Renegade Stories: A Study of deathworkers using social approaches to dying, death and loss in Australia.

Thesis - October 2018

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Some of the authors of this publication are also working on these related projects:

Caring at End of Life View project
Renegade Stories:
A study of deathworkers using social approaches to dying, death and loss in Australia.

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Doctor of Philosophy (Social Science)

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2018
Dedication

For Abbey & Kate.
Don’t be afraid
to fall out
of the boat
while
you
are
rocking it.
Acknowledgements

This research would not have been possible without the people who came forward to be interviewed. I want to thank you for your contribution. You shared deeply and freely, and trusted me with personal and professional experiences. Your stories have influenced my thinking and challenged my own practices as a deathworker.

I am incredibly grateful to Sid Hammel our ‘family historian’ for sharing his research, stories and memories of our family. I hope Gertrude, May and Vera are proud. I certainly think they would approve.

I’d like to thank my supervisors Debbie Horsfall and Rosemary Leonard. There were many twists and turns along the way. I am extremely grateful for your advice, mentoring and feedback. It stretched and challenged me at every stage. Many thanks for your patience and for holding the space long enough for me to get there.

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To all the crew at The Parade in Hazelbrook, for excellent coffee and encouragement.

To my family, especially John, Abbey and Kate for being so patient during my candidature and the many hours of writing.

I wrote this thesis while living and working primarily on the land of the traditional lands of the Darug and Gundungurra peoples. I would like to acknowledge that this land was, is and always will be Aboriginal land.
Statement of Authentication

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

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## Abbreviations

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<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>ACP</td>
<td>Advance Care Planning</td>
</tr>
<tr>
<td>ACD</td>
<td>Advance Care Directive</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>ACSQHC</td>
<td>Australian Commission on Safety and Quality in Health Care</td>
</tr>
<tr>
<td>CDW</td>
<td>Community deathworker</td>
</tr>
<tr>
<td>GP</td>
<td>General practitioner</td>
</tr>
<tr>
<td>IDW</td>
<td>Institutional deathworker</td>
</tr>
<tr>
<td>PCA</td>
<td>Palliative Care Australia</td>
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<tr>
<td>PCOC</td>
<td>Palliative Care Outcomes Collaboration</td>
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A Beginning...

On the first day of my PhD candidature I received a phone call from my friend Jude. She had just spoken with her local palliative care team. They had requested a meeting with her carers before they made their next home visit and Jude wanted to know if I could attend. She wanted someone who was ‘in the know’ and who would help her and her family access the support they might need in order for her to die at home.

“Of course, I will. What do you need me to do?”, I replied.

“Be my voice.”

“Ok, how?”

“Well you know I want to die at home.”

“Yes…”

“Well, I don’t think they think I can.”

“Palliative care?”, I asked.

“Yes. They want me to have a hospital bed…”

“Uh huh.”

“…and a commode chair and…”

“OK…”

“…and to stop walking to the beach,” Jude said.

No one who knew Jude would ask her to stop her daily walk. It meant so much to her. Jude had tumours in her lungs that were growing towards her windpipe. It meant that her every breath was laboured. She knew eventually the cancer would restrain her, but she felt she “wasn’t quite that bad yet”.
“They don’t want me to fall over and get sent to hospital by ambulance. I may never get out again.”

“Ok. I’ll be there,” I replied.

I walked into the hospital, part friend, part advocate and supporter to Jude’s family. There were four people who loved Jude in the clinic room that day. Her brother, two lifelong friends and myself. As I listened to the conversation that morning, I grew increasingly frustrated and angry.

When Jude’s brother, talked about his sadness and exhaustion, the response from the team felt overly clinical and efficient.

“Don’t worry, Jude can come in for some respite, let us look after her for a while,” said one of the palliative care team.

“Jude wants to die at home though, isn’t that why we are all here, to find a way to keep Jude at home?!’ Jude’s brother responded.

The conversation continued and I was shocked. At one stage the palliative care doctor said to Jude’s brother,

“It's ok, if she comes into hospital and deteriorates, she won’t be able to go home again and most people don’t mind by that stage. They are too unwell.”

Jude’s so-called ‘strong will’ seemed up for discussion too. She was labeled non-compliant; still smoking, not taking her medications as directed, not accepting the hospital bed, not wanting a commode chair, and still walking to the beach.

I knew the palliative care team meant well. They were clearly kind and well meaning. I couldn't stop the phrase 'benign paternalism' repeating in my mind. The advice from the palliative care team was very persuasive and they
were communicating two key things: we are the experts and we do not think Jude can die at home.

I left confused and worried about how it would be possible for Jude to die at home if the palliative care team did not think it possible.

“How did it go?” Jude asked when I arrived at her home.

“I’m not sure to be honest,” I replied.

I remember we sat in silence for a few moments while Jude slowly finished her cigarette.

“I think you are right – they don’t know you very well. I feel worried they are trying to ‘get you into’ hospital because you won’t follow their advice,” I said.

“OK”, she said, “so now what?”

“Let’s make a plan.”

We spent the next hour talking deeply about what Jude wanted. What was important to her now and what she needed from the palliative care team.

The plan was simple. Say yes to everything including that “fucking bed and commode chair”. Then privately Jude would do whatever she wanted.

The last time I saw Jude she was sitting at the dining room table, rolling a cigarette and drinking a whiskey. 10 hours later she died.

At home.

Jude was fully aware she was dying. She wasn’t avoidant or in denial. She didn’t need rescuing; she needed the palliative care team to meet her equally, on her on own terms and to share their expertise in managing breathlessness
and pain. I could not shake the feeling the doctors and nurses had overlooked how meaningful family, walks to the beach, and the arts were to her.

I was left wondering how this kind of behaviour serves anyone receiving end-of-life care? Have our health services forgotten their place?

I am extremely grateful to Jude. She taught me a lot about dying and how to face dying. She also wanted me to share her story, which I do here in the hope that I might do her legacy justice. I did not know that day how my thesis would unfold but I have returned to Jude’s story many times over the past six years. It has become a touchstone of sorts for this research and my own clinical practice in palliative care.
Chapter One: An Introduction to Renegade Stories

This chapter provides an overview of the key questions and concepts of this research, setting the scene for the subsequent chapters. First I introduce the inspiration, aim and research questions, my theoretical model and the scope of this qualitative study. To provide a cultural context for this research, I introduce the death system concept as a way to examine the social structures and processes that influence the current way of death, dying and loss in Australia.

Introduction

There are all sorts of people who are important. Politicians are important to set the overall framework. There’s users, consumers are important because they tell the story from their point of view, innovators are important because they come from the outside, but absolutely critical are people who are on the edge of the system, inside and outside so there are people a bit like renegades. They are people who can talk to the system as well as having credibility with the system, be critical of it. So, people who are allies inside the system, but can see how it needs to change... you will need to challenge conventional wisdom, vested interests, the status quo.

Unless you are prepared to do that in really tangible ways you won’t get change.

One way to understand the nature of social change is to ask the people and organisations currently engaged in change work. Renegade Stories is a qualitative and critical examination of the lived experiences of 12 deathworkers in Australia who, despite the dominant biomedical paradigm, are guided by a social approach to dying, death and loss. In examining their lived experiences, this thesis embodies the change that is occurring about how people experience death. It does this by asking: What are the stories and experiences of deathworkers who have a social approach to death, dying and loss? How is this deathwork shaped and influenced? And, How are they making a difference?

