understanding of individual experiences but also shed light on the way in which these experiences are constructed and modulated by societal expectations and social interactions. With these requirements in mind, I selected constructivist grounded theory as a guiding framework for the research study. My decision stemmed from Charmaz's (2014) contention that grounded theory is a research methodology that is recognised as being of considerable value in examining social processes. In particular I viewed grounded theory methods as providing me with the tools to analyse the conditions under which dying roles emerge and the way in which meanings and actions concerning dying roles change over time through the interplay between individuals and their contexts.

I chose the specific strand of constructivist grounded theory based on the complexity, variability and evolving nature of role change at end of life. As such, I sought a methodology which acknowledged that my examination of dying roles would be founded on the unique social and temporal context in which the study was undertaken. Furthermore, the adoption of a constructivist stance appealed to me in that it enabled me to recognise my own interpretive processes in constructing theory, as distinct from 'discovering' extant theory that had been otherwise hidden.

1.6 THEORETICAL PERSPECTIVES INFORMING STUDY DESIGN AND ASSOCIATED ANALYSIS

One of the strengths of grounded theory research method is that it affords a degree of flexibility in accommodating the application of additional theoretical lenses that may be of benefit in examining a particular research question. This "methodological eclecticism" allows grounded theorists to utilise approaches to data collection and analysis that are best suited to the process or problem that they are studying (Charmaz, 2014, p. 27). I blended two additional theoretical perspectives with grounded theory methodology to support my study design and associated data collection and analysis processes. These theoretical perspectives are symbolic interactionism (with a particular emphasis on dramaturgy) and narrative inquiry.

1.6.1 Symbolic interactionism and dramaturgy

Symbolic interactionism is a theoretical perspective that researchers often draw on to complement grounded theory studies. With its focus on the way in which social processes occur and evolve over time, symbolic interactionism is epistemologically well-aligned with grounded theory as a methodology (Nayar, 2015). Indeed, Charmaz (2014, p. 20) considers symbolical interactionism to be so closely aligned with grounded theory that she describes the two as a "theory-methods package".

Given the focus of roles and role change in this research, the adoption of a symbolic interactionist perspective was of considerable value in shaping my research design. In undertaking this study, I needed to develop an understanding of the evolution of roles and role relations up to and following a dying diagnosis. Symbolic interactionism offered an excellent guiding framework to support this analysis. Symbolic interactionism stems from the idea that an individual's sense of self is developed through social interactions and experiences (Mead, 1934; 1972). This occurs through a dynamic, interpretive, internal dialogue in which people come to view themselves founded on their perception of the way they believe they are viewed by others and, in turn, their imagined judgement of these others regarding the impression they convey (Cooley, 1902). Moreover, the socially constructed meanings attributed to objects, symbols and processes within the lived world contribute to an individual's understanding of expected role performance (Blumer, 1969). Human behaviour and social roles are thus understood as being shaped by the family, community and society in which an individual lives and as unfolding in relation to the reciprocal roles of others with whom the individual interacts (Blumer, 1969; Mead, 1934; 1972).

Importantly, for my study, the application of symbolic interactionism as an analytical lens helped me to examine the different ways in which role enactment and role relations played out across different social environments depending on the various symbols, cues, people, structures and processes present at that time (Blumer, 1969). Furthermore, it shed light on the fact that these same social structures that modulate dying roles and dying role relations are, themselves, constructed, reproduced (and in some instances altered) as a consequence of human interaction (Charmaz, 2014).

Dramaturgy is a particular strand of symbolic interactionism that utilises the metaphor of the theatre as a means of understanding social processes and human interactions - in this case, those that surround dying. Dramaturgical analysis assumes that, during social interactions, people will conduct themselves like actors on a stage in order to convey particular impressions to those around them (Goffman, 1959). As such, social roles (like those associated with dying) are considered in relation to their function in supporting successful social interactions in everyday life within a particular community or society (Dillon, 2014). I used dramaturgy to help me examine the various scripts, cast members, sets, props and costumes that influenced enactment of dying roles at different times during the drama of dying (Goffman, 1959). Dramaturgy was also useful in analysing key differences in relation to the ways in which dying persons and their caregivers behaved during more tightly scripted "front stage" social interactions compared to the times when they were in private "backstage" settings, hidden from public view (Goffman, 1959, p. 114).

Although I used dramaturgy to enrich the interactional aspects of data analysis throughout the research, its application is most evident in Chapter Six of this thesis, where it has been applied as a framework to examine, in detail, each dramatic unit in the drama of dying.

1.6.2 Narrative Inquiry

Narrative inquiry examines experiences, milestone events, key characters and chronology (Creswell, 2013; Thomas, 2012). I used this lens to help me make sense of major points of change in participants' lives and the way in which key people around them shaped their experience of these events. Using narrative inquiry as an analytical lens assisted in examining key events and milestones in participants' lives, such as first presentation of symptoms, receipt of a dying diagnosis, giving up work, transition to palliative care and special family events. Narrative inquiry also assisted in understanding the timeframe and sequencing of these key experiences; the physical, cultural and institutional contexts in which the experiences took place; as well as the way in which the experiences were shaped by interactions and relations with other actors. As an example of this, the differences in the way in which dying persons described their time spent in hospitals and/or other healthcare settings as compared to home, offered insights into how these different contexts influence dying role enactment and associated dying role relations.

1.7 THESIS STRUCTURE

1.7.1 Overall structure

In keeping with the expected methodology of grounded theory research, the analytical procedures in this study were iterative rather than linear and, as such, the focal points for each chapter in this thesis are derived from the findings of the preceding work. This meant that I did not set out with pre-established research phases and/or chapter topics. Instead, upon completion of a portion of my analysis I would pause and reflect on my findings and ask myself what part of the picture needed to be examined next. I would then revisit my data and/or gather new data to gain insights into aspects of role change at end of life that I did not yet understand. This flexible approach to data collection prevented me from trying to force data into pre-existing schema and, consequently, assisted me in constructing an authentic account of the insights and experiences of participants. However, it has also resulted in a degree of necessary conceptual overlap between some of the findings chapters in this thesis. For example, Chapter Six was developed based on residual questions stemming from categories presented in Chapters Four and Five. This means that, to some extent, the findings presented in the latter chapters of this thesis do not serve as stand-alone analyses. Instead, they offer a progression of the analyses outlined in the preceding findings chapters.

Although I commenced my PhD journey with the intention of producing a grand theory or all-encompassing conceptual framework that explains role change at end of life, I make no claim to having done so. As the research evolved, I became increasingly aware that this is not possible, given the complexity and diversity of the experiences of participants. Instead, I have carefully examined dying as a dynamic, layered and nuanced process and shed light on a number of elements of this process that were otherwise under-examined in the academic literature. This is not to say that my research lacks either theoretical or clinical importance; rather it emphasises the multi-faceted and variable nature of the end-of-life experience. My learning through undertaking this research has highlighted for me that it is only in acknowledging this complexity that responsive, meaningful and person-focused support for dying people and their caregivers becomes possible.

1.7.2 Overview of thesis chapters and content

Chapter One (this chapter) offers an overview of the thesis as a whole. It outlines my motivation for undertaking the study and details the background and context of my research. It also outlines the research aims and explains the way in which I have applied the theoretical lenses of symbolic interactionism (in particular, dramaturgy) and narrative inquiry to addresses these aims. The chapter concludes with a summary and overview of thesis content and structure.

Chapter Two examines the literature regarding dying and dying roles from the perspectives of philosophy, history and sociology. It details the existing evidence base concerning contemporary dying roles and highlights key gaps in the current state of knowledge.

Publication

Lowrie, D., Ray, R., Plummer, D., & Yau, M. (2018). Exploring the contemporary stage and scripts for the enactment of dying roles: A narrative review of the literature. *OMEGA-Journal of Death and Dying, 76*(4), 328-350. doi:10.1177/0030222817696541

Chapter Three explains the constructivist grounded theory methodology and associated processes for data collection and analysis undertaken in this study. Chapter Three concludes with an overview of the processes built into the research design to promote analytical rigour and maintain ethical conduct.

Chapter Four presents the first of three findings chapters related to this research. This chapter examines the way in which dying people transition from living to dying roles when presented with a dying diagnosis. It highlights the challenges associated with the enactment of dying roles in the face of prognostic uncertainty and an elongated dying timeline. It further argues that dying people periodically foreground and background their living and dying selfhood as a means of managing these challenges.

Publication

Lowrie, D., Ray, R., Plummer, D., & Yau, M. (2019a). Examining the transitions between living and dying roles at end-of-life. *Death Studies, 43*(10), 601-610. doi:10.1080/07481187.2018.1504836

Chapter Five focuses on role relations at end of life among dying persons and their family / caregivers. This chapter examines situations of role alignment and role mismatch between dying people and members of their social networks and explores the reasons why mismatches in role relations often occur. It argues that very positive outcomes can occur for all parties when role relations are well aligned whereas mismatched role relations can result in considerable distress.

Publication

Lowrie, D., Ray, R., Plummer, D., & Yau, M. (2019b). Alignment and mismatch in role relations at end-of-life: A constructivist grounded theory study. *Death Studies*, 1-10. doi:10.1080/07481187.2019.1648330

Chapter Six explores the enactment of dying roles through a dramaturgical lens. It draws on the perspectives of dying people, their family / caregivers and the health professionals who care for them by examining the way in which the drama of dying unfolds over time. In doing so, this chapter highlights the influence of various cast members, scripts, sets and props in shaping the process and experience of dying role enactment across the drama of dying.

Chapter Seven summarises my study findings and examines the implications of my research for palliative and end-of-life care. It also analyses the important function that public health initiatives such as the Compassionate Communities and Death Awareness Movements could play in promoting positive role relations between dying persons and members of their social networks. It then discusses the way in which my finding can be used to inform education, palliative care practice design and delivery as well as future research. Specific recommendations are provided concerning changes to practice and education that have the potential to improve the quality of care to dying persons as well as their families and friends.

CHAPTER TWO: EXPLORING THE CONTEMPORARY STAGE AND SCRIPTS FOR THE ENACTMENT OF DYING ROLES. A NARRATIVE REVIEW OF THE LITERATURE.

Prior to commencing this research, it was critical for me firstly to develop a solid understanding of the current state of knowledge concerning roles and role change at end of life. I wanted to ensure that my examination of the literature extended my understanding of dying roles beyond the clinically-focused perspective that I was accustomed to through my professional role in palliative care. Therefore, literature was sought that offered insights into death, dying and dying roles from the perspectives of philosophy, history, anthropology and sociology. This broad base of literature challenged many of my taken-for-granted, clinically-orientated assumptions about the end of life by shedding light on the social construction of dying roles and social control over the process of dying.

The above-mentioned literature was used in constructing a narrative review that explored the contemporary stage and scripts that shape the enactment of dying roles. The paper was published in OMEGA – Journal of Death and Dying in 2018. The first published page of the article is included in Appendix 1. The article in its entirety is presented here as Chapter Two of this thesis. Minor modifications to the formatting of this journal article have been made in this chapter to maintain consistency with thesis presentation. These changes include the introduction of numbers for sub-headings, renaming of Appendix 1 of the published article to Table 1 in this thesis and alteration of the spelling of some words to align with Australian English. The remainder of the written text of the article has been reproduced word-for-word.

Exploring the contemporary stage and scripts for the enactment of dying roles. A narrative review of the literature

Daniel Lowrie BHSc (OT), MSc

Lecturer and PhD Candidate. College of Healthcare Sciences, James Cook University, Townsville, Australia.

Robin A. Ray BEd, MHSc, PhD

Associate Dean, Research Education. College of Medicine and Dentistry, Anton Breinl Research Centre for Health Systems Strengthening. James Cook University, Townsville, Australia.

David Plummer AM, MB, BS, PhD

Adjunct Professor. College of Medicine and Dentistry, James Cook University, Townsville, Australia.

Matthew Yau BAppSc, MCom, MSc (Hons), PhD, OTR, CST

Head and Professor. Department of Rehabilitation and Social Sciences, Tung Wah College, Kowloon, Hong Kong.

Published - March 2018

OMEGA - Journal of Death and Dying, 76(4), 328-350. doi: 10.1177/0030222817696541

Keywords

Dying roles, death, dying, role change, palliative care.

2.1 ABSTRACT

This narrative review explores the literature regarding the drama of dying from several academic perspectives. Three key themes were identified including: *'The impact of blurred boundaries on roles and transitions'*, *'The orchestration of death and dying through time'* and *'Contemporary dying and new machinery of control'*. The review reveals the manner in which tightly scripted dying roles serve the needs of the living to a greater extent than those of the dying, by ensuring the depiction of both dying and death as phenomena which have been brought under the control of the living, thereby countering death anxiety. An incongruence between the actual experience of dying and contemporary dying scripts is also highlighted. The authors argue that this incongruence is hidden from the broader societal audience through the maintenance of a dying role that demands serenity and acceptance, thus downplaying or even hiding the actual end-of-life experiences of the dying themselves.

2.2 BACKGROUND – ROLES AND ROLE CHANGE AT END OF LIFE

Roles serve an important function within society by offering a set of norms to guide people's behaviours and attitudes in particular social situations (Turner, 1990). Roles also contribute significantly to an individual's sense of personal identity and, in doing so, act as a key juncture between an individual and the society in which he or she lives (Lynch, 2007). Role performance is not shaped by individuals in isolation; rather, it is an interactive and negotiated process between various actors (Lynch, 2007; Turner, 1956). During the course of their lives, individuals will transition into and out of a variety of roles. Role transitions frequently accompany key life milestones (such as puberty, marriage or retirement) and will be marked by a variety of rituals and symbols to indicate the perishing of an old self and subsequent birth of the new (van Gennep, 1909/1960). Role change thus serves as a powerful mechanism of social control by ensuring the transition from one set of social scripts to another. Role change at end of life acts in the same way by enabling the relinquishment of a previous social status and the emergence into a new role for dying people and those around them. In a sense, the 'pronouncement' and subsequent social recognition of dying (and, at a later stage, death) trigger the orchestration of sequential acts in a broader drama of dying (Goffman, 1959).

The drama of dying represents life's final act. Knowledge of this drama, therefore, might reasonably be regarded as critically important. Useful insights have been offered in research by Parker-Oliver (2000) who presented a dramaturgical analysis of hospice care in directing the transition from the 'sick role' to the 'dying role' for people approaching end of life. The findings of this study outline the key entry points, scenes, scripts and props that accompany dying and highlight the important function of the hospice community in facilitating the enactment of the dying role. More recently, Emanuel, Bennett, and Richardson (2007) examined the dying role from the perspective of role theory. They describe the dying role as having practical, relational and personal elements that, while interactive in nature, are in essence distinguishable from each other. The analyses within both of these papers consist of a fusion of the literature regarding role enactment and palliative care, framed in the context of the authors' clinical experience. It is noteworthy that both also emphasise the centrality of health professionals in nurturing an awareness of the dying role among individuals nearing end of life.

This narrative review of the literature builds on these existing perspectives regarding the stage and scripts that shape contemporary dying roles by exploring the published literature across a broad variety of academic fields. In doing so, it offers new insights into numerous factors that influence the enactment of the drama of dying and, in turn, the experience of dying for both people approaching end of life and those around them.

2.3 APPROACH TO SEARCHING THE LITERATURE

The research team undertook a literature search using Medline, CINAHL, PsychInfo and Scopus databases. Keywords were used to identify literature which addressed the concepts of “roles”, “experience” or “change” and “death”, “dying” or “palliative care”. The specific search terms were expanded and customised for each database using Medical Subject Headings (MeSH) (Medline), ‘Suggest Search Terms’ (CINAHL) and ‘thesaurus’ (PsychInfo). Scopus was searched using the combination of search terms identified from each of the other databases. A detailed breakdown of specific search terms and number of hits retrieved within each database is included within Table 1 (at the end of this chapter).

A total of 5170 articles were identified. The principal researcher (first author) initially screened these articles based on their titles and abstracts (and removed duplicate articles). From this first screening process 180 articles were flagged by the principal researcher as potentially relevant and full-text copies sourced. The principal researcher then undertook a more detailed appraisal of the remaining papers in order to identify articles of particular pertinence to the topic. Articles were included if they focused on the experience or understanding of dying or specifically addressed dying roles. Non-English language articles and articles which focused on only one aspect of dying (such as symptom management) were excluded. No limits were placed on date of publication. Following this secondary screening process, a total of 33 articles were found to be relevant for inclusion in the narrative review.

Weekly alerts were set up for each of the above database searches to ensure that the examination of the literature remained current. As well as this, additional references (including seminal textbooks) were sourced by the principal researcher through reference mining and the use of the 'cited by' function for key articles. This process was continued until no new relevant references were identified. Through these additional processes a further 45 sources of literature were added. The combined total of 78 sources of literature form the basis of the construction and analysis of the key themes within this narrative review paper.

While the search has been undertaken in a systematic manner, the use of a framework such as PRISMA to structure the review was not considered suitable. This is because the research question is exploratory in nature and will not, therefore, generate items of evidence that can be compiled and compared. Instead, the goal is to examine a wide range of literature from several academic fields in order to develop a broad understanding of the drama of dying within contemporary society. Identification of key themes within this narrative review occurred iteratively and involved the principal researcher engaging in a preliminary reading of each literature source to examine the key ideas within it, with subsequent readings undertaken in order to evaluate the implications of these ideas, specifically in relation to the context of dying roles. Themes were initially identified by the principal researcher and then refined over several meetings of all members of the research team. This process helped to promote analytical rigour and ensure that relevance to the central topic of dying roles was maintained. In undertaking the steps described above, three broad themes were identified by the research team, namely: *'The impact of blurred boundaries on roles and transitions'*, *'The orchestration of death and dying through time'* and *'Contemporary dying and new machinery of control'*. Each of these themes forms a section of this narrative review.

2.4 THE IMPACT OF BLURRED BOUNDARIES ON ROLE TRANSITIONS

2.4.1 Living, dying and death

In order for the recognition and subsequent enactment of dying roles to occur, recognisable boundaries demarcating living, dying and death are required. While, at face value, the recognition of both dying and death may appear conceptually straight-forward, in many circumstances there is ambiguity regarding their timing and nature. For example, debate exists as to whether an irreversible coma with absent brain stem reflexes constitutes death or whether death should, instead, be defined as the complete loss of critical functions of a body (Beecher, Adams, & Barger, 1984; Bruno, Ledoux, & Laureys, 2009). The advent of new technologies to artificially extend life or initiate brain repair serve to further complicate this picture, (Hart, Sainsbury, & Short, 1998) foregrounding a philosophical dimension to what might otherwise be perceived as a biomedical debate (Bruno et al., 2009).

The boundaries separating the worlds of the living and the dead become further blurred when viewed from a social perspective. Howarth (2000) provides the example of the social death of an elderly woman with senile dementia who is no longer recognisable to her loved ones, having long since lost the roles and relationships that shaped her identity. While biologically alive, this woman may already be considered deceased from the perspective of her loved ones, existing in a state of extended liminality in which she is neither socially alive nor physically dead. Conversely, Howarth (2000) describes numerous situations in which individuals may be considered biologically dead but kept socially alive by others. For example, it is very common for people to engage in conversations with deceased loved ones or to nurture their ongoing biographies through celebrations of key milestones, anniversaries, birthdays and ‘deathdays’ or to maintain shrines or memorials for persons who have died (Howarth, 2000).

Given the degree of ambiguity surrounding the nature of death, it is perhaps not surprising that the construct of dying also lacks conceptual clarity. This is because dying, like death, is not only a medical phenomenon but also an existential, psychological and social experience (Kellehear, 2009a). At its heart, therefore, debate around both the timing and nature of dying is one that is philosophical in nature and reflective of the multiple significances attributed to different forms of dying. An examination of the different facets of this debate is critical to understanding role change among the dying since it exposes the manner in which different perspectives can influence beliefs as to who can be regarded as dying and how dying is thought to occur.

A useful starting point is to note that dying and living need not be mutually exclusive states, nor is dying the opposite of living. For example, logic seems to suggest that it is necessary for a dying person to be alive; otherwise, they are not dying, but dead (Scarre, 2009). Certainly, the ethos of the palliative care movement emphasises the principle of living well while dying, pointing to a conceptual understanding of living and dying as overlapping states of being (Palliative Care Australia, 2005; World Health Organisation, 2007). Further to this, there are some who argue that, given the inevitability of death, all people are, in fact, dying from the day they are born (Bowman, 1965), while others contend organisms undergo a significant period of maturing before they would normally be considered to be in a state of dying (Scarre, 2009).

Such points of theoretical division are very important and largely unexplored when considered in the context of dying roles, particularly with regard to status changes. If dying is simply considered to be a state in which individuals are cognisant of their own mortality, then many of the functions and behaviours surrounding dying roles should be observable in people for whom no formal ‘pronouncement’ of dying has been offered. In essence, therefore, strong similarities between core functions of ‘living roles’ and ‘dying roles’ would be present. If this were to be the case then, as death draws nearer, individuals would experience an escalation (and in some cases an enrichment) of key aspects of what is an already familiar dying role rather than a transition into an entirely new status. However, if entry to the dying role represents the transition of a dying person into a new and unfamiliar status, then the emphasis on the point at which dying is recognised, as well as the rites of passage, functions and experience of the dying role, take on a different significance.

A further possibility is that dying may not be a status in its own right; rather, it represents the liminal phase between the statuses of living and dead (Froggatt, 1997; Seale, 1998). Turner (1974), building on the earlier work of anthropologist Arnold van Gennep (1909/1960), described the rites of separation and symbolic behaviours that accompany the liminal phase between an individual's separation from one status and eventual incorporation into another. According to Turner (1974), within this liminal phase, the person undergoing a status transition will be cut off from wider societal structures, entering into a realm in which normal social rules and hierarchies do not exist. As such, an 'anti-structure' will be created, offering a sacred space within which transitions can occur (Turner, 1974). In her examination of the rites of passage within hospice culture, Froggatt (1997) likens hospice care to the institutional embodiment of liminal space in which status transitions occur, pointing to elements of the hospice environment that allow the withdrawal from normal modes of social action and support the negotiation of the boundaries between life and death.

2.4.2 Managing boundaries – the declaration of dying and death

The potential for ambiguity arising from the lack of an obvious point in time in which dying may be regarded to have commenced is, to a large extent, overcome by one of the key actors in the drama of dying, this being the person who pronounces dying. In recent times this role has been predominantly enacted by medical professionals or (in the case of state executions) judges. These actors are responsible for setting in motion the opening act in the drama of dying through a declaration that death is near and, in doing so, authorising the transition into a new social status of ‘a dying person’. Once this occurs, social systems will organise around this new status and orchestrate the process.

The need for such actors lays bare the social sanctioning of dying, thus adding weight to the argument that particular forms of dying are considered more legitimate than others (Kellehear, 2009b) depending on the prevailing values and beliefs particular to the culture (and time) in which they occur (Seale, 1998). Consequently, understandings of dying become filtered through a specific, but limited, lens which, in turn, exerts a powerful influence in shaping health policy, clinical practice, research and public perception (Kellehear, 2009b). This narrowed perspective serves a valued (although arguably unhelpful) societal function in shaping a public perception of death and dying as phenomena that are both predicable and manageable and thus under the control of the living.

The consequence of such a narrowed perspective is the creation of a dying underclass to whom a socially sanctioned status of dying is rarely afforded on the basis that it is not easily recognised and / or controlled by medical professionals. In recent times, this dying underclass has been composed of people who experience less predictable, non-linear or non-illness related dying processes as a result of causes such as old age, dementia, poverty, homelessness and suicide (Hayslip, 2003). Individuals among these groups may not experience dying roles due to a lack of awareness and acceptance of dying among both themselves and those around them (Field, 1996). Unsurprisingly, perhaps, very little is known about the experience of role change in people who undergo these socially marginalised forms of dying. For such individuals, established models for understanding role transitions which emphasise clear boundaries and permanent, socially sanctioned status changes such as that of van Gennep (1909/1960), may not be easily applied.

2.5 THE ORCHESTRATION OF DEATH AND DYING THROUGH TIME

Experiences of death and dying today reflect processes that have developed over thousands of years, evolving in step with cultural and social norms of the time (Kellehear, 2007b). These cultural and social norms have exerted a powerful influence over elements of the dying process such as the location and setting of death as well as the expected roles, responsibilities and associated behaviours of both people who are dying and those around them (Elias, 1985; Walter, 1994). Analyses of death and dying through history, therefore, provide a useful background for examining modern practices by shedding light on a dying process that, while constantly evolving, has remained socially constructed and controlled since the dawn of humanity.

2.5.1 Dying roles among early humans

In his *"A Social History of the Dying"* Kellehear (2007b) argues that the ceremonial burial practices of early humans approximately 30,000 to 50,000 years ago, such as the elaborate dressing of the deceased and the provision of grave goods, point to a belief in a post-death 'dying journey' for which such valuable commodities would be essential if it were to be undertaken successfully. Kellehear's (2007b) analysis is an important one as it offers the earliest clear example of the social construction of both dying and dying roles among early humans. For these people, knowledge of and beliefs concerning dying would have been shaped almost entirely through their participation in the post-death rites of passage provided to other social group members who had died before them. In witnessing these rituals, they would have developed an understanding of dying as a process that is both reliant on and controllable by the efforts of the social group surrounding the dying individual. Furthermore, these ceremonies will have also served a social function by formalising a point of role relinquishment by the deceased, thus allowing others to fill the role void he or she leaves behind (Walter, 2003). The role of the dying, therefore, becomes somewhat secondary to the roles of those around them in order to maintain the stability of social structures needed by the living. In essence, this marks the beginning of a socially sanctioned dying process, both controlled by and serving the interests of the living, which has been repeated throughout history.

2.5.2 Pre-modern dying roles

It is through this lens of socially sanctioned dying that a tension between the notions of autonomy and familiarity associated with the 'tamed' deaths of medieval times, famously proposed by French historian Phillippe Aries (1974, 1981), becomes apparent. While, at least at face value, the more central role of individuals with regard to the processes surrounding their own dying would seem to point to greater autonomy, realistically the choices that were afforded to the dying individual will have been shaped and sanctioned according to the familiar prevailing social norms of the time. For example, during the period of time that formed the basis of Aries' (1974, 1981) pre-modern analysis, socially approved dying scripts within Western societies reflected the dominance of the Christian church. A morally good death was thus one which was Christ-like in nature and, as such, social expectations were that the dying individual would avoid temptations such as despair, loss of faith or spiritual pride (Walters, 2004). Steps to ensure the achievement of a morally good death went as far as the creation of illustrated scripts for dying known as the '*ars moriendi*' (the art of dying) that were developed to guide the dying person and those around them towards the accomplishment of a saintly death by avoiding any behaviours that might steer him or her from this path (Gittings, 2009).

2.5.3 Modern dying roles

The rise of the natural sciences and medical positivism and the subsequent relegation of religion, philosophy and humanism during the 18th century ushered in new key actors and significantly altered scripts in the drama of dying. During this time, powerful professional groups, particularly medicine, established control over the dying process (Hart et al., 1998). Given the focus of biomedicine on curing illness, dying came to be framed as problematic and, therefore, control over dying centred on death prevention (or more realistically, postponement). This paved the way for the engineering of death and dying into a secularised, technical and depersonalised affair that was managed by professional and bureaucratic institutions, shrouded from the view of the majority of the population and, indeed, often hidden from the dying themselves (Glaser & Strauss, 1965, 1968).

Many argue that the hidden, lonely and impersonal nature of modern dying was clearly exemplified by the way in which dying people were managed both prior to and after death. Concerns surrounding the medicalisation of dying were brought to popular attention by Elizabeth Kubler-Ross (1969) who bemoaned modern dying as having become *"gruesome, lonely, dehumanised and mechanical"* (Kubler-Ross, 1969, p. 6). Others point to the relocation of the elderly and the dying to nursing homes and hospices as a social mechanism to assist in removing thoughts of death and the dying from public consciousness (Stephenson, 1985). Elias (1985, p. 23) highlights the *"screening off"* of the dying from others (particularly children), describing a sense of embarrassment experienced by the living when in the presence of dying people. Processes such as these resulted in dying people finding themselves bit-part players at best or, at worst, roleless in the narrative of their own death.

2.6 CONTEMPORARY DYING AND NEW MACHINERY OF CONTROL

The emergence and subsequent growth of the modern hospice movement since the late 1960s, the increasing focus on death in films, plays and novels and the debate around euthanasia have all contributed to a gradual rekindling of public discourse of death (Doka, 2003; Walters, 2004). It should be noted, however, that 'the revival of death', as described by Walter (1994) really refers only to illness-related death, while almost all other forms of death remain hidden and unrecognised (Field, 1996; Kellehear, 2009b). Regardless, death is no longer the taboo subject that it once was (Bingley et al., 2006; Seale, 1998; Walters, 2004). Furthermore, the rise of individualism and the perceived right to autonomy as a moral prerogative within Western society have resulted in challenges to established medical hegemony, bringing openness about diagnosis, prognosis and patient choice to the forefront of care (Field, 1996; Seale, 1998). At face value at least, these changes would point to a renewed and more self-directed role for the dying individual in relation to his or her own death. However, as has been the case throughout history, new mechanisms of control significantly curtail the scope in which the dying roles of dying people and their families can be enacted.

2.6.1 The rise of palliative care

The availability and provision of palliative care services are often highlighted as serving a critical function in ensuring quality end-of-life care. Good, contemporary evidence exists, demonstrating the benefits of palliative care services in improving patient quality of life (Higginson, Costantini, Silber, Burman, & Edmonds, 2011; Lyons & Bakitas, 2009; Temel et al., 2010; Zimmermann et al., 2013). Palliative care services include among their stated aims a commitment to patient (and family) centredness, recognition of individual uniqueness and delivery of collaborative, holistic care, all of which, at least theoretically, should foster an approach to dying that is markedly more open, personalised and humanistic than that of the modern era (Dahlin, 2013; Palliative Care Australia, 2005; World Health Organisation, 2007). Recent survey data of the attitudes of 47 internal medicine doctors and 39 hospice nurses would seem to support this position, with 100 percent of respondents indicating a belief that hospice care gives patients some autonomy and 95 percent agreeing that it provides patients with a sense of control (Bakanic, Singleton, & Dickinson, 2016).

The rise and growth of palliative care has not, however, been without its critics. Numerous authors have pointed to an entrenched state of bureaucratization within hospices as contributing to considerable homogeneity and routinisation in the design and delivery of palliative care services, consequently compromising the implementation of individualised care (Floriani & Schramm, 2012; James & Field, 1992; McGrath et al., 2005; Seale, 1998).

The expanded scope and medicalisation of palliative care has also been a source of some criticism. As early as two decades ago, Walter (1994) asserted that palliative care had metamorphosed into little more than a façade behind which modern medical practice continued to control the dying process, under the auspices of an ‘imagined tradition’ of holistic, person-focussed, non-hierarchical care. Walter (1994) argued that this change was clearly observable through the rise of the medical sub-specialty of palliative medicine and consequent subjugation of other professions and lay workers within palliative care. He further suggested that this transition had brought with it an increased emphasis on pharmacological symptom control, replacing the historical focus on the act of caring for the dying, which once was regarded as the hallmark of the hospice movement. Recent literature, arguing for the expansion of palliative medicine, does certainly place emphasis on the importance of symptom management, not just at end of life, but throughout the illness trajectory. It should be noted, though, that other elements of care, such as support with decision-making and future planning, quality of communication and spiritual assessment are also detailed as being key to the delivery of effective palliative care (Hughes & Smith, 2014; Strand, Mansel, & Swetz, 2014).

It is, perhaps, because of this broadened focus that doctors within palliative care settings might (somewhat paradoxically) also find themselves prone to the well-established critique as to whether a more holistic approach within medicine results in an extension of the profession's sphere of control beyond that of individuals' physical bodies, to also encompass the way that they think, feel and behave (Armstrong, 1986; Illich, 1975). Of course, such criticisms do, to some extent, leave palliative care physicians in the unenviable position in which they are open to criticism of medical imperialism if they attempt to engage in more holistic care or medical reductionism if they do not.

When considered in the context of dying roles, however, these observations do point to a broadening of medical (and institutional) control over what were once personal elements of the dying process. Furthermore, they are suggestive of a propensity (albeit well-intentioned) among palliative care professionals to emphasise the centrality of their service in ensuring the successful enactment of dying roles (Emanuel et al., 2007; Parker-Oliver, 2000). While such positions are not necessarily problematic (and might often be helpful), they do bring with them the risk of obscuring the strengths and expertise that patients and their informal care networks might already possess in the management of their own needs (Hughes, 2015).

2.6.2 The 'good death' and the 'good patient'

'The good death' according to Kellehear (2007b, p. 90) is one which *"conforms to the wider community expectation of making death as positive and meaningful as possible to as many people as possible."* This definition acknowledges the powerful influence that societal norms and expectations have in shaping and framing preferences and beliefs around the dying process. While death may be personally experienced by the dying person, the meanings and associated practices surrounding death are, in essence, a product of society. As such, health professionals, family members and the broader community all exert a powerful influence in the construction of what may be regarded as ‘good’ and conversely ‘bad’ deaths (Kellehear, 2007b; McNamara, 2004). There is now a large body of published literature stemming from a variety of health professions either directly or indirectly addressing the concept of, or strategies for, the achievement of ‘the good death’(Granda-Cameron & Houldin, 2012). This is, perhaps, reflective of a perception among health professions regarding their critical role in enabling a positive dying experience and arguably evidence of their efforts to ‘own’ aspects of it. Whatever the intention behind this strong interest in defining and fostering ‘the good death’, such efforts bring with them the risk of nurturing a professionally dominated approach to the management of dying. Furthermore, if not managed well, the large number of professionals vying for a centre stage position in one or more acts of the drama of dying runs the unintended, but not insignificant, risk of fostering role confusion and diminishment for the dying person and his or her loved ones.

As cultural understandings of death and dying have evolved over time, so too have contemporary beliefs and practices concerning what constitutes the good death. In their review of the literature regarding ‘the good death’, Proulx & Jacelon (2004, p. 118) identified a number of common themes including: death with dignity, peacefulness, physical comfort, autonomy, preparedness, connectedness with loved ones, awareness, discretion, meaning and acceptance. Almost all of these themes have in common a requirement for the dying individuals to be both accepting of and at peace with their dying in order for the good death to be achieved. This observation is further evidenced by the findings of Zimmermann (2012) whose recent discourse analysis of palliative care literature found that ‘acceptance’ of dying was regarded as a necessary precursor to effective contemporary end-of-life care.

Zimmermann (2012) highlights that, while acceptance of death is welcomed by health workers, perceived denial of death will be met with professional resistance and offers of psychological assistance.

While, at face value, the serene acceptance of death may seem to be in the best interests of both individuals who are dying and their loved ones, critics point to concerns regarding the influence of such strong ideological beliefs in acting as a mechanism of social control. They argue that ‘good deaths’ are typically those which are judged to be socially desirable by the professional caregivers of the dying and that deaths that occur outside of these professionally derived norms are considered problematic (Hart et al., 1998; McNamara, Waddell, & Colvin, 1994). Patients who adhere to the parameters of ‘the good death’ are considered ‘good patients’ but those who do not are labelled as being at risk of a ‘bad death’ and will be gently cajoled into beliefs and behaviours that are compliant with the good death model (Hart et al., 1998; Li, 2004; Li & Arber, 2006). The result of this is the construction of a dying process that is reliant on new biomedical technologies and specialist professional input, thus further reinforcing professional power (Hart et al., 1998; Kellehear, 2007a; McNamara et al., 1994; Timmermans, 2005). In essence, the ideology of ‘the good death’ serves as a new form of social control over dying people, constraining their choices and tightly scripting the nature of their dying (Hart et al., 1998). It is, perhaps, in response to this that an increasing number of academics and clinicians have made calls for greater flexibility in any interpretation of the good death (Hardy & Good, 2014; Scarre, 2012; Walters, 2004).

Considered in the context of role change, the social value placed upon the attainment of a ‘good death’ places powerful pressure upon the dying to swiftly and effortlessly transition to normalised expectations and behaviours associated with the dying role. For many, these expectations will be in stark contrast to the social expectations surrounding the illness roles which they had until recently held (Parker-Oliver, 2000). The discourse of illness has long been recognised as being laden with war metaphors framing social expectations of the illness role as one in which an individual must fight and battle against the enemy that is their disease (Sontag, 1979). However, once doctors determine this battle has been lost, an expectation then falls upon the dying individual to relinquish their soldier-like characteristics and adopt, instead, a veneer of calm acceptance of the approach of their death. Those who resist this new identity may find themselves labelled as 'bad patients' at risk of a 'bad death' and thus be coaxed and encouraged to play the role expected of them.

2.6.3 The 'good death' and the 'good carer'

Idealised conceptualisations of the good death can also place significant pressure upon informal carers of the dying (such as family members and friends), particularly in relation to popular notions that the good death ought to occur at home (Pollock, 2015). Research suggests that up to two-thirds of the general public identify home as their preferred place of death (Higginson & Sen-Gupta, 2000; Leadbeater & Garber, 2010) and approximately 80 percent of patients who have never been admitted to a hospice wish to die at home (Arnold, Finucane, & Oxenham, 2015). Such beliefs, while not unreasonable, can result in a strong sense of obligation upon family members and friends of the dying to support a home death. The enactment of these unfamiliar caring roles can result in considerable emotional, physical (and sometimes financial) burden on both the carer and the dying individual, particularly if the process of dying proves lengthy or is accompanied by issues such as intractable pain (Pollock, 2015). It is unsurprising, therefore, that there are increasing calls for preferred place of death to be revisited on an ongoing basis as patients near end of life, so as to ensure that changing preferences are acknowledged and (where possible) acted on (Arnold et al., 2015; Pollock, 2015).

2.6.4 Contemporary cultural scripts for death and dying

Societal discourse serves a powerful and pervasive function in constructing contemporary understandings of what can be considered 'normal' end-of-life roles and thus in shaping the cultural scripts through which these roles are played out. One particularly powerful form of discourse is metaphor. Metaphor describes the process through which people talk and think about one thing in terms of something else. Doing so serves as a lens through which we can mediate what is known and what is not known, thus shaping our conscious and unconscious understanding of the world in which we live (Ritchie, 2013). Metaphors surrounding dying and death tend to fall into one of two broad categories. The first of these categories conveys images of struggle and heroism and the second attempts to soften and even nullify death. Both sets of metaphors act to serve the interests of the living by supporting them in denying the impact of death.

Metaphors equating the dying process to a heroic struggle are well documented in academic literature and are clearly observable both within the modern media and general parlance. The seminal work of Susan Sontag (1979) revealed the prevalence of war metaphors in relation to cancer. Words such as ‘battle’, ‘fight’, ‘bombard’ or ‘eradicate’ were noted as having a strong influence in shaping understandings of the disease and its management. Several other researchers report a similar propensity towards the use of military metaphor in cancer treatment, highlighting concerns that such language promotes the masculinised and paternalistic management of the disease at the expense of a focus on alternative illness experiences (Byrne, 2008; Lupton, 1994; Penson, Schapira, Daniels, Chabner, & Lynch, 2004). Seale (2001) extends this picture to include metaphors reflective of sporting struggle in relation to cancer. However, he challenges suggestions that ‘struggle language’ is universally problematic in cancer discourse, arguing that stories of struggle, triumph and personal growth (even in defeat) can have a positive influence on the illness experience.

It is important to note that the vast majority of the ‘heroic struggle metaphors’ focus on efforts to overcome a disease. It is unusual for them to be used to describe the process of dying (i.e. ‘heroic dying’), until the actual point of death at which stage an individual will be noted to have ‘lost his or her battle’. As such they are, to a large extent, being used to describe what Parsons (1951) labelled the ‘sick role’ since these metaphors relate to efforts to curtail death, rather than the phenomena of death or dying per se. To this end, they serve the interests of the living by depicting death as something that can and should be avoided. In doing so, this type of metaphor clouds the distinction between sick and dying roles by framing the role of the dying person as resisting death at all costs.

The second major cluster of dying metaphors encompasses those that act to soften, negate or hide death and dying. Phrases such as ‘passed away’, ‘deceased’ and ‘expired’ all serve this purpose by fostering a picture of death as being peaceful and calm (Durkin, 2003; Hayslip, 2003). ‘Journey’ metaphors that are often employed to describe illness and dying have rich, positive connotations, evoking images of holidays and adventures (Harrington, 2012; Reisfield & Wilson, 2004). These metaphors act as a convenient mechanism to avoid the confrontation of dying as a dirty, messy and potentially distressing experience (Lawton, 1998). Consequently, they serve to reinforce the societal expectation that dying is something that should be sanitised, whispered about behind closed doors or, if possible, not discussed at all.

Both the electronic and print media also have a profound influence in reinforcing social scripts targeted at negating the reality of death. While representations of dying are commonplace within both popular fiction and mainstream news, the notion of any sense of ‘normalness’ around dying tends to be obscured, with dying instead dramatised as being either a violent, tragic or heroic event. As a result, death is conceptually distanced from the general public through its characterisation as something that happens to ‘someone else’ who was unfortunate enough to find him or herself in a situation resulting in his or her demise. For example, within mainstream news media, little attention is afforded to ‘ordinary deaths’ among ‘ordinary people’ (excluding, perhaps, a brief mention in the obituaries section of a newspaper). Air time or column space tends to be reserved for the death of the political, economic or cultural elites or to report on deaths that occur due to extraordinary or violent circumstances (particularly if the deceased might be seen as vulnerable, such as children or the elderly) (Hanusch, 2010; Walter, Littlewood, & Pickering, 1995).

Where potential exists for a particular death narrative to strike an empathetic chord, the depiction of death will most likely be either hidden from view or, at least, softened so as not to create discomfort. Thus, the potential for heightened death anxiety in the media is typically counterbalanced with inbuilt mechanisms that obscure death, in effect suppressing thoughts and / or fears about the process (Hayslip, 2003). This is, perhaps, most observable within cinematic depictions of death and dying, in which focus is typically placed on the event of death, rather than the process of dying, with the death itself implied rather than shown (McInerney, 2009).

These media portrayals of death again offer explanatory value through the way in which they nurture popular understandings of dying as a process that is under the control of the living. The problem with these depictions, however, is that they differ significantly from the actual dying process itself which can often be marked by poorly managed symptoms, bodily decline, distress and even mundanity (Kellehear, 2009b; Lawton, 1998). This results in feelings of confusion, inadequacy, isolation and even alienation among individuals whose experiences of dying do not coincide with the popularised expectation of the good death.