Renegades, like many other activists in the end-of-life and deathcare space are struggling to find ways to have their perspective and experiences heard above the dominant approach toward death and dying. This thesis, in a small way, provides a space for their experiences to be heard.

In Australia, our population is ageing, our morbidity rates are low, and our health and aged care services are under pressure to modernise. This is a very particular and urgent time to critically examine the care and support available to people who are dying, and their families. It is a period of revival and innovation on the one hand (Swerissen & Ducket, 2014; Walter, 1994) and a space that continues to be dominated by a conservative and largely professionalised death system on the other. Despite the best efforts of the reformers and activists you will meet in this research, end-of-life care and deathcare has not fundamentally changed since the last critical turn, the modern hospice movement that began in the late 1960s.
The hospice movement was a response to the increasing medicalisation of death during the first half of the twentieth century. However, over the past 50 years the once radical hospice movement has been mainstreamed and dying and death became dominated by a biomedical approach (Kellehear, 2005). In Australia, dying people are institutionalised and end-of-life is medicalised; it is now the norm to die in an institution, even though a large proportion of end-of-life care happens in private and residential homes. Likewise, the care of the dead has been professionalised. Dead bodies create fear and horror (Breithallahmi, 2012) and we call on specialised professionals to ‘handle’ them. For the first time in human history, exposure to dying people and dead bodies is avoidable in the western world, because the structures in our death system have the primary role of managing and packaging illness, dying and death. Our cultural practices have been sanitised and our societal norms are driven by institutional rules and policies, rather than by family needs, or spiritual and religious beliefs about what it means to be a human being who is dying, grieving or caring. Swerissen and Duckett, (2014) and Borgstrom (2015) note that over the past two decades the care of the dying has “generally not improved or indeed kept pace with demographic and epidemiological shifts” (p. 273; Borgstrom, 2015).

At the same time, thanks to modern palliative care, we have never been more equipped as a society to manage end-of-life symptoms and pain and to provide supportive care to people who are dying and their families. Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the
prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care (according to the WHO 1996 definition) has the goal to:

- provide relief from pain and other distressing symptoms;
- affirm life and regards dying as a normal process;
- intend neither to hasten or postpone death;
- integrate the psychological and spiritual aspects of patient care;
- offer a support system to help patients live as actively as possible until death;
- offer a support system to help the family cope during the patient’s illness and in their own bereavement;
- use a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- enhance quality of life, and may also positively influence the course of illness;
- be applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

In Australia, it is estimated that approximately 20% of the 160,000 people who die each year have access to some of the palliative care services listed above. End-of-life care, or care in the last year of life, is provided in various ways through general practice, aged care and community health
services. However, Australia’s ageing demographics have created a crisis for the sectors that provide care at the end-of-life. In less than a decade, the number of deaths in Australia will begin to overtake the number of births (ABS, 2016).

Given this, in the past decade there have been numerous position and policy papers calling for change and new innovations to enable better care and support for our ageing and dying (for example, Australian Commission on Safety and Quality in Health Care, 2013; Swerissen & Duckett, 2014), including calls for end-of-life reforms (Productivity Committee, 2017). This reform is imperative as there are not enough medical resources, hospital beds, aged care places, nurses, doctors, carers, or multidisciplinary teams to continue down the route of institutionalised care for our aged and dying. Nevertheless, the practice and delivery of end-of-life care has not radically changed, despite these demands, and significant investment from Commonwealth and State governments in educating health professionals about palliative care, and advance care planning.

Critically responding to the question of how the health system and the social structures in Australia will cope is now urgent. I have come to see these tensions as an opportunity to actively advocate for innovation and the radical redesign of end-of-life care in the Australian community. A catalyst for many of the ideas in this space were the books *Health Promoting Palliative Care* and *Compassionate Cities* by Allan Kellehear (1999, 2005), an Australian sociologist. Kellehear, using the five principles of the Ottawa Charter (WHO, 1986)—build healthy public policy, create supportive environments, strengthen community actions, develop personal skills, and reorient health services—invites palliative
care services to think beyond patient care and to engage deeply with the local community it serves. Kellehear argues that a public health approach complements the medical approach by supporting people outside the realm of service provision (Kellehear & O'Connor, 2008). It does this by providing palliative care alongside community development strategies that develop the capacity of individuals and their communities to care. The public health approach has been supported in numerous policy documents in Australia over the past decade. The Australian state of Victoria led the way globally with the development of health promoting palliative care policy and funding for statewide demonstration projects between 2003 and 2009 (Salau, Rumbold, & Young, 2007). The approach has not been systematically embraced in practice by mainstream palliative care services in Australia, and over the past decade these programs have been defunded, and eventually were ceased altogether about five years ago.

**Why this research? Why now?**

Over the past decade there has been a growing dissatisfaction about the professionalisation of end-of-life and deathcare in Australia. I have observed my colleagues become increasingly frustrated about the misconceptions around palliative care and the ever-growing symptom checklists and measures aimed at improving end-of-life care. This research was influenced by these conversations and by the observation that a rising number of social enterprises and businesses were innovating to respond to this dissatisfaction. Outside of the mainstream health system, there were markers of social change too, such as the growing media interest in social phenomenon such as death cafés and new
social practices such as death midwifery/end-of-life doulas. These changes all
signalled the emergence of a growing dissatisfaction with the current way of
doing death; I noticed too that friends and colleagues who worked outside of
end-of-life care were also willing to step forward and openly declare they
wanted to do death differently.

In 2009, I decided to ‘step up’ and do something too. I was inspired to
action, following a life-changing visit to the Neighbourhood Network Programs
(NNP) in Kerala India (Kumar & Numpeli, 2005). I had the opportunity to meet
and work alongside the young people volunteering in palliative care programs
across the city. Driving in the palliative care home nursing vans, we wove our
way through coconut tree lined dusty villages and down backroads to schools
and medical clinics to meet young people of all ages volunteering to support
palliative care. I still find that using the term ‘volunteers’ to describe and label
the work of these young people unsettling (Johansson, Leonard, & Noonan,
2009). This is because the only model of palliative care volunteering that I had
participated in was the traditional model of palliative care volunteering here in
Australia. In Kerala, the volunteers were well trained in palliative care and
communication skills, but it seemed to me they had a more autonomous role. In
fact, they were encouraged to share and develop new ideas that would both
support dying people and engage or ‘sensitise’ the community (Kumar &
Numpeli, 2005). Over the past six years social entrepreneurship has grown
greatly in India and the palliative care volunteers developed a number of social
enterprises to support the wellbeing of palliative care patients and their
families, and to raise funds for the service. The ‘Footsteps’ program was
developed by volunteers and it enabled people with chronic and life threatening illnesses to learn new skills, such as making jewellery, pens, books, and bags. Students would then sell these products at markets and other events, enabling people who would otherwise have no income to send their children to school and feed their families.

I wrote in my diary at the time:

The life force in India feels so strong, and we talked about my tendency to want to go hard and direct into the issue of death and dying. I want to explore it and pull it apart and try and understand attitudes and experiences. This I have discovered is completely incompatible with the Indian experience... and well, really, the experience in most places.

I have a very fantastic and strong memory of an afternoon in Calicut with the volunteer students. I was sitting on the ground outside The Institute of Palliative Medicine and in between the motorbikes, the rickshaws and cars driving to and fro, we were discussing their experiences in palliative care. They spoke about their bond to the patients, their friendships with their ‘brothers and sisters’ the other volunteers from colleges in the surrounding areas and about social responsibility, caring for the people in the society who need it most. We talked about football, cricket, food, family, their hopes for the future, their studies and their future work. We talked least of all about death or about dying, at least not explicitly. There was no fear or lack of acknowledgement of death or of Palliative Care, but instead a strong connection to living no matter what your stage of life!

When I returned to Kerala in 2010 I again met with many student leaders in palliative care aged 18 to 22. They were organising an event for a 1000 students. I cannot imagine what it would involve bringing that many young people together. The gathering in India would be the first time in the
world this many people have come together to learn about palliative care and how they can contribute in their local communities as volunteers! I was fortunate enough to sit in on the group and was amazed at their closeness and respect for each other’s opinions. It led me to thinking about how were they able to successfully bring together the palliative care community? And what could the Australian palliative care community’s learn from these students and the volunteer programs in Kerala?

I asked if they would share their stories about volunteering, attempting to understand more deeply what the work means to them. There were three ideas from their stories that have remained with me even today. First, the idea that young people are ‘not useless, they are used-less’. A young woman named Rashmi reminded me that even in India there is a view that young people do not have the capacity to contribute to social issues such as end-of-life care. As noted in the dairy entry on the previous page, my curiosity about death and dying was not shared by the student volunteers

Second, is ‘self-actualisation’. I had never heard palliative care volunteers of any age talk about palliative care volunteering in this way before. I asked Saif Mohammed, the coordinator of the Neighbourhood Networks Program about this and to demonstrate the meaning he told me his story of becoming a palliative care volunteer, a pharmacist and then a leader in the network working at the Institute of Palliative Medicine. Third, a sense of intergenerational contribution. Ayaz, another volunteer viewed his experience as something that would not end when he finished his college degree. I recall
him sharing with me “I’ll give to community, and when I marry and settle down into a job, I can donate money back to palliative care”.

There are now a number of articles that feature the NNP in India (Kumar & Numpeli, 2005; Johansson, Leonard & Noonan, 2012; Paleri & Numpeli, 2005; Stjernward, 2007; The Economist Intelligence Unit, 2010). Over the past decade the volunteer program has grown to over 30,000 people all over Kerala. The grassroots work continues to be an inspiration to many public health practitioners.

It was on my return to Australia in early 2010, that I cofounded The GroundSwell Project, a not-for-profit organisation, with Dr Peta Murray, a playwright and producer. When we began The GroundSwell Project our goals were to use a health promotion approach to create cultural change about death, dying, and loss in Australia. We wanted to find and test new and more creative ways to engage with community members. This new organisation was like many start-ups in the social enterprise space: it was entrepreneurial, resourceful and responsive to requests from other organisations. Our first project was based on the work of The St Christopher’s Hospice schools project (Hartley, 2011, 2012). We facilitated a 6 month project with 20 young people (15 to 16-year-old year 11 drama students) and people living with Motor Neurone Disease. This school-based project demonstrated the benefits of using the existing creative arts curriculum as a doorway to meaningful engagement with young people about death and dying. In 2011, we wrote:

Our drama project is in its second year, and, informed by a public health approach to death, dying, and bereavement (see Allan Kellehear’s
book *Compassionate Cities*, it epitomises The GroundSwell Project’s belief that young people—when given the opportunity—can and will contribute significantly to community conversations about big ‘life and death’ topics such as transplant and organ donation issues (last year the topic was Motor Neurone Disease).

These young people are, after all, our future carers, healthcare providers and policy makers! Why wait until children are ‘older’ to talk about death when it’s part of our everyday lives? (Noonan & Murray, 2011)

Throughout the project, we observed the possibilities in bringing together young people with people with a lived experience for the purposes of creating theatre for their communities, and the project, to build individuals’ capacity. We, and the students and participants, felt personally transformed by the learning experience too. I remember developing a deep appreciation for experiential learning. Over the five years that we ran the school drama project, each year we received similar feedback. Students, and in some cases the families and friends of students who participated, reported they felt more equipped to have difficult conversations in their daily lives about death and loss.

The St Christopher’s arts program pioneered working with young people in the palliative care space (Hartley, 2007, 2011, 2012, 2016). The program used theatre, storytelling, multi-media, songwriting, visual arts, and fashion design programs to enable young people and terminally ill people to learn about each other’s lives. The arts are an incredible medium for both talking about death and exploring the many complexities and layers associated with the topic of death.
This first project helped The GroundSwell Project build a template for the development of other programs and experiences. We have since helped to facilitate over 60 programs in and with communities all over Australia. We used this learning to develop a national film festival with the Organ and Tissue Donation Authority in Australia. This program ran for three years, and resulted in over 100 short films made for the purpose of encouraging other young people to learn more about the organ and tissue donation process. As part of the project we evaluated the impact for the filmmakers and for their family and personal communities. It helped us to understand more about the role that art-making creativity has in health education. Over 80% of young people had increased their knowledge and had talked to their families about the donation wishes.

Throughout human history storytelling has been a way to share information and history. It made sense to me that sharing stories about death and loss would also be a way for people to pass on their learning to other people and in both the theatre and organ donation projects the intergenerational storytelling was effective. As a researcher I had experienced this too as part of the Caring at End-of-life research projects 2009 to 2015. End-of-life carers, their friends and families shared stories about the acts of caring they had participated in while supporting someone with a terminal illness at home.

I was grateful to work with the Caring at End-of-Life Research Team at Western Sydney University. This team were supportive and encouraging of the work we were doing at The GroundSwell Project and together we delivered a
death literacy conference in 2014 that brought together many people working for change in the end-of-life sector. My understanding of carers and caring networks was challenged and transformed by listening to the stories of end-of-life carers and their networks. They educated me about the act of caring and it struck me how they did not use the passive language used in the research literature. The end-of-life carers that I met were actively participating in creating the conditions that would enable family members to die at home (Horsfall, Yardley, Leonard, Noonan & Rosenberg, 2015). Carers were not passively waiting for health professionals to tell them what to do or how to care; instead, they were actively navigating the act of caregiving and the health system. They were also making deliberate decisions about building their support networks.

During this period, the Caring at End-of-Life Research Team coined the phrase ‘death literacy’ to talk about the transformational learning experience associated with end-of-life caring (Noonan, Horsfall, Leonard & Rosenberg, 2016). When we first began communicating our research findings in 2012 (Horsfall, Noonan & Leonard, 2012), the concept of ‘death literacy’ was a unique offering to the end-of-life sector. The research identified and articulated the tension health professionals experienced when thinking about how to best contribute to the care networks of people who were being cared for at home (Rosenberg, Horsfall, Leonard & Noonan, 2017). There was evidence reflecting the experience of my friend Jude, that the behavior of health professionals was unhelpful and unsupportive in a home care situation. As a health professional
and a member of a palliative care team, I felt extremely conflicted by these findings and by comments made by our research participants like this:

Well I’m just thinking of community development. I’ve done quite a bit of community development as well. There are whole theories around community development. How do you mobilise community? How do you get them involved – when somebody’s dying, how do we work together, how do we do it? Yes. How do we do it, how do we make it happen? (health provider, focus group participant, in Horsfall, Leonard, Noonan & Rosenberg, 2013, p. 335).