While these different experiences could potentially expose an incongruence in the contemporary drama of dying, such incongruence is hidden from the broader societal audience by tightly woven, socially constructed scripts requiring an acceptance of the dying process by the dying themselves.

2.7 CONCLUSION AND IMPLICATIONS

This narrative review of the literature has outlined the socially constructed nature of the various roles enacted within the drama of dying. It has highlighted a pattern throughout history in which dying has been depicted as being under the control of dominant societal groups, thus fostering tight adherence to a set of dying scripts which serve the needs of the living above and beyond those of the dying.

The centrality of powerful societal institutions in fostering a professional dominance over the dying process has been detailed. Particular attention has been paid to the way in which professional bodies regulate transitions into and out of dying roles and elevate the importance of aspects of dying that relate to their perceived domain of expertise (and hence, control) over others. The authors have argued that this professional influence over the drama of dying has resulted in the diminishment of the role of the dying person to a position of relative obscurity. An examination of post-modern discourse and media portrayals of dying has also revealed a tendency to soften (and hide) the dying experience or, alternatively, sensationalise it such that it feels distant and irrelevant to most members of society. This has laid the foundation upon which an ongoing disengagement with dying among the general public has been nurtured, thereby paving the way for even further professional control over the dying process.

While this ‘façade of control’ over dying benefits health professionals in terms of emphasising the importance of their role and (arguably) assists the general public by negating death anxiety, it comes at a particular cost to those who are dying and their informal carers. To quote Scarre (2012, p. 1084), *“It looks as though we die tranquilly only by pulling the wool over our own eyes.”* In essence, the tendency towards contemporary dying scripts which emphasise a ‘good death’ as one in which the dying person achieves a sense of serenity and acceptance, has contributed to a silencing of dying people with regard to experiences of and potential frustrations with a process of dying that do not conform to this popularised ideology. These findings highlight the need for further research that offers insights into the perspectives of dying roles from the viewpoint of dying people themselves. As part of this, specific attention should be paid to the experiences of people who undergo marginalised forms of dying and who, as a result, might not currently be afforded the opportunity for the enactment of dying roles of any sort.

REFERENCES

Aries, P. (1974). *Western attitudes toward death.* (H. Weaver, Trans.). London: John Hopkins University Press.

Aries, P. (1981). *The hour of our death.* (H. Weaver, Trans.). New York: Alfred A. Knopf.

Armstrong, D. (1986). The problem of the whole-person in holistic medicine. *Holistic Medicine., 1*, 27-36.

Arnold, E., Finucane, A. M., & Oxenham, D. (2015). Preferred place of death for patients referred to a specialist palliative care service. *BMJ supportive & palliative care, 5*(3), 294-296. doi:10.1136/bmjspcare-2012-000338

Bakanic, V., Singleton, M., & Dickinson, G. E. (2016). Hospice Attitudes of Physicians and Nurses: A Pilot Study. *American Journal of Hospice and Palliative Medicine, 33*(1), 34-40. doi:10.1177/1049909114552124

Beecher, H. K., Adams, R. D., & Barger, C. (1984). A definition of irreversible coma. Report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. *JAMA: The Journal of the American Medical Association, 252*(5), 677-679. doi:10.1001/jama.1984.03350050065031;10.1001/jama.252.5.677;

Bingley, A. F., McDermott, E., Thomas, C., Payne, S., Seymour, J. E., & Clark, D. (2006). Making sense of dying: A review of narratives written since 1950 by people facing death from cancer and other diseases. *Palliative Medicine, 20*(3), 183-195.

Bowman, F. P. (1965). *Montaigne: essays*. London: E. Arnold.

Bruno, M., Ledoux, D., & Laureys, S. (2009). The dying human in biomedicine. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 51-75). Cambridge: Cambridge University Press.

Byrne, M. (2008). Spirituality in palliative care: what language do we need? *International Journal of Palliative Nursing, 14*(6), 274-280.

Dahlin, C. (2013). A view from the board. Clinical practice guidelines for quality palliative care. *Journal of Hospice & Palliative Nursing, 6* (3) 141-141. doi.org/10.1097/00129191-200407000-00001

Doka, K. J. (2003). The death awareness movement. In C. D. Bryant (Ed.), *Handbook of death & dying* (pp. 50-56). Thousand Oaks, California: Sage Publications.

Durkin, K. F. (2003). Death, dying, and the dead in popular culture. In C. D. Bryant (Ed.), *Handbook of death & dying* (pp. 43-49). Thousand Oaks, Calif: Sage Publications.

Elias, N. (1985). *Loneliness of the Dying*. Oxford: Basil Blackwell Ltd.

Emanuel, L., Bennett, K., & Richardson, V. E. (2007). The dying role. *Journal of Palliative Medicine, 10* (1), 159-168. doi.org/10.1089/jpm.2006.0134

Field, D. (1996). Awareness and modern dying. *Mortality, 1*(3), 255-265. doi:10.1080/13576279609696247

Floriani, C. A., & Schramm, F. R. (2012). Routinization and medicalization of palliative care: Losses, gains and challenges. *Palliative and Supportive Care, 10*(4), 295-303. doi:10.1017/S1478951511001039

Froggatt, K. (1997). Rites of passage and the hospice culture. *Mortality, 2*(2), 123-136. doi:10.1080/713685862

Gittings, C. (2009). The art of dying. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 163-187). Cambridge: Cambridge University Press.

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying.* Chicago: Aldine Transaction.

Glaser, B. G., & Strauss, A. L. (1968). *Time for dying.* Chicago: Aldine Transaction.

Goffman, E. (1959). *The presentation of self in everyday life*. New York: Doubleday.

Granda-Cameron, C., & Houldin, A. (2012). Concept Analysis of Good Death in Terminally Ill Patients. *American Journal of Hospice and Palliative Medicine, 29*(8), 632-639. doi:10.1177/1049909111434976

Hanusch, F. (2010). *Representing Death in the News: Journalism, Media and Mortality*. Basingstoke: Palgrave Macmillan Ltd.

Hardy, J. R., & Good, P. (2014). A good death in hospital. *Internal Medicine Journal, 44*(4), 313-314. doi:10.1111/imj.12378

Harrington, K. J. (2012). The use of metaphor in discourse about cancer: a review of the literature. *Clinical Journal of Oncology Nursing, 16*(4), 408-412. doi:10.1188/12.CJON.408-412

Hart, B., Sainsbury, P., & Short, S. (1998). Whose dying? A sociological critique of the 'good death'. *Mortality, 3*(1), 65-77. doi:10.1080/713685884

Hayslip, B. (2003). Death denial. Hiding and camouflaging death. In C. D. Bryant (Ed.), *Handbook of death & dying* (pp. 34-42). Thousand Oaks, California: Sage Publications.

Higginson, I. J., Costantini, M., Silber, E., Burman, R., & Edmonds, P. (2011). Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: A randomised fast-track trial to test timing of referral and how long the effect is maintained. *Postgraduate Medical Journal, 87*(1033), 769-775. doi:10.1136/postgradmedj-2011-130290

Higginson, I. J., & Sen-Gupta, G. J. A. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine, 3*(3), 287-300. doi:10.1089/jpm.2000.3.287

Howarth, G. (2000). Dismantling the boundaries between life and death. *Mortality, 5*(2), 127-138. doi:10.1080/713685998

Hughes, M. E. (2015). A Strengths Perspective on Caregiving at the End-of-life. *Australian Social Work, 68*(2), 156-168. doi.org/10.1080/0312407x.2014.910677

Hughes, M. T., & Smith, T. J. (2014). The Growth of Palliative Care in the United States. *Annual Review of Public Health, 35*, 459-475. doi:10.1146/annurev-publhealth-032013-182406

Illich, I. (1975). *Medical nemesis: the expropriation of health*. London: Lothian Pub. in association with Calder & Boyars.

James, N., & Field, D. (1992). The routinization of hospice: Charisma and bureaucratization. *Social Science & Medicine, 34*(12), 1363-1375. doi:10.1016/0277-9536(92)90145-G

Kellehear, A. (2007a). The end of death in late modernity: An emerging public health challenge. *Critical Public Health, 17*(1), 71-79. doi:10.1080/09581590601156365

Kellehear, A. (2007b). *A social history of dying*. New York: Cambridge University Press.

Kellehear, A. (2009a). On dying and human suffering. *Palliative Medicine, 23*(5), 388-397. doi:10.1177/0269216309104858

Kellehear, A. (2009b). *The study of dying. From autonomy to transformation.* Cambridge: Cambridge University Press.

Kubler-Ross, E. (1969). *On death and dying. What the dying have to teach doctors, nurses, clergy and their own families.* Abingdon: Routledge.

Lawton, J. (1998). Contemporary hospice care: The sequestration of the unbounded body and 'dirty dying'. *Sociology of Health and Illness, 20*(2), 121-143. doi:10.1111/1467-9566.00094

Leadbeater, C., & Garber, J. (2010). *Dying for change.* London: Demos.

Li, S. (2004). ‘Symbiotic niceness’: constructing a therapeutic relationship in psychosocial palliative care. *Social Science & Medicine, 58*(12), 2571-2583. doi:10.1016/j.socscimed.2003.09.006

Li, S., & Arber, A. (2006). The Construction of Troubled and Credible Patients: A Study of Emotion Talk in Palliative Care Settings. *Qualitative Health Research, 16*(1), 27-46. doi:10.1177/1049732305284022

Lupton, D. (1994). Femininity, responsibility and the technological imperative: discourses on breast cancer in the Australian Press. *International Journal of Health Services., 24*(1), 73-89.

Lynch, K. D. (2007). Modeling Role Enactment: Linking Role Theory and Social Cognition. *Journal for the Theory of Social Behaviour, 37*(4), 379-399. doi:10.1111/j.1468-5914.2007.00349.x

Lyons, K. D., & Bakitas, M. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *JAMA : The Journal of the American Medical Association, 302*(7), 741. doi.org/10.1001/jama.2009.1198

McGrath, P., Moore, A., McNaught, M., Palmer, G., Greene, A., & Atkinson, D. (2005). Another form to fill in! Clients' reflections on the hospice use of questionnaires. *Supportive Care in Cancer, 13*(9), 691-701. doi:10.1007/s00520-005-0795-6

McInerney, F. (2009). Cinematic visions of dying. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 211-232). Cambridge: Cambridge University Press.

McNamara, B. (2004). Good enough death: autonomy and choice in Australian palliative care. *Social Science & Medicine, 58*(5), 929-938. doi:10.1016/j.socscimed.2003.10.042

McNamara, B., Waddell, C., & Colvin, M. (1994). The institutionalization of the good death. *Social Science & Medicine, 39*(11), 1501-1508. doi:10.1016/0277-9536(94)90002-7

Palliative Care Australia. (2005). Standards for providing quality palliative care for all Australians. 4th Edition. Canberra: Palliative Care Australia.

Parker-Oliver, D. (2000). The social construction of the "dying role" and the hospice drama. *OMEGA - Journal of Death & Dying, 40*(4), 493-512. doi.org/10.2190/yt9d-12y2-54ly-tcmn

Parsons, T. (1951). *The social system*. Glencoe, Ill Free Press.

Penson, R.T., Schapira, L., Daniels, K.J., Chabner, B.A., & Lynch, J.T.J. (2004). Cancer as metaphor. *The Oncologist, 9*(6), 708-716. doi:10.1634/theoncologist.9-6-708

Pollock, K. (2015). Is home always the best and preferred place of death? *BMJ-British Medical Journal, 351*, h4855. doi:10.1136/bmj.h4855

Proulx, K., & Jacelon, C. (2004). Dying with dignity: the good patient versus the good death. *The American journal of hospice & palliative care, 21*(2), 116-120. doi:10.1177/104990910402100209

Reisfield, G. M., & Wilson, G. R. (2004). Use of metaphor in the discourse on cancer. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology, 22*(19), 4024-4027. doi:10.1200/JCO.2004.03.136

Ritchie, L. D. (2013). *Metaphor*. Cambridge: Cambridge University Press.

Scarre, G. (2009). Dying and philosophy. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 147-162). Cambridge: Cambridge University Press.

Scarre, G. (2012). Can there be a good death? *Journal of Evaluation in Clinical Practice, 18*(5), 1082-1086. doi:10.1111/j.1365-2753.2012.01922.x

Seale, C. (1998). *Constructing death: the sociology of dying and bereavement*. Cambridge, England: Cambridge University Press.

Seale, C. (2001). Sporting cancer: struggle language in news reports of people with cancer. *Sociology of Health and Illness, 23*(3), 308-329. doi.org/10.1111/1467-9566.00254

Sontag, S. (1979). *Illness as metaphor*. London: Allen Lane.

Stephenson, J. S. (1985). *Death, grief and mourning: Individual and social realities.* New York.: Free Press.

Strand, J. J., Mansel, K., & Swetz, K. M. (2014). The growth of palliative care. *Minnesota Medicine, 97*(6), 39-43.

Temel, J. S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A, . . . Lynch, T.J. (2010). Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *The New England Journal of Medicine, 363*(8), 733-742. doi:10.1056/NEJMoa1000678

Timmermans, S. (2005). Death brokering: constructing culturally appropriate deaths. *Sociology of Health & Illness, 27*(7), 993-1013. doi:10.1111/j.1467-9566.2005.00467.x

Turner, R. H. (1956). Role-Taking, Role Standpoint, and Reference-Group Behavior. *The American Journal of Sociology, 61*(4), 316-328. doi:10.1086/221763

Turner, R. H. (1990). Role Change. *Annual Review of Sociology, 16*(1), 87-110. doi:10.1146/annurev.so.16.080190.000511

Turner, V. (1974). *Dramas, fields and metaphors: Symbolic action in human society.* New York.: Cornell University Press.

van Gennep, A. (1909/1960). *The rites of passage*. Chicago: University of Chicago Press.

Walter, T. (1994). *The revival of death*. London: Routledge.

Walter, T. (2003). Historical and cultural variations on the good death. *BMJ Quality & Safety, 327*, 218-220. doi.org/10.1136/bmj.327.7408.218

Walter, T., Littlewood, J., & Pickering, M. (1995). Death in the News: The Public Invigilation of Private Emotion. *Sociology, 29*(4), 579-596. doi:10.1177/0038038595029004002

Walters, G. (2004). Is there such a thing as a good death? *Palliative Medicine, 18*(5), 404-408. doi:http://dx.doi.org/10.1191/0269216304pm908oa

World Health Organisation. (2007). *Definition of Palliative Care*. Geneva: World Health Organisation.

Zimmermann, C. (2012). Acceptance of dying: a discourse analysis of palliative care literature. *Social Science & Medicine (1982), 75*(1), 217-224. doi:10.1016/j.socscimed.2012.02.047

Zimmermann, C., Yuen, D., Mischitelle, A., Minden, M. D., Brandwein, J. M., Schimmer, A., . . . Rodin, G. (2013). Symptom burden and supportive care in patients with acute leukemia. *Leukemia Research, 37*(7), 731-736. doi:10.1016/j.leukres.2013.02.009

TABLE 1

Summary of search terms and record of hits and relevant sources of literature

Database	**Search Terms**	**Hits Retrieved**	**Relevant on title and abstract review**
CINAHL	1. “Terminally Ill Patients” OR "Terminal Care" OR "Palliative Care" OR "Hospice*" OR "Hospice Care" OR "Hospice and palliative nursing" OR "Cancer Care Facilities" OR "life limiting illness" OR "Hospice Patients"	39088	
	2. “role*” OR "sick role" OR "sick roles" OR "family role" OR "family roles*" OR "self concept" OR occupation* OR identit* OR "social identity" OR "identity crisis"	294770	
	3. “change*” OR "social change" OR "social changes" OR "role change" OR "role changes" OR "transition*" OR "health transition" OR "loss*" OR "adapt*" OR "adaptation psychological" OR "adaptation occupational" OR "life experiences" OR "LIFE CHANGE EVENTS" OR "SOCIAL ADJUSTMENT" OR "social adjustments"	304381	

	OR "Attitude to illness" OR "Attitude to death" OR "Attitude to health" OR "Life purpose" OR "psychosocial aspects of illness"		
	1,2,3 COMBINED (with AND)	**1108**	**73**
Medline	1. “terminal care” OR "end of life care" OR PALLIATIVE OR HOSPICE* OR "bereavement care" OR "TERMINALLY ILL" OR "life limiting illness"	93871	
	2. “role*” OR "sick roles" OR "sick role" OR "self concept" OR occupation* OR identit*	184039	
	3. “change*” OR transition* OR loss* OR adapt* OR "patient perspective*" OR lived experience* OR experience* OR “LIFE CHANGE EVENTS” OR "life experience" OR "life experiences" OR "adaptation psychological" OR "health transition" OR "SOCIAL ADJUSTMENT" OR "social adjustments" OR "behaviors adaptive" OR "behavior adaptive" OR "ATTITUDE TO HEALTH"	1062543	
	1,2,3 COMBINED (with AND)	**1155**	**45**

PsychInfo	1. “terminally ill patients” OR "terminal cancer" OR "hospice*" OR "palliative care" OR "death and dying"	10273	
	2. “roles” OR "role conflict" OR "role conflicts" OR "role perception" OR "role expectations" OR "role satisfaction" OR "role taking" OR "self concept" OR "sense of coherence" OR "self congruence" OR "self perception" OR "social identity" OR "identity formation" OR "identity crisis" OR "ego identity" OR "group identity" OR "self actualization" OR "symbolic interactionism" OR "social networks"	120669	
	3. “change*” OR ""attitude change" OR "change (social)" OR "life changes" OR "life experiences" OR "experiences (events) OR "death anxiety" OR "attitudes" OR "death attitudes" OR "health attitudes" OR "adjustment" OR "occupational adjustment" OR "emotional adjustment" OR "personal adjustment" OR "psychological adjustment" OR "social adjustment"	408889	
	1,2,3 COMBINED (with AND)	**56**	**4**

SCOPUS	All key terms for palliative (from previous searches)	2136738	
	All key terms for roles (from previous searches)	580426	
	All key terms for change (from previous searches)	94244	
	1,2,3 COMBINED (with AND)	**2851**	
	LAST 10 YEARS	**1629**	**58**

CHAPTER THREE: METHODOLOGY

My choice of research methodology stemmed from the focus of my research upon examining the process of role change at end of life. This required a methodology that would enable the analysis of the way in which roles change for both dying persons and members of their social circles as well as the way in which role relations evolve across the drama of dying. I chose grounded theory as an overarching research methodology because of its value in answering ‘how’ questions in relation to the way in which a social process or phenomenon occurs (Charmaz, 2014). In particular, I viewed the simultaneous data collection and analysis processes associated with grounded theory research as being key to my ability to construct in-depth and refined analyses of role change and role relations at end of life.

Furthermore, I was aware that grounded theory has a strong pedigree in research relating to the process of dying. Indeed, the methodology itself was developed as part of Glaser and Strauss’ (1965) landmark study examining the social organisation of dying within hospitals in the United States of America. Since this time, grounded theory has been adopted in a wide range of studies examining different forms and aspects of the dying experience (Belgrave & Charmaz, 2014).

3.1 CONSTRUCTIVIST GROUNDED THEORY METHODOLOGY

3.1.1 Relevance of constructivist grounded theory to this study

Since its inception, grounded theory has undergone two significant theoretical divisions, resulting in three divergent traditions. These three traditions are known respectively as classic, Straussian, and constructivist grounded theory (Kenny & Fourie, 2014). Although a number of core similarities remain across all three of these traditions, each is founded upon different philosophical standpoints with resultant variation in methods of analysis (Kenny & Fourie, 2015).

I drew specifically on constructivist grounded theory as a guiding framework for this study. My choice was founded on the premise that in examining role change at end of life, I would be deriving interpretations regarding the meanings attributed by individuals to experiences that had unfolded through a highly complex interplay between themselves and the society in which they lived. As such, I needed a methodology that embraced the relativist ontological notion that reality is not universal; instead, it is multiple and constructed. I considered constructivist grounded theory to be ideally suited to achieve this because, unlike classic and Straussian grounded theory, constructivist grounded theory recognises the role of the researcher in *constructing* theory, as distinct from *discovering* pre-existing theory. This means that researchers undertaking constructivist grounded theory studies present an interpretive representation of the process that they examine, instead of laying claim to producing an exact picture (Charmaz, 2014).

Constructivist grounded theory as a guiding methodology proved to be very useful when it came to data analysis. As the process of data collection and analysis progressed, it became particularly evident that the values, beliefs and expectations that people held in relation to death, dying and dying roles shaped many of the social interactions described by participants. I also became aware, however, of the reciprocal influence of these social interactions in reinforcing, challenging or altering the meanings that people attributed to dying. This led me to realise that my findings were contextually specific in relation to the time, place and socio-cultural context in which the data had been gathered. I therefore found that the relativist ontological and interpretivist epistemological positioning of constructivist grounded theory allowed me to situate my findings in an honest and transparent manner that reflected both the complex and contextualised nature of dying and dying roles.

Furthermore, the adoption of a constructivist stance enabled me to recognise that data collection and analysis were not “neutral acts”, thereby nurturing an authentically reflexive position in relation to my own role in theory generation (Charmaz, 2014, p. 240). In particular, this assisted me to recognise the way in which my own perspective, lived experience and professional privilege had the potential to influence my interpretation of meanings and actions associated with death, dying and dying roles. Beyond this, the constructivist stance also assisted me to appreciate that the process through which I gathered data (e.g. entering dying persons’ home and sitting down to discuss death and dying) inevitably influenced the nature of the stories that participants shared and the way in which they shared them.

This point of recognition was of profound value to my research journey for two reasons. Firstly, it highlighted the critical importance of what I would otherwise have regarded as ‘background disturbances’ to the development of an authentic understanding of the drama of dying. For example, periodic interruption during interviews with dying persons by caregivers who needed to provide medication or check on the wellbeing of the dying person, shed light on the reality of these caregivers being ‘on-call’ for weeks, months or even years. By adopting a constructivist stance, I was able to recognise that these individuals were not (as I might otherwise have clumsily assumed) interrupting my analysis of the drama of dying. Instead, the drama of dying was playing out in the homes of the participants whom I was visiting and my very presence was temporarily altering this drama in some way.

As a health professional, I needed to stop and reconsider the countless observations on which I had based my understanding of death and dying. These background disturbances laid bare the notion that the conditions in which health professionals, such as myself, come to know the drama of dying and are inextricably entwined in our presence in the drama at that point in time. To this extent, our interactions as health professionals form part of the drama of dying but do not reflect the broader whole. For both researchers and health professionals, this means that assumptions regarding the broader drama of dying that are founded upon our relatively brief roles within it, may compromise our ability to properly understand the lived experience of dying persons and members of their inner and outer social circles. Hence, research that sheds light on otherwise hidden dimensions of the drama of dying is of importance for quality clinical care.

3.2 PARTICIPANT SELECTION AND RECRUITMENT

3.2.1 Inclusion and exclusion criteria

Given the relational nature of end-of-life roles, I decided that it would be important to examine the perspectives of a variety of key informants regarding their experiences of roles and role change. As such, I sought interviews with dying people and their caregivers and/or family members as well as health professionals who work in palliative and end-of-life care. My inclusion criteria encompassed individuals who had been diagnosed as having a life expectancy of six months or less; caregivers of individuals diagnosed as having a life expectancy of six-months or less; and health professionals or volunteers working in community or inpatient palliative care settings. As a condition of research ethics approval (Appendix 2) it was also determined that all dying persons who were interviewed in this study needed to have been told of their dying diagnosis by a medical professional.

Individuals were considered ineligible for participation in this research if they had rapidly deteriorating conditions and/or were identified by a doctor as being within the last 48 hours of life. People younger than 18 years of age were also excluded from the study. All of these exclusion criteria centred on protecting participants for whom an interview may have been potentially harmful.

I made a pragmatic decision to limit recruitment to one (local) health service region, this being the Townsville Hospital and Health Service. I considered it important to interview dying persons face-to-face, so that I could appropriately read body language and other forms of non-verbal communication and manage my interview approach accordingly. With this in mind, I judged the time and costs associated with travel to other regional areas of Australia for face-to-face interviews would be too high. My concerns were compounded by the fact that the unpredictable nature of some participants' health might mean that, by the time I had travelled to a regional area, a dying person's condition may have deteriorated to the extent that he or she was no longer well enough to take part in an interview.

3.2.2 Approach to awareness raising, recruitment and sampling

Participants were recruited purposively through the adoption of a theoretical sampling approach. This means that I intentionally sought the involvement of participants in the study based on their potential contribution to the development and refinement of the emergent theory (Creswell & Poth, 2018; Morse, 2010). In grounded theory research, sampling occurs in an ongoing and evolving manner, beginning quite broadly but then becoming increasingly focused and circumscribed as the research progresses (Charmaz, 2014; Dey, 2010). This theoretical sampling approach was key to my study because it facilitated the systematic comparison of dying role enactment and dying role relations across a variety of different actors, settings and scenes (Dey, 2010).

I began my broad sampling approach by raising awareness of my study through an information session with the local palliative care team to discuss the purpose of and processes associated with my research. In this meeting, I distributed copies of an information flyer that outlined the purpose of the study, as well as the inclusion and exclusion criteria and contact details of myself as Principal Researcher (Appendix 3). A copy of this flyer was also posted on the information board in the regional Palliative Care Centre. Further copies of the information flyer and copies of the participant information sheet (Appendix 4) were provided to members of the local palliative care outreach team for distribution to individuals who they believed might be interested in participating in the study and who met the inclusion and exclusion criteria.

The involvement of the palliative care outreach team in raising awareness of my study proved to be critical to the success of my research. The large majority of participants who expressed an interest in this study heard about it via this team. Furthermore, as the study progressed and theoretical sampling became increasingly focused, I was able to discuss my sampling requirements with this team. For example, I became increasingly aware of the considerable importance of the stories of caregivers within the drama of dying. Although I had initially regarded the carer perspective as valuable, I had not been aware of the extent of their influence in shaping role relations or the profound impact of role change upon them. Being able to indicate to key members of the palliative care outreach team that I was looking to interview caregivers with both good and bad experiences of role relations at end of life made it possible to develop and refine my data analysis and associated theory construction. Just as importantly, this theoretical sampling approach helped to ensure that participants who would be unlikely to add to the existing research picture were not unnecessarily burdened through participation in an interview.

It should also be acknowledged, however, that by relying so heavily on palliative care professionals to assist with awareness raising for my research, I unintentionally positioned these professionals in the role of gatekeepers into the study. This means that some participants who may have wanted to share their stories may not have found out about my study if, for example, the professional working with them considered them to be vulnerable and in need of protection. To some extent, this might have influenced the findings of my research in that some participants, who may have appeared to be struggling to come to terms with their situation, may not have been made aware of the study. It is unclear as to what extent and/or in what way this gatekeeping role impacted on recruitment into my study. However, many participants in the study did appear distressed about and frustrated with their circumstances, perhaps indicating that dying persons and/or caregivers who professionals considered to be in need of protection may still have been informed about the research.

3.2.3 Recruitment challenges

Recruitment into this research was slower and somewhat more difficult than I had anticipated. Data collection took approximately three and a half years to complete. On five occasions, dying persons who had expressed an interest in taking part in the study experienced an unexpected and rapid deterioration in their health. On three of these occasions, the potential participants died before the arranged interview took place and, on the other two occasions, it became apparent that it would be inappropriate to undertake an interview based on the individual's deteriorating health.

In some ways, though, the slow rate of participant recruitment proved advantageous. It enabled me to spend more time revisiting my data and engaging in memo writing, both of which helped to shape, challenge and modify my coding and theory development. This assisted me to better prepare for upcoming interviews so that I could explore particular lines of inquiry as needed to extend and refine theory construction. In addition, having additional time to critically review my interview transcripts enabled me to identify instances where I had unintentionally missed, blocked or detoured from important threads of discussion. In recognising this, I was able to improve my open-ended interviewing skills as the study progressed.

Interestingly, recruitment of health professionals into my study was slower than it was for dying people and/or caregivers. There are many possible reasons for this; however, I suspect that a combination of the busy workloads of these professionals and a lack of obvious focus on recruitment of professionals in my initial awareness-raising sessions are the most likely causes. A more concerted effort in the recruitment of health professionals towards the end of my data collection phase did result in increased interest in the study.

Because of the slower uptake of health professionals into my study, my first two published findings papers (presented as Chapters Four and Five in this thesis) focus only on the perspectives of dying people and their caregivers. Although it was not part of the intended study design, this narrower focus during the early phase of my research may have been beneficial to my overall analysis. Given my professional background as an occupational therapist in palliative care, I was at least somewhat familiar with professional perspectives on dying and dying roles. An early emphasis on professional perspectives may have simply led me to consolidate my own pre-existing assumptions and, in doing so, distanced me from the viewpoints of dying people and their caregivers. Interviewing professionals towards the end of my data collection process enabled me examine their perspectives on elements of the drama of dying in the light of what had been identified as important by dying people and their caregivers. In hindsight, I believe that this enriched the quality of the data that I gathered in my interviews with professionals.

3.2.4 Final participant sample

Theoretical sampling continued up to the point at which both my supervisory team and I agreed that theoretical sufficiency had been achieved. In grounded theory studies, theoretical sufficiency is determined as the point at which no new variant cases are arising and enough data has been gathered in order to define, check and explain relationships and variance both between and within theoretical categories (Charmaz, 2014). Once these criteria are met, researchers are able to recognise the achievement of theoretical sufficiency within their study (Dey, 1999). The final sample of participants in my study comprised thirteen dying people, eight caregivers and five health professionals. The demographic details of the final participant sample is presented below in Table 2. None of the dying persons or caregivers who participated in the study were known to me prior to data collection. Three out of the five health professionals were known to be due to my previous working role as an occupational therapist within the health service in which the study was undertaken.

Table 2: Participant demographics

Code	Status	Dyad?	Gender	Age	Cultural background	Religion	Diagnosis	Time since receiving news of terminal diagnosis
P1	Dying person	N	M	80-89	Scottish Australian	Catholic	Metastatic stomach cancer	4 months
P2	Dying person	N	F	70-79	White Australian	Atheist	Pancreatic cancer	22 months
P3	Dying person	N	F	40-49	White Australian	Christian	Metastatic stomach cancer	6 months
P4	Dying person	Y (C1)	F	70-79	White Australian	None	Metastatic breast cancer	4 months
P5	Dying person	N	M	60-69	White Australian	Christian	Metastatic prostate cancer	24 months
P6	Dying person	N	F	40-49	White New Zealander	Baptist	Vaginal cancer	16 months
P7	Dying person	N	M	60-69	White New Zealander	Catholic	Metastatic lung cancer	2 months
P8	Dying person	Y (C2)	F	60-69	White Australian	Christian	Metastatic breast cancer	48 months

Code	Status	Dyad?	Gender	Age	Cultural background	Religion	Diagnosis	Time since receiving news of terminal diagnosis
P9	Dying person	Y (C3)	M	70-79	English (63 years in Australia)	Christian	Oesophageal cancer	6 months
P10	Dying person	Y (C4)	M	60-69	White Australian	Catholic	Metastatic lung cancer	14 months
P11	Dying person	N	M	70-79	White British	Catholic	MND	23 months
P12	Dying person	Y (C5)	M	80-89	White British (16 years in Australia)	None	COPD	6 months (estimate)
P13	Dying person	N	M	80-89	White Australian	None	Multiple diagnoses	Not stated
C1	Carer (for mother)	Y (P4)	F	40-49	White Australian	None	Metastatic breast cancer (mother)	4 months
C2	Carer (for mother)	Y (P8)	F	30-39	White Australian	None	Metastatic breast cancer (mother)	48 months
C3	Carer (spouse)	Y (P9)	F	70-79	White Australian	Christian	Oesophageal cancer (husband)	6 months
C4	Carer (spouse)	Y (P10)	F	50-59	White Australian	Catholic	Metastatic lung cancer (husband)	14 months
C5	Carer (spouse)	Y (P12)	F	80-89	White British (16 years in Australia)	None	COPD (husband)	6 months (estimate)
C6	Carer (spouse)	N	M	50-59	Aboriginal Australian	Catholic	MND (wife)	60 months (estimate)
C7	Carer (spouse)	N	F	60-69	White Australian	Anglican	Bowel cancer (husband)	66 months
C8	Carer (for Father)	N	F	30-39	Italian Australian	Atheist	Metastatic lung cancer (father)	40 months
HP1	Priest	N/A	M	40-49	White Australian	Anglican	N/A	N/A

Code	**Status**	**Dyad?**	**Gender**	**Age**	**Cultural background**	**Religion**	**Diagnosis**	**Time since receiving news of terminal diagnosis**
HP2	Occupational therapist	N/A	F	20-29	White Australian	Catholic	N/A	N/A
HP3	Doctor	N/A	M	60-69	Western cosmopolitan	Atheist	N/A	N/A
HP4	Nurse	N/A	M	30-39	White Australian	None	N/A	N/A
HP5	Social worker	N/A	F	60-69	White Australian	Christian	N/A	N/A

It is important to note that the perspectives of most participants in this research were not limited to their experience in a single role; instead, they reflected their involvement in a wide variety of roles relating to multiple dramas of dying. This is because people often transition in and out of the drama of dying in a variety of roles prior to their own experience of dying. For example, many of the dying persons interviewed spent time discussing their previous roles as caregivers for other people who were dying. Similarly, a number of health professionals who were interviewed also described their lived experiences in relation to the death of family members or friends. This breadth of experience added to the richness of the data collected in this study as individuals shared stories relating to numerous dramas of dying. Importantly, it also offered the opportunity to examine the way in which previous experiences of dying roles influence dying persons' beliefs and wishes regarding their own dying experiences.

3.3 DATA COLLECTION

3.3.1 Interview structure

Data in this study were collected predominantly through in-depth, semi-structured interviews with participants. Three interview guides were developed, based on the collective professional and research experience of myself and my supervisory team as well as on a broad-ranging review of the literature. These interview guides served as prompting devices to assist me in structuring and guiding interviews. One interview guide was used for interviews with dying people, the second for interviews with caregivers and the third for interviews involving health professionals (Appendix 5).

Modifications to the interview guides in response to data analysis ensured that interviews focused on emerging areas of interest and thus helped in the construction and refinement of my theory (Charmaz, 2014; Minichiello, Aroni, & Hays, 2008). When making modifications to the interview guide, I remained cognisant of the fact that, in constructivist interviewing, pursuance of theory should not compromise the ability of participants to share elements of their story that are of importance to them (Charmaz, 2014). With this in mind, the modifications to the interview guides generally took the form of additional questions or prompts, rather than changes to the overall interview structure. This approach was of particular importance to my research since I was undertaking only one interview with each participant; this meant that participants had only one opportunity to share their thoughts and experiences (Charmaz, 2014).

Prior to the commencement of each interview, I took time to revisit the purpose of the research and explain the steps that would be involved in gathering data. As part of this process, I encouraged participants to share their stories by focusing on the aspects of their experiences that were of most importance to them. I also made sure that I took time to establish rapport to help build trust and demonstrate my genuine interest in each participant's story. This process of 'setting the stage' for an interview is crucial to the establishment of the respect and understanding needed for participants to feel safe in sharing their experiences with a stranger (Brinkmann & Kvale, 2015; Minichiello, Aroni, & Hays, 2008).

The participant sample included five dying person / caregiver dyads. On two occasions I conducted interviews with both the dying person and caregiver present based on the request of both parties. While conducting interviews with participants together might help in understanding shared experiences, it can also result in one or both individuals withholding thoughts or ideas that they may regard as sensitive or personal (Kendall et al., 2009). My experience of interviewing dying persons and caregivers together reflected these concerns. During one interview in particular, I found it very difficult to elicit the thoughts of the caregiver who seemed reluctant to say anything that her husband might not agree with. As a result, this individual's thoughts, ideas and experiences remained somewhat obscured.

3.3.2 Interview location and duration

Most interviews with dying people or their caregivers were conducted in participants' homes. Two interviews occurred at different locations with one caregiver choosing to be interviewed in my office at the university and one by phone. Interviews with health professionals were undertaken either at the university or in a quiet room at their workplace. Carrying out interviews in participants' homes brought with it a few practical challenges, such as difficulties with control of background noise and occasional (albeit brief) interruptions from unexpected visitors, phone calls and pets. However, I found the benefits of home-based interviews to be very considerable. Firstly, the fact that I was entering participants' homes seemed to help in negating any unintended and unhelpful power differential between myself (as researcher) and the person(s) being interviewed. Brinkmann and Kvale (2015) suggest that conducting interviews in participants' homes can be particularly valuable if the research question centres on the biographies or family life of the people being interviewed. Interviewing participants in their own homes seemed to result in their feeling relaxed and open to discussion regarding aspects of their lives and relationships that might have remained obscured had the interviews been conducted in a less familiar setting. Furthermore, as a researcher I was able to make observations, field notes and subsequent memos concerning important aspects of participants' lived worlds, such as items and artefacts, physical, social and personal dimensions of home and daily routines that might have gone unnoticed if I had been reliant on interview data alone (Creswell & Poth, 2018).

Interview lengths ranged from 30 to 177 minutes and averaged 85 minutes. The 30-minute interview was stopped early because of ongoing difficulties with pain experienced by the participant. This participant had been very motivated to be interviewed as part of the research and requested I visit him at his home again at a later date so that he could finish telling his story. Unfortunately, however, this was not possible as the participant's health continued to deteriorate over the next few weeks to the point that I considered it inappropriate to attempt to re-arrange the interview.

All interviews were audio recorded and transcribed verbatim. The typed transcripts were then coded and analysed through a series of analytical processes as detailed below.

3.4 DATA ANALYSIS

3.4.1 Initial and focused coding

In keeping with the principles of data analysis in grounded theory research, coding in this study was not undertaken at a distinct stage; instead, it occurred progressively throughout the research process (Holton, 2010). As has been discussed in Chapter One, I embraced the theoretical flexibility afforded by grounded theory, by adopting the lenses of dramaturgy and narrative inquiry to support my analysis. When undertaking data analysis in this study, I was guided by the broad recommendations for constructivist grounded theory coding suggested by Charmaz (2014). This entailed analysing data iteratively throughout the research process, commencing with initial coding before later engaging in a focused coding phase.

I began with initial coding. This involved close examination of individual fragments of data in order to develop early analytic ideas. Charmaz (2014) states that during this phase of coding, it is of particular importance to avoid making early conceptual leaps, to maintain an open mind, to stay close to the data and to make comparisons between data. She emphasises the need to ensure that the codes fit the data, rather than attempting to force data to fit pre-conceived or poorly conceived codes.

On reflection, some of my early attempts at initial coding in this research were probably influenced by my professional suppositions. For example, I placed considerable emphasis on participants' accounts of seeking home as a place of sanctuary and of fearing dependence more than death. Although the potential importance of these codes should not be dismissed outright, they are indicative of my viewing participants' narratives through the lens of an occupational therapist. As an occupational therapist, my working role would centre around assisting people to remain at home as long as is possible and maintain independence in activities (occupations) that they value (Boyt Schell, Gillen, & Scaffa, 2014). My early coding efforts might, therefore, have been reflective of my unconscious and unintended wish to validate the usefulness of my professional role. In making this point, I take comfort from the words of Saldana (2013, p. 10) who states "rarely will anyone get coding right the first time". Charmaz (2014) also indicates that grounded theorists will often unwittingly allow their taken-for-granted assumptions to permeate their analysis. Certainly, the codes in my study evolved considerably through the initial coding phase. Maintaining a reflective journal, frequently constructing analytical memos and discussing my codes with my supervisory team all played a crucial role in strengthening reflexivity in my coding.

In relation to the coding process itself, I used NVivo Pro software$^{©}$ (version 11) to assist me in organising data during the analysis process. I began with line-by-line coding. This approach enabled me to examine what might otherwise have been hidden patterns in the data and, in doing so, revealed new ideas that could be pursued and investigated further (Charmaz, 2014). I complemented line-by-line coding with incident-by-incident coding. This involved my closely examining and comparing key incidents within and between the narratives of my research participants. This approach to coding draws on the constant comparative methods first described by Glaser and Strauss (1967). When undertaking these initial coding processes, I strove to identify and examine significant processes in participants' lives. As a guide to this, I remained cognisant of a range of analytical prompts recommended by Charmaz (2014, p. 127) outlined below:

- What process is at issue here? How can I define it?
- How does this process develop?
- How does the research participant act while involved in this process?
- What does the research participant profess to think and feel while involved in this process? What might his or her observed behaviour indicate?
- When, why and how does the process change?
- What are the consequences of the process?

My transition from initial coding to focused coding did not occur at a specific point but rather as a graded shift over time. It involved revisiting participant transcripts as well as the initial codes that I had constructed and evaluating their relevance, centrality and explanatory power (Charmaz, 2014; Holton, 2010). During focused coding, I consolidated the very large number of codes that I had developed during my early analysis and decided which of these most warranted further examination in subsequent interviews. Although not all of my early 'hunches' stemming from my focused codes proved fruitful, many did and the overall process aided considerably in sparking new ideas, tightening my analysis and honing in on emergent theory. Diagrammatic representations of the initial and focused codes that informed the construction of each of the three findings chapters of this research are included in Appendices 6, 7 and 8.

3.4.2 Memoing

I found that the memoing I had undertaken throughout the research process to be of critical value during the focused coding phase. This is, perhaps, not surprising, given that blurring and intertwining of analytic memo writing with coding throughout the research process have long been recognised as hallmarks of the grounded theory method (Glaser & Strauss, 1967). The benefits of memoing are well established, as highlighted by Saldana (2013, p. 42) who states: *"... whenever anything related to and significant about the coding or analysis of the data comes to mind, stop whatever you are doing and write a memo about it immediately."*

My own research memos took many forms, ranging from handwritten entries in my research diary (or, on one or two occasions, scribbled notes on loose pieces of paper found in my car) to thoughts on codes and coding logged as memos and/or annotations in NVivo Pro software$^{©}$ (version 11). These memos addressed a wide range of topics including: lessons learned from participant interviews and notes to remember for subsequent interviews; emergent patterns and concepts from the data; possible patterns and connections between codes and concepts; and thoughts regarding the direction of the study (Saldana, 2013). An example of one of my (briefer) memos is included below. This particular memo did go on to shape both my focused coding and theory development, although in a modified form than the ideas presented here would suggest:

> *"13.02.2017*
>
> *This phrase "living day-by-day" comes up all the time. What function does this serve? Is it the only way to cope with an uncertain, undefined prognosis. Given that people don't know how long they have got, perhaps it is the only option available to them. Living each day as dying would be difficult for sure. But what does this mean in terms of roles? It seems to contribute to a degree of partial acceptance and / or oscilation in and out of the dying status. No wonder that 'dying scripts' are so hard to come by. I need to explore more about what living day-by day is like for people. Does it mean something different from what it does for me?"*

3.4.3 Theory construction

The final phase of my data analysis entailed the examination of relationships between my focused codes and the development of hypotheses as to how these contribute to explanatory theory. To facilitate this, I discussed my focused codes, analytical memos and early thoughts on explanatory theory in detail in meetings with my PhD supervisory panel. Alternative perspectives, interpretations and hypotheses were often raised during these meetings. These helped me to acknowledge and manage many of my 'taken-for-granted' beliefs, values and assumptions, thus nurturing reflexivity in relation to my interpretation of data. These discussions, therefore, facilitated the gradual progression towards a more credible, trustworthy, original and useful explanatory framework concerning the process of role change at end of life.

3.5 STRATEGIES TO MAINTAIN RESEARCH QUALITY

Many and varied perspectives exist in relation to the appropriate procedures for determining the quality of qualitative research, including the terms and criteria against which it should be appraised. In part, the debate regarding quality criteria stems from differences in opinion regarding to what extent it is reasonable and/or useful to draw on positivist approaches (and terminology) in evaluating qualitative analysis (Creswell & Poth, 2018). With this in mind, criteria for determining research quality tend to align with the research discipline as well as the ontological and epistemological standpoint of the methodology itself. Charmaz (2014) recommends four criteria that can be used specifically in evaluating the quality of constructivist grounded theory research. These are credibility, originality, resonance and usefulness. The application of each of these criteria to the research presented in this thesis is outlined below.

3.5.1 Credibility

Credibility refers to the degree to which the research data have been shown to justify the researcher's claims (Charmaz, 2014). To achieve this, logical links between gathered data and the categories and arguments presented must be made apparent to the reader. In this study, credibility has been promoted in a variety of ways. Key findings have been substantiated with participant quotes and/or researcher observations (in the form of field notes, memos and research diary entries). Progression of codes from initial coding to focused coding and category development have also been mapped diagrammatically to enable transparency and allow the reader to evaluate the steps taken in arriving at findings (Appendix 6). Furthermore, coding and theory generation have been discussed with my PhD supervisory panel throughout the research process. This has enabled corroboration of evidence through triangulation of analysis (Creswell & Poth, 2018).

Given the interpretivist positioning of this research, credibility was highly reliant on my maintenance of researcher reflexivity throughout the research process. Reflexivity requires a researcher to clearly understand and outline the way in which his or her lived experience, values and assumptions may influence the processes of data collection and analysis (Creswell & Poth, 2018). I maintained a reflexive stance by keeping a research journal in combination with the frequently completing research memos. This allowed me to track the progression of my thinking in relation to particular findings. As part of this, I remained mindful of my clinical background as an occupational therapist in palliative care and was cautious not to unduly prioritise aspects of my analysis that elevated this role. On occasions where I was concerned that this might be occurring, I noted my thoughts for further discussion with my supervisory panel so that my ideas could be aired and critiqued.

3.5.2 Originality

Originality describes the extent to which the research offers new and significant insights regarding the process being examined (Charmaz, 2014). In order to ensure originality, this study commenced with a thorough literature review spanning a variety of academic disciplines and perspectives so that gaps in knowledge could be identified and addressed. This review also assisted in ensuring that my research findings and associated implications were situated appropriately in relation to existing evidence. Feedback received from my supervisory panel on coding and theory development also promoted originality. On a number of occasions, my supervisory panel identified aspects of my analysis as being too descriptive, monochromatic and/or lacking in depth. When this occurred, they prompted me to continue to ask analytical questions of the data so that I could further develop my analysis. This feedback was of key value in driving the development of a theoretical understanding of role change at end of life that was nuanced and original.

3.5.3 Resonance

Guidance and feedback from my supervisory panel also helped in promoting the resonance of my research. Resonance is achieved when research findings articulate the fullness of the experience being studied in a manner that makes sense to those who have shared their stories (Charmaz, 2014). As a research team, my supervisory panel and I brought with us a variety of personal and professional experience in relation to death, dying and end-of-life care. Collectively, our experience spans medicine, nursing and allied health roles in end-of-life care, as well as the roles of caregivers to family members and friends who were dying. This breadth of experience meant that, at each stage, the development of research findings were scrutinised and refined from a variety of perspectives, thereby promoting a layered and authentic analysis.

I chose not to undertake member checking in this study. I made this decision based on the premise that I was investigating the dynamic and evolving construct of role change at end of life. Many of the dying people and caregivers interviewed were experiencing circumstances that were highly changeable. However, since my interest centred on participants' thoughts and recollection of experiences at the time of being interviewed, I deemed member checking unnecessary and inappropriate. Furthermore, due the time-lag between data collection, data transcription and data analysis, many of my participants may have experienced deteriorations in their health or died by the time member checking became an option. As a result, I considered it ethically unsound to attempt to recontact participants for this purpose.

3.5.4 Usefulness

The criterion of usefulness poses the question as to whether the research produced is of value in the everyday world. Charmaz (2014) suggests that both credibility and originality promote the usefulness of research. My supervisory team and I regularly discussed the applicability of my findings to practice in palliative and end-of-life care, policy formulation, death awareness campaigns and future research. These shared experiences offered a means of evaluating the usefulness of my findings to dying persons and members of their social circles. Clinical, societal, policy and research implications are outlined in each published paper presented within this thesis. Implications relating to the study as a whole are presented in the final two chapters.

3.6 ETHICAL CONSIDERATIONS

Qualitative research involving people nearing end of life is often assumed to be particularly ethically challenging because of the potential emotional vulnerability of participants. However, a growing body of published evidence is emerging which suggests that, for many dying people, involvement in research can bring with it a variety of benefits. A recent integrative review of the literature identified that dying people often value the chance to be involved in research, particularly if it is seen as having the potential to help others (Bloomer, Hutchinson, Brooks, & Botti, 2018). Research has also been undertaken specifically examining palliative care patients' perspectives on qualitative interviews (Gysels, Shipman, & Higginson, 2008). This research found that many dying people appreciate the opportunity to have their story heard, consider the chance to help others to be empowering and do not tend to consider qualitative interviews distressing.

As with all research, however, it remains both important and necessary to ensure the protection of participants involved in the study (Ballinger & Wiles, 2006). To achieve this, a number of considerations are required including informed consent, confidentiality and protection from harm (Brinkmann & Kvale, 2015).

3.6.1 Ethical approval

This study was granted ethical approval through the local Health Service Human Research Ethics Committee (approval number HREC/14/QTHS/196) and University Human Research Ethics Committee (approval number H6101). Two ethics extensions were approved by the local research ethics committee, each allowing for an additional year of data collection firstly up to March 2018 and then up to March 2019 (Appendix 2).

3.6.2 Informed consent

Prior to interviews taking place, potential participants were provided with a Participant Information Sheet (Appendix 4) and given time to read through this sheet and discuss any questions that they may have had in relation to the research. As part of this process, I emphasised to participants that they were in no way obliged to take part in the study and that they had the right to withdraw from the study at any point prior to the processing of their data. For the dying persons and/or caregivers, I further explained that their decision whether or not to participate would have no impact upon the nature of the care they receive through health services.

All participants were provided with an informed consent form to sign, indicating that they understood the study and wished to be involved (Appendix 9). When the interviews were completed, I undertook a secondary (verbal) consenting process through which I checked to ensure that the individual was still happy for his or her recording to remain a part of the research data. This secondary consenting process is important in qualitative research because it gives participants an opportunity to exclude any content they wish, given the unpredictable nature of discussions that may arise during interviews (Byrne, 2001; Creswell & Poth, 2018).

3.6.3 Confidentiality and anonymity

Participants' confidentiality and anonymity were maintained at all times through the research process. I took the following specific steps to ensure this:

- An identifying code was allocated to interview recordings to remove the need for personal identification within transcripts.
- Electronic copies of recorded interviews were copied to a secure, password-protected university server immediately following each interview. The interview was then deleted from the digital recorder.
- A confidentiality agreement was signed by the paid transcription provider, prior to recordings being sent for transcription.
- Once I received typed transcripts, all potentially identifiable details of participants and/or other individuals (such as friends, health professionals etc.) were altered within the transcripts.
- Identifying codes (rather than names) were (and will continue to be) used in all published materials and presentations.
- Information regarding which participants consented to partake in the study was not communicated to staff within the palliative care or community outreach teams.
- Consent forms have been digitalised and stored in the James Cook University secure repository where they will be retained for 15 years. All raw data pertaining to the project has been stored electronically on a password-protected university server. This data will be kept for five years following completion of this research, after which time it will be deleted.

3.6.4 Protection from harm

Given the sensitive nature of the topics that were discussed during interviews, there was potential for emotional harm in this study. For this reason I arranged for a hospital social worker to be available to provide support and counselling to any participants who felt this was needed after an interview; but no participants indicated that this was required. However, it was not uncommon during interviews for participants to discuss memories, thoughts or feelings that triggered an emotional response. Whenever this occurred, I offered to pause the interview and checked whether the participant wanted to take a break and/or cease the interview altogether. Most participants remained happy to continue; on one occasion, however, a dying person requested that we pause the interview for a few minutes before continuing.

I was also cognisant of the potential for physical burden on participants who might be feeling fatigued or physically unwell. I took steps to manage this by undertaking interviews at a time and place of the participants' choice, most often for dying people and/or their caregivers, in their home. I also made a habit of calling participants the day before the scheduled interview to make sure they were feeling well enough for the interview to take place. On one instance, this led to the cancellation of an interview. On a separate occasion, I decided not to pursue an interview as the participant seemed too unwell upon my arrival. A third interview was ceased after approximately 30 minutes because of pain being experienced by the participant. All three of these participants experienced a continued deterioration in their health and, as such, I did not attempt to re-schedule the interviews.

Given my concerns regarding participants' fatigue, I was surprised at the length of time some participants wanted to engage in conversation. I had anticipated interview durations of up to one hour; however, they generally ran for longer with a few interviews lasting more than two hours. When this occurred, participants usually had a short break at some stage during the interview process.

3.7 METHDOLOGICAL LIMITATIONS

There are several methodological limitations associated with this study that may have affected scope and quality. Perhaps the most noteworthy of these is the overt focus on illness-related dying. As detailed in Chapter One, ethical approval for this study stipulated that I could interview only dying people who had been informed of their dying status by a medical professional. The application of this criterion, therefore, obscured the first-hand perspective on non-illness related dying that I had also hoped to capture, based on the findings of my literature review. It was, however, a necessary decision to secure advancement of the research and, most likely, to protect the well-being of the participants involved.

A second methodological limitation lies in the fact that, although all dying persons whom I interviewed had been identified as having a prognosis of less than six months, I did not interview anyone who was thought to be in the final few days of life. Again, this decision was premised on the importance of ensuring that I did not inadvertently harm any participants through the interview process. The effect of this limitation is that my research lacks a first-hand perspective of late stage dying from dying persons. Although dying people, caregivers and health professionals did share stories of the final days of life of other people, these stories did not come from dying persons themselves.

I also did not interview any people who might be considered and/or might consider themselves as belonging to dying persons' outer social circles. This resulted in a limitation of my understanding of the experiences of these individuals in relation to their engagement with and/or disengagement from dying persons. Given that, in some interviews, dying persons expressed considerable frustration with the response of members of their outer social circle to their dying status, gathering the perspectives of these individuals would have assisted in gaining a more complete picture of the challenges and opportunities associated with end-of-life role relations.

As discussed previously in this chapter, I made a pragmatic decision to undertake interviews with dying persons who lived within the Townsville Hospital and Health Service boundaries. All participants who expressed an interest in the study lived within an hour of the city, meaning that I did not interview any dying persons or caregivers living in isolated rural and remote areas. It is entirely possible that both role change and dying role relations at end of life unfold very differently within communities in which geographic isolation necessitates close community support. Any interpretation of my study findings should be made in light of this fact.

Finally, although participants in this study came from a variety of cultural backgrounds, only one participant identified as Aboriginal and/or Torres Strait Islander. I made a number of efforts, without success, to increase participation in this study by Aboriginal or Torres Strait Islander people who comprise 7.9% of the population of the Townsville local government area (Queensland Government Statistician's Office, 2017). Hearing the thoughts and experiences of more participants from these backgrounds, as the original inhabitants of the lands on which this study was undertaken, would have been of considerable value. Future research into this topic should aim to gather this important perspective.

CHAPTER FOUR: EXAMINING THE TRANSITIONS BETWEEN LIVING AND DYING ROLES AT END OF LIFE

The findings and discussion presented in this chapter reflect the first phase of my data analysis during which I aimed to examine the way in which dying people transition from living roles to dying roles at end of life. In particular, I sought to identify the perspectives of dying people and their caregivers about their experience of role change and dying roles that I had identified in my literature review as being largely missing from the contemporary evidence base.

As I immersed myself in my interview data, it became very apparent that the windows into dying persons' worlds that I had been afforded through my clinical career as an occupational therapist offered only brief snippets of a much larger story. Furthermore, the way in which I had come to understand dying through my clinical role had been shaped by both my professional paradigm and associated approach to care. My particular professional role led me to encounters with dying people during periods of their lives in which they were experiencing symptom progression and/or functional decline. The professional lens through which I had come to understand dying, therefore, emphasised experiences of deterioration, loss and change. Based on my clinical experience, I had assumed that these points of foci would dominate dying persons' narratives. Instead, what I found were themes centred on uncertainty, ambiguity and resistance.

There seemed to be a tension associated with the dying role arising from long periods of relative stability during which dying people attempted to carry on with living while simultaneously faced with the reality of their dying status. For many participants, there appeared to be a drawn-out middle phase of dying which differed from what they had been expecting. Although this middle phase of dying was generally less dramatic than periods of rapid change, such as when a dying person first finds him or herself confronted with a dying diagnosis or during episodes of marked deterioration in health, it was troublesome in other ways. The more stories I listened to, the more I became aware that considerable difficulties seemed to stem from dying people remaining aware of their dying status for markedly longer than in times gone by. As such, many dying people find themselves faced with challenges associated with managing the twin realities of living while dying and dying while living over a very long time:

> "*Well, I was going to pass away within 12 months, everyone believed... and since then I've been at home, going backwards and forwards to the hospital waiting for something to happen.*" (P5)

In my research memos, I questioned what this elongated period of dying would mean to dying persons and their caregivers and how they would respond to the challenges and opportunities that it might bring. I also wondered whether the dying role would be sustainable for dying persons for long periods of time. Although the dying people I interviewed reported a clear understanding that death was approaching and unavoidable, many seemed to crave control over aspects of the dying journey that could be managed. This control appeared hampered by a lack of information and clarity regarding their likely prognosis.

With these early observations in mind, I constructed my first findings paper in which I focused on dying persons' experience of role transitions within an elongated and ambiguous dying space. This paper was first published (online) in Death Studies in 2018. The first page of the article is included in Appendix 1. A conceptual code map detailing the different layers of codes that informed the eventual findings of this chapter is outlined in Appendix 6. The article in its entirety is presented here as Chapter Four of this thesis. To maintain consistency with thesis presentation, minor modifications to the formatting of this journal article have been made in this chapter. These changes include the numbering of sub-headings, the repositioning of Figure 1 to align with relevant text, alteration of the spelling of some words to align with Australian English and presentation of numbers to conform to APA referencing standards. However, the written text of the article has otherwise been reproduced word-for-word.

Examining the transitions between living and dying roles at end of life

Daniel Lowrie BHSc (OT), MSc

Lecturer and PhD Candidate. College of Healthcare Sciences, James Cook University, Townsville, Australia.

Robin A. Ray BEd, MHSc, PhD

Associate Dean, Research Education. College of Medicine and Dentistry, Anton Breinl Research Centre for Health Systems Strengthening. James Cook University, Townsville, Australia.

David Plummer AM, MB, BS, PhD

Adjunct Professor. College of Medicine and Dentistry, James Cook University, Townsville, Australia.

Matthew Yau BAppSc, MCom, MSc (Hons), PhD, OTR, CST

Head and Professor. Department of Rehabilitation and Social Sciences, Tung Wah College, Kowloon, Hong Kong.

First published (online) – 4th October 2018. Published in hard copy of journal in 2019.

Death Studies, 43(10), 601-610 1-10. DOI: 10.1080/07481187.2018.1504836

4.1 ABSTRACT

Improvements in the diagnosis and disclosure of dying mean that nowadays dying people typically live with an awareness of their status for longer than they have previously. However, little is known regarding how transitions between living and dying roles occur during this time. In this grounded theory study, we investigated role transitions at end of life. We found that dying people periodically foreground and background living and dying selfhoods, focus on living day-by-day and goal-by-goal and reframe dying roles with an orientation to living. We argue that, with better understanding of role transitions at end of life, more compassionate and responsive care becomes possible.

4.2 BACKGROUND

It has been over half a century since Glaser and Strauss (1965) published their seminal work titled *Awareness of Dying*. Their research highlighted a tendency for the health professionals and loved ones of dying people to hide their dying status from them for large portions of the dying journey, with open awareness of dying occurring only when death was very near. Much has changed in relation to disclosure and awareness of dying since that time. Improvements in the diagnosis of dying, coupled with a tendency among doctors towards greater openness and transparency in the disclosure of dying, mean that many dying people live with awareness of their status for long periods of time (Field, 1996; Field & Copp, 1999). This knowledge has been identified as bringing with it several benefits such as the ability to better plan for and control various aspects of the dying process (Field & Copp, 1999; Howe, 2016; Seale, Addington-Hall, & McCarthy, 1997) as well as greater peace with dying (Lokker, Zuylen, Veerbeek, Rijt, & Heide, 2012). Changes to clinical practice have also been accompanied by a broader societal shift in relation to awareness of dying, resulting in a gradual rekindling of death and dying in films, plays, novels and general parlance (Doka, 2003; Walter, 1994; Walters, 2004). More recently, successful efforts to further normalise discussion regarding death and dying at a community level have been noted in relation to initiatives such as the Dying Matters Coalition (Nyatanga, 2013) and Death Café movement (Baldwin, 2017; Miles & Corr, 2017).

Despite these developments in the recognition and management of dying, little is known of what way, if any, they have influenced the enactment and experience of contemporary dying roles. The need for a better definition, identification and enactment of the dying role as a means of improving end-of-life care was discussed over 40 years ago by Noyes and Clancy (1977). In particular, Noyes and Clancy highlighted a lack of clear distinction between sick roles and dying roles, suggesting that role confusion resulting from extension of the sick role compromised the completion of key end-of-life tasks such as completion of wills and transfer of authority in household and business affairs. Given the important function that dying roles can play, there has been surprisingly little published research specifically focusing on these roles over recent decades. Two notable exceptions to this can be found in an application of role theory to palliative care by Emanuel, Bennett, and Richardson (2007) and Parker-Oliver (2000).

Emanuel et al. (2007) describe the dying role as having practical, relational and personal features. They assert that the practical facets of the dying role include tasks such as construction of wills, completion of advance directives and funeral planning. Relational dimensions of the dying role entail tasks including symbolic handover of role responsibilities, permission to the living to ‘move on’, and efforts by the dying person to finalise his or her life story and forge legacy. Finally, personal features of the dying role incorporate revisiting (and/or acting on) existential beliefs regarding end of life, adjusting to loss and change and seeking closure of (and, at times, growth in) relationships (Emanuel et al., 2007). Although Emanuel et al. (2007) acknowledge that uncertainty exists in the way in which dying people transition between living roles and dying roles, their paper focuses predominantly on the form and function of the dying role rather than the way in which it unfolds over time.

Insights into the process of role change at end of life are, however, offered in Parker-Oliver's (2000) dramaturgical analysis of dying within the context of hospice care. Parker-Oliver (2000) emphasises the inadequacy of the sick role in the drama of the dying and highlights the value of the hospice community in acting as a catalyst for the effective transition to the dying role. She suggests that successful role transitions are achieved when the hospice team members act as co-directors in the drama of dying (along with the dying person and close relatives), thus preventing role confusion among the various actors for whom dying roles will often be new. Her analysis focuses on three key scenes, namely the introduction of the dying role, the fulfilment of the dying role and the deathbed scene. Details are provided in relation to each of these scenes concerning the potential function of the hospice community in guiding dying people and their loved ones in a manner that supports them in achieving role clarity and extracting meaning and fulfilment from the time remaining. While the ideas presented by Parker-Oliver (2000) are valuable, they focus heavily on the function of hospice services in shaping role transitions and role relations. Her analysis is thus limited in scope to the elements of the dying journey in which hospice staff play a prominent role. Although these scenes are important, they do not necessarily reflect the broader drama of dying, most of which is played out beyond the reach and influence of hospice services.

The research presented in this paper aims to build on the evidence base described above by offering an examination of the relationship between living and dying roles within the context of the contemporary drama of dying. Particular attention is paid to the way in which dying people and those around them negotiate role transitions within what nowadays is often a lengthy period of time between diagnosis of dying and the actual event of death. Priority has also been given to the perspectives and experiences of dying people and their family and friends. It is hoped that, in doing so, a more comprehensive picture of the dying experience will be achieved, thus positively influencing health care practice.

4.3 METHODOLOGY

The findings presented here form part of a broader Australian-based study examining the process of role change at end of life. The overarching research adopted a qualitative design utilising a constructivist grounded theory approach to guide the process of data collection and analysis. The findings specifically described in this paper relate to one of the categories arrived at through this process, *'oscillating between living and dying selfhoods'*.

Grounded theory is a research methodology that supports the development of a robust explanatory framework regarding a social process, action or interaction founded on the views of participants. Grounded theory studies involve a progressive process of in-depth analysis of individual cases from which researchers extrapolate more general explanations concerning the process being studied (Bryant & Charmaz, 2010). It is through this ongoing and systematic process of categorisation and comparison of research data that the development of theory occurs. In constructivist grounded theory studies, key concepts and subsequent theory are derived from, and are grounded in, research data but the role of the researchers in interpreting data and constructing theory are acknowledged (Charmaz, 2014).

4.3.1 Sampling and recruitment

In order to better understand the relational nature of dying roles, this research examined the perspectives of dying people as well as the perspectives of their family members and/or caregivers. Participants in this research project were recruited purposively through the adoption of a theoretical sampling approach to promote maximum variation within the sample (Creswell, 2013; Morse, 2010). Theoretical sampling began quite broadly and became increasingly focused and circumscribed as the study progressed, thereby enabling the development and refinement of emergent theory (Dey, 2010).

Potential participants were made aware of this study through an information flyer and participant information sheet. Copies of these were displayed in the regional Palliative Care Centre and were provided to members of the local Palliative Care Outreach Team for distribution to individuals who might be interested in participating in the study. Participants were deemed eligible for inclusion in this study if they had been diagnosed as having a life expectancy of six months or less, or were a family member and/or caregiver of an individual with a life expectancy of six months or less. Potential participants were considered ineligible for the study if they were younger than 18 years of age, had rapidly deteriorating conditions, were identified as being within the last 48 hours of life, or had conditions or symptoms that negated their ability to participate meaningfully in an interview.

The sample size for the research project was based on the principle of data saturation. Therefore, recruitment continued until no new variant cases emerged and no new themes were identified within the interview data (Glaser & Strauss, 1967). A total of 21 participants were interviewed in this study - 13 dying people (identified in this paper as P1 to P13) and eight family caregivers (identified as C1 to C8). Five dying person-caregiver dyads (totalling 10 participants) were present among the participant sample. Twelve participants were women (five dying people and seven caregivers) and nine were men (eight dying people and one caregiver). Participants' ages ranged from 30 to 87 and averaged 69 for dying people and 57 for carers. Thirteen participants identified as White Australian, one as Aboriginal Australian, five as White British and two as White New Zealander. All participants were living in Australia. Eleven participants described themselves as working class and 10 as middle class. Among the 13 dying persons, 10 had cancer diagnoses, one had motor neurone disease, one had chronic obstructive pulmonary disorder and one indicated having multiple diagnoses.

4.3.2 Data collection and analysis

Data were collected with semi-structured interviews undertaken by the first author. Two interviews were conducted with the dying person and caregiver both present; the remainder were undertaken individually. An interview guide was used as a flexible tool for structuring interviews and as a prompting device. The research team (all four study authors) developed this interview guide based on their professional and research experience as well as on a broad ranging review of the literature. The interview guide was modified by the research team following preliminary data analysis after each interview in order to enable the continued refinement of emergent theory (Charmaz, 2014).

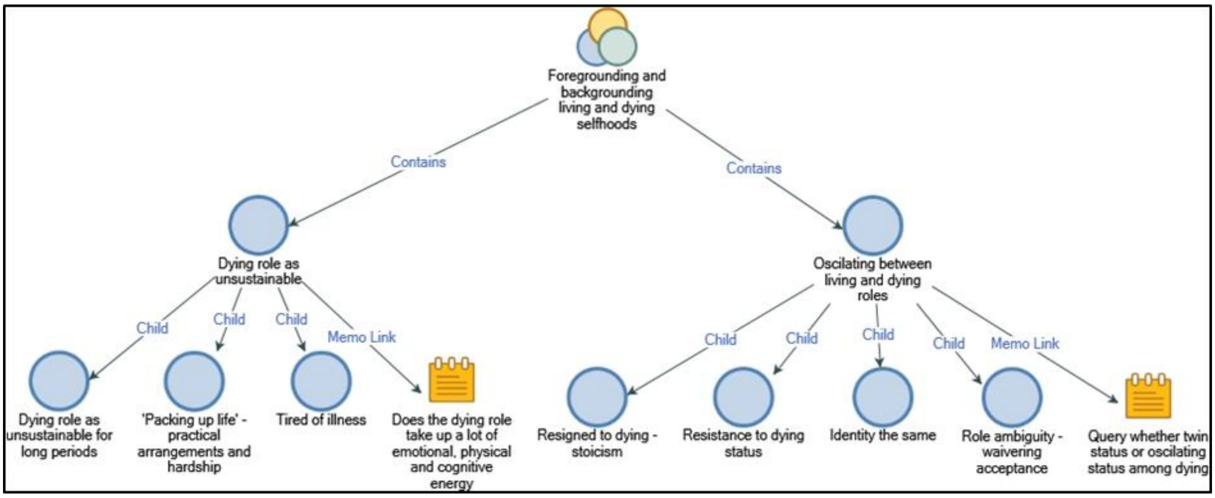
Interviews were conducted at a time and location agreed upon by the participant and the first author, most often in participants' homes. Interviews ranged in length from 30 minutes to 177 minutes, with the average interview length being 88 minutes. All interviews were digitally recorded and transcribed verbatim to enable data analysis. NVivo Pro software© (version 11) was used to assist in organising data during the analysis process.

Data were analysed through the use of a grounded theory framework (Glaser & Strauss, 1965) with modifications recommended by Layder (1993) to accommodate observational evidence, documents and artefacts and also by Charmaz (2014) to reflect a constructivist and interpretive stance. Theory was developed and refined through the iterative processes of coding, analysis and comparison. Theory generation was further guided through the blended application of narrative inquiry and dramaturgical analytical lenses. The lens of narrative inquiry assisted in facilitating an understanding of the reciprocal relationship between each participant and his or her social context by focusing on experiences, milestone events, key characters and chronology (Creswell, 2013; Thomas, 2012). Dramaturgy (which draws on the metaphor of theatre as a framework examining human interactions) served as an analytical device in examining role enactment and role relations at end of life (Goffman, 1959). Specifically, it enabled analysis of the various scripts, props, costumes, gestures and so on employed by the various actors in co-constructing and maintaining the drama of dying through their interactions (Goffman, 1959).

Substantive coding of the research data began with open (initial) coding. The first author undertook a process of line-by-line coding of data, in which ‘key incidents’ from the participants’ narratives were compared to each other and to the emerging concept. This process of line-by-line coding helped in ensuring that no important categories were omitted and that the identified categories were saturated with rich and relevant data (Glaser & Holton, 2004). Initial codes were discussed among the whole research team and revised, based on feedback and discussion. Focused coding was then conducted in order to refine the emerging conceptual framework. This process involved the targeted collection and analysis of data, through theoretical sampling and constant comparison, to refine the logic and boundaries of the theory (Holton, 2010).

Theoretical notes (‘memos’) were recorded by the first author throughout the data collection and analysis phases. These memos were used in mapping the emergence of codes and categories and, in turn, the development of theory. Memos were discussed with the research team along with the open and selective coding processes to guide analysis and foster a robust and transparent reasoning process (Saldana, 2013). The first author also maintained a research diary in order to make notes on thoughts, feelings and observations relating to interviews for later discussion and analysis. Both the diary entries and theoretical memos assisted in identifying, examining and appropriately managing researcher perspectives and biases, thus promoting reflexivity (Snowden, 2015) and provided an audit trail of the analytic processes. An example of the progressive development of codes, memos and theory in this research is outlined as a conceptual map in Figure 1 (below). This particular conceptual map relates to the development of one theme from this study ('*foregrounding and backgrounding of living and dying selfhoods*').

Figure 1: Sample of conceptual map showing the process of thematic development from codes and memos



4.3.3 Ethical considerations

The study received ethical approval through the local Health Service Human Research Ethics Committee (approval number HREC/14/QTHS/196) and University Human Research Ethics Committee (approval number H6101). Participants were informed in writing that they were not obliged to participate in the study and that they had the right to withdraw at any stage without consequence (prior to the final processing of their data). Given the sensitivity of the research topic, consent was revisited after the completion of each interview to ensure that participants remained happy for their narrative to form part of the study (Byrne, 2001). Participant confidentiality was maintained by the removal of all identifying information at the point of transcription. Identifying information relating to people mentioned by participants in their interviews was also removed at this point.

4.4 FINDINGS

Four interrelated themes were identified through the data analysis process. The first theme, *'existing in an elongated and ambiguous space'* highlights the difficulties that dying people and their family and/or caregivers experienced in navigating the experience of living with a dying diagnosis. The remaining themes of *'foregrounding and backgrounding living and dying selfhoods'*; *'living contingently'*; and *'preserving hope through reframing dying roles'* all discuss the way in which dying people and their caregivers respond to these difficulties.

4.4.1 Existing in an elongated and ambiguous dying space

Both the dying people and their family/caregivers in this study made frequent references to the existence of an elongated and ambiguous timeline between the diagnosis and the actual event of dying. Interestingly, almost all of the dying people interviewed reported to have far exceeded the prognoses suggested to them by their treating doctors. For example, P8 stated: *"When I got diagnosed with the brain cancer, they said, 'oh, you'll probably only last about three months'. That was four years ago."* A number of participants even reported that it had been suggested to them that they might have set some sort of survival record:

> *"The palliative care doctor didn't think I'd survive anywhere near where I am now. My GP [General Practitioner], I said to her the other day, 'look, I think that I'm going to make medical history.' And she said 'I think you already are making it.'"*
>
> (P2)

It would be unreasonable to suggest, based on this sample of dying people outliving their prognoses, that under-prognostication is routine, given the obvious fact that only people who were still alive were interviewed. The data does suggest, however, that it is not uncommon for dying people to remain alive far beyond the estimated prognoses indicated to them by medical professionals. Although, in many ways, living longer than expected might be regarded as positive, several participants highlighted the emotional burden associated with maintenance of a dying identity for long periods. As well as this emotional toil, the associated loss of prognostic clarity also brought with it a degree of difficulty and frustration for dying people and their caregivers who bemoaned the lack of control and inability to plan that accompanies an uncertain dying trajectory:

> *"Don't tell her she's got a month if you don't know it's going to be a month, because when the doctor told her you've got a month she expected to be gone in a month, and that was really hard when she wasn't… He was adamant. He said you're not going to be here at Christmas time, I'll guarantee you that… So I would recommend don't tell the person unless you're 100 per cent [voice breaks] certain that they've got X amount of time, because that really did her head in, it really did. In a way it did mine too because I was - I couldn't plan anything. I've got a boy whose birthday's before Christmas. [I thought] Oh, don't die on my boy's birthday, or close to there. It's going to do him in. Oh, is it going to happen at Christmas. Everybody's saying 'what are you going to be doing for Christmas?'… I didn't know what was going to be happening for Christmas because I didn't know if she was going to be here or not. So - don't tell people if you don't know."* (C1)

> *"I guess from the planning point of view it would be really nice to know this is exactly… how much time you've got… I guess that's one of the frustrations, is just not knowing. It doesn't seem to matter where you get to, you never know how much time you've got left, you know?"* (P10)

In being confronted by the knowledge that they are in a dying state, compounded by the lack of clarity as to when they would actually die, participants found themselves existing in highly contingent states of being. Given the emotional burden associated with the dying role, most seemed to resist identifying themselves as dying persons by focusing on themselves as living beings for the majority of the time. Nevertheless, the reality that death was nearing remained ever present. Participants managed this duality through the processes of periodically foregrounding and backgrounding their living and dying selfhoods, living contingently and reframing dying roles as living roles.

4.4.2 Foregrounding and backgrounding living and dying selfhoods

The dying people in this study did not describe linear and/or fixed status shifts from living to dying; instead, they seemed to periodically foreground and background their living and dying selfhoods at different times. For example, one participant described the way in which he foregrounded his living self when at home but backgrounded this when in hospital:

> *"I like to live two lives. I like to live the life that I've got at home and all of the happiness and everything around with my grandkids, and all of the things that I can do with them now, even with the limitations that I have... I like to live that life and then, if I have to go into the hospital...I live that life on that day or in that week. Then when I leave there, that's it, I'm back to my other life, and it works... It just keeps me from falling into a depressive state or whatever."* (P5)

The decisions as to which facet of self to project and role to play lie ultimately with the dying persons themselves but this is heavily influenced by a variety of events and contextual factors, particularly if these factors are deemed to be important to them. For example, many participants recounted stories regarding the point at which their treating doctors first indicated that their condition was incurable and subsequently referred them to palliative care. During this time, the dying self was foregrounded as the dying person attempted to adjust to his or her changed status and deal with the immediate practical and relational implications that accompanied it:

> *"So they were big times of talking through a lot of things, talking through end-of-life things, just [my wife] and myself. Just thinking, well okay, if we have to face that this is what we're facing, then we have to do it together. We have to do all this - and making preparations, doing things that we know will be helpful later."* (P9)

This focus on dying served a particular purpose at the time. In subsequent (and non-medical) social encounters, however, these same individuals would often block attempts from members of their social network to draw them towards a projection of themselves as dying:

> *"... generally, I find people come out wanting to know the ins and outs of everything, how you're feeling today, where is it and all this sort of stuff. You get fed up with that. I'm not going to talk about that anymore."* (P9)

All the dying people interviewed seemed to resist the dying identity by foregrounding their living selfhood for the majority of the time. However, periodically they would instead endeavour to foreground their dying self as they engaged in tasks such as arranging their affairs or as they attempted to speak with their loved ones regarding their thoughts and feelings about dying. Curiously, many participants described these attempts at foregrounding their dying selfhood with close friends and families as being met, at times, with resistance, resulting in the dying role remaining out of bounds.

4.4.3 Living contingently

By far, the most common phrase in the narratives of dying people and their caregivers related to the necessity of 'living day-by-day'. When using this phrase, participants sometimes seemed to be describing efforts aimed at making the most of their remaining time. Participant P2 offered an example of this: *"So yeah, so that's where I'm at, at the moment, just taking it a day at a time and making the most of every day."* Participant P6 expressed similar sentiments highlighting the importance of being at home in living life to the fullest:

> *"So I'm grateful to be in our own home and just, as I say, I take one day at a time. It's just make the most of everything and, you know."*

There was also, however, a second meaning at play that centred on the ambiguity and uncertainty emanating from the lack of clarity as to when the final stages of dying might actually begin. This resulted in a highly contingent state of being for dying people and their caregivers who were faced with the impending reality that the dying person would die sometime soon although there was a lack of certainty as to when. For example, participant P8 described the loss of control that accompanied prognostic ambiguity: *"So at the moment, I just wake up every morning, I'm always it's another day, you know, so I just think, well, just go with it. There's nothing I can do about it."* In response to these situations of uncertainty, dying people and their caregivers attempted to regain a sense of agency through the foregrounding of role relations founded on a tentative cycle of day-by-day living. As such, they seemed to be ad-libbing much of life's final act while they awaited the declaration that the closing scene had arrived:

> *"I think I've just put it out of my mind and I live my life day-by-day. As my wife says, 'you know, yeah, you're going to die but not today'. We've both sort of operated on that sort of level."* (P5)

One way that dying people and their caregivers extended the sense of control over the dying process involved shifting their mindset from living day-by-day towards living on a goal-by-goal basis. Goal-by-goal living helped in ensuring that each scene in life's final act had a point of focus and purpose, thereby countering some of the uncertainty and mundanity of day-by-day living. Each milestone offered a source of hope that alleviated thoughts and feelings of simply waiting for death, thus allowing the dying person to nurture a stronger hold on his or her living selfhood:

> *"I've got at the moment a little bucket list going, so I'm sort of trying to just get to do them… I've got [grandson], right here. [daughter] [40] next year, [granddaughter] is 16 next year… [Interviewer – You just keep ticking them off, do you?]*
> *"Yep. I think it keeps me going."* (P8)

> *"Then of course, he probably would have told you [daughter]'s having a baby next year so we will be grandparents for the first time in April. So now that's become a really big focus for him; that I'm going to work hard to stay around for the baby's birth and all that sort of stuff. So yeah, it's about giving him some hope and some forward thinking when everything gets too tough."* (C4)

4.4.4 Preserving hope by reframing dying roles

Dying people and those closest to them also lessened the emotional burden associated with the dying role by leveraging the conceptual overlap between living and dying. This overlap allowed key elements of the dying role to be enacted under the guise of a focus on living. This was particularly evident in situations such as special social gatherings that had been arranged for the dying person by their families. Generally, such events were highly regarded. For example, participant C3 recounted the story of a recent family holiday that had been organised by her children; *"We went up to [small town] to the village up there, and had a wonderful time. The children came from [out of state] for the school holidays so we went up there for a couple of days."* Similarly, participant P5 spoke at length about his feelings of excitement in relation to an upcoming getaway; *"We've got a house booked over on the island, a beautiful home, and the whole family's going to be there."*

It is worthy of note that, although everyone knew the intention of these events, there tended to be an unspoken requirement for all parties to adhere to a social script in which reference to or focus on dying remained off-limits. This led to encounters in which, although all parties knew of the dying individual's status, it was not discussed or even acknowledged. While, at face value, this state of affairs may seem contradictory, it served a purpose in allowing at least some relational and personal elements of the dying role to be enacted, without highlighting the dying status of the dying person:

> *"[P10] sort of said at his birthday party to everybody 'I'm not a man of many words… all I can say is see you next year for my birthday next year'. Anyway, [daughter] said to me later, 'Mum, do you really think he thinks that he may be alive next November?' I said, 'Darling, I don't know'. She said, 'Oh, surely he knows that'. I said, 'Well, I'm certainly not going to say it to him'… and also the people who are here, they want to have hope as much as he wanted to have hope. So we can't take that away from people but even she felt - I could tell that she knew. I mean, everyone knows."* (C4)

In a similar fashion, following their dying diagnosis, some participants undertook activities that were focused on making the most of moments with their family. Again, by couching these activities in terms of living life to the fullest, the dying persons and those around them were able to enact some aspects of the dying role (such as forging memories) without the need to acknowledge dying per se. An important and influential taboo concerning the fear of destroying hope is at play in all of these circumstances. Maintenance of hope is regarded as a central tenet in the contemporary drama of dying and all actors are exposed to considerable social pressure not to do or say anything to undermine it. By accepting and enacting a position of shared pretence whereby the dying person's status is backgrounded, all parties ensure that this taboo is not broken.

Although, for the most part, this shared pretence seemed to work well, it did, on some occasions, result in missed opportunities that a more overt acknowledgement of dying might have afforded. For example, participant P6 reflected on conversations that she had wanted to have with her immediate family who had visited from overseas but had not managed to because of a busy schedule focused on doing things together: *"I think [voice breaks] there were things that probably needed to be said too, that didn't get talked about."*

4.5 DISCUSSION

Our research findings suggest that heightened awareness of dying in what is increasingly an elongated dying space can result in significant emotional burden for dying people and their caregivers. Taken collectively, the findings of our research offer insights into a number of ways in which dying people and those close to them might manage this emotional burden. As such, these findings have important implications both conceptually and clinically.

The tendency for dying people to periodically foreground and background their living and dying selfhoods points to the idea that the transition to a dying status is not a fixed or linear process for many individuals. In historical times, fixed status shifts may have served a necessary function because the time between recognition (or disclosure) of the dying status and the event of death tended to be brief (Aries, 1981; Kellehear, 2007). Hence, the dying role needed to be (and typically was) enacted in a relatively quick and ongoing manner. However, these fixed status shifts do not seem to be sustainable in the lengthier drama of contemporary dying, especially with respect to the personal and relational facets of the dying role. In response to this, dying people oscillate between living and dying roles with a tendency towards projection of their living selfhood for the majority of the time. The notion of dying as an oscillating state of being and the associated challenges that this can bring for dying people and their caregivers have been discussed previously in the literature (Breen, Aoun, O'Connor, Howting, & Halkett, 2018; Kellehear, 2009). Our findings add to this picture by highlighting the possibility that the emotional burden associated with the contemporary dying role render these temporary transitions both commonplace and necessary in protecting the well-being of dying people as well as their family and /or caregivers.

Our findings also suggest that, to some extent, heightened awareness of dying, without prognostic clarity, seems to compromise, rather than enhance, the sense of agency and control over one's life that disclosure of dying is intended to provide. Although disclosure of dying unquestionably enables timely enactment of the practical dimensions of the dying role, many of its relational and personal aspects are most suited to the closing scenes of life and there is often considerable uncertainty as to when this will commence. The rather tentative focus of dying people and their caregivers upon day-by-day and goal-by-goal living can be understood as a means of re-asserting a degree of control and clarity back into their lives.

The manner in which many participants in our research reframed dying roles in the context of living can also be seen as a mechanism for coping with prognostic uncertainty in an elongated dying space. This mindset reflects a contemporary extension of what Glaser and Strauss (1965, p. 64) termed "mutual pretence" (p. 64). Mutual pretence refers to an awareness context in which all parties know of a dying person's status but nobody openly acknowledges or discusses it. Mutual pretence seemed to serve a protective function for many of the participants in our research by ensuring that, despite being aware of their dying status, they did not have to refer to it for the majority of the time. Interestingly, by reframing the dying as having a focus on living, dying people and those close to them managed to enact many of the dying role's personal and relational elements, without overtly and/or prematurely foregrounding the dying selfhood.