I recognised there were more people in the health sector who were also asking these questions. What would they say about their work in the health system? Were they challenged and conflicted like I was?

As a result of this research and learning, The GroundSwell Project also started using the term ‘death literacy’, and in 2013 we ran the first annual Dying to Know Day promoting individual and community action to build death literacy. This was a grassroots campaign with no core funding that is now in its 6th year.

As part of my work at The GroundSwell Project I began to meet other like-minded and creative individuals and organisations. Some were new, some were more established but we were all trying to work more creatively with and in local communities. The GroundSwell Project started to talk about our work and this provided us with a platform for invitations to collaborate and create new work with other arts and creative organisations. We were aware that our presence was disruptive, but I believe because we were not providing direct services to people who were dying, The GroundSwell Project was largely
unknown and/or unnoticed by the palliative care sector. At the early stages of The GroundSwell Project palliative care services had a very conservative approach to community engagement and death education. In contrast, The GroundSwell Project used an action-learning model and we applied this to experiment with creative death education, digital media and social media. We were now engaging with people who were working across a variety of sectors and creative spaces, such as visual artists, filmmakers and creative researchers.

Finally, I began to wonder about the role and function of deathworkers in our current death system. These are the people who care for the dying, move dead bodies, conduct rituals after death, organise funerals, dig graves, support grievers, and educate the community. These workers now do what family members, clergy and neighbours once did for each other, and their professional or expert roles have an important mediating role in modern society (Walter, 2007a). If we were going to encourage a greater uptake of social approaches in the end-of-life and deathcare sector, I also wondered what role might these new deathworkers have in the system?

**Renegades.**
The word renegade is often used to describe “a rebel, an outcast” (*The Australian Oxford Dictionary*, 1997). However, the idea of a ‘renegade’ was inspired by a comment from social innovator Charles Leadbeater at the Dying for Change forum held in Sydney in 2011. The Dying for Change report critically reviewed end-of-life care in the UK and Leadbeater and Garber (2009) concluded that to meet the demands of end-of-life care in the future, palliative care services and end-of-life practices must be radically redesigned. They take
the view that the innovators best positioned to create this social change are the ‘renegades’. These change-makers were the ‘workers’ who have credibility in both the formal and informal end-of-life care sector. They were people who had an ability to have ‘one foot in each camp’ (The GroundSwell Project, 2011). This, in his opinion, enables effective communication to influence and enable social change.

This idea of ‘the renegade’ caught my attention for a number of reasons. I was curious about the ‘renegades’ in the Australian death system. Where are they? What were they doing? Who are they and what kind of social change work, if any, are they engaged in? Working as a psychologist in the health system I’d experienced first-hand how difficult it was to be a change-maker and innovator. Certain aspects of the health system, in my experience, seemed extremely resistant to change and the increasing number of policies and procedures seemed to work to maintain, rather than challenge the status quo. Changing clinical practices in the health system, when it does occur, is most often slow and tedious with the time between clinical research and the implementation of new health interventions often taking as long as 17 years (Morris, Wooding, & Grant, 2011).

In 2007, I began working for a social enterprise with a social entrepreneur. I met people who were creating new organisations and businesses with the dual goals of sustainable business practices and social change. Here I experienced both a furious pace of change and a new way of thinking about how change occurs. Change happened quickly, it happened often and it happened in a constant cycle of planning-action-reflection (Fenwick,
2003; Revans, 1983). The action-learning model was both chaotic and exhilarating and it caused me to reflect deeply on change in the health system and end-of-life care in the community.

The idea that a change-maker or ‘renegade’ can work to develop credibility and shared language helped explain the change-makers I had seen in action. Many of my colleagues were working outside of the health system as deathworkers and we often discussed the role of informal and formal caregivers in the death system. As a friend, family member and community deathworker outside of the formal health system, I had also experienced negativity about change efforts in the deathcare sector and on occasion a reluctance to believe or accept that deathwork exists outside the healthcare system. When my colleagues and I discussed our frustrations about ‘changing the system’, we often ended up sharing the strategies we employed to navigate these challenges and blocks. Then, part way through my PhD I changed employment and returned to the public health system as a clinical psychologist in a palliative care ward. This transported me from community deathworker and arts practitioner to a member of a multidisciplinary inpatient team in one of the largest acute hospitals in Australia.

The transition was significant both personally and professionally. In my personal community, no topic felt like it was off limits. At The GroundSwell Project I was used to talking about all aspects of ageing, dying, death and grief, from the physical, spiritual and emotional to the care of the dead body. In contrast, in the hospital and within the multidisciplinary team, everyone had their specialised job to do and mine, as the clinical psychologist, was to focus on
the psychosocial concerns of families and patients. It took me at least 6 months to adapt to the culture. I focused on trying to figure out my place and fit into the team. I experienced the demarcation of deathwork as restrictive and unnatural but I loved learning from my colleagues and being part of a team again. I was also very happy to be working in palliative care, however I could not shake my concerns about the role psychology has had in pathologising grief and dying.

Although my job title is ‘clinical psychologist’ my values align with community or critical psychology (Prilleltensky, 2001). As such, my clinical practice is informed by social justice and family systems practices. I work with a deep commitment to collaborative practices both within my team and when I am working with people who are dying and their families. Over time I have been able to carve out a unique role for myself, one that focuses on an asset-based approach to well-being and resilience (Breen & O’Connor, 2009). This means I can support and work with staff and develop programs that support the palliative care service as a whole. I see families, friends and communities of people as required. I work in other wards in the hospital, I’ve helped nurses turn patients and I’ve made many cups of tea. I found a way to do the work in my own unique way through and with my relationships with the other staff.

I have been able to apply an action-learning approach to build relationships and connect with people. I know that my practices do not always conform with the expectations a hospital has of a clinical psychologist and that my behaviours can be disruptive for the health system. I feel like I am constantly adapting and negotiating this role and my practice with my
colleagues. This also makes me one of the change-makers, and the renegades that are the topic of this thesis.

**The ‘new’ deathworkers.**
There are new opportunities evolving every week in the death system for new forms of deathworkers. Emerging groups, such as end-of-life doulas, have for example, developed from a need to educate and reclaim end-of-life care and deathcare as a family and community experience. In western societies, many people are no longer looking to our religious leaders or to religion to guide our end-of-life choices, or indeed to relieve fear of death (Walter, 1994). We are increasingly turning to health professionals and other experts. In the field of death and dying our ‘experts’ are particular people from particular professional groups, however lay experts are also increasingly contributing to the changing discourse (Ashton, 2014). I will discuss the increasing role of ‘lay experts’ in greater detail in Chapter Two.

There is an emerging group of death professionals with a public profile who are popularising the topic of death. Dr. Atul Gawande (2014), an American surgeon, recently wrote a best-selling book that included a discussion on the death of his father. The book reminds us that medicine does not have the cure for death and Atul advocates for health literacy and encourages the reader to make individual choices to achieve a good death. Australian oncologist Dr. Ranjana Srиваstra is another best-selling author with a regular column in *The Age* newspaper. Intensive care specialists Dr. Ken Hillman and Dr. Peter Saul here in Australia, also call for medicine to intervene less. Their philosophy again focuses on individual choice, but also acknowledges that in order to have choice
individuals must be more aware of the limits of medicine (Hillman, 2017). Their work aims to bring greater awareness about ‘futile treatment’ and educate the public, particularly about the role of intensive care (Lewis, Cardonia-Morell, Ong, Trankle & Hillman, 2016). Intensive care units (ICU) and acute health crisis are poorly understood by the general public; however, the very existence of ICUs means that people who are dying naturally end up in the unit due to a lack of acknowledgement of death. Hillman and Saul regularly question the ethics of transferring a frail older person from a nursing home to a hospital emergency department, and then to an ICU where, after a prolonged dying process, they eventually die under the harsh lights of a hospital, connected to machines and surrounded by strangers.