A central theme concerning the preservation of hope is present in all of the findings presented in this paper. Discussions between doctors and dying people regarding prognostic record-breaking, the foregrounding of the living selfhood (and living roles) and the emphasis that dying people place on goal-by-goal living might all be understood in this light. Furthermore, the tendency for dying people and those close to them to avoid overt acknowledgement of the dying status (in most situations) is reflective of the presence of a deep taboo regarding the destruction of hope.

Recent research has indicated that dying people place considerable importance upon the maintenance of hope, regardless of their disease stage (Broadhurst & Harrington, 2016). Research also shows, however, that in some situations dying people can experience a sense of social obligation to present an outward appearance of hope, as a means of protecting their loved ones (Sachs, Kolva, Pessin, Rosenfeld, & Breitbart, 2013). Similarly, recent evidence suggests that some caregivers avoid preparatory tasks related to dying based on fears that engaging in such actions may compromise hope and hasten death (Breen et al., 2018). Our findings add to this picture by highlighting that missed opportunities to address important end-of-life matters can be lost in circumstances where emphasis on hope necessitates the backgrounding of dying.

When considering the clinical implications of our findings, it is important to first note that we do not intend to imply here that disclosure and awareness of dying are problematic per se. The importance and value that dying people and their caregivers tend to place on full and honest communication regarding dying is well established (Caswell, Pollock, Harwood, & Porock, 2015; Hancock et al., 2007). Our findings do suggest, however, that earlier recognition of the dying status can also bring with it hidden complications for dying people that warrant consideration. For health professionals, recognising the extent to which dying people struggle with the ambiguity of the dying trajectory and understanding the steps they take to manage this ambiguity is important for the provision of quality care. Achieving complete accuracy in prognostication will never be possible. Furthermore, recent research evidence suggests that most doctors already acknowledge the limits relating to prognostic estimations with their patients (Henselmans, Smets, Han, de Haes, & van Laarhoven, 2017).

Regardless, it is in the management of the challenges and opportunities associated with the twin realities of *living while dying and dying while living* that dying people and those close to them might need understanding and support (Clemmer, Ward-Griffin, & Forbes, 2008). Better understanding of the way in which dying people attempt to manage the elongated drama of contemporary dying is thus critical to the design and delivery of more sensitive, flexible and compassionate care.

4.6 LIMITATIONS

To be eligible for participation in this study, participants needed to be both aware of their dying diagnosis and well enough to participate in an interview. These requirements may have affected the nature of our findings in that data was not gathered from individuals with rapidly progressing disease or from people who had not yet been made aware of their dying status. With this in mind, it is likely that the ideas discussed in this paper will not be applicable to all forms of dying and should, therefore, be interpreted with caution. The inclusion and exclusion criteria also meant that participants who considered themselves as being very close to death were not interviewed. The way in which the dying role unfolds in the final scenes of life and the way in which role enactment in the preceding scenes may affect this process were beyond the scope of this study. Although it would be valuable to undertake further research into experiences during this phase of dying, doing so would be ethically challenging (Aoun, Slatyer, Deas, & Nekolaichuk, 2017; Bloomer, Hutchinson, Brooks, & Botti, 2018). Interviewing family and/or caregivers after the death of their loved one may lead to some valuable insights; however, researchers would need to remain mindful of the potential for the perspectives of dying people to be lost through such an approach.

4.7 CONCLUSION

In this paper, we have examined the transitions between living and dying roles at end of life from the viewpoints of dying people and their caregivers and/or family members. We have identified that improvements in diagnosis of dying, coupled with uncertainty regarding prognostication can result in an elongated and ambiguous dying trajectory. We have suggested that dying people respond to this by periodically foregrounding and backgrounding living and dying selfhoods, living contingently and reframing dying roles with a focus on living. All of these approaches serve an important function in promoting and maintaining hope for dying people and their loved ones. However, sometimes they can also result in missed opportunities for addressing end-of-life matters that dying role relations would otherwise afford.

REFERENCES

Aoun, S., Slatyer, S., Deas, K., & Nekolaichuk, C. (2017). Family caregiver participation in palliative care research: Challenging the myth. *Journal of Pain and Symptom Management, 53*(5), 851-861. doi:10.1016/j.jpainsymman.2016.12.327

Aries, P. (1981). *The hour of our death.* (H. Weaver, Trans.). New York: Alfred A. Knopf.

Baldwin, P. K. (2017). Death cafés: Death doulas and family communication. *Behavioral Sciences, 7*(2), 1-8. doi:10.3390/bs7020026

Bloomer, M. J., Hutchinson, A. M., Brooks, L., & Botti, M. (2018). Dying persons' perspectives on, or experiences of, participating in research: An integrative review. *Palliative Medicine, 32*(4), 851-860. doi:10.1177/0269216317744503

Breen, L. J., Aoun, S. M., O'Connor, M., Howting, D., & Halkett, G. K. B. (2018). Family caregivers' preparations for death: A qualitative analysis. *Journal of Pain and Symptom Management.* doi:https://doi.org/10.1016/j.jpainsymman.2018.02.018

Broadhurst, K., & Harrington, A. (2016). A mixed method thematic review: the importance of hope to the dying patient. *Journal of Advanced Nursing, 72*(1), 18-32. doi:10.1111/jan.12765

Bryant, A., & Charmaz, K. (2010). *The SAGE handbook of grounded theory* (Pbk. ed.). Los Angeles: Sage.

Byrne, M. (2001). The concept of informed consent in qualitative research. *AORN journal, 74*(3), 401-403. doi:10.1016/S0001-2092(06)61798-5

Caswell, G., Pollock, K., Harwood, R., & Porock, D. (2015). Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study. *BMC Palliative Care, 14*(1), 35. doi:10.1186/s12904-015-0032-0

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London: Sage.

Clemmer, S. J., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: the enactment of multiple roles. *Canadian Journal on Aging, 27*(3), 267-283.

Creswell, J. W. (2013). *Qualitative inquiry and research design: choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Dey, I. (2010). Grounding categories. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 167-190). Los Angeles: Sage.

Doka, K. J. (2003). The death awareness movement. In C. D. Bryant (Ed.), *Handbook of death & dying* (pp. 50-56). Thousand Oaks, CA: Sage.

Emanuel, L., Bennett, K., & Richardson, V. E. (2007). The dying role. *Journal of Palliative Medicine, 10*(1), 159-168. doi.org/10.1089/jpm.2006.0134

Field, D. (1996). Awareness and modern dying. *Mortality, 1*(3), 255-265. doi:10.1080/13576279609696247

Field, D., & Copp, G. (1999). Communication and awareness about dying in the 1990s. *Palliative Medicine, 13*(6), 459-468. doi:10.1191/026921699668763479

Glaser, B. G., & Holton, J. A. (2004). Remodeling grounded theory. *Forum Qualitative Sozialforschung, 5*(2).

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying.* Chicago.: Aldine Transaction.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine Pub. Co.

Goffman, E. (1959). *The presentation of self in everyday life*. New York: Penguin Books.

Hancock, K., Clayton, J. M., Parker, S. M., Walder, S., Butow, P. N., Carrick, S., . . . Tattersall, M. H. N. (2007). Discrepant perceptions about end-of-life communication: A systematic review. *Journal of Pain and Symptom Management, 34*(2), 190-200. doi:https://doi.org/10.1016/j.jpainsymman.2006.11.009

Henselmans, I., Smets, E.M.A., Han, P.K.J., de Haes, H.C.J.C., & van Laarhoven, H.W.M. (2017). How long do I have? Observational study on communication about life expectancy with advanced cancer patients. *Patient education and counseling, 100*(10), 1820-1827. doi:10.1016/j.pec.2017.05.012

Holton, J. A. (2010). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 265-289). Los Angeles: Sage.

Howe, E. (2016). The "dying role": A new path, already well trodden. *Psychiatry, 79*(3), 208-211. doi:10.1080/00332747.2016.1222159

Kellehear, A. (2007). *A social history of dying*. New York: Cambridge University Press.

Kellehear, A. (2009). *The study of dying. From autonomy to transformation.* Cambridge: Cambridge University Press.

Layder, D. (1993). *New strategies in social research: An introduction and guide*. Cambridge, U.K: Polity Press.

Lokker, M., Zuylen, L., Veerbeek, L., Rijt, C., & Heide, A. (2012). Awareness of dying: It needs words. *Supportive Care in Cancer, 20*(6), 1227-1233. doi:10.1007/s00520-011-1208-7

Miles, L., & Corr, C. A. (2017). Death cafe: what is it and what we can learn from it. *Omega - Journal of Death and Dying, 75*(2), 151-165. doi:10.1177/0030222815612602

Morse, J. M. (2010). Sampling in grounded theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 229-244). Los Angeles: Sage.

Noyes, R., Jr., & Clancy, J. (1977). The dying role: Its relevance to improved patient care. *Psychiatry, 40*(1), 41-47. doi.org/10.1080/00332747.1977.11023918

Nyatanga, B. (2013). Dying matters awareness week: Refocusing on sensitivities of dying. *British Journal of Community Nursing, 18*(4), 202. doi.org/10.12968/bjcn.2013.18.4.202

Parker-Oliver, D. (2000). The social construction of the "dying role" and the hospice drama. *OMEGA - Journal of Death & Dying, 40*(4), 493-512. doi.org/10.2190/yt9d-12y2-54ly-tcmn.

Sachs, E., Kolva, E., Pessin, H., Rosenfeld, B., & Breitbart, W. (2013). On sinking and swimming: The dialectic of hope, hopelessness, and acceptance in terminal cancer. *American Journal of Hospice and Palliative Medicine, 30*(2), 121-127. doi:10.1177/1049909112445371

Saldana, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). London: Sage.

Seale, C., Addington-Hall, J., & McCarthy, M. (1997). Awareness of dying: Prevalence, causes and consequences. *Social Science & Medicine, 45*(3), 477-484. doi:10.1016/s0277-9536(96)00379-6

Snowden, M. (2015). Use of diaries in research. *Nursing Standard, 29*(44), 36-41. doi:10.7748/ns.29.44.36.e9251

Thomas, S. (2012). Narrative inquiry: Embracing the possibilities. *Qualitative Research Journal, 12*(2), 206-221. doi:10.1108/14439881211248356

Walter, T. (1994). *The revival of death*. London: Routledge.

Walters, G. (2004). Is there such a thing as a good death? *Palliative Medicine, 18*(5), 404-408. doi:http://dx.doi.org/10.1191/0269216304pm908oa

CHAPTER FIVE: ALIGNMENT AND MISMATCH IN ROLE RELATIONS AT END OF LIFE

In the previous chapter, I presented evidence to argue that dying persons do not typically undergo fixed status transitions into the dying role but, instead, periodically foreground and background their living and dying selfhood. Although this approach did seem to assist in managing the emotional and physical demands of an elongated dying trajectory, I came to realise that it also brought about challenges of its own. The benefits of fixed status shifts lie in the fact that they enable all actors in a given social situation to be reasonably confident of their part in the role relations within that situation. However, with the foregrounding and backgrounding of living and dying roles, situations of mismatch in role relations seemed to occur frequently among dying persons and members of their inner and outer social circles. This resulted in social encounters that were often unsatisfactory and frequently even distressing for one or more parties.

I thus turned my attention to examining, in detail, the experience of mismatched role relations at end of life and the reasons why such mismatches occur. My findings were published (online) in Death Studies in 2019. The first published page of the article is included in Appendix 1. A conceptual code map that details the different layers of codes that I focused on when constructing the findings of this chapter is outlined in Appendix 7. The article is presented here in its entirety as Chapter Five of this thesis. As was the case with Chapters Two and Four, minor modifications to the formatting of this journal article necessary for consistency with thesis presentation have been made in this chapter. These changes include the numbering of sub-headings, modifications to the presentation of numbers so that they adhere to APA referencing standards and alteration to the name of what was

Table 1 in the published paper to Table 3 in this thesis. Aside from these changes, the written text of the article has been reproduced word-for-word.

Alignment and mismatch in role relations at end of life. A constructivist grounded theory study.

Daniel Lowrie BHSc (OT), MSc

Lecturer and PhD Candidate. College of Healthcare Sciences, James Cook University, Townsville, Australia.

Robin A. Ray BEd, MHSc, PhD

Associate Dean, Research Education. College of Medicine and Dentistry, Anton Breinl Research Centre for Health Systems Strengthening. James Cook University, Townsville, Australia.

David Plummer AM, MB, BS, PhD

Adjunct Professor. College of Medicine and Dentistry, James Cook University, Townsville, Australia.

Matthew Yau BAppSc, MCom, MSc (Hons), PhD, OTR, CST

Head and Professor. Department of Rehabilitation and Social Sciences, Tung Wah College, Kowloon, Hong Kong.

First published (online) – 9th August 2019

Death Studies, [online] 1-10 DOI: 10.1080/07481187.2019.1648330

5.1 ABSTRACT

In this Australian, constructivist grounded theory study, we undertook in-depth interviews with 11 dying people and eight caregivers to examine their perspectives on role relations at end of life. We found that situations of role alignment between dying people and their family and friends support positive relational and practical outcomes, whereas role mismatch can cause considerable distress. Factors contributing to role mismatch at end of life were: dying people and their caregivers' efforts to shield each other from emotional harm; fear of social exclusion; and unwanted focus on the dying identity. Our findings highlight a need for flexibility and adaptability in end-of-life role relations.

5.2 BACKGROUND

Dying roles serve an important function in guiding the enactment of key practical, personal and relational tasks during the end-of-life period (Emanuel, Bennett, & Richardson, 2007). Like all social roles, dying roles are not fixed entities, occurring instead as a negotiated process between individuals (Biddle, 1986). This means that different actors play an active role in shaping role relations (Lynch, 2007). Understanding the relational nature of dying roles is of particular importance in palliative and end-of-life care. Dying persons continue to exist within a network of socially reciprocal relationships; therefore, dying unfolds as a collective experience among dying persons and their loved ones rather than as a solitary affair (Broom & Kirby, 2013; Kellehear, 2008; Scarre, 2009). With this in mind, the dying process can be understood as bringing to the forefront complex needs, wishes and agendas not only for dying people but also for members of their social networks (Broom & Kirby, 2013; Kellehear, 2008).

Relationships between dying people and their friends and family are known to have a profound influence on the experiences of dying and end-of-life care (Broom & Kirby, 2013; Kellehear, 2008). It is well established that families and non-kin caregivers frequently provide considerable assistance to dying people in the form of emotional support, help with decision-making and provision of ongoing care at home (Burns, Abernethy, Leblanc, & Currow, 2011; Clemmer, Ward-Griffin, & Forbes, 2008; Hudson & Payne, 2011; Kirby, Broom, Good, Wootton, & Adams, 2014; Laryionava et al., 2018; Pleschberger & Wosko, 2017). Research, however, also indicates that, in many instances, families and/or non-kin caregivers feel ill-equipped to negotiate the numerous and challenging relational and practical processes that accompany dying (Hudson & Payne, 2011; Pleschberger & Wosko, 2017). This state of affairs can result in a variety of difficulties such as psychological distress, feelings of resentment, social isolation and financial strain, all of which can impact negatively on caregivers' health (Aoun, Kristjanson, Currow, & Hudson, 2005; Hudson & Payne, 2011; Laryionava et al., 2018).

The specific influence of roles and/or role relations as potential sources of difficulty at end of life have been described in a few papers. Research undertaken by Clemmer et al. (2008) and, more recently, Stone, Mikucki-Enyart, Middleton, Caughlin, and Brown (2012) point to the challenges associated with the juggling of multiple (and, at times, contradictory) roles among family caregivers of the dying person, highlighting feelings of powerlessness, uncertainty, confusion, isolation and strain that can result. Other authors have suggested that conflict within the negotiated process of role transitions at end of life can occur when one party seeks to commence dying role relations while the other is not yet emotionally ready (Emanuel et al., 2007; Williams, 1982). Even among otherwise well-functioning family units, difficulties in communication have been shown to compromise relational dimensions of the dying experience, increasing the risk of emotional turmoil and psychological harm for all parties (King & Quill, 2006). Moreover, problems with communication can result in lost opportunities for shared problem solving, planning for the future and discussions regarding end-of-life preferences, all of which are important for quality care of dying people (Badr & Taylor, 2006; Wallace, 2013).

It is evident from the literature that a variety of challenges, as well as potential rewards, can be associated with role enactment at end of life for dying people and their caregivers. However, more still needs to be known regarding the reasons why situations of alignment or, conversely, mismatch in role relations between dying people and those close to them might occur, as well as the way in which these mismatches go on to influence the lived experience of one or both parties. This paper aims to address these questions by examining the interface between the role relations among dying people and members of their social networks.

5.3 METHODOLOGY

The findings presented in this paper form part of a broader, constructivist grounded theory research project examining the process of role change at end of life. Grounded theory is a research methodology that involves the progressive, in-depth analysis of individual data sources with the goal of extrapolating more general explanations concerning a particular process being studied (Bryant & Charmaz, 2010). Researchers undertaking constructivist grounded theory studies derive key concepts and subsequent theory from the research data; they also, however, acknowledge the way in which their own perspectives shape theory construction (Charmaz, 2014). Furthermore, the meanings attributed to data are recognised as being multiple rather than singular and research findings are acknowledged as having been constructed in relation to particular times, spaces and situations (Belgrave & Charmaz, 2014).

Constructivist grounded theory is conceptually closely aligned with symbolic interactionism. Both assert that humans construct meaning in and through their interactions within a social world (Belgrave & Charmaz, 2014). This stance allows for the simultaneous examination of the way in which people act towards death and dying based on the meanings that these hold for them as well as how these personal meanings are constructed, modified and reaffirmed through social interaction (Belgrave & Charmaz, 2014; Mead, 1972). Constructivist grounded theory, therefore, recognises dying and death as being intensely personal yet fundamentally social experiences (Belgrave & Charmaz, 2014).

The findings outlined here relate specifically to one of the categories from the overarching study, namely “alignment and mismatch in role relations”. For other published components of the study, readers are directed to Lowrie, Ray, Plummer, and Yau (2018).

5.3.1 Sampling and recruitment

We adopted a purposive approach to participant recruitment using theoretical sampling to unearth rich and detailed data (Creswell, 2013; Morse, 2010). Given our interest in examining the relational nature of dying roles, we sought the perspectives of dying people as well as the perspectives of their family members and/or caregivers. Theoretical sampling in this study began quite broadly and became increasingly focused and circumscribed over time. This approach supported the development and refinement of emergent theory as the study progressed (Dey, 2010).

We raised awareness of this study through the production of an information flyer, copies of which were displayed in the regional Palliative Care Centre. Copies were also given to members of the local Palliative Care Outreach Team for distribution to individuals potentially interested in being involved in the study. Individuals were considered eligible for inclusion in the study if they had been diagnosed as having a life expectancy of six months or less, or were a family member and/or caregiver of an individual with a life expectancy of six months or less. Potential participants were regarded as ineligible for inclusion in the study if they were younger than 18 years of age, had rapidly deteriorating conditions, were identified as being within the last 48 hours of life or had conditions or symptoms that negated their ability to participate meaningfully in an interview.

We determined the sample size based on the principle of data saturation, meaning that recruitment continued until no new variant cases arose and sufficient data had been gathered to define, check and explain relationships between and within theoretical categories (Charmaz, 2014). In total, we interviewed 21 participants—13 dying people (described in the findings as P1-P13) and eight caregivers of dying people (described as C1-C8). Two interviews were undertaken with the dying person and caregiver together and the remainder were carried out individually. Five dying person-caregiver dyads (totalling 10 participants) were present among the participant sample.

All participants were living in Australia. Twelve participants were women (five dying people and seven caregivers) and nine were men (eight dying people and one caregiver). Thirteen participants identified as White Australian, one as Aboriginal Australian, five as White British and two as White New Zealander. The age of participants ranged from 30 to 87 with an average of 69 for dying people and 57 for carers. Eleven participants described themselves as working class and 10 as middle class. Of the 13 dying persons, 10 had cancer diagnoses, one had motor neurone disease, one had chronic obstructive pulmonary disorder and one indicated having multiple diagnoses. The time since participants had been told of their dying status ranged from two to 48 months with a median of 10 months. One participant did not indicate when his dying diagnosis had been received. Specific demographic details of individual participants are presented in Table 3 (below).

Table 3: Demographic details of study participants

Code	Status	Dyad?	Gender	Age	Cultural background	Religion	Diagnosis	Time since receiving the news that diagnosis was terminal (Approximate only)
P1	Dying person	N	M	80-90	Scottish Australian	Catholic	Metastatic stomach cancer	4 months
P2	Dying person	N	F	70-80	White Australian	Atheist	Pancreatic cancer	22 months
P3	Dying person	N	F	40-50	White Australian	Christian	Metastatic stomach cancer	6 months
P4	Dying person	Y (C1)	F	70-80	White Australian	None	Metastatic breast cancer	4 months
P5	Dying person	N	M	60-70	White Australian	Christian	Metastatic prostate cancer	24 months
P6	Dying person	N	F	40-50	New Zealander	Baptist	Vaginal cancer	16 months
P7	Dying person	N	M	60-70	New Zealander	Catholic	Metastatic lung cancer	2 months
P8	Dying person	Y (C2)	F	60-70	White Australian	Christian	Metastatic breast cancer	48 months
P9	Dying person	Y (C3)	M	70-80	English (63 years in Australia)	Christian	Oesophageal cancer	6 months
P10	Dying person	Y (C4)	M	60-70	White Australian	Catholic	Metastatic lung cancer	14 months
P11	Dying person	N	M	70-80	White British	Catholic	MND	23 months

Code	Status	Dyad?	Gender	Age	Cultural background	Religion	Diagnosis	Time since receiving the news that diagnosis was terminal (Approximate only)
P12	Dying person	Y (C5)	M	80-90	British (16 years in Australia)	None	COPD	6 months (estimate)
P13	Dying person	N	M	80-90	White Australian	None	Multiple diagnoses	Not stated
C1	Carer (for mother)	Y (P4)	F	40-50	White Australian	None	Metastatic breast cancer (mother)	4 months
C2	Carer (for mother)	Y (P8)	F	30-40	White Australian	None	Metastatic breast cancer (mother)	48 months
C3	Carer (spouse)	Y (P9)	F	70-80	White Australian	Christian	Oesophageal cancer (husband)	6 months
C4	Carer (spouse)	Y (P10)	F	50-60	White Australian	Catholic	Metastatic lung cancer (husband)	14 months
C5	Carer (spouse)	Y (P12)	F	80-90	British (16 years in Australia)	None	COPD (husband)	6 months (estimate)
C6	Carer (spouse)	N	M	50-60	Aboriginal Australian	Catholic	MND (wife)	60 months (estimate)
C7	Carer (spouse)	N	F	60-70	White Australian	Anglican	Bowel cancer (husband)	66 months
C8	Carer (for Father)	N	F	30-40	Italian Australian	Atheist	Metastatic lung cancer (father)	40 months

5.3.2 Data collection and analysis

The first author (DL) gathered data through a series of semi-structured, open-ended interviews. An interview guide developed by the research team (all four authors of this paper) was used flexibly in steering the interviews. The interview guide was modified by the research team following preliminary data analysis (from the first three interviews) and further modified periodically thereafter to support continued analysis and refinement of emergent theory (Charmaz, 2014).

Interview lengths ranged from 30 to 177 minutes and averaged 88 minutes. All but one interview were conducted in participants' homes. Interviews were digitally recorded and then transcribed. NVivo Pro software© (version 11) was used to assist in organising data during the analysis process. Analysis was guided broadly by a grounded theory framework as described by Glaser and Strauss (1965; 1967). This approach, however, was modified by drawing on recommendations by Layder (1993) to accommodate observational evidence, documents and artefacts and also by Charmaz (2014) to reflect a constructivist epistemological stance. Additionally, narrative inquiry was used as a further analytical tool to support analysis. Narrative inquiry encourages examination of the reciprocal relationship between each participant and his or her social context, particularly in relation to experiences, milestone events, key characters and chronology (Creswell, 2013; Thomas, 2012). The use of narrative inquiry as an analytical lens thus offered us insights into key events and milestones in participants' lives, such as symptom development and progression, receipt of a dying diagnosis, transition to palliative care and visits from friends and relatives. Additionally, narrative inquiry assisted in developing an understanding of the timeframe and sequencing of these key events; the physical, cultural and institutional contexts in which events took place; and the way in which interactions and relations with other actors shaped various end-of-life experiences.

Analysis of transcripts commenced with open coding. This entailed DL undertaking line-by-line coding of data in order to elicit ‘key incidents’ from participant narratives and then comparing these to each other (Glaser & Holton, 2004). These initial codes were discussed and revised over time in a series of meetings involving the research team. Following open coding, focused coding, involving the targeted collection and analysis of data through theoretical sampling and constant comparison, was undertaken as a means of refining the logic and boundaries of the theory. This process enabled the refinement and solidification of the emerging conceptual framework and the testing of its explanatory power (Holton, 2010).

DL maintained a research diary throughout the research process in order to note thoughts, feelings and observations following interviews and to record emerging ideas. DL also compiled theoretical notes (‘memos’) during the data collection and analysis phases as a means of guiding and mapping the emergence and refining codes and subsequent theory. Diary entries and memos were routinely discussed among the research team as a means of ensuring a robust and transparent reasoning process and appropriately managing researcher perspectives and interpretations (Saldana, 2013; Snowden, 2015).

5.3.3. Ethical considerations

Ethical approval for the study was received from the Townsville Hospital and Health Service Human Research Ethics Committee (approval number HREC/14/QTHS/196) and the James Cook University Human Research Ethics Committee (approval number H6101). The Participant Information Sheet and Informed Consent Form both stipulated that individuals were not obliged to participate in the study and that they had the right to withdraw, without consequence, at any stage prior to the final processing of their data. Written consent was gained prior to each interview and then revisited verbally upon interview completion (Byrne, 2001). In order to ensure confidentiality, all identifying information regarding participants and/or individuals or organisations described in their narratives was removed at the point of transcription.

5.4 FINDINGS

Four interrelated themes were identified through analysis of the data. The first of these, *'role alignment and mismatch'*, is an overarching theme that juxtaposes the positive outcomes that can result from situations of alignment in role relations between dying people and their friends and family with the distress and harm that can stem from mismatched role relations. The remaining three themes, *'the issue of protection'*; *'fear of social exclusion'*; and *'unwanted focus on the dying identity'* highlight a number of factors that contribute to mismatched role relations.

5.4.1 Role alignment and role mismatch

Alignment in role relations occurred when all parties in a particular social encounter preferred and adhered to the same set of social scripts. On some occasions, this alignment involved continuity of living role relations; on other occasions it entailed extension of role relations based on the sick role and, on yet other occasions, the enactment of dying role relations. These various forms of role relations each served different purposes, such as maintenance of social (or leisure) pursuits; provision of assistance and support during periods of ill health; or advancement of practical, personal or relational end-of-life matters. When role alignment occurred between dying people and members of their social networks, positive outcomes generally ensued, with all parties seeming satisfied with the encounters that unfolded:

> *"I guess all my riding buddies… what they'll often do is on a Saturday morning now they'll go for a ride… and then they'll come down to here and then we'll have coffee... So they call in and that works really well."* (P10)

> *"… like, at one stage I couldn't do anything. I was just bed, chair, bed, chair... and [husband] never cooked. So friends came around and brought soup and things like that, which was really nice…"* (P6)

In contrast to these situations of role alignment, most participants also described examples of times when mismatches in role relations occurred. These mismatches typically happened when one party sought continuity in living role relations while the other sought the overt acknowledgement of the dying status. Given the importance placed on relationships between the dying person and close friends or family, these mismatched role relations often resulted in considerable distress and anguish, particularly when efforts at initiating enactment of the personal and/or relational dimensions of the dying role were repeatedly blocked. P2 offered a pertinent example, highlighting the angry response she received from her children when she attempted to discuss her end-of-life wishes:

> *"Well, they became really abusive with me and… they said all you're doing is thinking about dying, and that's not what you should be thinking about. They got very, very upset. They missed the whole point of... please talk to the person who's dying and let them tell you how they feel, let them bring back memories. Tell them what they would like to happen, you know, in the future or to them after I die. You know, I wish that you'd do this or do that, or whatever… I'd love to be able to just talk about how I feel about my funeral arrangements and what songs I want and all this sort of thing. That's the most important thing I think families can do for a dying person."* (P2)

On some occasions, family members of the dying person reported having their attempts at discussing issues relating to dying blocked. For example, C8 expressed a deep sense of fear that her father would die before he felt ready and willing for her to share her thoughts and feelings with him:

> *"It's very, very difficult. It's been the hardest part of this whole journey, is having him not emotional and present because of things that I need him to be emotionally present for. I have a million questions to ask him… Medical questions, his wishes… I want to be able to say to him, can I buy a bunch of cards, one for my 50th birthday, one for the birth of my first child and can you write messages in them for me, Dad? I'll seal them up and write on the front… this is for your 50th, this is for your first born... It's lonely and it kills me that there are so many of these things that I'm not going to get, simply because me asking for it is going to kill him."* (C8)

5.4.2 The issue of protection

Mismatched role relations often manifested because one party assumed (sometimes correctly) that the other wanted or needed to be shielded from emotional harm. In some circumstances, this assumption involved caregivers and family members holding back on displays of emotion out of a concern that dying persons would be worried about the sadness that their dying might cause. As a result, caregivers and/or family members felt a sense of pressure to present a strong front as a means of indicating to the dying person that they were going to be okay:

> *"I don't know. I don't want her to see it. It makes her worse because she hates me being hurt, and she knows it's because of her that I am hurt… So it would hurt her more to see me, because then she knows what she's leaving behind... So I don't cry a lot."* (C2)

> *"I said to him, while we're chatting about this stuff, you know, I said I just want to clarify you don't want to see us crying or upset or anything, do you? He was just like, no, I don't, not at all… He wants to believe that us girls are going to be okay, you know..."* (C8)

On other occasions, efforts at protection involved the active choice to avoid sharing thoughts and feelings regarding dying, based on the belief that the other party was not yet emotionally ready to cope with end-of-life discussions:

> *"It's very hard for him. I accepted it a lot faster than what he did… It was like I was talking to a brick wall… [voice breaks]… I don't think he's been ready. I mean, there are a lot of things I'd like to say but he hasn't been able to accept it. I think, you know, he's still young and although he's not going to find another me, I want him to be happy. If he can find another partner, that would make me so happy."* (P6)

People's efforts at protecting others from the emotional burden associated with dying role relations were undertaken altruistically but often came at a profound personal cost. Many participants feared that they might miss opportunities to discuss important end-of-life matters. Others stated that they had elected to withhold their feelings, even though they felt that doing so would result in harm to themselves in the longer term:

> *"So I decided in my head, just pull yourself together, you've got a few weeks, and whatever emotional damage you do to yourself by not grieving properly, over this next two weeks, three weeks, whatever, you've got time after that to give yourself that care to undo that emotional damage that you might cause by not crying at the moment..."* (C8)

5.4.3 Fear of social exclusion

The tendency among dying people to favour living role relations with members of their extended social networks also stemmed from a concern that a focus on dying might result in exposure, othering and social exclusion. In many cases, the dying people interviewed seemed to be suggesting that acknowledgement of their dying status risked in some way contaminating relationships, events and discussion. P11 indicated a belief that many of his friends had deliberately distanced themselves from him once his non-curable illness became known:

> *"Simple as that… your friends disappear. Very few people come in to visit you because they don't want to become involved…because you are a stigma... They don't want to know because, as I say, you're a stigma, a thorn in their sides."* (P11)

Other participants described efforts to circumvent exclusion by keeping their dying status to themselves:

> *"We've got a friend at the moment who's… just about to have chemotherapy. She doesn't want to see anybody. She just wants to have it, and not be exposed as vulnerable, different to what she used to. I'm a bit like that, really."* (P12)

Some participants recounted stories in which family members, friends or colleagues of a dying person had engaged briefly in dying role relations but had then withdrawn when the dying person remained alive for longer than expected:

> *"My brothers all raced up… to see her because they knew it was going to happen within that month. But since that month has been and gone, they've had very little communication."* (C1)

> *"…we had a good friend who… was in charge of a private hospital and he got very ill, and everybody thought he was a goner there in hospital… and arrangements were made, alternative arrangements. But then he got better, the doctor came back... people have done their grieving and closed off… [there was] a lot of anger at him. Not overtly expressed but you could pick it up… He should be dead, he should have died."* (P12)

It is, perhaps, out of fear of responses such as those described above that many of the dying people interviewed suggested that they would be more prepared to discuss their dying only when it was evident that death was nearing: *"So you know... you may as well go out there and enjoy yourself, and hopefully let no one know that you are dying until the right time."* (P5)

5.4.4 Unwanted focus on the dying identity

In contrast to the situations of social exclusion described above, misaligned role relations also sometimes occurred when dying persons experienced what they considered too much contact from members of their social circles, particularly if this resulted in unwanted focus upon themselves as dying individuals. On some occasions, this happened when members of the dying person's social network attempted to initiate dying role relations before the dying person wanted to do so. This often seemed be the case with members of dying people's extended social networks with whom they had only occasional contact. The mismatch appears to stem from a reliance on historical scripts for dying role enactment that were founded on the premise of there being a relatively brief duration between declaration of dying and the actual event of death. For people who see the dying person only occasionally, a focus on dying is seen as affording them the window to enact what they consider to be their small part in the dying drama (e.g., to offer condolences, forge final memories or even to say goodbye). The emotional burden associated with this interaction is manageable for non-dying individuals because for them it is a one-off or occasional exchange. However, in the contemporary and elongated drama of dying, the dying person will experience multiple encounters of this nature, with numerous people and over long periods of time. This means that the burden is compounded for dying persons and they may, therefore, become frustrated with and/or strive to avoid such interactions:

> *"Yeah, they're all coming to visit [laughs]. Everyone wants to see me. In the last six months we've had visits from basically all the siblings… Mum and Dad usually come over every year but they've been over three times I think in the last six months. It's starting to get a little bit wearing, actually… It's the same with my friends. I'm getting an awful lot of visits from friends that I don't usually see quite so frequently. It just gets to me – I like my alone time. I'm not getting much of that anymore."* (P3)

> *"No, but generally, I find people come out wanting to know the ins and outs of everything, how you're feeling today, where is it, and all this sort of stuff. You get fed up with that. I'm not going to talk about that anymore."* (P9)

One participant expressed particular angst about the unsolicited attention he received from distant family. These family members might well have been trying to enact what they saw as their part in the drama of dying by demonstrating support for a member of their kin. Nevertheless, for the dying person, these intrusions were not welcomed:

> *"But then there are some people, some of my relatives, who I haven't heard from for years and years. Suddenly, I get a phone call, or now with social media, you'll get something on Facebook or something completely out of the blue, and they'll want to know how you are and what's going on… It's quite possible that they're family and they feel that that's part of the family role to contact me…You kind of just go, well,*

> *why do we want to have these conversations…? I don't particularly want to talk about it, particularly to someone who I haven't seen for so long who's not going to be of any help to me. I just don't understand it."* (P10)

Unwanted attempts at contact such as this were not uncommon in participants' narratives and generally seemed to be well-intended. However, the incongruence between the intentions of the individual making contact and the way in which the recipient perceived the interaction further emphasises the uncertainty that exists for many people in relation to their expected role in the contemporary drama of dying.

5.5. DISCUSSION

In undertaking this research, we set out to examine the interface between the role relations among dying people and members of their social networks, as well as the way in which these role relations affect the lived experience of one or both parties. We found numerous situations described by participants of role alignment which generally resulted in positive practical, relational and personal outcomes. However, the dying people and their caregivers we interviewed also discussed several examples of role mismatch and highlighted the way in which these contributed to feelings of frustration, distress and even anguish. Our analysis also identified three factors that seemed to contribute to mismatched role relations - the issue of protection, fear of social exclusion and the unwanted focus on the dying identity.

A number of important clinical and conceptual insights arise from these findings. Prior to outlining these implications, however, it is important to note that we are not asserting in this paper that there is an idealised form of role relations between dying people and those around them that should be adhered to in all circumstances. The way in which dying roles are enacted is shaped by the complex interplay of individual agency coupled with familial, social, cultural and historical influences, meaning that a degree of diversity is inevitable (Broom & Kirby, 2013). Moreover, the hazards associated with homogeneity in the management of dying are well documented (Broom & Kirby, 2013; Hart, Sainsbury, & Short, 1998; King & Quill, 2006; McNamara, 2004). Clearly, there will be times when dying people and their loved ones have needs and wishes that do not align. Nevertheless, conflict, confusion or divisions that occur between dying people and those around them due to misplaced assumptions and expectations concerning the enactment of dying roles are mostly unhelpful and often avoidable. The stark difference found in our study between the positive outcomes that arose in situations where role alignment occurred, compared to the missed opportunities, frustration and distress that manifested in instances of role mismatch, highlights this point.

Our finding in relation to the way in which altruistically intended efforts at protection can compromise role alignment points to the importance of honest, but also considered, communication at end of life. Previous papers have highlighted the way in which fear of upsetting loved ones can result in individuals hiding their thoughts and feelings, often at a personal cost to themselves (Keeley, 2016; Zhang & Siminoff, 2003). Indeed, without quality end-of-life communication, opportunities for affirmation and closure of relationships, validation of beliefs and reconciliation may be lost, potentially resulting in emotional exhaustion, depression, regret and difficulties with grief (Bachner & Carmel, 2009; Keeley, 2007; Weiner & Roth, 2006). Research also indicates, however, that not all communication among dying persons and their families at end of life is helpful. Scott and Caughlin (2014) argue that communication quality, rather than quantity, is key at end of life and that blanket openness can often be harmful. Our research findings add to this perspective by highlighting that, unless alignment exists between parties in relation to the specific goals of end-of-life conversations, the communication encounter is unlikely to be successful. Moreover, given that different actors' preferences in relation to role relations vary over time, the point of focus and approach to communication may need to be both flexible and tentative in response.

The concerns expressed by some participants regarding the possibility (or actuality) of social exclusion resulting from their dying status becoming known resonate with a belief that death and dying remain a source of stigma in some social situations (Kellehear, 2007). Participants' experiences and/or fears of being avoided due to their dying status appear reflective of an early and, to some extent, gradual form of social death. Within the context of healthcare, the concept of social death is generally used to describe a loss of identity and social connectedness, as well as bodily disintegration experienced by ill or dying persons prior to the event of their actual biological death (Borgstrom, 2017; Králová, 2015). This loss of identity and connectedness can hamper the enactment of important interpersonal dimensions of end-of-life roles and compromise the ability of the dying person to negotiate dying role relations (Borgstrom, 2017).

It is important to note here, however, that although a number of the dying persons in our study reported feelings and/or fears of exclusion, we did not seek the perspectives of the individuals who the dying person suggested either had withdrawn or may withdraw from them. As such, we have not examined whether these individuals had knowingly withdrawn from the dying person and, if this was the case, why they had done so. Regardless, the actual or perceived withdrawal of some members of the dying person's social circle was a source of frustration and, in some instances, distress for the dying individual. Curiously, however, our study also identified situations in which dying persons felt frustrated with what they perceived as too much contact from some members of their social circles, particularly when this contact focussed on their dying status. This leaves members of a dying person's social circle in the unenviable position of not knowing if, when and how often they ought to maintain contact with the dying individual. Future research, drawing specifically on the views and experiences of friends, families and acquaintances of dying people, may help in shedding light on this important aspect of end-of-life role relations.

Taken collectively, our findings highlight the potential for confusion and misalignment in end-of-life role relations, resulting from a lack of clarity and associated uncertainty regarding role expectations at any given time. Recent research has indicated that the contemporary drama of dying often plays out over a longer timeframe than in historical times and, in response to this, dying persons periodically transition into and out of the living and dying selfhood (Breen, Aoun, O'Connor, Howting, & Halkett, 2018; Kellehear, 2009; Lowrie et al., 2018). Our research suggests that, to some extent, contemporary social scripts to guide dying role relations have not yet evolved to reflect this longer and more variable drama of dying. The challenge in addressing this issue lies in the fact that clarity concerning role expectations may be neither achievable nor appropriate, as it is flexibility and adaptability that are, instead, often required. Therefore, from a clinical perspective, there well may be value in working with dying people and their family and friends in foreshadowing the potential for mismatched role relations and highlighting that different forms of these role relations might be sought at different times. If successful, this approach has the potential to promote opportunities for greater role alignment and, in turn, improved relational outcomes as the drama of dying unfolds.

5.6 LIMITATIONS

Although all interviews in this study were undertaken with people who had been identified as having a prognosis of less than six months (or with their caregivers), for ethical reasons we did not interview anyone thought to be in the final few days of life. This means that the insights we offer regarding role alignment and mismatch may not apply readily to late-stage dying. Interviewing family and/or caregivers after the death of their loved one may also offer some insights into role relations during the final scenes of life, but would need to account for the fact that the perspectives of dying people themselves would be obscured. Furthermore, although we set out to examine the interface in role relations between dying people and members of their social networks, our sample is entirely limited to dying people and their close caregivers. This means that some of the views shared regarding role relations between dying people and their social circle are rather one-sided. Further research to examine the viewpoints of members of dying person's outer social circles would add an additional and important dimension to research of this nature. Finally, although our research drew on the perspectives of 21 individuals, we do not claim that the experiences that they shared are representative of those of all dying people. Only three of the dying persons interviewed were aged younger than 50 and our recruitment process limited our study to individuals experiencing illness-related dying. A broader sample may have added to the generalisability of our findings.

5.7 CONCLUSION

In this paper, we have examined role relations at end of life. We identified that role alignment often leads to very positive relational and practical outcomes whereas role mismatch can be a significant and ongoing source of distress for dying people as well as for their family and/or caregivers. We have highlighted a number of factors that contribute to role mismatch between dying people and members of their social circle, including efforts to shield each other from emotional harm; fears of social exclusion; and unwanted focus on the dying identity. Finally, we have argued that recognition of the need for flexible and adaptable dying role relations may support role alignment between dying people and those who matter to them.

REFERENCES

Aoun, S. M., Kristjanson, L. J., Currow, D. C., & Hudson, P. L. (2005). Caregiving for the terminally ill: at what cost? *Palliative Medicine, 19*(7), 551-555. doi:10.1191/0269216305pm1053oa

Bachner, Y. G., & Carmel, S. (2009). Open communication between caregivers and terminally ill cancer patients: The role of caregivers' characteristics and situational variables. *Health Communication, 24*(6), 524-531. doi:10.1080/10410230903104913

Badr, H., & Taylor, C. L. C. (2006). Social constraints and spousal communication in lung cancer. *Psycho-Oncology, 15*(8), 673-683. doi:10.1002/pon.996

Belgrave, L. L., & Charmaz, K. (2014). Studying illness and dying through constructivist grounded theory. In L. Van Brussel & N. Carpentier (Eds.), *The Social Construciton of Death. Interdisciplinary Perspectives.* (pp. 34-52). London: Palgrave Macmillan.

Biddle, B. J. (1986). Recent developments in role theory. *Annual Review of Sociology, 12*(1), 67-92. doi:10.1146/annurev.soc.12.1.67

Borgstrom, E. (2017). Social death. *QJM, 110*(1), 5-7. doi:10.1093/qjmed/hcw183

Breen, L. J., Aoun, S. M., O'Connor, M., Howting, D., & Halkett, G. K. B. (2018). Family caregivers’ preparations for death: A Qualitative Analysis. *Journal of Pain and Symptom Management, 55*(6), 1473-1479. doi:10.1016/j.jpainsymman.2018.02.018

Broom, A., & Kirby, E. (2013). The end of life and the family: hospice patients’ views on dying as relational. *Sociology of Health and Illness, 35*(4), 499-513. doi:10.1111/j.1467-9566.2012.01497.x

Bryant, A., & Charmaz, K. (2010). *The SAGE handbook of grounded theory* (Pbk. ed.). Los Angeles: Sage.

Burns, C. M., Abernethy, A. P., Leblanc, T. W., & Currow, D. C. (2011). What is the role of friends when contributing care at the end of life? Findings from an Australian population study. *Psycho-Oncology, 20*(2), 203-212. doi:10.1002/pon.1725

Byrne, M. (2001). The concept of informed consent in qualitative research. *AORN journal, 74*(3), 401-403. doi:10.1016/S0001-2092(06)61798-5

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London: Sage.

Clemmer, S. J., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: the enactment of multiple roles. *Canadian Journal on Aging, 27*(3), 267-283.

Creswell, J. W. (2013). *Qualitative inquiry and research design: choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Dey, I. (2010). Grounding categories. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 167-190). Los Angeles: Sage.

Emanuel, L., Bennett, K., & Richardson, V. E. (2007). The dying role. *Journal of Palliative Medicine, 10*(1), 159-168. doi:10.1089/jpm.2006.0134

Glaser, B. G., & Holton, J. A. (2004). Remodeling grounded theory. *Forum Qualitative Sozialforschung, 5*(2).

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying.* Chicago: Aldine Transaction.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine Pub. Co.

Hart, B., Sainsbury, P., & Short, S. (1998). Whose dying? A sociological critique of the 'good death'. *Mortality, 3*(1), 65-77. doi:10.1080/713685884

Holton, J. A. (2010). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 265-289). Los Angeles: Sage.

Hudson, P., & Payne, S. (2011). Family caregivers and palliative care: Current status and agenda for the future. *Journal of Palliative Medicine, 14*(7), 864-869. doi:10.1089/jpm.2010.0413

Keeley, M. P. (2007). Turning toward death together': The functions of messages during final conversations in close relationships. *Journal of Social and Personal Relationships, 24*(2), 225-253. doi:10.1177/0265407507075412

Keeley, M. P. (2016). Family communication at the end of life. *Journal of Family Communication, 16*(3), 189-197. doi:10.1080/15267431.2016.1181070

Kellehear, A. (2007). *A social history of dying*. New York: Cambridge University Press.

Kellehear, A. (2008). Dying as a social relationship: A sociological review of debates on the determination of death. *Social Science & Medicine, 66*(7), 1533-1544. doi:10.1016/j.socscimed.2007.12.023

Kellehear, A. (2009). *The study of dying. From autonomy to transformation.* Cambridge: Cambridge University Press.

King, D. A., & Quill, T. (2006). Working with families in palliative care: One size does not fit all. *Journal of Palliative Medicine, 9*(3), 704-715. doi:10.1089/jpm.2006.9.704

Kirby, E., Broom, A., Good, P., Wootton, J., & Adams, J. (2014). Families and the transition to specialist palliative care. *Mortality, 19*(4), 323-341. doi:10.1080/13576275.2014.916258

Králová, J. (2015). What is social death? *Contemporary Social Science, 10*(3), 235-248. doi:10.1080/21582041.2015.1114407

Laryionava, K., Pfeil, T. A., Dietrich, M., Reiter-Theil, S., Hiddemann, W., & Winkler, E. C. (2018). The second patient? Family members of cancer patients and their role in end-of-life decision making. *BMC Palliative Care, 17*(29), 1-9. doi:10.1186/s12904-018-0288-2

Layder, D. (1993). *New strategies in social research: An introduction and guide*. Cambridge, U.K: Polity Press.

Lowrie, D., Ray, R., Plummer, D., & Yau, M. (2018). Examining the transitions between living and dying roles at end-of-life. *Death Studies*, *43*(10), 601-610. doi:10.1080/07481187.2018.1504836

Lynch, K. D. (2007). Modeling role enactment: Linking role theory and social cognition. *Journal for the Theory of Social Behaviour, 37*(4), 379-399. doi:10.1111/j.1468-5914.2007.00349.x

McNamara, B. (2004). Good enough death: autonomy and choice in Australian palliative care. *Social Science & Medicine, 58*(5), 929-938. doi:10.1016/j.socscimed.2003.10.042

Mead, G. H. (1972). *Mind, self, and society from the standpoint of a social behaviorist*. Chicago: University of Chicago Press.

Morse, J. M. (2010). Sampling in grounded theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 229-244). Los Angeles: Sage.

Pleschberger, S., & Wosko, P. (2017). From neighbour to carer: An exploratory study on the role of non-kin-carers in end-of-life care at home for older people living alone. *Palliative Medicine, 31*(6), 559-565. doi:10.1177/0269216316666785

Saldana, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). London: Sage.

Scarre, G. (2009). Dying and philosophy. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 147-162). Cambridge: Cambridge University Press.

Scott, A. M., & Caughlin, J. P. (2014). Enacted goal attention in family conversations about end-of-life health decisions. *Communication Monographs, 81*(3), 261-284. doi:10.1080/03637751.2014.925568

Snowden, M. (2015). Use of diaries in research. *Nursing Standard, 29*(44), 36-41. doi:10.7748/ns.29.44.36.e9251

Stone, A. M., Mikucki-Enyart, S., Middleton, A., Caughlin, J. P., & Brown, L. E. (2012). Caring for a parent with lung cancer: Caregivers' perspectives on the role of communication. *Qualitative Health Research, 22*(7), 957-970. doi:10.1177/1049732312443428

Thomas, S. (2012). Narrative inquiry: embracing the possibilities. *Qualitative Research Journal, 12*(2), 206-221. doi:10.1108/14439881211248356

Wallace, C. L. (2013). Family communication and decision making at the end of life: A literature review. *Palliative and Supportive Care, 13*(3), 815-825. doi:10.1017/S1478951514000388

Weiner, J. S., & Roth, J. (2006). Avoiding iatrogenic harm to patient and family while discussing goals of care near the end of life. *Journal of Palliative Medicine, 9*(2), 451-463. doi:10.1089/jpm.2006.9.451

Williams, C. A. (1982). Role Considerations in Care of the Dying Patient: What is the professional role in caring for the dying? *Journal of Nursing Scholarship, 14*(1), 8-11. doi:10.1111/j.1547-5069.1982.tb01496.x

Zhang, A. Y., & Siminoff, L. A. (2003). Silence and cancer: Why do families and patients fail to communicate? *Health Communication, 15*(4), 415-429. doi:10.1207/S15327027HC1504_03

CHAPTER SIX: A DRAMATURGICAL ANALYSIS OF DYING ROLES

Thus far, in this thesis, I have provided evidence to argue that role change at end of life occurs, not in any fixed manner but, instead, in the form of periodic foregrounding and backgrounding of the dying selfhood. I have further argued that the foregrounding and backgrounding of dying roles can result in situations of both role alignment and role mismatch between dying people and those around them. This led me to question why and how dying roles come to be foregrounded and backgrounded at various times by different individuals.

To investigate such questions I needed an approach to analysis that would assist me to moderate my own professional viewpoint and thereby circumvent any tendency to focus narrowly on and/or problematize the thoughts and feelings of individuals. To this end, I sought an analytical lens that would allow a systematic examination of the way in which context shapes and modulates social roles and associated interactions. With these factors in mind, I chose dramaturgy to guide my analysis within this phase of my study. Among its many advantages, dramaturgy in particular afforded the opportunity to analyse the key contextual features of the drama of dying across each sequential dramatic unit. In doing so, it accommodated a structured sociological examination of the influence of society, institutions and professions on the construction and enactment of dying roles.

6.1 APPLICATION OF DRAMATURGY AS AN ANALYTICAL TOOL

Dramaturgy originates from the symbolic interactionist theoretical tradition where it is asserted that human actions (and interactions) are central to the construction of both self and society (Mead, 1934; 1972). Symbolic interactionism considers symbols and language as being key to the formation of shared meanings between people. It highlights the reciprocal and cyclical relationship between interpretation and action whereby people act in accordance with their understanding of a situation and these actions themselves serve to consolidate or alter present and future understandings of such situations (Blumer, 1969; Cooley, 1902; Mead, 1934; 1972).

Dramaturgy is founded specifically on the premise that, during social interactions, people will conduct themselves like actors on a stage with the aim of conveying particular impressions to those around them (Goffman, 1959). Thus, it draws on the metaphor of theatre to help examine and explain human interactions (Goffman, 1959; Manning, 1991). Dramaturgical analysis affords particular insights into the expected actions and behaviours aligned with "the rights and duties attached to a given status" (Goffman, 1959, p. 16). As such, social roles are viewed as providing the scripts and structures needed for successful social interactions in everyday life as deemed appropriate within a particular community or society (Dillon, 2014).

The specific analytical methods in this chapter draw on the metaphor of the theatre to facilitate an understanding of role enactment, role change and role relations. Burke (1945, p. xv) states that analysis of dramatic units (known as acts, scenes or episodes) entails the evaluation of the *act* (what took place); *scene* (the situation in which the act occurred); *agent* (person or persons who performed the act); *agency* (means or instruments used in performing the act) and *purpose* (reason for having performed the act). Given the focus of this study on death and dying, I opted to use the term 'dramatic units' to describe what might otherwise be called 'acts' and have used the term 'cast members' rather than 'actors' in this chapter. My decision was made to ensure that the chapter appropriately reflected the gravity of the processes being examined and did not in any way trivialise the experiences of dying persons and their caregivers.

In this chapter I have also drawn on Goffman's (1959) description of front stage and backstage to distinguish between social encounters in which a performance occurs (such as a dying person's meetings with friends) and the preparatory activities and interactions that go into staging this performance. Features such as scripts, sets and props have been examined in relation to the way in which they can shape individual's perceptions of reality. Furthermore, I have analysed how these scripts, sets and props might be used as means of what Goffman (1959, p. 203) terms "impression management" which refers to strategic efforts to shape others' perceptions.

6.2 PREVIOUS DRAMATURGICAL ANALYSES OF DEATH AND DYING

Two previously published research papers have utilised dramaturgy in examining the process of dying. Parker-Oliver (2000) explored the way in which the hospice community facilitate the transition from the "sick role" as termed by Parsons (1951, p. 193) to a dying role. The findings of Parker-Oliver's (2000) research are derived from a blend of her clinical experience with established theory and documented cases. Her analysis spanned three scenes, commencing with the introduction to the hospice community, followed by the fulfilment of the dying role and culminating in the deathbed scene. Parker-Oliver (2000) highlights the way in which the hospice team, together with the dying person and close relatives, co-construct a script for the drama of dying in order to promote a dying process that has a sense of value, meaning and purpose. Although many valuable insights are offered in this paper, Parker-Oliver (2000) does acknowledge the limitations of her analysis in that it does not examine aspects of the drama of dying that occur outside of the hospice community.

Leichtentritt and Rettig's (2001) investigation of dying from the perspective of older Israelis also draws on dramaturgy as an analytical method. They examine participants' views regarding ‘the good death’ commencing from the time period in which an individual becomes aware of his or her dying status, followed by the last days and moments of life and then the post-death period (including funerals and continuity of identity after death). While Leichtentritt and Rettig’s (2001) paper sheds light on the views of older people regarding death, it focuses predominantly on the perspectives of these individuals speculating about their future dying status rather than exploring thoughts and feelings related to current or previous events.

In this chapter, I have extended the evidence base described above through the presentation of a dramaturgical examination of the narratives of a variety of cast members in the drama of dying, including dying people, their caregivers and health professionals. To complement this analysis I have also drawn on my research field notes and research diary entries that shed light on unspoken dimensions of the drama. A conceptual code map that details the different layers of codes that shaped the findings of this chapter is presented in Appendix 8. The chapter focuses on five parts in the drama of dying, namely: the rehearsals; prologue; opening dramatic unit (ascription of the dying status); second dramatic unit (middle scenes) and third dramatic unit (final scenes). While the post-death period (epilogue) has not been discussed specifically in this chapter, it has been described elsewhere (see Leichtentritt & Rettig, 2001; Parker-Oliver, 2000).

6.3 REHEARSALS OF THE DRAMA OF DYING

6.3.1 Formulation of scripts and role expectations

People’s understandings of dying roles are first formulated long before their own experience of end of life. From a very early age, individuals will be periodically exposed to death and dying, either in relation to other people’s dying or through social representations of dying (such as in childhood play, public discourse, books, television or other forms of media). These various points of exposure act as rehearsals for an individual's own drama of dying at a later stage of life and can have a considerable influence in determining beliefs and expectations as to the way in which the drama of dying should unfold. Understanding these rehearsals of the drama of dying thus helps to make sense of the thoughts, feelings and interactions of dying people and those around them as end of life nears.

It is important to note that, in many instances, the social scripts that accompany rehearsals of the drama of dying may not adequately prepare people for the actual drama of dying. For example, as has been outlined in Chapter Two of this thesis, much of the discourse surrounding dying in books, movies and even general parlance depicts dying in a manner that nullifies, softens and, in some cases, romanticises the dying experience. This can create difficulties when individuals' expectations of dying do not resemble their actual dying, sometimes resulting in uncertainty, confusion and even guilt, as exemplified by participant P10:

> *"…it's just not the way you would like your life to finish up. I mean… you see movies of people with terminal illness and they gradually fade off and die. You don't see the pain and you don't see the anguish and the nastiness that comes out of me sometimes, just because either I'm feeling unhappy for myself or I'm just in a lot of pain… So those things I find disappointing and frustrating."* (P10)

Rehearsals of the drama of dying also occur through an individual's involvement with other people's dying experience. It is important to note, however, that these rehearsals are experienced from the perspective of a supporting character, as distinct from the central protagonist. Regardless, through the enactment of these supporting roles, friends and family of dying persons become at least somewhat familiar with elements of the drama of dying that are often otherwise unseen. To a degree, therefore, these rehearsals provide an opportunity for people to think about and plan for dying as it might apply to them. In this way, exposure to other people's dying experience serves to shape an individual's own end-of-life preferences. A few of the dying people in this study described having previously occupied caregiver roles for relatives or friends who were dying. In some cases, negative experiences associated with these roles profoundly influenced their thoughts and decisions with respect to key aspects of their own dying:

> *"I was there the next morning when she passed away, and I think it will just haunt me forever. The night before she died, the doctors were trying to get a cannula into her arm to put her on a drip and she was screaming out in pain... That will always haunt me. My poor, beautiful, lovely, caring mother, to go through an end like she had was just something that really stuck with me for the rest of my life… My mother-in-law, she had another terrible death… My husband's sister nursed her through the week… and I looked after her of a weekend. Even though I was working myself through the week, I looked after her during the weekends, giving my sister-in-law a break. But nobody thought about me having a break (laughs)... All those things have really scarred me for life, and made me very determined never to let my family give up their lives to look after me… I just cannot ask my daughters to do what I did. I just don't want them to do it."* (P2)

6.3.2 Periodic engagement in dying role behaviours

Curiously, individuals without a dying diagnosis may also periodically undertake some of the behaviours associated with dying roles during situations in which they are reminded of their own mortality. Activities such as attending funerals, visiting gravesites and reading about or discussing dying all have the potential to bring the certainty of one's own death to the forefront of consciousness. When this occurs, people can then find themselves pulled towards some of the practical and/or relational elements of the dying role, even though they may be unaware of it at the time. Indeed, on numerous occasions during the course of undertaking this research, I developed a growing recognition of my own engagement in behaviours normally associated with the dying role when I found myself thinking about death and dying as it pertains to me. Perhaps the most prominent example of this occurred shortly after a particularly difficult funeral I had attended. I reflected upon my thoughts, feelings and behaviours surrounding this event in my research diary:

> *"Recently, I went to a funeral. A horrible, heart-wrenching funeral for a young man who had suicided. I came home feeling exhausted. I thought about how precious and precarious life is and how important it is to make the most of the time we have. I spent time with my children and ensured I was genuinely 'present' with them throughout. I realised that too often in recent times I had been 'there', but not 'there'. I thought about my future, about wills, financial security etc. I worried about the well-being of my loved ones. I planned ways of spending precious time with my family. I imagined our next holiday and began to make mental preparations for it. I became acutely aware that too much precious time had been lost over several years due to the pressure of a very demanding full-time job coupled with completion of a PhD . I asked myself if it is worth it. I paused to review my priorities.*
>
> *And then, over a few days, this faded. I reverted to old ways. Previous, habitual patterns of living, working and being. What had happened?*

On reflection, I recognised that the thoughts and actions noted above mirrored those of many of the dying people in this study. However, my thoughts and actions were undertaken in a more muted manner and for a considerably shorter duration compared to individuals confronted by a formal dying diagnosis. On further examination, I came to realise that this difference seemed to stem from the fact that the cues that acted as a reminder of the inevitability of my own death (in this case, attendance at a funeral) were considerably less impactful than factors such as fears and/or confirmation of a dying diagnosis or disease progression. In short, the extent and duration of dying role behaviours appear proportionate to the perceived magnitude and importance of the cues presented to an individual as well as the proximity (in terms of both time and physical distance) of these cues.

This observation assists in understanding the enactment of dying roles throughout each of the dramatic units in the drama of dying as it sheds light on the way in which key incidents, cast members, sets and props might either draw an individual towards or away from dying roles at any given time. The magnitude of being alerted for the first time to a dying diagnosis will be likely to pull people strongly towards dying roles. As time passes, however, and the dying individual spends more time away from the cast members, sets and props that serve as reminders of this diagnosis (for example, in hospitals) enactment of living roles may be able to resurface. Similarly, factors such as news of further disease progression, increasing symptom burden or ongoing hospital appointments tend to draw people back towards the dying selfhood and associated roles. Indeed, a few of the dying people interviewed in this study indicated that they no longer wanted to be informed about the extent of their disease progression because it brought an unwanted return to a focus on their dying status:

> *"Because I think it affects my mental state. I think it would create - it could only create more stress. Given that I know that what I have is terminal, I don't think knowing more about how many more cancers I've got, given that they can't do anything about the ones that I've got, knowing that there's more or that they're*

> *bigger… is only going to make me more anxious or more depressed... So it's probably better that I don’t.”* (P10)

Given that the presence, timing and influence of these features pulling people towards or away from dying role enactment will differ considerably among individuals, the drama of dying will also vary from person to person. Furthermore, although dying persons might feel drawn towards a particular role status and associated role expectations, they retain a degree of individual autonomy and may resist social pressures to behave in a particular way. Consequently, the concept of a unitary social script guiding the different cast members through the drama of dying is, for the most part, unhelpful. The drama can be better understood as a complex, dynamic and evolving interplay between various incidents, cast members, sets and props, which is marked by tension associated with role uncertainty and role resistance.

6.4 PROLOGUE TO THE DRAMA OF DYING

6.4.1 The path to diagnosis

For illness-related dying, the formal opening in the drama of dying generally commences with the ascription of the dying status by a medical professional. In most cases, however, a prologue precedes the opening scene. For participants in this study the experiences within this prologue varied; but often they entailed the development of signs or symptoms of disease, followed by investigations and diagnosis and, in some cases, one or more treatment phases. Given the heavy focus on diagnosis and treatment, the prologue to the drama of dying is predominantly centred on hospital appointments and treatment:

> *“I was sick for 18 months before this was diagnosed… I can't remember most of them but there quite a few different blood tests; CT scans, ultrasounds of all sorts of bits*

> *and pieces… the GP referred me, to a gastroenterologist, because they thought it was liver. So they wanted someone to check out the liver and they did an endoscopy and a colonoscopy then, and the endoscopy found the stomach cancer."* (P3)

The resultant exposure to systems, routines and symbols of the health care system means that many dying persons become accustomed to the cast members, props, costumes, stages and sets that would later re-present in the drama of dying. However, during the time preceding their dying diagnosis, these features were viewed in the context of the illness role and their meanings and purpose were thus associated with efforts towards cure.

For some dying persons, the prologue to the drama of dying was very brief, as was particularly the case for one participant who received a dying diagnosis from his orthopaedic surgeon in a phone call during which he had been expecting to hear about potential surgery for arthritic hip pain. For other dying people, the prologue was a more drawn-out and turbulent affair. The lead-in to the drama of dying for these individuals was a trying time, both emotionally and physically, as they sought answers regarding their condition, while clinging to hope as they simultaneously grappled with illness and uncertainty. The various scenes within the diagnostic phase of the prologue were predominantly set within the hospitals and health systems and were tightly regimented in relation to medical appointments and diagnostic assessments. The narratives of dying persons and their caregivers reflect a marked loss of control during this period as they found themselves bound to the systems, processes and expectations of the healthcare system. This loss of control was compounded for some participants who felt that they remained poorly informed regarding the diagnostic processes and findings. Participant P9 and his wife (C3) discussed feeling as if they were in a *"whirlpool"* as they underwent a long series of medical referrals in pursuit of a diagnosis:

> *"I think we were just dead. We were just dead up here. Oh, today we have to go here, we have see this person. Tomorrow we have to see that person over there. Then we might have a day at home. Then you're back again. Next week we've got the same sort of thing, you know, over here, up there, down here, around there and nobody really telling us anything. That was one of the things. Nobody was telling us anything."* (P9)

Several of the dying people in this study had waited months or years to receive a correct diagnosis of their illness. For some of these individuals, this delay contributed to a general sense of mistrust in health services, particularly if they felt that health professionals had repeatedly dismissed their concerns about their health. Participant P11 described waiting for over three years to receive a diagnosis of Motor Neurone Disease. He stated that, during this time, he saw dozens of doctors but felt his concerns were overlooked until he was eventually seen and diagnosed by a neurologist. Stories such as this highlight the emotional burden that can accompany the period of diagnostic and prognostic uncertainty prior to the attribution of a dying status:

> *"Well, you're wandering around as if you're in a vacuum... I couldn't sleep. (My wife) was starting to worry. I was concerned. I wasn't eating. I was losing weight, what was happening to me? Of course, if they are not helping, some people… could even probably have thought about suicide…"* (P11)

6.4.2 Forfeiting control in pursuit of recovery

For many participants, the prologue to the drama of dying initially entailed diagnosis of a potentially curable illness and so the build-up to their formal declaration of a dying status involved ongoing immersion into the health care system in pursuit of recovery. The pressure to comply with health systems and processes remained strong during this time. Most participants seemed clear regarding the expectations associated with the illness role during the treatment phase. As part of this, they were generally willing to adopt a relatively subservient stance in their interactions with health professionals. The reasoning for this appeared manifold. Some participants placed high importance on maintaining the impression of a *'good patient'*, which they believed is best achieved by adhering to the expectations of health professionals and health systems. This association between the good patient and the compliant patient sheds light on the pervasive and powerful mechanisms of control within the health care system:

> *"I mean, the little time that I had in hospital to observe, some people are good and some were not so good. Some were wanting to fight and argue and criticise. What about that bloke, that cancer patient opposite us; you couldn't call him a good patient. If I judge me by him, and compare me with him, I wouldn't be a bad patient… The doctor says this is what it needs, that's what it needs. That's what you do. If they're going to take blood, they're going to take blood. They're going to take it one way or another…"* (P9)

A second explanation lies in the fact that most participants were also focused on cure during the treatment phase and, therefore, viewed compliance with treatment regimens and associated processes to be critical to that end. Indeed, many participants declared that they had been willing to undergo considerable hardship in order to promote their chances of survival:

> *"…the last week of treatment I was in hospital. It certainly wasn't pleasant but you've got to do what you've got to do. I thought I was doing something that would help fix the problem. But in the end it didn't."* (P6)

Health service control over the prologue to the drama of dying sometimes occurred overtly due to systems, processes and rules that stymied individual choice and, arguably, compromised the receipt of timely support with potentially urgent need:

> *"They wait until he's almost dead and we have to take him to ED before anything will happen. This whole time that sort of thing... You can't just go up to the department. You can't just ring that department and say 'how can we make an appointment'? It's like, well, your next appointment's not scheduled for three months... The whole time I'm fighting with them and they're just going, oh yeah, ED, or you need another referral."* (C8)

Other forms of control, although far less obvious, still served as repeated reminders to health service users that they were inevitably just a small part in a very large system. For example, several participants discussed the fact that they were repeatedly required to declare the same information to large numbers of health professionals. Such processes reinforced a power imbalance where professionals assumed a directing role in health care encounters with service users pressed into bit-part roles:

> *"At this point, I think we were at the stage where, you know, all this stuff is on computer, all your history, every time you go to see someone they type it all out and it's all on the computer. It didn't seem to us that anybody was conferring with what had been said before... You know, we were just thinking we go through this story. Every time we come here, (my husband) has got to sit down and try and think it all through again, think about what date was this and what date was that, and how did this all come together, when it's all there on the computer."* (C3)

Many participants described having been offered several lines of treatments in pursuit of cure. For these individuals, the offer of each treatment option seemed to afford a renewed sense of temporary hope. However, when these treatments proved unsuccessful or became too much to bear, participants were gradually forced to accept that their chances of cure were becoming increasingly unlikely. To some extent, this cycle of hope being raised and then dashed edged individuals gradually closer to an emerging realisation that a cure would soon no longer be an option:

> *"They had to stop the chemotherapy… because I was not doing well with it. All my feet were cracking and my fingernails, I couldn't pick things up and there was a general feeling of unwell. So they stopped the chemotherapy and they said, 'well, we don't really have much ammunition left in the tin.'"* (P5)

On the other hand, it is noteworthy that, despite the diminishing success and ongoing burden of treatments aimed at prolonging life, many individuals remained focused on cure for a very long time. Palliative care consultant (participant HP3) suggested that this curative emphasis arose as a by-product of a health system that stifles choice in relation to alternative management options. He argued that, if presented with information concerning the pros and cons of ongoing treatment, many individuals might choose to cease curative treatment at an earlier stage and focus instead on quality of life. From a dramaturgical perspective, the approach advocated by participant HP3 can be seen as a means of fostering choice through the promotion of a set of scripts that offer an alternative approach to cure at all costs. In some cases, such choices may aid in bringing to a close what can be an unnecessarily and unhelpfully long prologue to the drama of dying:

> *"Well, I guess empowerment is about people feeling they have control over their own destiny. I guess one of the products of - or the consequences of modern medicine is that people are subject to protocols and plans and treatment plans, and so on. So rather than a focus on them as a whole person, the focus is on their disease and how*

> *you treat the disease… But in fact, they're also very demanding of patients in terms of attendance and compliance with taking things and turning up on the day you're supposed to turn up, and having your blood taken as necessary, and… those treatments may make you feel quite unwell… It becomes disease centred treatment rather than patient centred treatment… So I think you can change the focus… Do you want a longer journey or… are there particular things you want to do?... There are plenty of people who have had treatments for a long time and, in retrospect, they say 'I don't know why I did all that. I missed out on the opportunity to do this, that or the other', and people need to know that."* (HP3 – Palliative care consultant)

6.5 DRAMATIC UNIT 1 – ASCRIPTION OF THE DYING STATUS

6.5.1 Confirmation of dying

Once the prologue is complete, the opening dramatic unit in the drama of dying begins. In most cases, it is the responsibility of a medical professional to provide formal confirmation to an individual of a dying status and, in doing so, set the drama of dying in motion. As part of this process the doctor will (among other things) attempt to alert the dying person to his or her dying status and, usually on request, attempt to offer an estimation of prognosis. This estimation provides guidance on the time frame in which the various scenes may unfold. For some of the participants in this study, confirmation of the dying status was communicated clearly and directly, making it absolutely clear that cure was no longer an option:

> *"Whilst I was there they basically told me that the cancer has spread right through my whole body… and that I should get my life together and … prepare to die because that was going to happen at some stage in the future."* (P5)

However, many other participants experienced a less clear-cut transition into the dying status, resulting in considerable confusion marking the opening scene. Some simply did not understand the news that had been presented because of the timing and method of delivery. Participant P10 described receiving a phone call while he was at work from his doctor during which he was informed of his diagnosis of stage IV lung cancer. However, he was not officially told what this meant until a subsequent appointment four days later:

> *"He said 'I've got some news for you about the MRI'... I think he just talked about the hip first but then he said 'and you also have a something or other squamous or whatever thing, on your left lung'... he just said 'I'm sorry to have to give you that news'... I had no idea what I was in for... I don't know; they must assume that we walked around with a medical dictionary in our head knowing what the hell stage four lung cancer is..."* (P10)

Although it was not always the case, the tendency for health professionals to present information in a way that seemed either incomplete or incomprehensible to dying persons occurred frequently throughout the drama. This lack of clear and/or understandable information was a major source of frustration for dying persons and their caregivers and often contributed to feelings of uncertainty and anxiety. Participant P5, for example, sought clarification regarding his likely illness trajectory, particularly because of his fears concerning the potential for paralysis due to metastatic spinal cord compression. However, despite repeated attempts to discuss this issue, he felt that answers, of any sort, were not forthcoming:

> *"But I'd like to know what's going to happen to me, how I'm going to feel... roughly how much pain I'm going to have. If I'm going to be paralysed or just a general idea... They just really don't listen. As soon as you start talking that way, they just*

> *keep writing in their book or whatever and move on. Just don't give you the time to even discuss it. I find the registrars are a little better. They'll listen but they won't give you any more information. They'll sort of say - they'll refer it to back to the other one and they'll say, well, why don't you talk to (consultant oncologist) about that, and you really don't get information anyway. That's the simple of fact of the matter; you just don't get the information."* (P5)

It is entirely plausible that health professionals are unable to answer questions such as those posed by participant P5 because it is not possible to predict with sufficient accuracy how any individual's illness will progress. These professionals may have chosen, therefore, to avoid such questions as a means of steering scripts away from topics on which they felt either uncertain or uncomfortable. Alternatively, the medical professionals in these situations might have considered it potentially harmful to engage in conversations with dying persons about outcomes that remained highly uncertain. By curtailing such discussions until the dying person's prognosis became clearer, the doctor may have been trying to prevent unnecessary fear based on speculation. Although such approaches may have been aimed at maintaining the dying person's sense of hope for the future and/or confidence in the health care they were receiving, regrettably they seemed to have the opposite effect, with some dying persons feeling that important information was simply being withheld.

For a few of the dying persons interviewed in this study, the experience of receiving incomplete or unclear information involved their being informed by one doctor that they were dying and then, by another, that this was not necessarily the case. In these instances there seemed to be a degree of disagreement between different medical teams as to whose responsibility (or, perhaps, right) it was to deliver such news:

> *"... I went into palliative care and they gave me questions like... where would I want to die, whether it would be in a hospital, whether it would be at home... At that stage, I didn't realise that I was terminal. No doctor had told me. Then I went back to the radiation doctor and he basically said... no one has said that you're terminal yet because they still hadn't had the results of the chemo and radiation."* (P6)

This stop-start entry into the dying status was generally confusing and distressing for the dying persons and their caregivers. To some extent, it seemed to arise from healthcare systems and processes that were both compartmentalised and principally focused on cure. It also reveals a political struggle surrounding the question of when the drama of dying should be set in motion and which doctor should initiate its commencement. In the instance described above, both the palliative care and radiation oncology doctors recognised the extreme gravity of the declaration of dying and seemed intent on supporting the dying person in what they considered to be the best way possible. However, an ideological difference appeared to be at play, in which the palliative care doctors considered timely entry into the dying status to be important, whereas the radiation oncology doctors believed the conversations regarding dying should not be initiated until it was certain that cure was no longer possible.

Again, it could be argued that instances in which doctors offer new avenues of curative hope for dying persons are a reasonable and humane response to a person in desperate need of positive news. These doctors may well have been playing what they saw as their part in the drama of dying by remaining focused on the chance of cure for as long as was possible. Their actions would reflect, therefore, an attempt to revert the drama of dying back to the prologue due to what they considered a premature commencement of the opening dramatic unit. However, another possibility, suggested by one caregiver who had been very frustrated with her father's medical care, was that doctors were reluctant to discuss a dying diagnosis because of their own discomfort with death:

> *"The one thing I've learned about the medical profession in this whole process is these people might be doctors, whatever, 95 per cent of them are not comfortable with death at all. They cannot handle it."* (C8)

Regardless of the reason for the confusion concerning confirmation of the dying diagnosis, the participants who recounted these experiences described feelings of angst and uncertainty as they awaited further confirmation of their dying status:

> *"Oh, I was just a mess for days. I probably just drank two bottles of wine. Yeah, I was a mess. Then when I saw the radiation doctor, I'd come down again because I was thinking 'we haven't had the results of the chemotherapy or radiation, so they have jumped ahead'. That is what was in my mind. Then for me to get the results to say it hadn't worked, yeah, I thought maybe they knew something that I didn't… I don't know why they would have asked me those questions in the first place, because I was on the understanding I was in palliative care for pain relief and nothing else."* (P6)

As might be expected, receipt of a dying diagnosis came as a terrible blow for the large majority of the dying people and many of the caregivers interviewed in this research. Even those who had experienced a lengthy and graded transition to dying struggled with the news that cure was no longer a possibility. On hearing the news, they described a wide array of emotions including anger, sadness and bewilderment:

> *"(It was) very teary, very upsetting… yeah, for me both me and for my sister. I spent a lot of time that week crying… yeah, that kind of threw it in your face there… it was*

> *fine last week and I'm not this week... Then it starts to set in that I'm not going to be living here too much longer."* (P3)

An exception to this occurred among some participants who were older. These individuals seemed to find it easier to come to terms with the declaration of their dying status by rationalising that they had led a full life and reached a suitable age at which to die. News of a dying diagnosis in older age was seen as being better aligned with the expected script in the drama of dying. These participants contrasted their situation with those of younger people for whom they felt a dying diagnosis was unfair:

> *"So it's a different business - talking with us at 86, it's entirely reasonable to me, to die at some time now, as opposed to 33 or 14 or something. So I mean it's just part of the cycle in life, as far as I'm concerned."* (P12)

Many of the dying persons who were interviewed indicated that, shortly after being told of their dying diagnosis, they were also informed about and referred to palliative care services. The introduction of the palliative care team brought to the stage a new set of cast members whose role, as time passed, came to be valued by most participants. However, several participants reported that they initially felt a sense of shock and fear at first hearing mention of palliative care. For some, it seemed that the arrival of the palliative care team was akin to Death itself having walked onto the stage, ready to bring the entire drama of dying to a premature close:

> *"Then after that, they referred us to the palliative care unit. I think at that time, we suddenly started to think this is not a good time; this is not good, because you think of palliative care as the absolute end. That's the end. I mean, I think if you speak to most people, that's what they would think, that palliative care, oh, you know, there's no hope for anything."* (C3)

Indeed, two participants suggested that, based on the extent to which the public synonymise the term ‘palliative care’ with the last days of life, a name change may be needed to prevent unnecessary anxiety among individuals referred to the service:

> *“If they had another name for it but they didn't. But the word palliative, it means the ending, the last ending, last days, last death, because I know several people who've gone to hospital and died in palliative care.”* (P11)

6.5.2 Response to status change

Once their dying status was confirmed, the dying persons in this study generally alerted a small number of close friends and family to the news. Almost all participants described the role of the principal caregiver as becoming particularly prominent around this time. Although the dying person’s partner often took on this role, in some cases other family members or friends occupied it. While, in many instances, the principal caregiver had already been providing support in relation to illness roles, the dying status shifted the meaning and nature of this care. From the point of the dying diagnosis onward, the principal caregivers shared the stage with the dying person for much of the time, often playing a key role in assisting with impression management during the dying person’s encounters with other cast members. For the caregivers themselves, formal confirmation of the dying status of the dying person often meant sidelining or relinquishing other valued roles:

> *“Well… in November when it was, no more, and we were told then she only had a month to live, I just immediately took leave. So I haven't been working since the end of November.”* (C1)

For some caregivers, this constituted the beginning of what would prove to be a long, drawn-out and, in many cases, lonely process of role juggling and/or role suspension, in which their caregiver responsibilities took precedence over most other aspects of their lives:

> *"I prefer to be the daughter. I don't like being the carer… Yeah, I'd like somebody else to have a turn at being the carer, but there's not, so you just do it."* (C1)

> *"It's on hold. The old me is on hold... I'm in this process… I don't know who I am anymore, as my purpose is Dad."* (C8)

Although no one wanted the dying diagnosis, many participants did appreciate the clarity that it provided. For some, it brought to a close a prologue that had felt both burdensome and chaotic. Despite the obvious distress that arose from receiving a dying diagnosis, for most participants there appeared to be a high degree of certainty regarding role expectations during the opening dramatic unit in the drama of dying. The recentness and magnitude of the news regarding the dying diagnosis promoted the foregrounding of dying roles. The expected behaviour of dying people during this time seemed to be guided by clear social scripts with key relational tasks of dying (e.g. alerting family members and friends to the dying status) and practical tasks of dying (e.g. completion of wills etc.) often prioritised:

> *"It was out in the open. We had talked about with the family and so it was on the table. End of life was on the table. Everybody knew. If we wanted to talk about something it was there, everybody knew where we were coming from with that."* (P9)

Others suggested it afforded them the chance to re-evaluate their priorities, plan for their death and/or make the most of the remaining time available:

> *"I'd have to say it wasn't a hard decision to make when after we'd done the immunotherapy treatments and they didn't work, even though it was distressing and we were upset. Again, we went and sat down by the river and had a chat and decided that we would accept the prognosis and that we would just try and enjoy whatever*

> *time we had left, and that it was better to have six to 12 months of me not being sick all the time…"* (P10)

6.6 DRAMATIC UNIT 2 – MIDDLE SCENES

6.6.1 Changes to sets, props, cast members and scripts

The second dramatic unit in the drama of dying encapsulates the period after the receipt of and the initial response to the diagnosis of dying and before the terminal phase of dying (that is, the last days and weeks of life). The duration and focus of the second dramatic unit varies among individuals. For those with rapidly progressing dying processes, this phase of the drama will be a relatively brief affair, with an emphasis for the majority of the time on dying. For many others it plays out in a much more protracted manner with the almost constant tension and high drama associated with the declaration of the dying status shifting to a slower and more flexible but also less clearly scripted second dramatic unit.

The majority of the scenes within this second dramatic unit occur beyond health services and systems. Instead, the second dramatic unit unfolds predominantly in the home of the dying person with health professionals playing a less prominent role. For the dying people in this study, aside from periodic visits from community nurses, contact with health professionals during this time occurred most often on those occasions when their health became temporarily unstable or practical problems arose. In such situations, health professionals often provided advice and support in negotiating specific difficulties. Participant HP5 described part of her role as a social worker in offering emotional support and arranging professional assistance during times of difficulty:

> *"So we sort of offer our help so that they know that there's someone out there… We make a plan that the right people actually come to the rescue to help them. So that*

> *the carer can feel a bit more competent in managing or have a plan how they're going to cope with the immediate issues, whether it's admission or help at home or get (a doctor) to go and visit, or get the OT to go and help with equipment. So we pick up on those things*." (HP5 – Social Worker)

At times when the dying person is relatively well, there is a tendency for the role of health professionals to be backgrounded, with occasional follow-up calls or clinic appointments being their main forms of input. On the whole, dying persons and their caregivers seemed happy with this arrangement, preferring to focus their time and attention on life beyond health services and symptoms:

> *"Because again, like people don't want to be in hospital. They will avoid it if they can, and if they've got poorly controlled symptoms or they're anxious about their family situation, whatever it is, that's when we're seeing the people come back. They're not doing it for fun."* (HP2 – Occupational therapist)

Indeed, for many dying persons during the second dramatic unit, the requirement to revisit the scenes associated with the prologue to and the opening dramatic unit of the drama of dying was something that they sought to avoid whenever possible. The meaning that they had attributed to the cast members, sets, props and routines associated with health care institutions changed once cure was no longer an option, with many participants reporting time spent in health care institutions now to be much less palatable:

> *"Just walking into hospitals now, I just - my anxiety level is just high... I think just people poking and prodding and just hospitals in general, yeah, I'd sooner what I've got left, enjoy it. I don't want to be in there."* (P6)

Distance from the health service orientated features associated with the build-up to the dying diagnosis enabled greater freedom and control for dying persons and facilitated a shift in focus away from illness, death and dying. Dying persons and their caregivers generally viewed the changes in scenes and scripts that accompany this new dramatic unit very positively. Participant C3 discussed the profound sense of relief that she and her husband felt when they discovered that they would now be released from what had seemed a constant stream of hospital appointments:

> *"So I think that's where the palliative care has really been helpful, and we don't have to go back to the clinic if we don't want to. They'll keep in touch with us and I think - you know, that also was like a burden that lifted off us... We don't have to go for all these appointments and things again, that we don't have to go running around and being concerned with what day it is and where do we have to go, and what do we have to do. It was like a freedom, wasn't it? ... We were cut free and we can face life. We can face our life again."* (C3)

6.6.2 Impression management - Avoidance of the mono-status of a dying person

With more time spent away from health care facilities and services, dying people find themselves confronted by a different problem during this second dramatic unit. The flexibility afforded by the lack of definitive scripts within the second dramatic unit can also contribute to episodes of uncertainty, ambiguity and incongruence in role relations. Dying persons and members of their social circle are accustomed to social scripts for dying that emphasise a more rapid progression from declaration of an individual's dying status to the actual point of death. As a result, many of the key cast members in the middle scenes of the drama of dying find themselves unsure as to the terms on which they are meant to relate to the dying person. As outlined in Chapter Five of this thesis, mismatched role relations and inevitable faux pas thus arise with alarming frequency during this dramatic unit, often resulting in frustration or distress for one or more parties.