Funeral directors are also part of the emerging group of death professionals who are demystifying death. Caitlin Doughty, a Los Angeles-based funeral director who advocates for family-based funeral practices, has also written two best-selling books (2015, 2017) and has a large international following. Doughty is a proponent of the ‘death acceptance’ or ‘death positivity’ movement. Indeed, all of these publicly recognised death experts, and others, are in one way or another promoting death acceptance and challenging the idea that it is taboo to discuss death and dying.

**Promoting death acceptance.**

The classic article *The pornography of death* (Gorer, 1955) sparked a deeper analysis of the social norms related to talking about death (Aries, 1974). Gorer’s central argument was to warn that it was unnatural and indeed dangerous to restrict open conversations about death. Despite criticisms of Gorer’s Freudian
and moralistic tone, the idea that it was ‘wrong’ not to discuss death and dying was embraced by the palliative care and the death acceptance/awareness movement (Zimmerman & Rodin, 2004). It was not until the 1970s however that the term ‘death acceptance’ was coined by Feifel & Branscomb (1973) and Kastenbaum (1977). This led to what is now considered a ‘movement’ in the United States of America (USA) resulting in college classes and death education (Corr, 2015). The movement has been particularly concerned with how death is discussed in the community, communication between health professionals and patients, and more recently, end-of-life planning (Kastenbaum, 2007b; Walter, 1994). Although the term acceptance has come to mean many things, Zimmerman (2012) found three dominant themes when he examined the role of acceptance as a discourse in palliative care. These were: 1) acceptance as integral to the practice of palliative care, 2) positive characteristics of the accepting patient, and 3) the acceptance of natural death.

Health and medical professionals began to view acceptance as an integral part of palliative care, so important that it was considered a goal of end-of-life care. This finding was what Zimmerman (2012) called “unifying aspect of the philosophy of palliative care for health care workers” (p. 221). Kubler-Ross’s (1969) stages of grief also strongly influenced the focus on acceptance. So much so, it has reinforced the idea that awareness brings acceptance, and that then makes it possible to design psychological interventions to promote acceptance. In contrast, Zimmerman and Rodin (2004) argue that accessing good end-of-life care need not be dependent on
whether or not a patient or indeed the treating doctor is able to talk freely about death, they assert:

The denial of death thesis may have served a purpose at the beginning of the hospice and palliative care movements, where one aim was to advocate for dying people and give them a voice. However, the continued emphasis on the presumed denial of death in modern society is not only dated but may also exclude from palliative care a large population of patients who need and deserve such services. Many terminally ill patients are not ready to be labelled as ‘dying’, but all wish to stop suffering (p. 127).

However, the concepts ‘denial’ and ‘acceptance’ are so deeply embedded within the vernacular of palliative care that they are rarely challenged or examined. This highlights the tension between a traditional view that dying and grieving experiences can be orchestrated and managed in such a way as to render the resulting emotional outcome as ‘normal’. The ‘acceptance’ hypothesis therefore can still be considered an idea that privileges the biomedical approach to death, dying and loss. Contemporary grief theories however acknowledge a diverse range of grief experiences including the length of grief and the number of people who need specialist bereavement therapy following a death (Rumbold & Auon, 2014).

**In pursuit of a good death.**

The majority of deaths in Australia are institutional, medicalised and prolonged (Palliative Care Australia, 2009) despite this being inconsistent with the dominant view of a ‘good death’. In western societies, the notion of a good death has evolved as death has changed from a public activity that was embedded in
community to an increasingly private and institutional affair (Kellehear, 2007).

The good death ideal has been variously described as dying without symptoms, having awareness and preparation for death, a good relationship with healthcare providers and a sense of completion of life (Steinhauser, Clipp, McNeilly, Chrisiakis, McIntyre and Tulsky., 2000). A recent definition used by The Grattan Institute, states that a good death “gives people dignity, choice and support to address their physical, personal, social and spiritual needs” (Swerissen & Duckett, 2014, p. 2). Swerissen and Duckett (2014) also argue that people are not dying as they would wish in Australia and propose three reforms needed for a good death:

First, we need more public discussion about the limits of health care as death approaches, and what we want for the end-of-life. Second, we need to plan better to ensure that our preferences for the end-of-life are met. Third, services for those dying of chronic illness need to focus less on institutional care and more on people’s wishes to die at home and in homelike settings (p. 2).

These suggested reforms highlight the central role of individualism, autonomy and personal choice in our modern discourse about managing dying and death (Hart, Sainsbury, & Short, 1998; Walter, 1994). They are also consistent with the view that a good death has come to be seen as a “well managed death” (Howard, 2007; Kellehear, 2005). Or, as Somerville (2001) notes, in western cultures the construction of death is related to anxiety and fear; a ‘good death’ then becomes closely linked to the need to control death.

The modern view of a good death is only loosely connected to the original Judeo-Christian meaning of the concept. Suffering, for example, may
have been viewed as deeply meaningful in the past but the experience of pain and suffering in modern medicalised societies is deeply frowned upon (Illich, 1976). The tension between having a good death in the eyes of God and a good death in the eyes of an individual dying person is however most constrained when an individual requests death, or euthanasia. The good death discourse, though dominant in palliative care, struggles with the concept of patient autonomy when a patient requests death. Hart, Sainsbury and Short (1998) state that “these challenges cannot be palliated by better and more death technologies and ideological forms of social control. It is imperative that these struggles for change be given full voice, and that vested interests and professional power be made explicit” (p. 75).

The following sections, indeed this thesis, aims to give full voice to the challenges and struggles encountered by people involved firsthand in the death system and to make vested interests and issues around power more explicit.

**My personal/professional/researcher position/ing.**

I am a white, middle class woman, a mother, a daughter/granddaughter, a partner, a researcher and a health professional working in end-of-life care. I am a critical, feminist, social scientist interested in exploring power and knowledge and critiquing practice in the death system in Australia where the majority of end-of-life research has a biomedical ideology and a positivist position. I am contributing to social change in the death system and to the practice of disruptive innovation.

This thesis is a product of my lived experiences as a woman, daughter/granddaughter, deathworker, and as a clinical psychologist working in
palliative care, and as a researcher whose thinking and research approach has
been influenced by critical social scientists such as Fay (1996), and Freire
(1970). As an activist, I wanted to conduct research while paying attention to
my own power as a researcher (Leonard, 2003). As such, I use research
methods that enable participants to share their stories and lived experiences
via in-depth interviews. I also want to acknowledge how the stories in this
research have influenced my own practice in a way I did not expect when I
began. I have been challenged by how difficult it is for deathworkers to be
agents for change and I have been compelled to examine my own strategies. I
wondered what it was like for deathworkers to practice within a medicalised
system and to hold a set of beliefs not aligned with the dominant paradigm, and
now I am one of these deathworkers.

Additionally, this research was influenced by my own discomfort within
my role and by the body of literature that critiques the biomedical approach to
dying, death and loss; in particular, Tony Walter’s critical analysis of the
modern approach to death, *The Revival of Death* (1994) and his recent article
with Louise Brown (2013) examining a social approach to end-of-life care. I
would argue that *The Revival of Death*, though written in 1994, continues to
hold contemporary relevance in 2018. Walter (1994) reviews the influence of
the hospice movement, the role of medicalisation and institutionalisation of
death, and the danger that individualism and medicalisation may devolve
efforts to reengage local groups of people to work together to improve end-of-
life care. Walter’s (1994) concern that change may look "less like a consumer
revolt than a more sophisticated professionalised management of the dying and
bereaved, with experts propounding knowledgeably on the stages in which people die or the desirability of certain kinds of death” (pp. 198–199) motivated, alarmed and ultimately inspired me. I will return to this, in Chapter Two when I talk about what ‘innovation’ means in the death system.

A further point that interests me about Walter (1994), and Brown and Walter (2013) is they have also looked beyond the public health palliative care approach to incorporate ideas from the fields of social innovation (such as Leadbeater & Garber, 2009) and social movement theories (resonating with Kellehear, 1999, 2015). In reviewing the medical model, Illich (1976), Foucault (1973), McNamara and Rosenwax (2007), Conrad (1979, 1992, 2005), Howarth (2007), Kastenbaum (1979, 2004), Walter (1994), Lupton (2012), and McInerney (2000) have also been influential in my thinking.

The participants.
This thesis reflects the stories and experiences of a group of 12 deathworkers in Australia in 2012-13; and while I did not exclude any group of deathworker from participating in this research, the majority of this group were Anglo Celtic women. This cultural experience thus provides a particular view and experience of the death system, which I attend to, and will unfold in the text.

The workers in this study are practicing both inside and outside the formal institutions that dominate death in this country: healthcare, aged care, and the funeral industry. Their views have been influenced by their personal experiences as much as their professional experiences and the way they construct these stories is deeply influenced by a belief: that in order to change the fundamental relationship with death we must also change our interaction
with it. This means reorienting dominant practices to enable everyday citizens to reclaim acts of caring.

The stories also reveal the tensions that exist for deathworkers who are enacting new ways of working in the death system. Until recently, critical approaches to the construction of end-of-life care and deathcare have focused primarily on palliative care and the biomedical approach. In seeking out the stories of ‘renegades’ I hoped to illuminate the social change that is currently occurring in the ways of ‘doing death’.

**Key Concepts and Terms**

Underpinning this research is my belief that dying, death and loss are essentially social experiences. As such, this research is aligned with new public health approaches to end-of-life care (Kellehear, 1999, 2005) which is underpinned by the social model of health. The social model considers health and well-being to be multidimensional concepts that cannot defined by the absence of disease alone (Australian Institute of Health and Welfare (AIHW), 2016). The new public health approach to end-of-life care is “concerned with social efforts led by a coalition of initiative from governments, their state institutions, and communities, often in partnership with health and other social care ordinations, to improve health in the face of life threatening/limiting illnesses, caregiving and bereavement” (Karapliagkou, & Kellehear, 2015 p. 5). In Chapter Two I will examine the social and biomedical models of health and how they relate to the practice.
A social approach to death, dying and loss.
In this research I use the term ‘social approaches’ to refer to public health practices such as community development and health promotion. These methods are consistent with a social model of health because they promote social solutions to the challenges associated with dying, death and loss. As such when I use the term ‘social approaches to death, dying and bereavement’ in this research, my intent is to be inclusive of a variety of social approaches in the current end-of-life sector in Australia.

It is difficult to find one definition for a ‘social approach’ to death and dying in the interdisciplinary and sociological literature on death and loss. As such, there is no ‘one’ definition of the ‘social approach’ that is accepted or used universally in the literature; it is, instead, a series of statements, values and beliefs that are often used to express key ideas.

Social approaches to death and dying are aimed at building the knowledge, capacity and resilience of the whole community in relation to death, dying, and loss (Kellehear & Young, 2011). Community initiatives and research using a social approach emphasise social justice, participation, and wellbeing (Kellehear, 1999, 2005). A social approach refers principally to a way of responding to death and loss as a significant shared life event for human beings.

The death system.
In this research I use the ‘societal death system’ as a key conceptual framework because the concept of the death system acknowledges that physical death happens to individuals who are part of a society and community. In reviewing the components of the death system and its functions it is possible to examine
how, what and why the societal response to death changes (Kastenbaum, 1979).

The death system was first discussed by Kastenbaum in the early 1970s but the concept did not gain significant popularity in the academic literature. Tables 1 and 2 outline the functions and components of the death system in Australia. According to Kastenbaum (2003), the death system is "the interpersonal, socio-physical, and symbolic network through which an individual’s relationship to mortality is mediated by society" (p. 102).

Kastenbaum (2003) writes:

The concept of the death system invites our attention to interconnections, to the subtle network of relationships and meanings through which one sphere of action influences another. We face death alone in one sense, but in another and equally valid sense, we face death as part of a society whose expectations, rules, motives, and symbols influence our individual encounters (p. 77).

In 2015 the Omega Journal of Death and Dying published a special edition focused on the legacy of Kastenbaum’s work and the development of the death system concept. This included Kastenbaum’s influential analysis that challenged the idea that death was a taboo topic in America. His analysis used the functions and components of a death system to critique the cultural response to death. Through understanding these functions and components we can more deeply analyse the role of death-related activities in the community. He argued, the death system provides a multifaceted lens for this research to examine both the function and role of deathworkers. This includes being able to develop a deeper understanding of the influence of past practice on current
practice, and provide a structure to theorise about future models of social change.

In this thesis, I develop a deeper understanding of the death system. The death system concept provides flexibility to critically examine current and emerging death practices, thus the tables include palliative care, aged care, funeral care, death midwifery, and the compassionate communities approach. While these latter two are not part of the mainstream practices of the public healthcare system where the larger part of end-of-life care is delivered they exist as marginal practices and have an important role in the death system. The role of death midwifery, for example, has not been systematically studied in Australia at all. The role, function, and training of palliative care nurses on the other hand has been extensively researched both from the perspective of service delivery and patient outcomes (e.g.: Brajtman, Higuchi, & Murray, 2009; Kristjanson, Hudson, & Oldham, 2003).

Palliative care has had such a significant role in the Australian death system over the past 30 to 40 years that it is difficult to imagine it was once a marginal practice. Palliative care has changed the way medical professionals provide care and has transformed pain management practices (Maddocks, 2000). It has also played a role in professionalising death and dying, creating a new professional group to manage the needs of dying people that did not exist just 50 years ago. Palliative care, of which palliative medicine is an essential part, functions as one of the ways that modern society cares for the dying. It is a philosophy of care adopted by modern healthcare and has become the dominant approach to end-of-life care. Although the professional response to
dying has improved healthcare, the community is now less equipped to care for their dying family members and friends. Likewise, palliative care discourse promotes individual autonomy and agency (Walter, 2012) but in practice, and as discussed earlier, it has been criticised for restraining patient choice (Kauffman, 2005).