One of the main precursors to poorly aligned role relations lies in the fact that, for the most part, individuals who are dying see the attribution of a singular status of 'dying person' as problematic. Consequently, in an attempt to prevent this from occurring, these individuals seek to avoid enacting the dying role in the majority of social situations. The dying people interviewed in this research appeared concerned that allowing their dying status to be foregrounded would result in their previous roles, status and identity being relegated to a minor status beneath the master status of 'dying person'. As such, they appeared fearful of a subtle form of stigmatisation and social dislocation, which would see them nudged towards entry into a dying community:

> *"I do have discussions with other people, friends of mine, that have got the same sort of disease, and that sort of thing... But I don't talk to anyone else about it unless I really, really have to... I can't think of anything worse than losing all my friends because I've got cancer and having only the ones that I've got at the hospital. You know, how poor would that be? How sad would that be?"* (P5)

In response to such concerns, the dying person and the principal caregiver work in partnership during the second dramatic unit to ensure impression management through the projection of, and subsequent focus on, the living status of the dying person for the large majority of the time. As part of this, the dying person and principal caregiver often share backstage, preparatory moments that are otherwise shielded from the broader audience:

> *"We came home, we said we'll get the kids here, we'll tell them what's happened, and that's it. It's a need-to know basis. We're not going to spread this around... this is different. This is end time... To the friends that we know that ask you and say how are you. I'm fine. It's fine, it's okay. You're looking well. Oh, thank you. I'm feeling well, thank you. We let it ride at that."* (P9)

For participants in this study, impression management seemed to work most effectively when all cast members knew their part in a particular scene and were, therefore, able to stay on script. In some instances, deliberate efforts were made to ensure that the living status of the dying person remained foregrounded during a social encounter:

> *"You could have a friend who walks in and says, 'mate, can you help me? I just haven't a clue how to fix this', knowing the person sitting there is dying... 'Could you give me a hand, you know, and show me how to do this?' The person that's dying feels… (I am) helping somebody else. You know, it feels as though they're wanted, they're needed."* (C7)

However well intended, the apparent need for pretence in encounters such as described in the example above, reveals an unspoken tendency for dying persons to be viewed as individuals whose productive lives are over. Indeed, this view was even more apparent in situations in which friends, family members or associates inadvertently placed unwanted, overt attention on the dying status. In such instances, it was as though the mere mention of Death was enough to bring it centre stage and thus spoil an entire scene. Other cast members generally responded swiftly and firmly to mishaps such as this, with efforts made to draw all parties back to the preferred narrative. To prevent further disrupting the expressive order of the scene, these responses took place backstage, beyond earshot of the dying person. Participant C7 described her response in a conversation with family friends when they veered off script by focusing on her husband's dying status:

> *My attitude to them straight out was, hang on, we know he's dying but nobody in this earth can actually say, 'oh, he's going to be gone in three weeks'... Well, they looked at me and I said 'he's still the same person. You talk to him as though he's the same person. You don't come in and make it like a wake.'"* (C7)

6.6.3 Routines and disruption

For dying persons, one of the simplest and most commonly utilised means of shifting focus away from their dying status involved establishing or re-establishing routines at home. These attempts at regaining routine seemed aimed at supporting the resumption of a sense of normality after the relative chaos and shock of the events surrounding the initial dying diagnosis. However, during the second dramatic unit in the drama of dying, changes to some elements of the routines of dying persons also served as reminders of their dying status. This was particularly apparent in the gradual increases in dying persons' need for assistance with aspects of day-to-day living (such as personal care or practical tasks). Dying persons found the need for such support troubling. It seemed to hinder their efforts to foreground their living selfhood by having to accept a change in the nature of their role relations with family members and/or friends and diminishing their sense of themselves as productive and autonomous beings:

> "*As I get less able, my family have to do more and more for me. Some of the things that my wife has to do for me now, I guess to a certain extent it destroys that relationship. That relationship that you normally have as a husband and wife… we still obviously care for each other even more, I'm sure, but things have changed. So that now it's her having to look after me and even with my kids, some of the things they have to do for me… It's hard work looking after me… and to think that that's the future that my wife has to think about, yeah, I find that tough. It's not the way I'd like to finish up my life with my wife.""* (P10)

Typically, either the principal caregiver or the formalised health and/or social care services provided support with personal care and/or practical tasks. In some instances, however, other cast members were involved. For example, the palliative care social worker

(HP5) described a part of her role as identifying and mobilising extended family, friends, neighbours and others in offering periodic assistance to dying persons and/or their caregivers. Although this form of assistance was often helpful, it was also discussed that sometimes members of dying people's extended social networks can feel unsure as to how they ought to go about offering and/or providing support without intruding into the dying person's life:

> *"I think some people don't know what to do, don't know how to be helpful. So they feel what they can do is keep out of the way... Other people can be overly intrusive. Sometimes with some people, they also just volunteer their support and do it in all kinds of ways that are unobtrusive and yet really helpful. People react in different ways."* (HP3 – Palliative care consultant)

A number of participants described a particularly unwanted form of support involving an out-of-town relative who briefly enters the drama of dying with a view to fixing the situation, before departing again, often leaving behind a trail of disruption:

> *"... a child will come from out-of-town and they will say I'm here for the next month or I'm here for two weeks. They will put in all their two cents with how everything's going... Then you've got the husband or the wife, who's been doing this for a long time and it just throws their whole routine out of whack... and there's no acknowledgement (that the caregiver has) been doing this for months... We're here to save the day."* (HP2 – Occupational Therapist)

6.6.4 Special times and bucket lists

Even though, for most of the second dramatic unit, dying persons pursued a sense of normality and everydayness, almost all of the dying persons also described periodically engaging in special activities aimed at making the most of their remaining available time. For some, this involved simple events such as family get-togethers or short trips away.

Others undertook more elaborate *'bucket list'* activities such as world cruises and four-wheeled-drive trips across Australia. The sets, props and scripts associated with these scenes were in almost complete contrast to those of the build-up to the drama of dying. For both dying persons and their caregivers, these scene changes seemed to serve the function of clearly demarcating the preceding episodes in the drama of dying from the dying person's preferred scripts for the time ahead. To some extent, they constituted intermissions from the broader drama, allowing a temporary shift in focus away from the reality of the dying status:

> *"So we decided that we'd live, we're going to live, we're not going to allow this to crowd us again. We're going to live and we're going to do things, and that's why we decided we'll go to Sydney."* (C3)

To serve their purpose as a break away from the drama of dying, these special occasions required all parties to adhere strictly to social scripts in which the dying status was neither openly discussed nor overtly acknowledged. As has been outlined in Chapter Four of this thesis, however, these events did, in fact, allow for subtle engagement in the personal and relational dimensions of dying roles in that they nurtured opportunities for legacy construction and memory making. To this extent, although special times and bucket list activities appeared at face value to constitute a break away from the drama of dying, they simultaneously and surreptitiously formed an important part of it.

6.6.5 Graded shift towards the dying selfhood

Although most of the second dramatic unit involved efforts aimed at resisting the dying status, there were periods during this phase in the drama of dying when participants foregrounded their dying selfhood. This was more likely to happen when the sets, cues and props associated with a particular scene drew the individual towards dying roles. Such scenes occurred more frequently towards the end of the second dramatic unit as the dying person's condition fluctuated and/or deteriorated. This was often the case when an individual had to attend hospital appointments or required an inpatient admission; but it also happened increasingly over time during scenes within the home. As their condition deteriorated, a number of participants began to receive more contact within their homes from new cast members who brought with them a focus on (or, at least, a reminder of) dying. In some cases, the contacts occurred during home visits by health professionals and, in other instances, increasingly frequent visits by concerned friends and relatives:

> *"I've got three brothers who seem to not have much to do with mum. Then all of a sudden out of the blue when they know there's not much time left, they all rush up and all join in and, you know, 'oh, we're here, we're here'."* (C1)

Towards the end of the second dramatic unit, set changes, in the form of alterations to the home environment, also precipitated the emergence of dying roles. For example, the homes of several participants had begun to be filled with items such as wheelchairs, oxygen cylinders, hospital beds or other specialised medical equipment. Participant P7 made reference to the large numbers of religious items he had started to place around the hospital bed within his home. In a similar vein, participant P6 indicated that her husband had recently constructed a memorial garden for her in their backyard. While this was an act that she appreciated, it sometimes reminded her *"that time was short"* (P6). Set changes of this nature served important practical, spiritual or personal functions but also brought the individual's dying status and associated dying roles to the forefront. For some, these changes seemed to contribute to a realisation that the closing dramatic unit in the drama of dying was nearing, thereby precipitating the gradual re-introduction of social scripts that focused more on dying role relations:

> *"I'm seeing my mind is changing, or my emotions are changing. When I first got the diagnosis… I didn't turn people away but I certainly didn't encourage people to come and see me… People would ring and I wouldn't answer the phone. I guess I just didn't want to talk about it… But what I do notice is that's changed. Probably in the last month or so I've become a lot more open and I'm prepared to talk a lot more about it. So if somebody, you know, one of my buddies or something, wants to come around and discuss things I'm happy to sit down and talk to them about it. So something's changed. I don't know what's changed there… but maybe is it possible that knowing that I've got a little less time left that I'm thinking maybe I should spend more time with these people."* (P10)

By resisting cues and prompts towards dying role enactment during the majority of the second dramatic unit, dying persons were able to incorporate the dying status in a proportionate, rather than sudden, manner. Doing so allowed these individuals a degree of control over what they considered an unwanted and premature emphasis on dying role relations. Over time, however, as the reminders of the dying status became increasingly prominent, the dying persons appeared to become more willing to allow a focus on their dying status. This graded return to dying role enactment sets the scene for the final dramatic unit in the dying person's life.

6.7 DRAMATIC UNIT 3 – FINAL SCENES

The closing scenes in the drama of dying comprise the final days and weeks of life. These scenes may play out in an individual's home, in institutional care (such as hospitals, hospices or nursing homes) or in a combination of these. Dying persons often experience a medical and functional decline as death nears. As a result, increased contact with health professionals and/or greater presence of cues and props associated with ill health and dying are likely, regardless of the set on which the final scenes play out. As a means of proactively scripting these final scenes, a few of the dying persons and caregivers indicated that they had already made plans for an inpatient palliative care admission once death became close:

> *"But towards the end when things deteriorate and that sort of stuff, then she'll make her way back to the hospital. The hospital know that too… I think that's where you should be, because I think you get more care there than what you're going to get at home. You know, if something happens in the middle of the night, would you rather be in a hospital than be here, especially us living out here too. I'd hate something to happen in the middle of the night and it takes the ambulance half an hour, 45 minutes, to get here. It's too late by then."* (C2)

Others recounted stories of feeling better equipped to care for the dying person at home by drawing on guidance from health services concerning clinical aspects of care:

> *"I think in a sense as far as the carer's concerned with the professional, I think if that professional gives enough support that, look, you're doing a great job, we'll just give you these guidelines, you know, of how to give him this and how much of this to give him and everything else… I mean, in some sense, health carers have got to take control. Do you know what I mean, because not everybody can cope with it… We knew that if (husband) were sick... I would phone the palliative care nurses first. I'd get on the phone… and I would say 'can I talk to one of the nurses?'… They would say, 'can you hang up the phone? Within three minutes, I'll have somebody back to you'; and they did."* (C7)

Although the health professionals interviewed in this research described examples of professional input across each dramatic unit in the drama of dying, their role as a guide appeared to be most prominent in the final scenes. From a dramaturgical perspective, the function of health professionals during this time seemed to serve two potentially important functions. The first of these lay in the construction of an appropriate stage and set for dying through the creation or provision of safe and comfortable environments, either at home or in the hospital / hospice setting. Such environments enable ease of care; however, in doing so, they add a clinical aura to the scenes associated with the final dramatic unit. The second health professional function entailed guiding the generation of scripts suited to the last scenes of life by facilitating important conversations with dying people and those close to them as well as providing education about and support in the dying process:

> *"Families will say, 'I have noticed this'. That encourages us to have that conversation about, these changes are normal, this is what you can expect..."* (HP4 – Palliative care nurse)

These same professionals, however, emphasised that there are limits to their roles, highlighting that it is neither possible nor appropriate to be involved in some aspects of the dying journey:

> *"So the first thing is, okay, the patient's going to die whatever I do. I'm not in control of their dying but where I can help is in the process of dying, how they deal with their dying, whether I can make them comfortable. I can support their family in dealing with it, so what comes out the end seems as a normal and inevitable thing. I'm not trying to stop them from grieving or being sad...I'm here to help you deal with dying. That's the best you can do."* (HP3 – Palliative care consultant)

Interestingly, the scope and function of the palliative care service was an issue of contention for some team members. Participant HP2 described her frustrations with the increasingly medicalised focus of the service. In particular, she bemoaned the fact that issues that she and her other non-medical colleagues regarded as important were often dismissed as irrelevant by junior medical staff:

> *"But I just get this sense from the pal care doctors that we're a palliative medicine specialty, and that's what we do. We get our medicine right... We still have our MDT meetings but when you raise an issue, sometimes it's met with eye rolls, because you're wasting their time talking about this. But then we've got consultants, thank God, we've still got (Doctor's name) because she's the only one who can - she pulls all the doctors into line and says, hey, 'this is relevant' or 'you'd actually learn a thing or two from listening to this'. Yeah, it gets very uncomfortable in the meetings at the moment when that has to be said about what the rest of the team's contributing."* (HP2 – Occupational Therapist)

The observations of participant HP2 are important in that they demonstrate the way in which backstage activity, in this case in the form of morning multi-disciplinary team meetings, have a powerful influence upon impression management in interactions between dying persons and health professionals. The health professionals use these meetings as a means of ensuring what Goffman (1959, p. 207) terms "dramaturgical loyalty" (collective adherence to agreed scripts) among all team members during the frontstage performance. Participant HP2 also noted the clear presence of a decisional hierarchy within these backstage negotiations, with palliative care consultants in the role of stage director and, thereby, having the final call on what is considered as legitimate frontstage activity within the palliative care centre.

The concerns raised by participant HP2 also shed light on a political dimension impacting the professional delivery of end-of-life care. All the professionals in this study considered their role to be intrinsically valuable to dying persons and their caregivers at various times during the drama of dying. It is perhaps unsurprising, therefore, that individuals became frustrated when they felt that the potential of their role was overlooked or diminished by others. This sense of annoyance at being in some way shut out from the drama of dying was most apparent in the narrative of participant HP1 (chaplain) who described situations in which other professionals adopted what he considered to be a diminished version of his role:

> *"... if the nurses don't value the chaplain service they won't call a chaplain to come in and talk with the family... But if the person who gives all that support and advice is the nurse, or the doctor or the tea lady or whoever, they're running around with other patients and they may not have any experience in [that] sort of field... I've been in rooms where nurses or whoever else, social workers and psychologist, give this absolute airy-fairy thing on death... I find that quite often is detrimental to where we even start... There are a lot of people who believe faith is just this wishy-washy irrelevant thing that some people hold on to... I have seen many healthcare professionals, doctors, nurses and all across the field, who treat it that way."* (HP1 - Chaplain)

Frustrations, such as those discussed above, reveal a degree of discordance among professionals involved in the drama of dying. At worst it is indicative of a process in which professional cast members vie for a central place on the stage as they seek input into and/or control over, particular scenes within the drama of dying. At best, it highlights a lack of role understanding between professionals involved in end-of-life care. Whatever the explanation may be, professional disagreements of this nature run the risk of compromising the quality of support available to dying persons and their caregivers at key times during the drama of dying.

The closing scenes in the drama of dying are generally more tightly scripted than those in the preceding dramatic unit. The finality of these scenes resembles the shorter timelines associated with dying as popularised in contemporary media or with dying in historical times. As a result, most cast members are, at least somewhat, intuitively familiar with their expected roles. However, guidance is sometimes provided to assist in unifying the scripts upon which different cast members are drawing:

> *"But they're often relieved that we've been able to talk about it openly… that gives them permission also to say the words. So if I talk to the patient and the patient has a conversation with me about what's happening and the family are there, and they're listening, so that says two things: one, the patient is able to talk about their dying and, two, they now know the patient knows and everyone knows what's going on."* (HP3 – Palliative care consultant)

Participant HP3 highlights the palliative care doctor adopting the role of stage director by ushering in a new set of social scripts that he regarded as helpful in the closing dramatic unit of life. It is noteworthy that palliative care consultant (HP3) chose to speak openly about death by name, thereby accommodating its presence on stage. Such actions fostered opportunities for the enactment of dying roles by breaking down the taboo associated with the mention of death that had dominated much of the previous drama. However, despite such efforts towards the unification of scripts, in some situations differences of opinion can continue to exist, with disagreements around end-of-life management and family conflicts prominent even in the days and hours before death:

> *"A lot of families… come together quite well and are very accepting of it. They view the passing as more of a blessing and it's more of a happy environment, though there's still tears and emotions… Others, it can be very strange, you get some odd*

> *family dynamics… sometimes the tension's so thick… you can just feel it when you walk in. One person's more okay and accepting and one person… can want full active treatment."* (HP4 – Palliative care nurse)

Indeed, in recognition of the potential differences regarding end-of-life needs and wishes, most of the professionals interviewed emphasised the importance of a flexible approach to supporting dying persons and their family members and/or friends during the closing scenes of life:

> *"It depends on the family, so some just don't want to talk about it. They want to rather enjoy (the dying person) while they are still alive as opposed to being proactive and have everything sorted when there is a crisis. But whatever works for them, we go along with their conversation and help them put any stuff in place."* (HP5 – Social worker)

One health professional suggested, however, that some ward staff occasionally crossed the line between guidance and interference, pointing to what she saw as unnecessary involvement in personal dimensions of dying persons' lives. Her observations highlight that, unless appropriately managed, health professional assumptions concerning what constitutes a good death can have a pervasive and potentially unhelpful influence in controlling social scripts at end of life:

> *"But we can't solve people's life issues or relationship issues in two days in the palliative care centre... I cannot see how that would be possible to do, and I don't think that's an expectation that we should have. I understand that there are things that come up at end of life but I think sometimes we should really just let people deal with it themselves… I think that staff are almost uncomfortable with complex family dynamics, so they want it to be fixed."* (HP2 – Occupational therapist)

For dying persons and their family members and friends, the closing scenes in the drama of dying bring to a conclusion a turbulent episode marked by numerous and, often unexpected, physiological, emotional and social challenges. However, these scenes also constitute the final moments of a person's life and, as such, inevitably entail varied and heightened emotions. Different dramas will have different endings. For some people, the drama of dying will not conclude in a way that feels satisfactory for all cast members involved. For others, however, these final scenes will bring opportunities for last goodbyes, emotional and spiritual preparedness, closeness and comfort. One of the professionals interviewed in this study offered an example of such an ending when he recounted a personal story concerning his last hours spent with his dying foster son:

> *"We talked little bits about the funeral. We didn't talk massive amounts. Being at that stage… only 14, he didn't want to talk big about funerals. He talked about what he wanted to give to his siblings and all that sort of stuff... We arranged with one of the special ed. teachers at the high school… for a group of 20-odd of his mates to come up on the last Saturday... Then it was that night, early hours of the following morning, that he died."* (HP1 - Chaplain)

6.8 SUMMARY AND DISCUSSION

The dramaturgical analysis presented in this chapter provides a contextualised, sociological view of the social construction of dying. It has shed light on the various scripts, casts, sets and props that shape expectations regarding dying role enactment and dying role relations and the way in which these change across different scenes. This analysis has revealed a drama that unfolds through the complex interplay between the powerful influence of professionals, institutions and society and the agency of dying persons and their caregivers, some of whom seek to resist the dying role for large portions of the drama.

These findings also highlight that the enactment of dying roles in any given scene in the drama of dying can only be understood through an appreciation of the scenes that have preceded it. For example, rehearsals to the drama of dying go on to shape an individual's later preferences regarding dying roles and dying role relations. Similarly, events of the prologue to the drama of dying and the declaration of the dying status influence the middle dramatic unit in the drama and, in turn, the closing dramatic unit.

When viewed as a whole, the drama of dying entails the build-up and response to two sequential and major points of crescendo. The first of these crescendos is the receipt of a dying diagnosis and the second is the event of death itself. Each of these scenes constitutes both a crisis point and a resolution to the series of events that preceded it. Receipt of a dying diagnosis, although shocking, at least offers a degree of clarity to the circumstances of uncertainty and hardship that surrounded diagnosis of illness and treatment. Similarly, for many dying persons and caregivers, the event of death itself can be a relief in that it brings to a close a physically and emotionally exhausting episode in their lives. Although these moments of dramatic climax represent focal points in the drama of dying, the bulk of the drama occurs during the preceding scenes. Knowledge of the experiences and motives of dying persons within these scenes is, therefore, critical to enable support to be appropriately and effectively directed towards the wishes and needs of dying persons and their caregivers at any given time.

Up until the confirmation of the dying diagnosis, the defining features of the drama centre on role compliance. During the prologue to the drama, dying persons tend to adhere closely to the expectations aligned with the illness role. As part of this, dying persons accept a somewhat bit-part role in the broader drama. This requires ongoing and, largely, unquestioned adherence to relatively rigid, tightly controlled scripts dictated by health systems and processes. Health professionals, in particular doctors, hold centre stage in most scenes, controlling both the pace and direction of the drama. The various supporting cast members, costumes, stage and props associated with acute healthcare settings all serve to reinforce health professional control and maintain a script that focuses on diagnosis and cure.

The declaration of the dying status marks the crescendo of the prologue and sets the remainder of the drama of dying in motion. From this point onwards, the meanings that many dying persons and their caregivers had previously attributed to the structures, symbols and routines of the health care system change significantly. Although immersion into and compliance with the health system can often be unpalatable during the prologue to the drama, it also brings with it a semblance of hope. Once these hopes are dashed, many dying persons come to see health systems and services as unwanted reminders of both their illness journey and dying status. When cure is no longer an option and the spectre of Death has formally entered the drama, it is not long before dying persons seek to distance themselves from health services and structures. The curtains are thus drawn on the build-up to the drama of dying and the once prominent casts, sets and scenes associated with health services henceforth feature only periodically until the final dramatic unit.

Following the declaration of the dying status, the central theme of the drama of dying shifts from role compliance to role resistance. Although dying persons appeared to recognise that they would have to share the stage with Death for some scenes, many considered its presence on the stage to have a contaminating influence on both their identity as living beings and their relationships with other people. As such, they actively sought to resist the dying status. Resisting the dying status is difficult, however, due to the fact that dying is what Linton (1936, p. 114) describes as an “ascribed” and “irreversible” status. In essence, this means that dying persons cannot control whether other people attribute the dying status to them, nor can the status be discarded once it has been ascribed. This leaves dying persons with limited means with which to curtail or delay the dying role other than by keeping the dying status secret or manipulating social encounters so that the dying status remains backgrounded. It is because of this that efforts aimed at resisting the dying status through impression management represent a major and important feature of the middle dramatic unit in the drama of dying.

Without an understanding of the importance of impression management in the middle dramatic unit in the drama of dying, health professionals working with dying people and their caregivers run the risk of making ill-informed and inaccurate assumptions concerning a dying person's role preferences at this time. This risk is compounded because the presence of health professionals within the drama at any point in time will invariably influence the drama at that same point in time. The dramaturgical analysis presented in this chapter has demonstrated that the sets, cast members, props and scripts associated with health care services tend to draw individuals towards illness and, later, dying role enactment. As such, a dying person's attendance at clinic appointments or a health professional's visits to a dying person's home may, in many cases, precipitate dying roles that otherwise would have been backgrounded.

Crucially, if health professionals assume what they see in these encounters to be the norm, they may also consider it helpful to continue to offer interventions that focus on, or lead to, a foregrounding of the dying selfhood. Yet, in some instances this may be the very opposite of what a dying person wants and might, indeed, compromise his or her attempts at impression management. Well-intended health professional activity during the middle dramatic unit, such as offers of early intervention or frequent follow-up suggestions regarding support groups and provision of assistive technology, all have the potential to introduce scripts, cast members and props into the drama of dying at a time when they are unwanted.

My findings also suggest, however, that towards the end of the second dramatic unit and throughout the final dramatic unit in the drama of dying, dying people often come to view dying role relations with members of their social circle increasingly favourably. As the crescendo to the final moments of the drama of dying approaches, the personal and relational dimensions of the dying role seem both important to and manageable for most cast members. It is during this time that the efforts of health professionals to support the graded introduction of prompts and cues to guide the initiation or continuity of dying role relations may be of value to dying persons as well as to their family members and friend. However, successful guidance requires these health professionals to strike a delicate balance between support and control. Role alignment among the various cast members during the final scenes of life, although beneficial, may not always be achievable. Ultimately, therefore, flexibility in scripts will remain crucial to ensuring best outcomes for dying persons and members of their social circles.

CHAPTER SEVEN: IMPLICATIONS OF STUDY FINDINGS AND RECOMMENDATIONS FOR EDUCATION, PRACTICE AND RESEARCH

The dramaturgical analysis of dying roles presented in the previous chapter detailed the considerable influence of the professional, institutional and societal features of the drama in shaping dying roles and dying role relations. The analysis also revealed the way in which these contextual elements of the drama can often compromise the construction of the versatile scripts that are key to dynamic and evolving role relations. As a result, important (and sometimes lengthy) periods of the contemporary drama of dying can be challenging for dying persons and members of their inner and outer social circles because of confusion and uncertainty about expected role relations and subsequent mismatch in these relations.

Although these challenges are a cause for concern, they also offer insights into potential opportunities for positive practice change. Given that the scripts, casts, sets and props associated with the drama of dying can, at times, hinder end-of-life roles and role relations, it follows logically that changes to these elements of the drama might lay the foundations for more positive outcomes. Hence, in relation to role change and role relations at end of life, dramaturgy offers a framework to establish key design cues pertaining to the development and delivery of improved support for dying people and those who matter to them. This chapter, therefore, focuses initially on the implications of my research upon palliative and end-of-life care service design and delivery and discusses both the challenges and opportunities that lay ahead. Following this, specific practice and education recommendations designed to facilitate improvements in the delivery of palliative and end-of-life care as well as recommendations for future research are detailed. The chapter concludes with a synopsis of the overall findings of the research and its unique contribution to knowledge concerning the process of role change at end of life.

The various implications for practice and associated recommendations discussed in this chapter have been constructed in the light of the expanded view of the drama of dying identified in this research. The dramaturgical analysis within this study has shown the drama of dying to encompass a greater range of contexts and cast members than is otherwise often assumed by healthcare providers. This relatively restricted exposure to and understanding of the broader drama of dying among health professionals occurs, in part, because the presence of these professionals in any given scene brings to the forefront features of the drama of dying that relate to their particular role. As detailed in Chapter Six, this professionally orientated focus can reinforce the impression among professionals that their view of the drama, based on their part within it, is representative of the broader whole.

The importance of health professionals looking beyond their own sphere of influence so as to better understand the social aspects of dying have been discussed previously within academic literature (Kellehear, 1999). My research extends this viewpoint by highlighting the value of recognising not only how dying roles differ depending upon the social context in which they occur but also the way in which they unfold and evolve within these different contexts over time. Importantly, this study has demonstrated that many of the beliefs and assumptions regarding both the dying role and expected dying role relations are shaped long before the formal commencement of the drama. These beliefs will differ among various cast members because they are forged through each individual's unique exposure to dying throughout his or her life. This exposure may occur in a myriad of forms including, but not limited to, childhood play, media portrayals of dying or experiences relating to other people's dying. As a result, different individuals develop their own internalised death models based on their personal interpretation of the various experiences relating to dying to which they are exposed. These internalised death models play a significant part in influencing how different people approach end-of-life role relations. In essence, the way in which people come to know dying determines the scripts they draw on when responding to it.

It is because of this variability between different individuals' internalised death models that situations of role confusion, ambiguity and mismatch occur so frequently across the drama of dying. For example, some cast members may present with a romanticised view of death or see dying as a heroic struggle. Others may come to know dying as a process that should remain private and hidden. Conversely, some cast members may see a dying diagnosis as a cue to tie up loose ends or nurture special moments and memories. These different conceptions of dying will contribute to internalised expectations regarding the way in which the drama should unfold. When elements of the drama, such as its length, cast members, sets or scripts do not align with these expectations, role confusion, ambiguity and mismatch are more likely to manifest.

Internalised death models evolve over time as a result of the reciprocal relationship between self and society. As such, depending on an individual's exposure to dying and experience of dying role relations, internalised death models may be either reinforced or modified. Internalised death models are reinforced when the cast members, sets, props and scripts within the drama of dying align with an individual's expectations. It is for this reason that the scenes within the drama of dying that involve health professionals and/or occur within health care settings tend towards a patterned, predictable and, for the most part, professionally-orientated focus. Repeated exposure to these scenes contributes to the entrenchment of professionally derived assumptions regarding dying and can subsequently result in health professionals finding it hard to see beyond their existing perceptions of their role within the drama.

It is important to note, however, that modifications to people's internalised death models can happen when their encounters with dying are in some way at odds with their assumptions about it. These modifications occur through an interactive and reciprocal process in which different cast members have an influence upon each other and upon the broader drama of dying while, at the same time, key features of the drama have an influence upon them. This means that the drama of dying both modifies and is modified by the interactions of the cast members within it. Consequently, careful, considered and collaborative actions aimed at expanding professional and non-professional cast members' perceptions of the drama of dying and, in turn, their parts within it, offer a flexible and sustainable foundation for positive end-of-life role relations. With this opportunity in mind, the implications for practice and subsequent recommendations discussed below centre on processes by which health professionals and health services can assist in enabling these shifts in thinking to occur.

In prefacing this discussion, however, it is important to acknowledge that, for the reasons detailed above, the needs and preferences of dying persons and/or their caregivers vary markedly between individuals and often change over time as the drama of dying unfolds. Due to this complexity, any suggestions presented regarding the design and provision of health care must be considered in the light of the individualised and highly sensitive nature of palliative and end-of-life care. Given the profound importance and emotionally laden nature of end-of-life transitions, health professionals may often find themselves in situations in which they are particularly susceptible to criticism in relation to the care that they provide. With this in mind, the implications for practice and associated recommendations discussed in this chapter are not intended to be a one-size-fits-all panacea for the complex difficulties experienced by dying persons and members of their social circles during the drama of dying. Instead, they are aimed at offering alternative or, in some cases, refined viewpoints on the way in which professionals might conceive and enact their part in the drama of dying as part of a genuinely collaborative partnership with dying persons and their caregivers. In doing so, I hope to promote the reflective insight, flexibility and dynamism that are core to quality end-of-life care.

7.1 ENABLING DYING PERSONS AND CAREGIVERS TO DIRECT THE STAGE PRESENCE OF HEALTH PROFESSIONALS

The National Palliative Care Standards indicate that quality end-of-life care provision requires the appropriate assessment and support of dying persons, family members and caregivers (Palliative Care Australia, 2018). Successfully providing support to all of these groups necessitates an understanding of the nature of the challenges they experience not only during episodes of acute crisis but also across the entirety of the drama of dying. Such knowledge will enable health professionals to position themselves in readiness to provide timely, targeted, sensitive and sustainable support when, where and how dying persons and their caregivers require it. However, health professionals must also remain cognisant of the way in which their presence in the drama of dying can act as a reminder of the dying selfhood at those times when dying persons might be seeking to foreground their living selfhood. As such, there needs to be a delicate balance between ensuring that professionals are available to guide and support dying persons and their caregivers without immersing themselves unnecessarily or obtrusively into the drama of dying at the times when they are not required.

To be successful in this endeavour, health professionals should structure their assessment and information gathering processes to enable dying persons and their caregivers to identify what, if anything, they require from health professionals at any given time. For much of the drama of dying, this may require a shift in thinking about the way in which health professionals perceive holistic practice. Within health care, holistic practice is often described as that which supports the identification of and response to all aspects of an individual's physical, social, economic, emotional and spiritual needs (Russell, 2016). Although well intended, this all-encompassing approach to holistic practice can result in considerable burden upon dying persons and their caregivers who often find themselves expected to attend multiple appointments in diverse locations and repeatedly required to retell their story to different members of the multi-professional team. Of course, both the presence of multi-professional teams and the emphasis on holistic practice are intended to ensure that all aspects of a dying person's needs are acknowledged and addressed. In many cases, though, this approach can result in very similar scenes with a focus on dying being re-enacted unnecessarily and, in some instances, harmfully throughout the drama of dying.

In order to strike the appropriate balance between under-involvement and over-involvement in dying persons' lives, it may be better to reframe holistic practice in palliative care as the creation of the conditions in which dying persons and their caregivers can raise *anything* with health professionals as and when they wish to. Doing so would afford dying persons and their caregivers greater control over the timing, staging and scripting of the drama of dying such that it meets their evolving needs and wishes. It would also help in preventing circumstances in which health professionals unwittingly impose themselves into facets of the drama of dying in which they are not wanted or required.

The above-mentioned approach to holistic practice requires health professionals to have the insight and humility to understand when their presence on the stage is called for and when they might be better placed to wait in the wings. For example, it may be beneficial for health professionals to re-evaluate whether routine clinic appointments are of value to dying persons during periods of time when they are medically stable. In a similar vein, periodic contacts from different professionals might not be necessary for much of the drama of dying.

Some individuals may wish instead to be provided with written information concerning the variety of services available to them so that they can contact health professionals as and when they feel it is necessary. Others may prefer to identify a nominated keyworker to be a single point of contact as a means of limiting contact with health professionals at times when it is not wanted. For key worker models to be successful, however, role understanding among the various members of the palliative care multi-professional team will be critical. This means that professional disagreements concerning what does, and does not, constitute legitimate or worthwhile support for dying persons (as highlighted in Chapter Six) must be resolved. Without this shared understanding, dying persons and their caregivers will be less likely to have access to the right support from the right professionals at the right time.

7.2 RECOGNISING HOME AS THE PRINCIPAL STAGE AND SET FOR THE FOREGROUNDING OF THE LIVING SELFHOOD

My research indicates the particular importance of health professionals being mindful of the timing and nature of their interventions within a dying person's home. Previous research has established that the home constitutes not only a physical environment but also a personal and social one and consequently can be a place of considerable meaning for individuals (Tanner, Tilse, & de Jonge, 2008). As outlined in Chapter Six, dying persons in this study seemed to consider home as a place of familiarity, control and sanctuary. Hence, it served as a stage on which the foregrounding of their living selfhood was most easily achieved. Entry into the dying person's home environment by health professionals undertaking scheduled home visits and/or alterations to the physical makeup of the home environment through provision of home modifications or assistive technology has the potential to alter (temporarily or permanently) the meaning of home.

Reflecting on my own practice as an occupational therapist in palliative care, I can think of dozens of occasions when I filled a dying person's home with assistive technology such as hospital beds, hoists or commodes, based on the dying person's potential need for it in the near future. My actions were well intended, with the aim of making life easier for the dying person and preventing physical harm to the caregiver. However, such items may also have been unwanted by the dying person and/or caregiver, given their symbolic reminder of the dying status. Had I been mindful of the idea that the focus on dying that was evident during my visit was, for a large part, *because* of my visit, I might have been more tentative and sensitive about the way in which my recommendations altered the set on which key scenes in the drama of dying play out.

The importance of health professionals recognising home as a place of normalcy and familiarity for dying persons has been described previously by Rosenberg (2011). Moreover, most dying persons state a preference to either die at home or to remain at home as long as possible prior to their death (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). However, a dying person's preference to remain at home as long as possible when he or she might also be experiencing medical and functional deterioration creates a quandary for health professionals. The question arises as to how to provide the necessary health care while still promoting the dying person's wishes regarding home as the preferred place of care, without unduly disrupting the physical, social, emotional and spiritual dimensions of home that make it important.

Clearly, home visits by health professionals and the provision of equipment and technology to enable a dying person to remain at home will often be necessary as a dying person's health deteriorates. Indeed, recent research involving caregivers of dying persons identified that they value the provision of well-targeted health and supportive care services at home, with many respondents reporting an ability to maintain important aspects of their daily lives because of the presence of these services (Jack, O'Brien, Scrutton, Baldry, & Groves, 2015). However, for those health professionals who do provide services of this nature, a careful and considered approach that respects the role of home in maintaining a focus on the living selfhood is likely to promote best outcomes. This approach may involve consulting dying persons and their caregivers regarding their preferences as to when, where and how care and/or assistive technology is to be provided. For example, some dying persons and/or caregivers might wish for particular items of equipment to be stored ‘off-stage’, out of the sight of friends and family members. Others might prefer for necessary items to be arranged and presented in a way in which, as far as is possible, they blend unobtrusively into the existing set. Alternatively, some dying persons might be inclined to postpone the arrival of care and/or equipment for as long as possible or may not want it to be provided at all. By presenting options for dying persons and caregivers, as distinct from professionally derived solutions, a better balance between the preservation of the meaning of home and the management of the dying person’s physical needs at home becomes possible.

7.3 ENABLING THE CO-CONSTRUCTION OF END-OF-LIFE SCRIPTS THROUGH CONTEXTUALISED PROGNOSTICATION

Dying persons and caregivers in this study highlighted the considerable frustration they experienced with what they perceive as a lack of clarity and/or accuracy in prognostic information provided by health professionals. This frustration stems, in part, from the difficulties associated with scripting the drama of dying without knowledge of the amount of time the dying person has remaining and/or the likely pattern of physical and functional decline expected within that time. It should be acknowledged at this point that health professionals (and medical professionals in particular) are in a particularly unenviable position when it comes to the provision of information of this nature (Pontin & Jordan, 2013). The challenges associated with prognostication are well established and doctors may find themselves accused of being either brutally direct or unhelpfully vague depending on which approach they take (Patel, Periyakoil, Moore, Nevedal, & Coker, 2018).

It is clear, therefore, that the delivery of dying diagnoses and associated prognostic information can be a very difficult undertaking. It is also evident, however, that if this information is not presented in a way that can be readily understood and applied by dying persons, considerable difficulties can ensue. Interestingly, knowledge of the drama of dying might present a useful design cue to help doctors (and other health professionals) to better support dying persons and their caregivers when providing prognostic information. Rather than offering prognostic estimates centred principally on time, by establishing an understanding of what the dying persons and/or their caregivers hope to achieve in the time ahead, health professionals may be better able to provide the appropriate prognostic information to support the scripting and timing of particular elements of the drama of dying. Enquiring about key goals, milestones, responsibilities and wishes across different dramatic units may enable the co-construction of end-of-life scripts and thus prove empowering for all parties. Of course, as the dying person's health deteriorates, these scripts should be adjusted accordingly. The contextual knowledge derived by collaboratively exploring the aspects of the drama that are important to dying persons and caregivers will enable such scripts to be developed in a considered and meaningful way.

7.4 MANAGING ROLE RELATIONS MISMATCH

Chapter Five discussed the high prevalence of mismatched role relations at end of life and the way in which these often present within otherwise well-functioning family and/or social units. This means that the difficulties experienced between dying persons and members of their social circles may not be immediately obvious to those providing care. It is, therefore, very important for health professionals not only to be aware of the potential for role relations mismatch at end of life but also to develop an awareness of the sorts of situations that can result in mismatches occurring. Doing so will assist them in foreshadowing difficulties and, in turn, supporting dying people and those close to them in preventing and/or managing issues as they occur.

This proactive approach to the management of role relations mismatch has important implications regarding the way in which health professionals who work with dying people and/or their family members and friends, approach family-centred care. Effective family-centred practice is considered a hallmark of quality palliative care (Palliative Care Australia, 2018; World Health Organisation, 2019). Yet evidence suggests that palliative care services are often underprepared to support the caregivers and families of dying people (Hudson & Payne, 2011; King & Quill, 2006). The challenges associated with role relations identified in my study reinforce the notion that effective and authentic family-centred practice ought to extend beyond providing support to the various members within a family unit *as individuals* to a broader recognition of the needs of the family unit *as a whole*. This finding adds weight to the calls for the implementation of more structured models of family-centred care into palliative care practice, such as those advocated by Kissane (2016). It is also important to note here that, although all caregivers interviewed in the research presented in this thesis were immediate family members of dying persons, family-centred care must extend beyond principal caregivers and must also recognise the possible diversity related to who dying people's significant others might be. Indeed, assumptions on the part of health professionals concerning which cast members have a legitimate place on stage at any given time have the potential to cause considerable harm.

It is also important for professionals to be mindful of the highly complex nature of role mismatch at end of life and the wide variety of factors that may lead to such mismatches occurring. Confusion around role expectations due to misaligned scripts, conflicting beliefs about when (and in what way) calls to action were required, divergent emotional states, variability in preparedness for death and misplaced assumptions regarding the need to protect other individuals from emotional harm can all contribute to role uncertainty and mismatch among dying people and members of their social networks. Hence, palliative care professionals may find themselves inadequately equipped to support the prevention and management of role mismatch unless they take the time to explore and understand the particular reasons why mismatches either are, or are at risk of, occurring between different individuals.

Consequently, in order to promote role alignment and prevent role mismatch at end of life, palliative care professionals must adopt dynamic and flexible approaches to care by recognising diversity in relation to both the composition and functioning of the inner social networks of dying people. To be successful in this endeavour, health professionals will need to mindful of the way in which paternalistic approaches to care, based on assumptions regarding the wishes, needs and abilities of dying persons and their social networks may be a hindrance rather than a help at end of life (Rosenberg, Horsfall, Leonard, & Noonan, 2018). In doing so, palliative care professionals will be better positioned to identify and respond to situations in which role mismatch results in ongoing distress and harm for one or more parties. This approach will then enable palliative care professionals to work in partnership with dying persons and those who matter to them in the co-construction of end-of-life scripts that accommodate different people's preferences concerning the foregrounding of living and dying role relations at different times. Such actions may serve as a catalyst for each party to better understand the other’s needs, thereby cultivating the conditions for positive role relations (Lipsitt, 2016).

7.5 SUPPORTING CAREGIVERS

The importance of caring for caregivers is enshrined as a key dimension of palliative care policy and practice. The National Standards for Palliative Care detail the critical functions of the caregiver role and emphasise working with caregivers to understand the level of care they are willing and able to provide as being a core aspect of quality service provision (Palliative Care Australia, 2018). Consequently, it is of concern that, although all of the caregivers interviewed in this study remained willing to continue to provide care and support to their dying relative, many discussed feeling physically and emotionally worn out from doing so. Most had suspended other social roles to enable them to take on the caregiver role or found themselves juggling multiple roles over an unexpectedly long period of time. As discussed in Chapter Six, ongoing uncertainty regarding when the caregiver role would end added a further layer of complexity and concern for individuals providing care. Furthermore, changes to the nature of role relations, such as transitioning between familial and caregiver roles, were identified as being particularly challenging experiences for some participants.