Table 1: Components of the death system (based on Kastenbaum, 2004)

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<thead>
<tr>
<th>Components of the death system</th>
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<td>People</td>
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<td>Places</td>
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<td>Objects</td>
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<td>Symbols</td>
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As you can see from Table 1 the components of the death system according to Kastenbaum (2013) are people, places, times, objects, and symbols. There are a variety of people working with death in our societies – including health professionals, but beyond that we have florists, gravediggers, coroners, obituary writers, policy makers, clergy and policy. In Table 2 the major functions of the death system highlight the values and cultural norms that exist
in a society about death. This includes warning and predicting death, caring for the dying, disposing of the dead, social consolidation after death, making sense of death and killing. In examining the functions and components of the death system recent changes in it can be understood within a broader context of change.

Table 2: Functions of the death system (based on Kastenbaum, 2004)

<table>
<thead>
<tr>
<th>Functions of the death system</th>
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<tbody>
<tr>
<td>Warning and predicting death</td>
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<td>Government warnings – travel alerts, public health</td>
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<td>announcements about product recalls. This includes the</td>
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<td>people who work in these organisations Pathologists and</td>
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<td>people who provide tests to patients.</td>
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<td>Caring for the dying</td>
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<td>The practices in caring for the dying at home or in</td>
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<td>institutions.</td>
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<tr>
<td>Disposing of the dead</td>
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<tr>
<td>Removal of the body, rituals and methods of disposal.</td>
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<td>Social consolidation after death</td>
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<tr>
<td>When an individual dies other members of society need to</td>
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<td>adjust to this. Family, work, social settings, social</td>
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<td>media. What supports adjustment to loss. For example,</td>
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<td>counselling, retirement practices, mourning rituals,</td>
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<td>workplace and government policies about compassionate or</td>
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<td>bereavement leave. Views about the role of professional</td>
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<td>and social support are also important.</td>
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<td>Making sense of death</td>
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<td>Every society develops ways to understand and make sense of</td>
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<td>loss. For example, the funeral ritual provides a way to</td>
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<td>Killing</td>
</tr>
<tr>
<td>Every death system has norms about killing. This includes:</td>
</tr>
<tr>
<td>Capital punishment. Killing of animals (i.e. hunting,</td>
</tr>
<tr>
<td>animal euthanasia), war, sacrifice, terrorism, and natural</td>
</tr>
<tr>
<td>disaster.</td>
</tr>
</tbody>
</table>

The management of dead bodies is another significant change in the death system over the past 120 years. Law reform in Australia has provided a variety of body disposal methods. Burial, for example, was the standard practice for the first settlers in Australia and continued until the early 1900s when
cremation became available in South Australia and New South Wales in 1903 (Jalland, 2006). The past 50 years, has also seen a significant rise in cremation rates changing funeral customs and rituals. In NSW for example the rate of cremation is 65%. This is influenced by a number of factors including the rise of secularism (Howarth, 2007), the cost of burial (Laan & Moertman, 2017), and the rise of individualism (Walter, 1994). These factors and alarm about dead bodies has also had an influence on the role of the corpse in society. In contemporary Australian society, a dead body is more likely to be seen as something to be feared and as unnatural (Harper, 2010). As Lupton (2003) argues: an ideal (dying) body is a body which is “tightly contained, its boundaries stringently policed, its orifices shut, kept autonomous, private, and separate from other things and other bodies” (p. 57). Consequently, the care and disposal of the dead body has been professionalised and is now the domain of funeral directors (Harper, 2010; Larkins, 2009).

In Australia, health policies also function to enable this monopoly and it is common for hospitals and other institutions to have body-handling systems that actively discourage family members from caring for their dead directly, including transporting their dead home. The exception is where a baby and/or child dies and families are encouraged to spend time with the child after death (Chapple & Ziebland, 2010; Butler, Hall, Willets & Copnell, 2015). In this example of after deathcare, where families are actively encouraged to spend time with their baby or child, having access to the dead body is considered to be an important part of helping people to integrate and process the reality of the loss (Mowll, Lobb, & Wearing, 2016). In Australian hospitals for example, many
maternity services now provide ‘cuddle cots’ that are small portable cots that families can hire after a baby has died. These cots are fitted with a cooling plate that keeps the body of the baby from actively decomposing while in the family home. This service is not readily available for adults. Although the adult version of a cooling bed can be hired by families through a handful of family focused or holistic funeral directors and community deathworkers in Australia (Tender Funerals, 2018).

One of the functions of the death system is to care for and dispose of the dead, so this example highlights a difference in the way child and adult bodies are managed after death. When a child dies parents are actively supported to spend time with their dead child. Parents also have the opportunity to take their dead child home because this behaviour complies with society’s notion of what behaviours are expected in healthy grieving (Butler, Hall, Willets et al., 2015). Further, the very act of taking a child home can be seen as an attempt to ameliorate the unnatural act of a child’s death. In this situation, the parental rights to care for a child extend into death. Parents are considered to ‘own’ the dead body, while the movements of the adult body are more highly regulated. Legally however the dead body is not actually ‘owned’ by anyone (Larkin, 2011). Instead the next of kin is considered the legal ‘caretaker’ of the body until disposal. In this research, this complex interrelationship between the functions and components of the death system provokes deeper analysis of the role that institutions, policies and business practices can have on community death rituals and behaviours.
In western societies such as Australia, we tend to differentiate between the unprepared dead body as ‘a dangerous object’ and the prepared body as “an extension of self” (Hallam, Hockey & Howarth, 1999, p. 132–138). In Australia today, the majority of bodies are ‘prepared’ by hospital nurses (Bloomer, Endacott, O’Connor & Cross, 2013) and funeral directors. The perception that dead bodies are inherently dangerous is further reinforced by the lack of contact the majority of the population now has with death and/or dead bodies (Foltyn, 2008). Historically, in Australia it was common for the dead to be ‘laid out’ in the family home (Jalland, 2006; Larkins, 2007). Women traditionally cared for the dying and the dead body, while the men in the family and community participated in the disposal of the body. This contemporary belief that dead bodies are a disturbance to the living has reinforced the professionalisation of death rituals. This makes the notion of social change in the deathcare sector a challenging prospect. It also raises the issue of how effectively business models can influence the behaviours and attitudes of citizens.

It is however a time of complex societal change. While the death system up until now has reflected the social, cultural and political norms of a more conservative era, there are signs that components of the death system are being challenged. The following are three examples of new business innovations: 1) digital technologies with designers and artists leading the way with digital legacy, story-telling and digital wills; 2) the Urban Death Project (2018) is developing a composting method for human body disposal; and 3) Tender Funerals (2018) which is a not-for-profit funeral service supporting families to
have an active role in deathcare. Tender Funerals for example, will support families to spend time dressing and sitting with their family member. They state:

Our premises have been specifically designed to provide a comfortable, homely space for you and your community to spend as much time as you need with the deceased. You can also have a vigil at home if that would feel more comfortable. You may choose to have your loved one stay at our Port Kembla premises in our cool room until the day of the funeral.

We can transfer your loved one to our premises where our skilled staff will respectfully care for them on your behalf. Alternatively, you are able to do the washing and dressing of your loved one yourself. We can provide a staff member to assist you or allow you the space and time to manage the whole process yourselves (Tender Funerals, 2018)

Further disruption to the death system is evidenced by the recent research investigating deathcare and the funeral industry in Australia (Laan & Moerman, 2017). The study by Laan and Moerman (2017) examined the drivers of costs and prices in the Australian funeral industry, highlighting the current challenges for consumers in Australia noting that:

Since engagement with death-care and/or the funeral industry will occur for most Australians at some stage, often as a vulnerable consumer, it is a topic of social and regulatory significance (p. 37).