Similar findings regarding caregiver strain and the emotional burden associated with coping with changes brought about by the physical deterioration of a family member or friend have been reported elsewhere in the literature (Ray & Street, 2006, 2007; Sautter et al., 2014). Such findings suggest that more should be done to enable caregivers of dying persons to manage the physical and emotional burden associated with this role. Although formal health services should play a part in providing practical and emotional support to caregivers, more sustainable solutions suited to a protracted dying timeline necessitate greater involvement by informal support networks. Several authors have argued for the integration of more socially focused, participatory, public health principles into palliative care service models as a means of increasing the number and capability of informal networks engaged in the care and support of dying persons (Kellehear, 1999; Rao, Anderson, & Smith, 2002; Rosenberg, Mills, & Rumbold, 2016; Thomas, Hudson, Oldham, Kelly, & Trauer, 2010). One such approach that has gained particular momentum over the last decade is the Compassionate Communities Movement.

7.6 UNLOCKING THE CAPACITY OF COMPASSIONATE COMMUNITIES

Compassionate communities refer to the various networks around dying people that provide, or have the potential to provide, assistance, care and support beyond that offered by formalised health and end-of-life care services (Kellehear, 2013). Naturally occurring compassionate community networks are composed of individuals from the inner and outer social circles of dying persons and their caregivers (Abel, 2018; Abel & Kellehear, 2016). Abel, Bowra, Walter, and Howarth (2011) highlight the significant potential for such networks to assist with a wide variety of small but important practical and/or personal tasks to support dying people and their caregivers. They also indicate, however, that more knowledge is required regarding the factors that influence whether these networks operate successfully.

One barrier to cohesive, well-functioning compassionate communities stems from a lack of connection and differing priorities between formal health services and informal caregiver networks (Leonard, Horsfall, Rosenberg, & Noonan, 2018). Similarly, paternalistic attitudes of health professionals, privileging of professional knowledge and adherence to bureaucratic regulations have also been cited as disrupting influences upon the organisation and provision of informal care (Horsfall, Leonard, Noonan, & Rosenberg, 2013; Kellehear, 1999; Rosenberg et al., 2016). My research adds to this picture by identifying the way in which a lack of knowledge among health professionals concerning the elements of the drama of dying that occur outside formal health settings inhibits role understanding and, in turn, cohesive social scripts. What might appear as paternalism and/or the privileging of professional knowledge can thus be understood as occurring, not so much because of arrogance on the part of professionals, but instead due to their limited understanding of the drama as a whole. Hence, by prompting professionals to consider aspects of the drama of dying that occur beyond their sphere of influence, a more cohesive interface between professional and informal support structures for dying people becomes possible. The use of dramaturgical analysis as an educational approach would provide a useful medium for such learning to occur.

Another suggested reason for the unsuccessful functioning of naturally occurring compassionate communities is that dying persons and/or caregivers tend to reject support from friends and family when first offered, born out of concerns of being a burden on others. Once this initial rejection of assistance occurs, the individuals who had offered support tend to withdraw, resulting in isolation and a loss of a potential future source of help for the dying person and caregiver (Abel & Kellehear, 2016). In response to this problem, Abel and Kellehear (2016) recommend that dying persons and caregivers accept help whenever it is offered, as a means of ensuring that they will be well supported as their needs increase. Although, at face value, this suggestion seems sensible, it does not take into account all the reasons for which dying persons and caregivers may reject help from those around them.

For example, this study has highlighted that many dying people and their caregivers may be reluctant to accept support due to the potential for such assistance to alter the nature of role relations with friends and family by foregrounding the dying status of the dying person. In a lengthy drama of dying during which dying persons, for the most part, aim to background their dying selfhood, acceptance of care from friends and family may be seen as problematic in that it brings the dying selfhood to the fore. Conversely, however, my findings also indicate that more subtle social scripts that enabled practical support and companionship to be provided in a less obvious manner were often much more acceptable to some dying persons. These approaches allowed supportive dying role relations to be enacted without the overt acknowledgement of the intended purpose of visits. Such role relations are largely dependent upon a degree of subterfuge on the part of support providers or, alternatively, mutual pretence among all parties. However, they do provide a framework through which ongoing support can be provided to dying persons without compromising the dignity and preferred identity of the individual who is dying. Abel and Kellehear (2016) argue that public education is a key pillar of successful compassionate communities. My findings suggest that such education may be strengthened by highlighting approaches to offering support that are less intrusive and, therefore, more acceptable to dying persons.

Death awareness and death education initiatives provide a mechanism through which these more subtle approaches aimed at the support of dying persons and management of dying role relations can be promoted. However, if these initiatives are to be successful in facilitating such change, they might require a degree of recalibration from their current design.

7.7 BROADENING THE SCOPE OF DEATH AWARENESS AND DEATH EDUCATION INITIATIVES

Over the last 50 years, the Death Awareness and Death Education Movements have served a valuable function in raising public consciousness concerning death and dying. Increased attention to death and dying in research and other publications and the introduction of education regarding end-of-life care into many health care university curricula occurred because of this movement (Hoffnung et al., 2019). In recent times, death literacy initiatives have served an additional and important function in equipping communities with the necessary knowledge and skills to support dying persons at end of life (Noonan, Horsfall, Leonard, & Rosenberg, 2016). In contemporary Australia, charities such as The GroundSwell Project play a leading and valuable role in promoting both death awareness and death literacy among the general public and health professionals through events such as Dying to Know Day (Noonan, 2015). Death awareness initiatives such as these place considerable emphasis upon the importance of openness in discussions about death and dying at all times. Indeed, within The GroundSwell Project manifesto it is stated: *"No conversation about any aspect of dying, death or loss is off-limits"* (The GroundSwell Project, 2019).

Openness in discussions about dying can certainly bring with it many benefits. This study, however, has identified the potential for achieving a preferable outcome by a more nuanced style of conversation about dying and dying role relations. As highlighted in Chapter Four of this thesis, both dying people and members of their inner social circle find many aspects of the dying role to be too emotionally and, at times, physically exhausting to perform on an ongoing basis. As such, individuals often elect to oscillate between a preference for continuity of pre-dying role relations, founded on "*mutual pretence"* (Glaser & Strauss, 1965, p. 64) or "*suspended open awareness"* (Timmermans, 1994, p. 330) and dying role relations based on "*open awareness"*, in which dying is actively acknowledged (Glaser & Strauss, 1965, p. 79).

Moreover, my research suggests that dying people may want a different role status with different individuals or groups at any given time. For example, they may wish to have their dying status acknowledged by those closest to them, while simultaneously craving pre-dying role relations with their outer social circle. This variability of preferences again highlights the importance of greater flexibility in dying role relations if the needs of dying people are to be effectively met. This observation adds weight to the thoughts of Lipsitt (2016) and Emanuel, Bennett, and Richardson (2007) who caution against fixed schemas of and expectations relating to the dying role, arguing that these will often lack alignment with the wishes and behaviour of individuals who are dying. As Lipsitt (2016) advises, there is a requirement to cultivate options, conditions and information to assist dying people to make choices when and as they feel able, thereby maintaining their sense of self.

Death awareness, education and literacy initiatives have much to offer in nurturing the conditions in which flexible dying role relations can exist. However, to be successful these initiatives may have to broaden their scope to offer education and support regarding a wider variety of dying role relations. For example, resources such as 'Dying to Talk Discussion Starter Kits' have been championed as a means of steering people towards successful conversations about end-of-life matters (Palliative Care Australia, 2019). Similar resources could also be created that offer practical guidance concerning ways of maintaining meaningful relationships with dying persons, without presenting an overt focus on the dying status. Although it may appear paradoxical for death literacy and education resources to promote periodic shifts in focus away from the dying status of a dying individual, their development would help in nurturing the conditions in which dynamic and evolving role relations can occur. Resources of this nature will be of most value in the middle dramatic unit of the drama of dying, during which mismatched role relations currently appear most prevalent. If successful, they may assist members of dying people's social networks in maintaining supportive role relations founded on much needed sensitivity, adaptability and care.

7.8 RECOMMENDATIONS FOR EDUCATION AND PRACTICE

The implications of this study outlined thus far in this chapter bring to the fore a number of ways in which adaptations to education and practice can assist in improving the support and care available to dying persons and their family and friends. Specific recommendations for education and practice that will assist in bringing about these changes are detailed below.

7.8.1 Development of targeted strategies to facilitate flexible role relations at end of life

A shift in emphasis is needed in relation to death awareness and death literacy initiatives to accommodate dying role relations in which the dying status is not routinely foregrounded. As a first step, targeted strategies to better inform the general public could be initiated to raise awareness of the notion that dying people often seek continuity of pre-existing (living) role relations for much of the end-of-life journey. Advice regarding strategies for continuing to engage with dying persons in a way that emphasises their continued status as productive and valued members of society, regardless of their stage of illness, should form a central component of these strategies. If successful, these strategies have the capacity to furnish friends and family of dying persons with renewed social scripts that are better suited to the elongated, contemporary drama of dying. Additions and/or modifications to existing death awareness and education strategies such as Dying to Know Day or ‘Dying to Talk Discussion Starter Kits’ offer an excellent mechanism through which this important information could be provided.

7.8.2 Use of dramaturgy as an analytical tool for teaching

The use of dramaturgy as an analytical tool within this study has helped shed light on many important, but largely under-acknowledged, aspects of the experience of role change and role relations at end of life. An opportunity exists for dramaturgy to be utilised in a similar manner to support both undergraduate and post-graduate education in relation to palliative and end-of-life care. The benefits of this approach to education would be twofold. The first of these benefits would be in the capacity of dramaturgy to shed light on the way in which a dying person's preferences at any given point in the drama will have been influenced by the dramatic units that preceded it. This insight may help health professionals to realise that, unless they take steps to understand the drama as a whole, they may not be equipped to support dying persons and/or their caregivers during specific episodes of care.

Secondly, and perhaps most importantly, by prompting current and/or future health professionals to consider the whole of the drama of dying rather than their selective and relatively small parts within it, professional knowledge of the drama will be expanded so that it takes into account a wider variety of contexts and cast members. By drawing on the metaphor of the theatre, students will be able to examine the roles and functions of various cast members at different times during the drama of dying and analyse the way in which the stage, props, costumes and scripts influence role enactment. In doing so, they will have the opportunity to gain reflective insight into how their own interactions with dying persons and caregivers can either positively or negatively influence the drama of dying as a whole. Furthermore, this expanded view would help to move the perspective of health professionals much closer to the dying person's lived world and out of the rarefied atmosphere of rule-bound professional enclaves.

7.8.3 Raising public awareness of the focus and scope of palliative care

Despite the concerted efforts at a national level by Palliative Care Australia and at a local health service level by palliative care teams to better educate the public regarding the focus and scope of palliative care, more needs to be done. A number of participants in this study believed that their referral to palliative care meant they had reached the last days or weeks of their life. This caused unnecessary distress and created a barrier against taking up the services and support that were offered. Renewed efforts at better marketing the benefits of palliative care to health service users and the broader public may, therefore, be required.

7.8.4 Proactively addressing role ambiguity and role relations mismatch

The distress associated with role relations mismatch for one or more parties during the drama of dying indicates the potential value in foreshadowing and, where possible, preventing this from occurring. Health professionals can offer important support in relation to this issue by educating dying persons and members of their social networks about the potential for role mismatch and by discussing strategies by which it can be avoided. As part of this education, the value of flexibility and sensitivity in initiating end-of-life role relations among all parties should be addressed. Health professionals should not, however, be prescriptive in indicating when it is appropriate for dying persons and members of their inner or outer social circles to initiate dying role relations. Instead, they should offer suggestions as to how discussions concerning different individuals' preferences can be undertaken in a manner that respects the needs and wishes of all parties.

7.8.5 Continued focus on improving end-of-life communication

Although much progress has been made in relation to professional communication concerning end-of-life matters over recent decades, more work is required. Conversations regarding prognosis that are contextualised in relation to the goals, wishes, key milestones and responsibilities of dying persons and their caregivers may offer one strategy for delivering prognostic information in a way that is clear and useful to them.

7.8.6 Lobbying government for better caregiver support

The degree to which some caregivers of dying people in this study seemed to be experiencing physical and emotional exhaustion highlights the necessity for greater funding allocation targeted at appropriate respite and support. The critical role of informal caregivers in enabling preferred place of care for dying persons provides further impetus for action on this issue. As an urgent priority, palliative care professionals and associated professional bodies should lobby, collectively, to put pressure on government to ensure the capacity for better care of caregivers.

7.9 RECOMMENDATIONS FOR FUTURE RESEARCH

Although this study shed light on many important elements of the drama of dying within the contemporary regional Australian context, some aspects of the drama were not investigated. A number of recommended areas for future enquiry stemming from the findings and limitations of this study are outlined below.

7.9.1 Dying roles and role relations in rural and remote communities

It would be useful for future research to be undertaken that specifically focuses on end-of-life role change and role relations among people living in rural and remote communities. Such research would help in understanding the way in which the processes and experiences described in this study differ for people living outside urban centres. For example, it is possible that the sense of community connectedness may be stronger in rural and remote communities or, alternatively, it could be that the lack of available support from formal health and social care services results in increased burden upon dying persons and caregivers. By improving the understanding role change and role relations among dying persons and caregivers living in rural and remote settings, better-targeted support may be offered to them.

7.9.2 Experiences of dying role relations among members of dying persons' outer social circles

Although many dying people interviewed in this study expressed frustration at the way in which members of their outer social circles responded to them once their dying status became known, I did not gather the perspectives of individuals from these groups. Future research specifically examining the opinions and experiences of dying role relations among members of dying persons' outer social circles would help in better understanding their responses to dying persons. Such research would also assist in identifying ways in which to harness the potential support of these naturally occurring compassionate communities.

7.9.3 Dying persons' perspectives on dying roles during the last days of life

For ethical reasons, within this study I did not speak with dying persons thought to be in their last days of life. As a result, the findings I have presented relating to the final scenes of life privilege the perspectives of health professionals and, to a lesser extent, caregivers. Although future research aimed at examining dying role enactment and end-of-life role relations from the perspectives of dying persons themselves would be valuable, the study design should take into account the potential emotional burden associated with research of this nature during their last days of life.

7.10 SUMMARY AND CONCLUSION

I undertook this study with the goal of developing an improved understanding of the process of role change at end of life. In particular, I aimed to examine the way in which roles and role relations evolve over time for dying people and members of their social circles and how such changes impact upon the experience of dying.

Taken collectively, my research sheds light on role change at end of life as being a complex process in which dying persons oscillate between foregrounding and backgrounding their living and dying selfhood at different times. Although dying persons retain a degree of agency over whether to foreground or background their living or dying selfhoods at any given time, social expectations concerning dying role enactment have a powerful influence in shaping dying role relations. The various sets, scripts, cast members and props associated with dying roles across each dramatic unit will either draw dying persons towards the dying selfhood or accommodate and, in some instances, promote the projection of the living selfhood.

My research has highlighted that, because of the tendency for dying persons to oscillate between the living and dying selfhood during the drama of dying, role confusion and role mismatch between dying persons and members of their social circles can often occur. On occasions, this can result in considerable frustration and even distress for one or more of the parties involved. Although role mismatch can present at any point in the drama of dying, it is most prominent in what is nowadays an elongated and poorly scripted middle dramatic unit of the drama.

I have argued that one of the main reasons why role mismatches arise relates to an over-reliance on historical social scripts for dying role relations that are inadequate for large portions of the more protracted contemporary drama of dying. Sustained enactment of the dying role may have been manageable (and, perhaps, crucial) for dying people during the shorter dying timelines of the past. However, many of the relational and personal dimensions of the dying role are not suited to the months (and in some cases years) in which the middle dramatic unit now plays out. During this time, a predominant focus on the living selfhood and a resumption of pre-dying role relations may serve a protective function, given the emotional and physical toll of the dying role.

In the light of these findings, I have outlined a number of potential alterations to health service delivery and death literacy initiatives that would accommodate more flexible, sensitive and practically useful support in the management of end-of-life transitions. Many of these suggestions centre on creating the conditions in which dying persons can continue to foreground their living selfhood for longer portions of the drama of dying without compromising the availability of and access to appropriate support from health professionals and/or members of their inner and outer social networks. The distinctive understanding of role change at end of life presented in this thesis, therefore, provides a framework to guide professionals working with dying persons and their family members in the delivery of dynamic, reflexive and responsive support throughout the drama of dying.

REFERENCES

Abel, J. (2018). Compassionate communities and end-of-life care. *Clinical Medicine, Journal of the Royal College of Physicians of London, 18*(1), 6-8. doi:10.7861/clinmedicine.18-1-6

Abel, J., Bowra, J., Walter, T., & Howarth, G. (2011). Compassionate community networks: supporting home dying. *BMJ Supportive & Palliative Care, 1*(2), 129. doi:10.1136/bmjspcare-2011-000068

Abel, J., & Kellehear, A. (2016). Palliative care reimagined: A needed shift. *BMJ Supportive and Palliative Care, 6*(1), 21-26. doi:10.1136/bmjspcare-2015-001009

Aoun, S., Slatyer, S., Deas, K., & Nekolaichuk, C. (2017). Family caregiver participation in palliative care research: Challenging the myth. *Journal of Pain Symptom Management, 53*(5), 851-861. doi:10.1016/j.jpainsymman.2016.12.327

Aoun, S. M., Kristjanson, L. J., Currow, D. C., & Hudson, P. L. (2005). Caregiving for the terminally ill: at what cost? *Palliative Medicine, 19*(7), 551-555. doi:10.1191/0269216305pm1053oa

Aries, P. (1974). *Western attitudes toward death.* (H. Weaver, Trans.). London: John Hopkins University Press.

Aries, P. (1981). *The hour of our death.* (H. Weaver, Trans.). New York: Alfred A. Knopf.

Armstrong, D. (1986). The problem of the whole-person in holistic medicine. *Holistic Medicine., 1*, 27-36.

Arnold, E., Finucane, A. M., & Oxenham, D. (2015). Preferred place of death for patients referred to a specialist palliative care service. *BMJ Supportive & Palliative Care, 5*(3), 294-296. doi:10.1136/bmjspcare-2012-000338

Australian Bureau of Statistics. (2018). 2016 Census QuickStats. Retrieved from http://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/318?opendocument

Australian Institute of Health and Welfare. (2016). *Australia's health 2016. Australia's health series no. 15. Cat. no. AUS 199.* Canberra: AIHW.

Bachner, Y. G., & Carmel, S. (2009). Open Communication Between Caregivers and Terminally Ill Cancer Patients: The Role of Caregivers' Characteristics and Situational Variables. *Health Communication, 24*(6), 524-531. doi:10.1080/10410230903104913

Badr, H., & Taylor, C. L. C. (2006). Social constraints and spousal communication in lung cancer. *Psycho-Oncology, 15*(8), 673-683. doi:10.1002/pon.996

Bakanic, V., Singleton, M., & Dickinson, G. E. (2016). Hospice Attitudes of Physicians and Nurses: A Pilot Study. *American Journal of Hospice and Palliative Medicine, 33*(1), 34-40. doi:10.1177/1049909114552124

Baldwin, P. K. (2017). Death cafés: Death doulas and family communication. *Behavioral Sciences, 7*(2), 1-8. doi:10.3390/bs7020026

Ballinger, C., & Wiles, R. (2006). Ethical and governance issues in qualitative research. In L. Finlay & C. Ballinger (Eds.), *Qualitative research for allied health professionals: Challenging choices.* (pp. 46-60). Chichester.: John Wiley and Sons Ltd. .

Beecher, H. K., Adams, R. D., & Barger, C. (1984). A definition of irreversible coma. Report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. *JAMA: The Journal of the American Medical Association, 252*(5), 677-679. doi:10.1001/jama.1984.03350050065031;10.1001/jama.252.5.677;

Belgrave, L. L., & Charmaz, K. (2014). Studying illness and dying through constructivist grounded theory. In L. Van Brussel & N. Carpentier (Eds.), *The Social Construciton of Death. Interdisciplinary Perspectives.* (pp. 34-52). London: Palgrave Macmillan.

Biddle, B. J. (1986). Recent Developments in Role Theory. *Annual Review of Sociology, 12*(1), 67-92. doi:10.1146/annurev.soc.12.1.67

Bingley, A. F., McDermott, E., Thomas, C., Payne, S., Seymour, J. E., & Clark, D. (2006). Making sense of dying: A review of narratives written since 1950 by people facing death from cancer and other diseases. *Palliative Medicine, 20*(3), 183-195.

Bloomer, M. J., Hutchinson, A. M., Brooks, L., & Botti, M. (2018). Dying persons' perspectives on, or experiences of, participating in research: An integrative review. *Palliative Medicine, 32*(4), 851-860. doi:10.1177/0269216317744503

Blumer, H. (1969). *Symbolic interactionism: perspective and method*. Englewood Cliffs, N.J: Prentice-Hall.

Borgstrom, E. (2017). Social death. *QJM - An International Journal of Medicine, 110*(1), 5-7. doi:10.1093/qjmed/hcw183

Bowman, F. P. (1965). *Montaigne: essays*. London: E. Arnold.

Boyt Schell, B. A., Gillen, G., & Scaffa, M. E. (2014). *Willard & Spackman's occupational therapy*. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Breen, L. J., Aoun, S. M., O'Connor, M., Howting, D., & Halkett, G. K. B. (2018). Family caregivers' preparations for death: A qualitative analysis. *Journal of Pain and Symptom Management*. doi:10.1016/j.jpainsymman.2018.02.018

Breen, L. J., Aoun, S. M., O'Connor, M., Howting, D., & Halkett, G. K. B. (2018). Family Caregivers' Preparations for Death: A Qualitative Analysis. *Journal of Pain and Symptom Management, 55*(6), 1473-1479. doi:10.1016/j.jpainsymman.2018.02.018

Brinkmann, S., & Kvale, S. (2015). *Interviews. Learning the craft of qualitative research interviewing.* (3rd ed.). Thousand Oaks, CA: Sage.

Broadhurst, K., & Harrington, A. (2016). A mixed method thematic review: the importance of hope to the dying patient. *Journal of Advanced Nursing, 72*(1), 18-32. doi:10.1111/jan.12765

Broom, A., & Kirby, E. (2013). The end of life and the family: hospice patients' views on dying as relational. *Sociology of Health Illness, 35*(4), 499-513. doi:10.1111/j.1467-9566.2012.01497.x

Bruno, M., Ledoux, D., & Laureys, S. (2009). The dying human in biomedicine. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 51-75). Cambridge: Cambridge University Press.

Bryant, A., & Charmaz, K. (2010). *The SAGE handbook of grounded theory* (Pbk. ed.). Los Angeles: Sage Publications.

Burke, K. (1945). *A grammar of motives*. Berkeley: University of California Press.

Burns, C. M., Abernethy, A. P., Leblanc, T. W., & Currow, D. C. (2011). What is the role of friends when contributing care at the end of life? Findings from an Australian population study. *Psycho-Oncology, 20*(2), 203-212. doi:10.1002/pon.1725

Burns, E. J., Quinn, S. J., Abernethy, A. P., & Currow, D. C. (2015). Caregiver expectations: Predictors of a worse than expected caregiving experience at the end of life. *Journal of Pain and Symptom Management, 50*(4), 453-461. doi:10.1016/j.jpainsymman.2015.04.017

Byrne, M. (2001). The concept of informed consent in qualitative research. *AORN journal, 74*(3), 401-403. doi:10.1016/S0001-2092(06)61798-5

Byrne, M. (2008). Spirituality in palliative care: what language do we need? *International Journal of Palliative Nursing, 14*(6), 274-280. doi.org/10.12968/ijpn.2007.13.3.23273

Canadian Association of Occupational Therapists. (1997). *Enabling occupation: an occupational therapy perspective*. Ottawa: CAOT Publications ACE.

Caswell, G., Pollock, K., Harwood, R., & Porock, D. (2015). Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study. *BMC Palliative Care, 14*(1), 35. doi:10.1186/s12904-015-0032-0

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). London: SAGE.

Christiansen, C., & Townsend, E. A. (2010). *Introduction to occupation: the art and science of living: New multidisciplinary perspectives for understanding human occupation as a central feature of individual experience and social organization* (Vol. 2nd). New Jersey: Pearson.

Clemmer, S. J., Ward-Griffin, C., & Forbes, D. (2008). Family members providing home-based palliative care to older adults: the enactment of multiple roles. *Canadian Journal on Aging, 27*(3), 267-283.

Cooley, C. H. (1902). *Human nature and the social order*. New York: Charles Scribner's Sons.

Creswell, J. W. (2013). *Qualitative inquiry and research design: choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: choosing among five approaches* (4th ed.). Thousand Oaks, CA: Sage.

Dahlin, C. (2013). A view from the board. Clinical practice guidelines for quality palliative care. *Journal of Hospice & Palliative Nursing, 6* (3) 141-141. doi.org/10.1097/00129191-200407000-00001

Dey, I. (1999). *Grounding grounded theory*. San Diego, CA: Academic Press.

Dey, I. (2010). Grounding categories. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 167-190). Los Angeles: Sage.

Dillon, M. (2014). *Introduction to sociological theory: theorists, concepts, and their applicability to the twenty-first century* (Second ed.). Chichester, West Sussex: John Wiley & Sons.

Doka, K. J. (2003). The death awareness movement. In C. D. Bryant (Ed.), *Handbook of death & dying* (pp. 50-56). Thousand Oaks, CA: Sage.

Durkin, K. F. (2003). Death, dying, and the dead in popular culture. In C. D. Bryant (Ed.), *Handbook of death & dying* (pp. 43-49). Thousand Oaks, CA: Sage.

Elias, N. (1985). *Loneliness of the Dying*. Oxford: Basil Blackwell Ltd.

Emanuel, L., Bennett, K., & Richardson, V. E. (2007). The dying role. *Journal of Palliative Medicine, 10*(1), 159-168. doi.org/10.1089/jpm.2006.0134

Field, D. (1996). Awareness and modern dying. *Mortality, 1*(3), 255-265. doi:10.1080/13576279609696247

Field, D., & Copp, G. (1999). Communication and awareness about dying in the 1990s. *Palliative Medicine, 13*(6), 459-468. doi:10.1191/026921699668763479

Floriani, C. A., & Schramm, F. R. (2012). Routinization and medicalization of palliative care: Losses, gains and challenges. *Palliative and Supportive Care, 10*(4), 295-303. doi:10.1017/S1478951511001039

Froggatt, K. (1997). Rites of passage and the hospice culture. *Mortality, 2*(2), 123-136. doi:10.1080/713685862

Gittings, C. (2009). The art of dying. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 163-187). Cambridge: Cambridge University Press.

Glaser, B. G., & Holton, J. A. (2004). Remodeling grounded theory. *Forum Qualitative Sozialforschung, 5*(2).

Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying.* Chicago.: Aldine Transaction.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: strategies for qualitative research*. New York: Aldine Pub. Co.

Glaser, B. G., & Strauss, A. L. (1968). *Time for dying.* Chicago.: Aldine Transaction.

Goffman, E. (1959). *The presentation of self in everyday life*. New York: Penguin Books.

Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care, 12*(1), 7-7. doi:10.1186/1472-684X-12-7

Granda-Cameron, C., & Houldin, A. (2012). Concept Analysis of Good Death in Terminally Ill Patients. *American Journal of Hospice and Palliative Medicine, 29*(8), 632-639. doi:10.1177/1049909111434976

Gysels, M., Shipman, C., & Higginson, I. J. (2008). Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Medical Ethics, 9*(1), 7-7. doi:10.1186/1472-6939-9-7

Hancock, K., Clayton, J. M., Parker, S. M., Walder, S., Butow, P. N., Carrick, S., . . . Tattersall, M. H. N. (2007). Discrepant perceptions about end-of-life communication: A systematic review. *Journal of Pain and Symptom Management, 34*(2), 190-200. doi:10.1016/j.jpainsymman.2006.11.009

Hanusch, F. (2010). *Representing Death in the News: Journalism, Media and Mortality*. Basingstoke: Palgrave Macmillan Ltd.

Hardy, J. R., & Good, P. (2014). A good death in hospital. *Internal Medicine Journal, 44*(4), 313-314. doi:10.1111/imj.12378

Harrington, K. J. (2012). The use of metaphor in discourse about cancer: a review of the literature. *Clinical Journal of Oncology Nursing, 16*(4), 408-412. doi:10.1188/12.CJON.408-412

Hart, B., Sainsbury, P., & Short, S. (1998). Whose dying? A sociological critique of the 'good death'. *Mortality, 3*(1), 65-77. doi:10.1080/713685884

Hayslip, B. (2003). Death denial. Hiding and camouflaging death. In C. D. Bryant (Ed.), *Handbook of death & dying* (pp. 34-42). Thousand Oaks, CA: Sage.

Henselmans, I., Smets, E.M.A., Han, P.K.J., de Haes, H.C.J.C., & van Laarhoven, H.W.M. (2017). How long do I have? Observational study on communication about life expectancy with advanced cancer patients. *Patient education and counseling, 100*(10), 1820-1827. doi:10.1016/j.pec.2017.05.012

Higginson, I. J., Costantini, M., Silber, E., Burman, R., & Edmonds, P. (2011). Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: A randomised fast-track trial to test timing of referral and how long the effect is maintained. *Postgraduate Medical Journal, 87*(1033), 769-775. doi:10.1136/postgradmedj-2011-130290

Higginson, I. J., & Sen-Gupta, G. J. A. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine, 3*(3), 287-300. doi:10.1089/jpm.2000.3.287

Hoffnung, M., Hoffnung, R. J., Seifert, K. L., Hine, A., Paus , C., Ward, L., . . . Smith, R. B. (2019). *Lifespan development* (Fourth Australasian ed.). Milton, Queensland: Wiley.

Holton, J. A. (2010). The coding process and its challenges. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 265-289). Los Angeles: Sage.

Horsfall, D., Leonard, R., Noonan, K., & Rosenberg, J. (2013). Working together-apart: Exploring the relationships between formal and informal care networks for people dying at home. *Progress in Palliative Care, 21*(6), 331-336. doi:10.1179/1743291X12Y.0000000047

Howarth, G. (2000). Dismantling the boundaries between life and death. *Mortality, 5*(2), 127-138. doi:10.1080/713685998

Howe, E. (2016). The “dying role”: A new path, already well trodden. *Psychiatry, 79*(3), 208-211. doi:10.1080/00332747.2016.1222159

Hudson, P., & Payne, S. (2011). Family caregivers and palliative care: Current status and agenda for the future. *Journal of Palliative Medicine, 14*(7), 864-869. doi:10.1089/jpm.2010.0413

Hughes, M. E. (2015). A Strengths Perspective on Caregiving at the End-of-life. *Australian Social Work, 68*(2), 156-168. doi.org/10.1080/0312407x.2014.910677

Hughes, M. T., & Smith, T. J. (2014). The Growth of Palliative Care in the United States. *Annual Review of Public Health, 35*, 459-475. doi:10.1146/annurev-publhealth-032013-182406

Illich, I. (1975). *Medical nemesis: the expropriation of health*. London: Lothian Pub. in association with Calder & Boyars.

Jack, B. A., O'Brien, M. R., Scrutton, J., Baldry, C. R., & Groves, K. E. (2015). Supporting family carers providing end-of-life home care: a qualitative study on the impact of a hospice at home service. *Journal of Clinical Nursing, 24*(1-2), 131-140. doi:10.1111/jocn.12695

James, N., & Field, D. (1992). The routinization of hospice: Charisma and bureaucratization. *Social Science & Medicine, 34*(12), 1363-1375. doi:10.1016/0277-9536(92)90145-G

Keeley, M. P. (2007). Turning toward death together': The functions of messages during final conversations in close relationships. *Journal of Social and Personal Relationships, 24*(2), 225-253. doi:10.1177/0265407507075412

Keeley, M. P. (2016). Family Communication at the End of Life. *Journal of Family Communication, 16*(3), 189-197. doi:10.1080/15267431.2016.1181070

Kellehear, A. (1999). *Health promoting palliative care*. Melbourne: Oxford University Press.

Kellehear, A. (2007). The end of death in late modernity: An emerging public health challenge. *Critical Public Health, 17*(1), 71-79. doi:10.1080/09581590601156365

Kellehear, A. (2007). *A social history of dying*. New York: Cambridge University Press.

Kellehear, A. (2008). Dying as a social relationship: A sociological review of debates on the determination of death. *Social Science & Medicine, 66*(7), 1533-1544. doi:10.1016/j.socscimed.2007.12.023

Kellehear, A. (2009a). On dying and human suffering. *Palliative Medicine, 23*(5), 388-397. doi:10.1177/0269216309104858

Kellehear, A. (2009b). *The study of dying. From autonomy to transformation.* Cambridge: Cambridge University Press.

Kellehear, A. (2013). Compassionate communities: end-of-life care as everyone's responsibility. *QJM An International Journal of Medicine, 106*(12), 1071-1075. doi:10.1093/qjmed/hct200

Kendall, M., Murray, S. A., Carduff, E., Worth, A., Harris, F., Lloyd, A., . . . Sheikh, A. (2009). Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ, 339*(7739), b4122. doi:10.1136/bmj.b4122

Kenny, M., & Fourie, R. (2014). Tracing the history of grounded theory methodology: From formation to fragmentation. *Qualitative Report, 19*(52), 1-9.

Kenny, M., & Fourie, R. (2015). Contrasting classic, Straussian, and constructivist grounded theory: Methodological and philosophical conflicts. *Qualitative Report, 20*(8), 1270-1289.

King, D. A., & Quill, T. (2006). Working with families in palliative care: One size does not fit all. *Journal of Palliative Medicine, 9*(3), 704-715. doi:10.1089/jpm.2006.9.704

Kirby, E., Broom, A., Good, P., Wootton, J., & Adams, J. (2014). Families and the transition to specialist palliative care. *Mortality, 19*(4), 323-341. doi:10.1080/13576275.2014.916258

Kissane, D. W. (2016). The challenge of family-centered care in palliative medicine. *Annals of Palliative Medicine, 5*(4), 319-321. doi:10.21037/apm.2016.08.04

Králová, J. (2015). What is social death? *Contemporary Social Science, 10*(3), 235-248. doi:10.1080/21582041.2015.1114407

Kubler-Ross, E. (1969). *On death and dying. What the dying have to teach doctors, nurses, clergy and their own families.* Abingdon: Routledge.

Laryionava, K., Pfeil, T. A., Dietrich, M., Reiter-Theil, S., Hiddemann, W., & Winkler, E. C. (2018). The second patient? Family members of cancer patients and their role in end-of-life decision making. *BMC Palliative Care, 17*(29), 1-9. doi:10.1186/s12904-018-0288-2

Lawton, J. (1998). Contemporary hospice care: The sequestration of the unbounded body and 'dirty dying'. *Sociology of Health and Illness, 20*(2), 121-143. doi:10.1111/1467-9566.00094

Layder, D. (1993). *New strategies in social research: An introduction and guide*. Cambridge, U.K: Polity Press.

Leadbeater, C., & Garber, J. (2010). *Dying for change.* London: Demos.

Leichtentritt, R. D., & Rettig, K. D. (2001). The construction of the good death. *Journal of Aging Studies, 15*(1), 85-103. doi:10.1016/S0890-4065(00)00018-9

Leonard, R., Horsfall, D., Rosenberg, J., & Noonan, K. (2018). Carer experience of end-of-life service provision: A social network analysis. *BMJ Supportive and Palliative Care*, *0*, 1-7 doi:10.1136/bmjspcare-2017-001344

Li, S. (2004). 'Symbiotic niceness': constructing a therapeutic relationship in psychosocial palliative care. *Social Science & Medicine, 58*(12), 2571-2583. doi:10.1016/j.socscimed.2003.09.006

Li, S., & Arber, A. (2006). The construction of troubled and credible patients: A study of emotion talk in palliative care settings. *Qualitative Health Research, 16*(1), 27-46. doi:10.1177/1049732305284022

Linton, R. (1936). *The study of man: an introduction*. New York: Appleton-Century-Crofts.

Lipsitt, D. R. (2016). The "Dying Role": Its Time Had Come. *Psychiatry (New York), 79*(3), 216-226. doi:10.1080/00332747.2016.1222198

Lokker, M., Zuylen, L., Veerbeek, L., Rijt, C., & Heide, A. (2012). Awareness of dying: It needs words. *Supportive Care in Cancer, 20*(6), 1227-1233. doi:10.1007/s00520-011-1208-7

Lowrie, D., Ray, R., Plummer, D., & Yau, M. (2018). Exploring the contemporary stage and scripts for the enactment of dying roles: A narrative review of the literature. *OMEGA-Journal of Death and Dying, 76*(4), 328-350. doi:10.1177/0030222817696541

Lowrie, D., Ray, R., Plummer, D., & Yau, M. (2019a). Examining the transitions between living and dying roles at end-of-life. *Death Studies, 43*(10), 601-610. doi:10.1080/07481187.2018.1504836

Lowrie, D., Ray, R., Plummer, D., & Yau, M. (2019b). Alignment and mismatch in role relations at end-of-life: A constructivist grounded theory study. *Death Studies*, 1-10. doi:10.1080/07481187.2019.1648330

Lupton, D. (1994). Femininity, responsibility and the technological imperative: discourses on breast cancer in the Australian Press. *International Journal of Health Services., 24*(1), 73-89.

Lynch, K. D. (2007). Modeling Role Enactment: Linking Role Theory and Social Cognition. *Journal for the Theory of Social Behaviour, 37*(4), 379-399. doi:10.1111/j.1468-5914.2007.00349.x

Lyons, K. D., & Bakitas, M. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *JAMA : The Journal of the American Medical Association, 302*(7), 741. doi.org/10.1001/jama.2009.1198

Manning, P. (1991). Drama as Life: The Significance of Goffman's Changing Use of the Theatrical Metaphor. *Sociological Theory, 9*(1), 70-86. doi:10.2307/201874

McGrath, P., Moore, A., McNaught, M., Palmer, G., Greene, A., & Atkinson, D. (2005). Another form to fill in! Clients' reflections on the hospice use of questionnaires. *Supportive Care in Cancer, 13*(9), 691-701. doi:10.1007/s00520-005-0795-6

McInerney, F. (2009). Cinematic visions of dying. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 211-232). Cambridge: Cambridge University Press.

McNamara, B. (2004). Good enough death: autonomy and choice in Australian palliative care. *Social Science & Medicine, 58*(5), 929-938. doi:10.1016/j.socscimed.2003.10.042

McNamara, B., Waddell, C., & Colvin, M. (1994). The institutionalization of the good death. *Social Science & Medicine, 39*(11), 1501-1508. doi:10.1016/0277-9536(94)90002-7

Mead, G. H. (1934; 1972). *Mind, self, and society from the standpoint of a social behaviorist*. Chicago: The University of Chicago Press.

Miles, L., & Corr, C. A. (2017). Death cafe: what is it and what we can learn from it. *OMEGA - Journal of Death and Dying, 75*(2), 151-165. doi:10.1177/0030222815612602

Minichiello, V., Aroni, R., & Hays, T. N. (2008). *In-depth interviewing: principles, techniques, analysis* (3rd ed.). Sydney: Pearson Education Australia.

Morse, J. M. (2010). Sampling in grounded theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 229-244). Los Angeles: Sage.

National Health and Medical Research Council (Australia) & Australian Research Council & Australian Vice Chancellor's Committee. (2018). *National Health and Medical Research Council (NHMRC) National statement on ethical conduct in human research 2007*. Canberra Retrieved from https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018.

Nayar, S. (2015). Grounded theory. Uncovering a world of process. In S. Nayar & M. Stanley (Eds.), *Qualitative research methodologies for occupational science and therapy* (pp. 37-52). Abingdon, Oxon: Routledge.

Noonan, K. (2015). Dying to know day: a public health campaign in Australia. *BMJ Supportive & Palliative Care, 5*(Suppl 1), A14-A15. doi:10.1136/bmjspcare-2015-000906.46

Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. *Progress in Palliative Care, 24*(1), 31-35. doi:10.1080/09699260.2015.1103498

Noyes, R., Jr., & Clancy, J. (1977). The dying role: its relevance to improved patient care. *Psychiatry, 40*(1), 41-47. doi.org/10.1080/00332747.1977.11023918

Nyatanga, B. (2013). Dying matters awareness week: Refocusing on sensitivities of dying. *British Journal of Community Nursing, 18*(4), 202. doi.org/10.12968/bjcn.2013.18.4.202

Occupational Therapy Australia. (2015). *Position paper: Occupational therapy in palliative care*. Retrieved from http://www.otaus.com.au/sitebuilder/advocacy/knowledge/asset/files/21/positionpaper

-occupationaltherapyinpalliativecare%5Baugust2015%5D-occupationaltherapyaustralia.pdf

Palliative Care Australia. (2005). *Standards for providing quality palliative care for all Australians. 4th Edition.* Canberra: Palliative Care Australia.

Palliative Care Australia. (2018). *National Palliative Care Standards - 5th Edition.* Canberra: Palliative Care Australia.

Palliative Care Australia. (2019). About dying to talk. Retrieved from https://dyingtotalk.org.au/about-dying-to-talk/

Parker-Oliver, D. (2000a). The social construction of the "dying role" and the hospice drama. *OMEGA - Journal of Death & Dying, 40*(4), 493-512. doi.org/10.2190/yt9d-12y2-54ly-tcmn

Parsons, T. (1951). *The social system*. London: Routledge & Kegan Paul Ltd.

Parsons, T. (1972). Definitions of health and illness in the light of American values and social structure. In E. D. Jaco (Ed.), *Patients, physicians, and illnesses* (pp. 97-117). New York: The Free Press.

Patel, M. I., Periyakoil, V. S., Moore, D., Nevedal, A., & Coker, T. R. (2018). Delivering End-of-Life Cancer Care: Perspectives of Providers. *American Journal of Hospice and Palliative Medicine, 35*(3), 497-504. doi:10.1177/1049909117719879

Penson, R.T., Schapira, L., Daniels, K.J., Chabner, B.A., & Lynch, J.T.J. (2004). Cancer as metaphor. *The Oncologist, 9*(6), 708-716. doi:10.1634/theoncologist.9-6-708

Pleschberger, S., & Wosko, P. (2017). From neighbour to carer: An exploratory study on the role of non-kin-carers in end-of-life care at home for older people living alone. *Palliative Medicine, 31*(6), 559-565. doi:10.1177/0269216316666785

Pollock, K. (2015). Is home always the best and preferred place of death? *BMJ - British Medical Journal, 351*, h4855. doi:10.1136/bmj.h4855

Pontin, D., & Jordan, N. (2013). Issues in prognostication for hospital specialist palliative care doctors and nurses: A qualitative inquiry. *Palliative Medicine, 27*(2), 165-171. doi:10.1177/0269216311432898

Proulx, K., & Jacelon, C. (2004). Dying with dignity: the good patient versus the good death. *The American journal of hospice & palliative care, 21*(2), 116-120. doi:10.1177/104990910402100209

Queensland Government Statistician's Office. (2017). *Queensland regions compared, Census 2016*. Online: Queensland Government. Retrieved from http://www.qgso.qld.gov.au/products/reports/qld-regions-compared-c16/qld-regions-compared-c16.pdf.

Queensland Health. (2017). Palliative Care. Retrieved from https://www.health.qld.gov.au/townsville/services/palliative

Rao, J. K., Anderson, L. A., & Smith, S. M. (2002). End of life is a public health issue. *American Journal of Preventive Medicine, 23*(3), 215-220. doi:10.1016/S0749-3797(02)00500-7

Ray, R. A., & Street, A. F. (2006). Caregiver bodywork: family members' experiences of caring for a person with motor neurone disease. *Journal of Advanced Nursing, 56*(1), 35-43. doi:10.1111/j.1365-2648.2006.03977.x

Ray, R. A., & Street, A. F. (2007). Non-finite loss and emotional labour: family caregivers' experiences of living with motor neurone disease. *Journal of Clinical Nursing, 16*(3a), 35-43. doi:10.1111/j.1365-2702.2006.01722.x

Reisfield, G. M., & Wilson, G. R. (2004). Use of metaphor in the discourse on cancer. *Journal of Clinical Oncology : Official Journal of the American Society of Clinical Oncology, 22*(19), 4024-4027. doi:10.1200/JCO.2004.03.136

Ritchie, L. D. (2013). *Metaphor*. Cambridge: Cambridge University Press.

Rosenberg, J. (2011). Whose Business is Dying? Death, the Home and Palliative Care. *Cultural Studies Review, 17*(1). doi:10.5130/csr.v17i1.1971

Rosenberg, J., Mills, J., & Rumbold, B. (2016). Putting the 'public' into public health: community engagement in palliative and end of life care. *Progress in Palliative Care, 24*(1), 1-3. doi:10.1080/09699260.2015.1103500

Rosenberg, J. P., Horsfall, D., Leonard, R., & Noonan, K. (2018). Informal care networks' views of palliative care services: Help or hindrance? *Death Studies, 42*(6), 362-370. doi:10.1080/07481187.2017.1350216

Russell, G. (2016). Holism and holistic. *BMJ - British Medical Journal, 353*, i1884. doi:10.1136/bmj.i1884

Sachs, E., Kolva, E., Pessin, H., Rosenfeld, B., & Breitbart, W. (2013). On sinking and swimming: The dialectic of hope, hopelessness, and acceptance in terminal cancer. *American Journal of Hospice and Palliative Medicine, 30*(2), 121-127. doi:10.1177/1049909112445371

Saldana, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). London: Sage.

Sautter, J.M., Tulsky, J.A., Johnson, K.S., Olsen, M.K., Burton-Chase, A.M., Hoff Lindquist, J., . . . Steinhauser, K.E. (2014). Caregiver experience during advanced chronic illness and last year of life. *Journal of the American Geriatrics Society, 62*(6), 1082-1090. doi:10.1111/jgs.12841

Scarre, G. (2009). Dying and philosophy. In A. Kellehear (Ed.), *The study of dying. From autonomy to transformation.* (pp. 147-162). Cambridge: Cambridge University Press.

Scarre, G. (2012). Can there be a good death? *Journal of Evaluation in Clinical Practice, 18*(5), 1082-1086. doi:10.1111/j.1365-2753.2012.01922.x

Scott, A. M., & Caughlin, J. P. (2014). Enacted Goal Attention in Family Conversations about End-of-life Health Decisions. *Communication Monographs, 81*(3), 261-284. doi:10.1080/03637751.2014.925568

Seale, C. (1998). *Constructing death: the sociology of dying and bereavement*. Cambridge, England: Cambridge University Press.

Seale, C. (2001). Sporting cancer: struggle language in news reports of people with cancer. *Sociology of Health and Illness, 23*(3), 308-329. doi.org/10.1111/1467-9566.00254

Seale, C., Addington-Hall, J., & McCarthy, M. (1997). Awareness of dying: prevalence, causes and consequences. *Social Science & Medicine, 45*(3), 477-484. doi.org/10.1016/s0277-9536(96)00379-6

Snowden, M. (2015). Use of diaries in research. *Nursing Standard, 29*(44), 36-41. doi:10.7748/ns.29.44.36.e9251

Sontag, S. (1979). *Illness as metaphor*. London: Allen Lane.

Stephenson, J. S. (1985). *Death, grief and mourning: Individual and social realities.* New York.: Free Press.

Stone, A. M., Mikucki-Enyart, S., Middleton, A., Caughlin, J. P., & Brown, L. E. (2012). Caring for a parent with lung cancer: Caregivers' perspectives on the role of communication. *Qualitative Health Research, 22*(7), 957-970. doi:10.1177/1049732312443428

Strand, J. J., Mansel, K., & Swetz, K. M. (2014). The growth of palliative care. *Minnesota Medicine, 97*(6), 39-43.

Tanner, B., Tilse, C., & de Jonge, D. (2008). Restoring and sustaining home: The impact of home modifications on the meaning of home for older people. *Journal of Housing For the Elderly, 22*(3), 195-215. doi:10.1080/02763890802232048

Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V.A., . . . Lynch, T.J. (2010). Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *The New England Journal of Medicine, 363*(8), 733-742. doi:10.1056/NEJMoa1000678

The GroundSwell Project. (2019). The GroundSwell Project Manifesto. Retrieved from https://www.thegroundswellproject.com/manifesto

Thomas, K., Hudson, P., Oldham, L., Kelly, B., & Trauer, T. (2010). Meeting the needs of family carers: an evaluation of three home-based palliative care services in Australia. *Palliative Medicine, 24*(2), 183-191. doi:10.1177/0269216309351467

Thomas, S. (2012). Narrative inquiry: embracing the possibilities. *Qualitative Research Journal, 12*(2), 206-221. doi:10.1108/14439881211248356

Timmermans, S. (1994). Dying of awarenss - The theory of awareness contexts revisited. *Sociology of Health and Illness, 16*(3), 322-339. doi:10.1111/1467-9566.ep11348751

Timmermans, S. (2005). Death brokering: constructing culturally appropriate deaths. *Sociology of Health & Illness, 27*(7), 993-1013. doi:10.1111/j.1467-9566.2005.00467.x

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357. doi:10.1093/intqhc/mzm042

Townsville Hospital and Health Service. (2018). *Townsville Hospital and Health Service - Annual Report 2017-2018*. Retrieved from https://www.health.qld.gov.au/__data/assets/pdf_file/0032/729608/thhs-annual-report-2017-18.pdf

Turner, R. H. (1956). Role-Taking, Role Standpoint, and Reference-Group Behavior. *The American Journal of Sociology, 61*(4), 316-328. doi:10.1086/221763

Turner, R. H. (1990). Role Change. *Annual Review of Sociology, 16*(1), 87-110. doi:10.1146/annurev.soc.16.1.87

Turner, V. (1974). *Dramas, fields and metaphors: Symbolic action in human society.* New York.: Cornell University Press.

van Gennep, A. (1909/1960). *The rites of passage*. Chicago: University of Chicago Press.

Wallace, C. L. (2013). Family communication and decision making at the end of life: A literature review. *Palliative and Supportive Care, 13*(3), 815-825. doi:10.1017/S1478951514000388

Walter, T. (1994). *The revival of death*. London: Routledge.

Walter, T. (2003). Historical and cultural variations on the good death. *BMJ Quality & Safety, 327*, 218-220. doi.org/10.1136/bmj.327.7408.218

Walter, T., Littlewood, J., & Pickering, M. (1995). Death in the News: The Public Invigilation of Private Emotion. *Sociology, 29*(4), 579-596. doi:10.1177/0038038595029004002

Walters, G. (2004). Is there such a thing as a good death? *Palliative Medicine, 18*(5), 404-408. doi:10.1191/0269216304pm908oa

Weiner, J. S., & Roth, J. (2006). Avoiding iatrogenic harm to patient and family while discussing goals of care near the end of life. *Journal of Palliative Medicine, 9*(2), 451-463. doi:10.1089/jpm.2006.9.451

Williams, C. A. (1982). Role Considerations in Care of the Dying Patient: What is the professional role in caring for the dying? *Journal of Nursing Scholarship, 14*(1), 8-11. doi:10.1111/j.1547-5069.1982.tb01496.x

World Health Organisation. (2007). *Definition of Palliative Care*. Geneva: World Health Organisation.

World Health Organisation. (2019). WHO definition of palliative care. Retrieved from https://www.who.int/cancer/palliative/definition/en/

Zhang, A. Y., & Siminoff, L. A. (2003). Silence and Cancer: Why do families and patients fail to communicate? *Health Communication, 15*(4), 415-429. doi:10.1207/S15327027HC1504_03

Zimmermann, C. (2012). Acceptance of dying: a discourse analysis of palliative care literature. *Social Science & Medicine (1982), 75*(1), 217-224. doi:10.1016/j.socscimed.2012.02.047

Zimmermann, C., Yuen, D., Mischitelle, A., Minden, M. D., Brandwein, J. M., Schimmer, A., . . . Rodin, G. (2013). Symptom burden and supportive care in patients with acute leukemia. *Leukemia Research, 37*(7), 731-736. doi:10.1016/j.leukres.2013.02.009

APPENDICES

Article

OMEGA—Journal of Death and Dying
2018, Vol. 76(4) 328–350
© The Author(s) 2017
Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/0030222817696541
journals.sagepub.com/home/ome
SAGE

Exploring the Contemporary Stage and Scripts for the Enactment of Dying Roles: A Narrative Review of the Literature

Daniel Lowrie[1], Robin Ray[2], David Plummer[3], and Matthew Yau[4]

Abstract

This narrative review explores the literature regarding the drama of dying from several academic perspectives. Three key themes were identified including “The impact of blurred boundaries on roles and transitions,” “The orchestration of death and dying through time,” and “Contemporary dying and new machinery of control.” This review reveals the manner in which tightly scripted dying roles serve the needs of the living to a greater extent than those of the dying, by ensuring the depiction of both dying and death as phenomena which have been brought under the control of the living, thereby countering death anxiety. An incongruence between the actual experience of dying and contemporary dying scripts is also highlighted. The authors argue that this incongruence is hidden from the broader societal audience through the maintenance of a dying role that demands serenity and acceptance, thus downplaying or even hiding the actual end-of-life experiences of the dying themselves.

---

[1] College of Healthcare Sciences, James Cook University, Douglas, Australia
[2] College of Medicine and Dentistry, James Cook University, Douglas, Australia
[3] College of Public Health, Medical and Veterinary Sciences, James Cook University, Douglas, Australia
[4] School of Medical & Health Sciences, Tung Wah College, Kowloon, Hong Kong

Corresponding Author:
Daniel Lowrie, College of Healthcare Sciences, James Cook University, James Cook Drive, Douglas, Australia.
Email: daniel.lowrie@jcu.edu.au

Death Studies

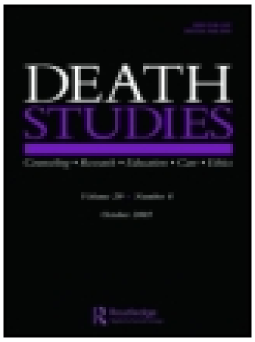
ISSN: 0748-1187 (Print) 1091-7683 (Online) Journal homepage: https://www.tandfonline.com/loi/udst20

Examining the transitions between living and dying roles at end-of-life

Daniel Lowrie, Robin Ray, David Plummer & Matthew Yau

To cite this article: Daniel Lowrie, Robin Ray, David Plummer & Matthew Yau (2019) Examining the transitions between living and dying roles at end-of-life, Death Studies, 43:10, 601-610, DOI: 10.1080/07481187.2018.1504836

To link to this article: https://doi.org/10.1080/07481187.2018.1504836



Death Studies

ISSN: 0748-1187 (Print) 1091-7683 (Online) Journal homepage: https://www.tandfonline.com/loi/udst20

Alignment and mismatch in role relations at end-of-life: A constructivist grounded theory study

Daniel Lowrie, Robin Ray, David Plummer & Matthew Yau

To cite this article: Daniel Lowrie, Robin Ray, David Plummer & Matthew Yau (2019): Alignment and mismatch in role relations at end-of-life: A constructivist grounded theory study, Death Studies, DOI: 10.1080/07481187.2019.1648330

To link to this article: https://doi.org/10.1080/07481187.2019.1648330

APPENDIX TWO: RESEARCH ETHICS AND SITE SPECIFIC APPROVAL LETTERS

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

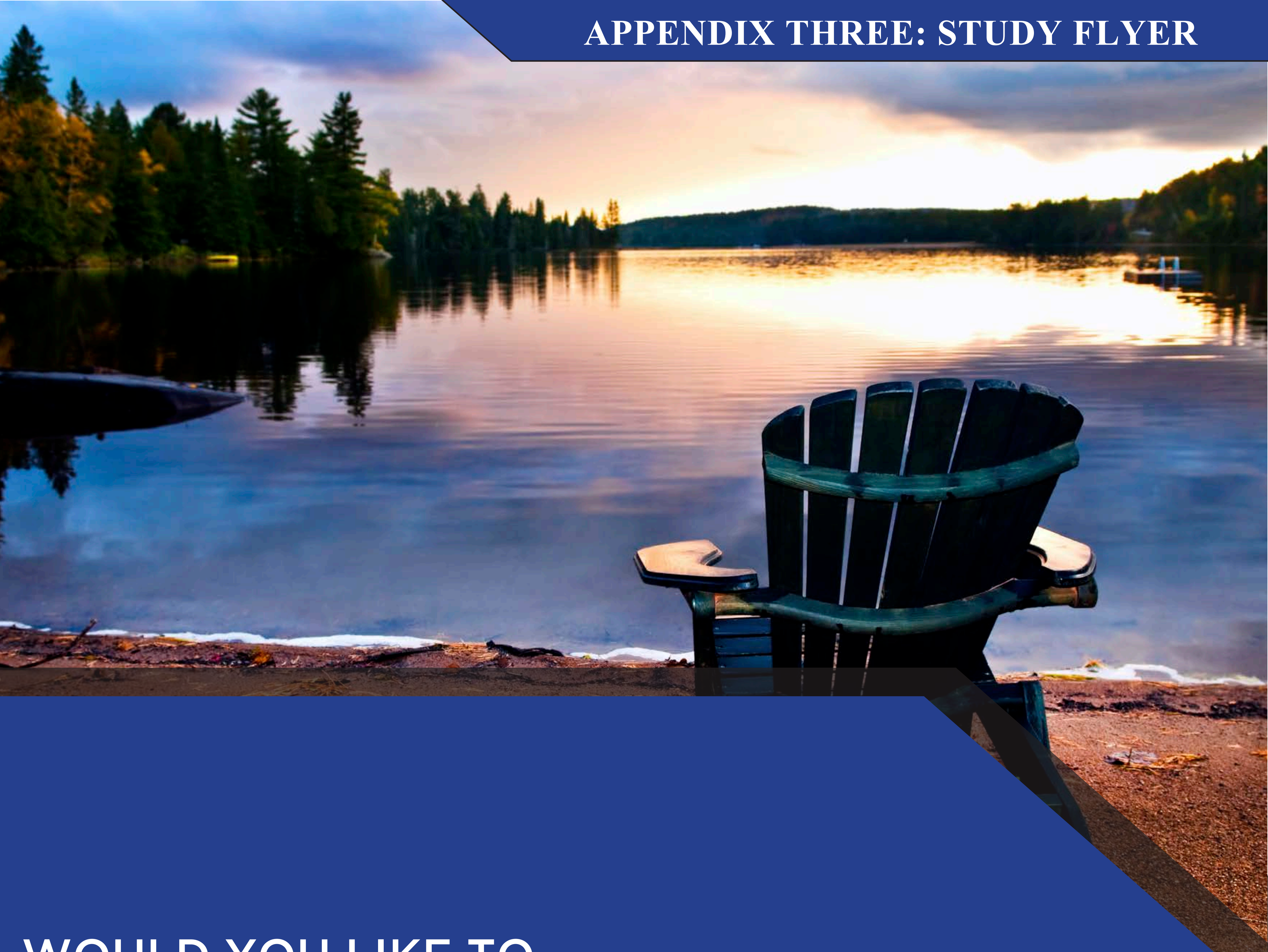
This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

This administrative form
has been removed

APPENDIX THREE: STUDY FLYER



WOULD YOU LIKE TO SHARE YOUR STORY?

I am looking for people to share their stories as part of a research project titled: **“An exploration of dying roles within contemporary regional Australia.”**

I AM HOPING TO INTERVIEW:

- People nearing end of life
- Family members of people nearing end of life
- Health professionals who work with people at end of life

If you would like to participate in, or hear more about this study, please contact me using the details below.

Daniel Lowrie (Lecturer and Occupational Therapist)
James Cook University
T: (07) 4781 5951 | M. 0409 119 866 | E: daniel.lowrie@jcu.edu.au

v1.0

APPENDIX FOUR:

PARTICIPANT INFORMATION SHEET

Project Title: An exploration of dying roles within a contemporary regional Australian context.

Invitation paragraph

You are invited to take part in a research project exploring dying roles. The researchers are hoping to hear about the experiences of people nearing end of life, as well their families and the health professionals who care for them. This study is being led by Daniel Lowrie as part of a PhD through James Cook University.

Before you choose whether or not to participate, it is important that you understand why the research is being completed and what it will involve. Please read the following information carefully. Please feel free to contact the research team if anything seems unclear, or if you would like to know more about this project.

What is the purpose of the study?

The different roles that people have help to shape their sense of who they are. As well as this roles often guide people's thoughts and actions in different social situations. Because of this roles, have a big impact on the way in which people experience the world around them.

The process of dying can have a major effect on the roles of dying people and their family. Previous roles may be lost or changed and new roles can emerge. These changes can affect the lives of people who are dying (and their loved ones), including their experience of care. However, very little is known about this experience, especially from the view point of dying people and their family members.

This research project aims to aim to improve knowledge of dying roles. It will do this by asking people nearing end of life as well as their family members and the health professionals who care for them about their experiences, thoughts and feelings. It is hoped that the results of this study might help improve the quality of the health care services received by people who are dying and their family members.

Do I have to take part?

Taking part in this research project is completely your choice. If you do take part, you can still withdraw at any time without giving a reason. If you withdraw from the study any unprocessed data will be removed. Participation in this study or withdrawal from the study will not impact on any current or future health care treatment received by **either yourself, or your family member** in any way.
If you wish to take part in this study, please contact either the principal researcher (Daniel Lowrie) or supervisor (Dr Robin Ray). The contact details for Daniel and Robin are at the end of this information sheet.

What will be involved for me if I take part?

If you contact the research team to say would like to take part in the project, you will be asked to sign a consent form and be offered an interview. **As part of this, you can ask the researcher any questions you want about the research to make sure you are happy with what you are agreeing to do.**

The interview will be audio taped, and should only take between 30 minutes and 1 hour. The interview will take place at a time and location of your choice. **Interviews can be stopped at any time, should you wish to do so. As well as this, you can choose to skip over any questions you don't want to answer.**

Once the interview is finished, the researcher will check that you are happy for your interview to be used as part of the research. If you would not like your interview to be used in the research the recording will be deleted.

Are there any risks?

You may find that you don't want to answer a particular question or continue a discussion. If this happens, you will be offered to skip that question or stop the interview. The principal researcher is an experienced health professional with over ten years' experience working in palliative care. He will therefore be able to offer you support should you feel upset or distressed. However, if you need extra emotional support it will be available through Rosemarie Labuschagne, Social Worker, within the Palliative Care Team at the Townsville Hospital (Phone: 07 4433 3128). **If you are from an Aboriginal or Torres Strait Islander background, Ian Pollard (Indigenous Liaison Officer) can also support. Rosemarie and Ian's full contact details will be given to you before the start of the interview.** Lifeline can also provide support if you need it. You can contact this service via their web-page www.lifeline.org.au or by phone on 13 11 14.

It is possible that at the time of your interview you might not feel physically or emotionally up to taking part. If this happens the interview will be postponed or cancelled (whichever you prefer).

Will my taking part be kept confidential?

All information that is collected about you in this research project will be kept strictly private. Consent forms will be kept in a locked cabinet during the research project and for 15 years after it is completed. During the research project, interviews will be stored on a password protected computer. When the recordings are being been typed out all names will be removed. The typed records of interviews will be kept as password protected computer files that only the researchers can access. When the project is finished the recordings will be deleted. The typed records will be put on a CD and kept in a locked cabinet within the researcher's office for 5 years.

What will happen to the results of this study?

The results of the study will be used in research publications, teaching and reports. All results from this study will have identifying information (such as names) removed. You will not be identified in any report or publication.

Who has reviewed this study?

This research has been reviewed and approved by The Townsville Health and Hospital Service Human Research Ethics Committee (Approved: 13th March 2015- HREC Reference No.: HREC/14/QTHS/196) as well as upheld through the James Cook University Ethics Committee (H6101).

Contact details for further information and/or to indicate interest

If you have any questions about the study or would like to be involved, please contact – Daniel Lowrie (principal investigator) or Dr Robin Ray (primary PhD supervisor) using the details below.

Principal Investigator: Daniel Lowrie
Occupational Therapy Lecturer
PhD Candidate
College of Healthcare Sciences
James Cook University
Phone:
Email: daniel.lowrie@jcu.edu.au

Primary Supervisor: Dr Robin Ray
Senior Lecturer
College of Medicine and Dentistry
James Cook University
Phone:
Email: robin.ray@jcu.edu.au

Thank you for considering taking part in this research project.

If you have any concerns regarding the ethical conduct of the study, please contact:

Primary contact:
Human Research Ethics Committee
The Townsville Hospital, 100 Angus Smith Drive, Douglas, QLD, 4814
Phone: (07) 4433 1440 (email: **TSV-Ethics-Committee@health.qld.gov.au)**

Secondary contact:
Human Ethics, Research Office
James Cook University, Townsville, Qld, 4811
Phone: (07) 4781 5011 (ethics@jcu.edu.au)

APPENDIX FIVE: SEMI-STRUCTURED RESEARCH INTERVIEW GUIDES

Exploration of Dying Roles - Interview Guide 1

1. **Consent:** Reminder regarding purpose of the study and confirmation of consent.

2. Descriptors

It would be helpful if we could begin with a brief discussion about your background and your current circumstances:

- Would you mind telling me your age?
- How would you describe your cultural background?
- What is your current living situation? (E.g. home, hospital, nursing home, palliative care unit etc.?)
- Do you have a spouse or partner / children / other close family?
- Can you tell me a little about your work history?
- Can you tell me about your education history?
  - Did you get the chance to finish school and / or go to University?
  - What is the highest level of education that you completed?
- How would you describe yourself; working class, middle class or upper class?
- Is there any religion or religious belief system that you feel connected to?
- Can you briefly tell me what you know about your illness?
  - When were you diagnosed?

3. Main interview

- Tell me about your story so far…

Prompts

- Can you tell me about your life before you became unwell?

- Can you tell me about the time when you first thought something might be wrong for you?

- Can you tell me about the events around the time of your diagnosis?

- How have things changed for you since you received your diagnosis?

  - In what way has your illness journey impacted on your roles and relationships?

  - Tell me about the important people around you at the moment

  - Have things changes in regard to what you need, want or are expected to do?

- Do you ever think of yourself as a dying person?

  - Can you tell me a bit more about this?

- What is important to you in the time ahead?

- What are your thoughts on the afterlife?

- What do you think about the way death and dying is handled?

- Reflecting on your observations of health services, what advice would you offer to:
  - Health professionals?
  - Family members of people nearing end of life?
  - Society?

- Do you have any further thoughts or reflections that you would like to share before we conclude the interview?

4. Review consent

Exploration of Dying Roles - Interview Guide 1b (Caregivers)

1. **Consent:** Reminder regarding purpose of the study and confirmation of consent.

2. Descriptors

It would be helpful if we could begin with a brief discussion about your background and your current circumstances:

- Would you mind telling me your age?
- How would you describe your cultural background?
- What is your current living situation? (E.g. home, hospital, nursing home, palliative care unit etc.?)
- Do you have a spouse or partner / children / other close family?
- Can you tell me a little about your work history?
- Can you tell me about your education history?
    - Did you get the chance to finish school and / or go to University?
    - What is the highest level of education that you completed?
- How would you describe yourself; working class, middle class or upper class?
- Is there any religion or religious belief system that you feel connected to?
- Can you briefly tell me what you know about (family member's) illness?
    - When was (family member) diagnosed?

3. Main interview

- Tell me about your story so far…

Prompts

- Can you tell me about how you got to know *[person]*?

- Can you tell me about the events around *[person's]* diagnosis?

- How have things changed for you since you (*person's*) received your diagnosis?

- In what way has (person's) illness journey impacted on your roles and relationships?

- Tell me about the important people around you at the moment

- What is important to you in the time ahead?

- What are your thoughts on the afterlife?

- What do you think about the way death and dying is handled?

- Reflecting on your observations of health services, what advice would you offer to:
  - Health professionals?
  - Family members of people nearing end of life?
  - Society?

- Do you ever thing of (person's name) as a dying person?

- Have you ever reflected on death and dying as it relates to you?

  - In what way have your experience influenced your thinking about your own death?

  - Can you tell me a bit more about this?

- Do you have any further thoughts or reflections that you would like to share before we conclude the interview?

4. **Review consent**

Exploration of Dying Roles - Interview Guide 2 (Professional Interviews)

1. **Consent:** Reminder regarding purpose of the study and confirmation of consent.

2. **Descriptors**
    - Age
    - Cultural background
    - Education
    - Profession / role?
    - How would you describe yourself; working class, middle class or upper class?
    - Is there any religion or religious belief system that you feel connected to?
    - How long have you been in your current role?
    - How long have you been qualified?
    - In what setting(s) is your work with dying people predominantly based?
        - (E.g. Inpatient, Palliative Care Centre, Nursing Homes, Community, Outreach, Combination?)
    - Were you working with dying people prior to your current role?

3. **Main interview**

    - Can you tell me about your working role with dying people and their families?
        - What influenced your decision to work in this field?
        - Can you give me a general idea of how you approach work with dying people and their families?
        - Can you tell me about occasions when your work with dying people and their families went really well?

    - How does your role with the dying person differ from your role with the close family / carer of the dying person?

    - What (if anything) do you see your role in working with people beyond the dying person and their immediate families or carers in regards to dying?

    - How do you see the interface between the dying person and those around them such as friends, family and others?

    - In what way have your personal views and experiences relating to death and dying influenced your professional perspective?

- In what way have your professional experiences influences your personal views?

- Where do you see your role beginning and ending in relation to your work with dying people and those that matter to them? Are there limits or boundaries to your role?

- What do you think about the systems and processes around dying as they currently exist within regional Australia?

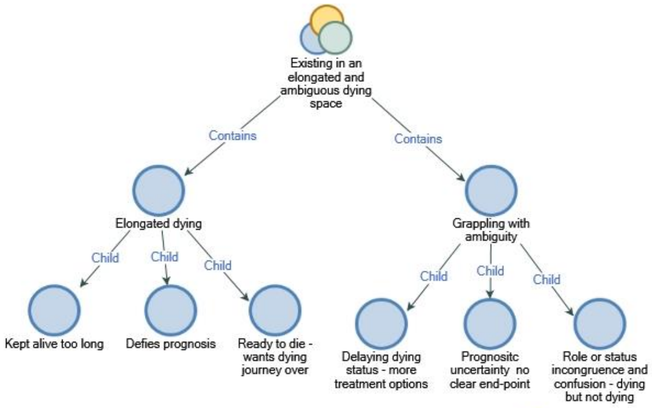
- Based on your observations of health care services provided to dying people, what advice would you offer to:
    - Health professionals who work with dying people?
    - Family members of dying people?
    - Society?

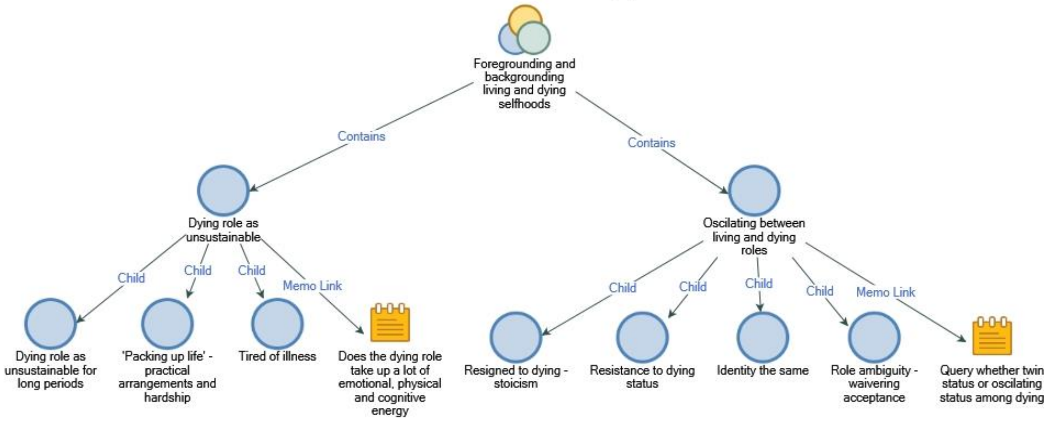
- Do you have any further thoughts or reflections that you would like to share before we conclude the interview?

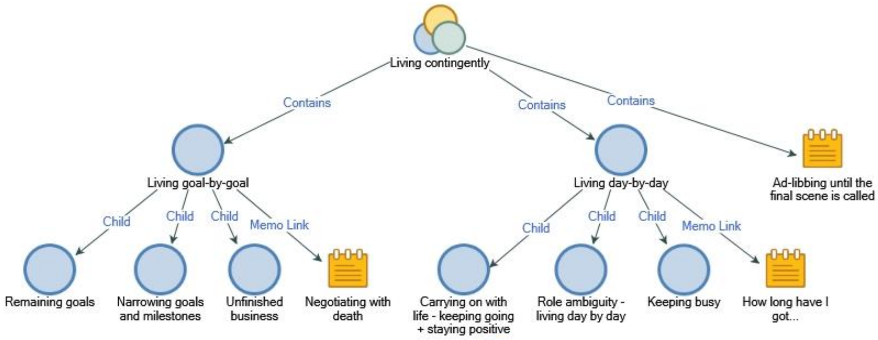
4. **Review consent**

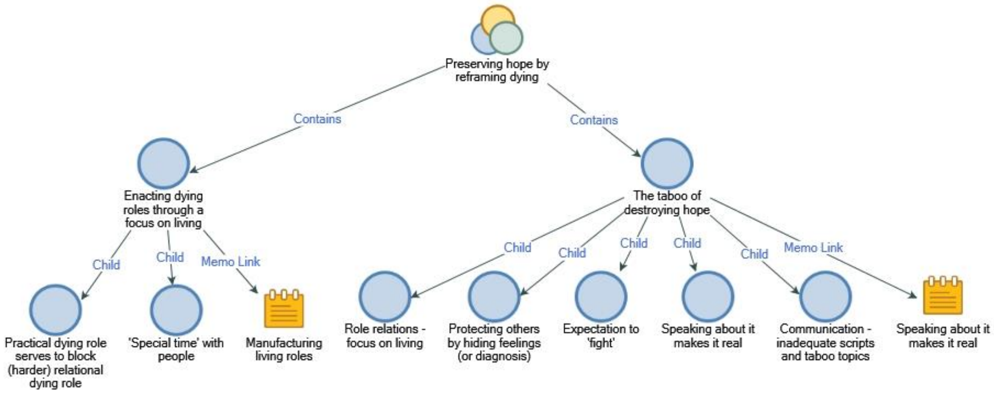
APPENDIX SIX: CONCEPTUAL CODE MAPS (CHAPTER FOUR)

Chapter Four – Examining the transitions between living and dying roles at end-of-life



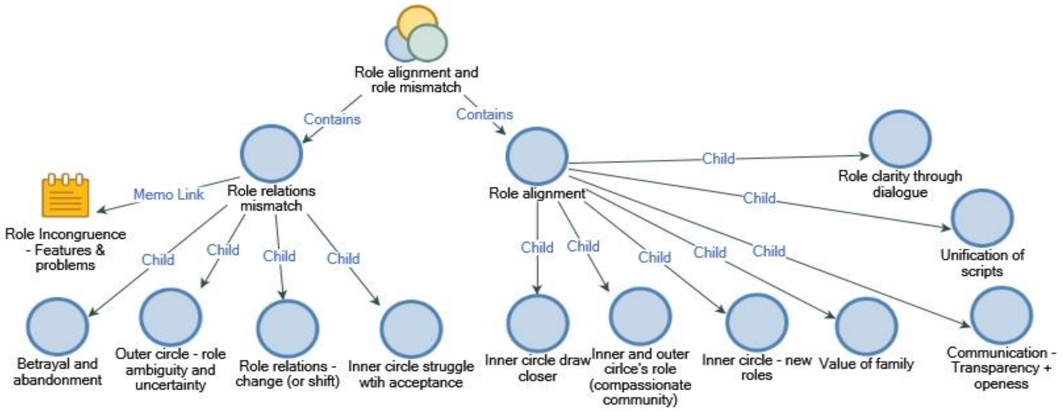


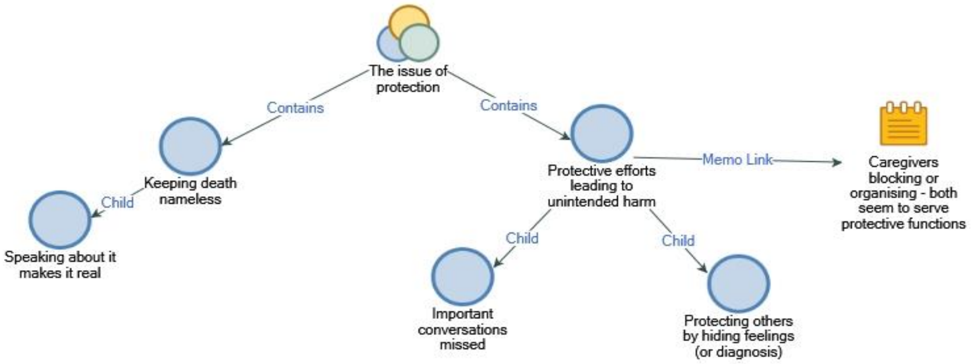


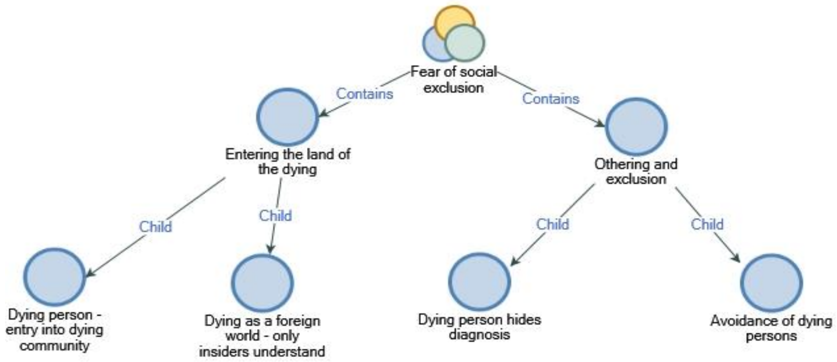


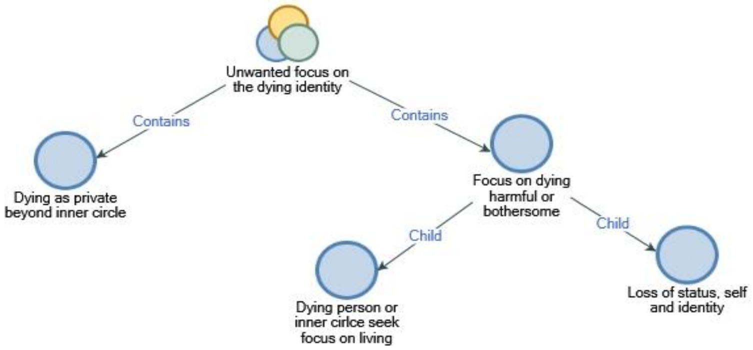
APPENDIX SEVEN: CONCEPTUAL CODE MAPS (CHAPTER FIVE)

Chapter Five – Alignment and mismatch in role relations at end-of-life



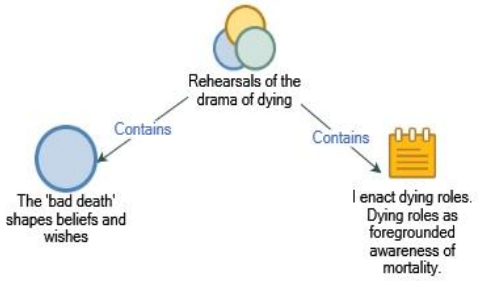


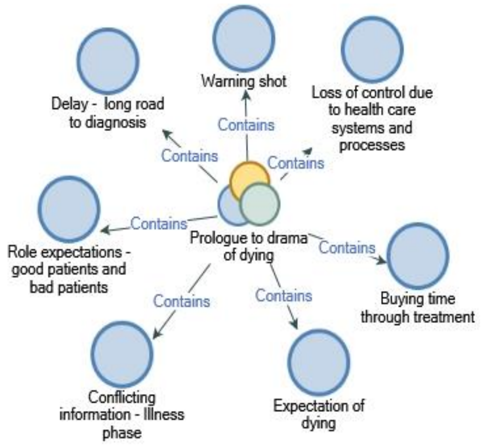


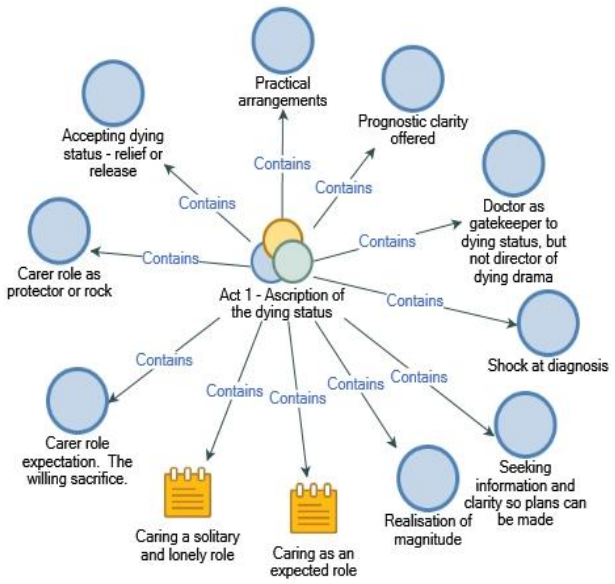


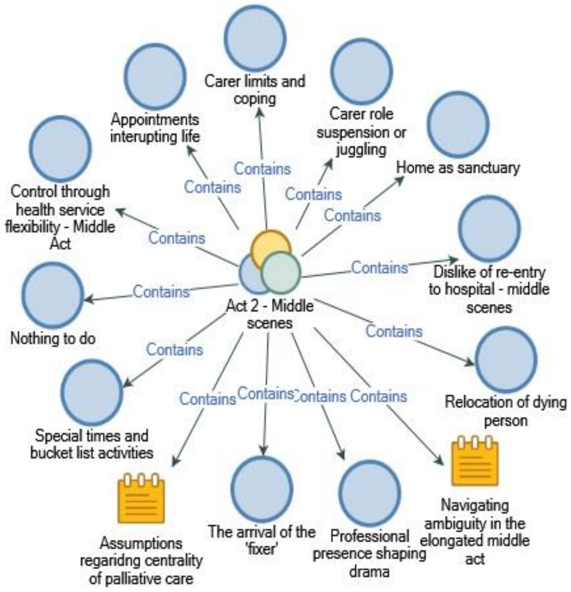
APPENDIX EIGHT: CONCEPTUAL CODE MAPS (CHAPTER SIX)

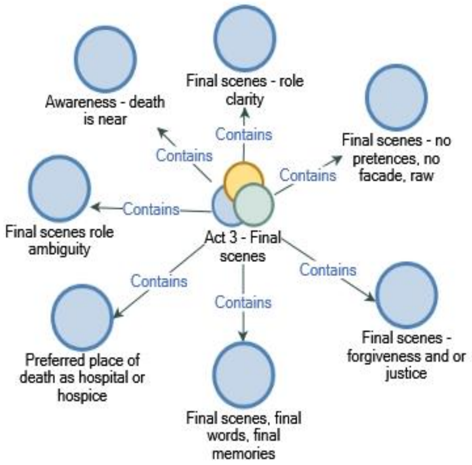
Chapter Six – A dramaturgical analysis of dying roles

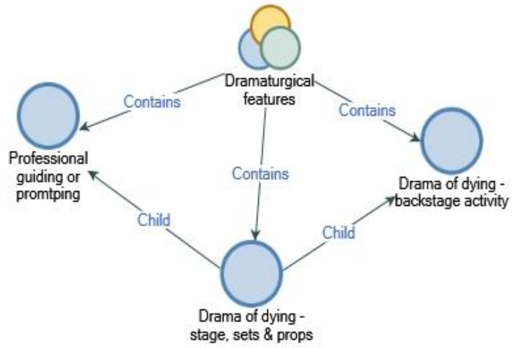












APPENDIX NINE:

INFORMED CONSENT FORM

This administrative form
has been removed

APPENDIX 10: COREQ CHECKLIST

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	88,117
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	i
Occupation	3	What was their occupation at the time of the study?	2
Gender	4	Was the researcher male or female?	i
Experience and training	5	What experience or training did the researcher have?	i
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	60
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	60
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	2
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7-11
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	56
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	57
Sample size	12	How many participants were in the study?	60
Non-participation	13	How many people refused to participate or dropped out? Reasons?	58
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	64
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	64
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	60-62
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	63
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	63
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	65
Field notes	20	Were field notes made during and/or after the inter view or focus group?	65
Duration	21	What was the duration of the inter views or focus group?	65
Data saturation	22	Was data saturation discussed?	59
Transcripts returned	23	Were transcripts returned to participants for comment and/or	72

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	66
Description of the coding tree	25	Did authors provide a description of the coding tree?	253
Derivation of themes	26	Were themes identified in advance or derived from the data?	67-69
Software	27	What software, if applicable, was used to manage the data?	67
Participant checking	28	Did participants provide feedback on the findings?	72
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	79-174
Data and findings consistent	30	Was there consistency between the data presented and the findings?	79-174
Clarity of major themes	31	Were major themes clearly presented in the findings?	91, 119
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	79-174

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357