Laan and Moerman were critical of the lack of information made available to consumers organising funerals. Their analysis of funeral costs across Australia found that the most influential factor associated with the higher cost of a funeral was who the funeral company was owned by (Laan & Moerman, 2017). As more new possibilities and innovations are developed and
released into the marketplace, they will further disrupt established components of the death system.

In reviewing the literature on innovation and developments in the death system, I have read widely in the public health, palliative care, and the sociological and psychological response to death literature. I searched for research that was relevant to my focus on the death system and deathwork. As I have already discussed, it was Leadbeater’s idea of the ‘renegade’—those with a foot in the formal and informal death system (The GroundSwell Project, 2011) that sparked my interest. This has taken me more broadly to the social innovation and systems change literature, which I will more fully explore in the next chapter.

Despite these innovations and changes in the death system, the disruption to the status quo has been relatively minor. Home death rates in Australia do not appear to be rising, and funeral directors are conducting the majority of the 160,000 funerals that take place each year. Awareness of end-of-life care and deathcare choices is a worthy goal, ultimately however, people have very few readily accessible options beyond the mainstream services available for the majority of Australians

**The changing death system in Australia.**

The professionalisation of death has led to a gradual deskilling of modern populations from care of the dying, to preparation of the death, to burial and even to moral and social prescriptions for grieving (Kellehear, 2005, p. 99).
Though death is a physical event experienced by individuals, it is also a social and community event with a complex system of social and cultural norms and rituals. The death system then is a sociological concept that provides a useful framework for understanding the factors that influence a society's attitudes and behaviours in response to dying, death, and bereavement.

In my own family my great-grandmother Gertrude, who was born in 1881, is remembered to have always worn black. This was a common tradition for the women of Sydney in the early twentieth century (Jalland, 2005). Gertrude was married and had the first of her 16 children in 1903 when she was 22. Michael died soon after birth, as did her next two children in 1903 and 1904. Gertrude had her youngest child Vera at age 42. Of the 16 children, 11 lived to adulthood, including my grandmother who was the eldest female sibling. It is not surprising that I remember my grandmother, May, often telling stories about death, disease, and sudden illness. Her brothers were prisoners of war in Changi prison and the Burma railway, both notoriously brutal prisoner of war camps where hundreds of Australians died during WWII. My grandmother had a sister with chronic illness and witnessed another sister seriously burnt in a fire in their family home. Apparently, she had been making soup on the open fire when her dress caught fire. My grandmother May was 16 years old at the time and had been washing clothes in the laundry while ‘taking care’ of her sisters that day. Her sister died a few weeks later in hospital from her injuries. She was 12. Stories like these were shared in everyday conversations with me, my brother, and other cousins.
While it was hard to relate to a 12-year-old being burnt in the family kitchen or to imagine what it was like to wait for people to return from war, I did learn about loss and death through hearing her stories of how she lived through it and how she managed to dodge death and illness, and live despite the sorrow and grief. Still, it is difficult to find synergies to my own experiences with dying, illness and death. At age 25 I started my first paid work as a psychologist. I was a bereavement counsellor with a community palliative care team. Gertrude my great-grandmother spent her 25th year pregnant and then burying her third baby. By the age of 30 she had birthed her sixth baby—my grandmother—and she would go on to have another 10 babies. Almost 100 years after my great-grandmother had her first child, I birthed my first child in 2002, then five years later my next. I had two pregnancies and two children. My parents were both alive, as were my aunts and uncles, my brother, all my cousins, my parents-in-law and almost all of my extended family. It is impossible to compare the first 30 years of my life with hers. When I recall the stories, they have an unreal, fairy-tale quality about them. It is probably why in my 46th year I can still remember them so vividly. These were big, slightly frightening tales from another era that had a magical quality.

In 2018, it is impossible to imagine living in a country where one in 10 infants die before their first birthday or where the average age of death is 41 (ABS, 2006). Over the past 120 years the lives of Australians have been transformed by shifting disease patterns and death rates, and in particular, the changes in the deathrate, the age at death, and the cause of death (ABS, 2006,
In 2015, 159,052 people (81,330 male and 77,722 female) died in Australia, or around 435 per day (ABS, 2016).

During the previous century between 1907 to 2013, the age-standardised death rate for males and females fell by 71% and 76% respectively (AIHW, 2016) meaning that people are living into old age and fewer children are dying.

In 1909, the deaths of children aged zero to four years comprised 24% of all deaths, whereas by 1999 this had declined and remains below 1% (ABS, 2001). Further, in the period 1901–1910, the average life expectancy of a newborn boy was 55 years and that of a newborn girl, 59 years. By 2015 a newborn boy could expect to live for 80 years and a newborn girl nearly 84 years (AIHW, 2017).

The cause of death has also been transformed. In 2016, the leading cause of death in Australia was ischaemic heart disease with 19,077 deaths. Dementia, including Alzheimer’s disease, remains the second leading cause of death, with 13,126 deaths accounting for 8.3% of all deaths, followed by Cerebrovascular diseases (6.6%), Cancer of the trachea, bronchus and lung (5.3%) and Chronic lower respiratory diseases (5.1%) (ABS, 2017). In contrast, infectious diseases accounted for approximately 15% of all deaths in 1920 and, in 1909, cancer accounted for only 7% of all male deaths and 8% of female deaths.

These changes have changed the way individuals, families and their communities relate to death. First, traditional family practices about end-of-life caring have given way with end-of-life care and death being a highly managed and institutionalised event for the majority of people in Australia; 60 to 70% of
Australians now die in hospital and aged care facilities. Surveys show that 60 to 70% of Australians wish to die at home; however, less than 20% of people do so (Palliative Care Australia, 2013). To manage this, dying now rarely occurs without a checklist, end-of-life protocols such as a care ‘pathway’ for the dying, and a relatively new healthcare construct ‘advance care planning’ has emerged.

The death rate has halved, meaning that young people are less likely to die. Fewer grandmothers have the tales to tell that mine did. Older people die from chronic and degenerative illnesses over months and years, leading to increased hospitalisations and medical management (AIWH, 2016). In 2009 for example, those aged 65 could expect more than half their remaining life to be lived with a disability, often severely limiting their quality of life (Swerissen & Duckett, 2014). This has contributed to the way that death and dying is experienced in the general population. Our ageing population and changing demographics has created a ‘sandwich generation’—those 447,500 Australians caring for both ageing parents and their own children (ABS, 2009).

Death is managed though medical expertise rather than traditional community practices of religious rituals (Walter, 2012). Once a family and community event, death now occurs for the majority of people in an acute hospital setting which requires death to be managed by experts and technologies. In Australia, it is estimated that approximately 25% of the health budget is now spent on futile treatments during the final year of life (Lewis et al., 2013). This is partly to do with the fact that we are living longer with chronic illnesses but also because up until the mid-twentieth century, the
elderly and dying were cared for in the home by women from the immediate and extended family (Jallard, 2006).

These institutionalised experiences have profoundly changed lived experiences with death and dying and influenced our values and beliefs toward end-of-life caring and contributed to society's discomfort about death (Howarth, 2007; Pederson & Emmers-Sommer, 2012). There is a growing divide between the medicalised and social response to this change too. Quite simply, health services can undervalue and under recognise the role of community and as a result, 'lay' or tacit knowledge about end-of-life care has changed, further increasing reliance on healthcare and medical systems for end-of-life care (Gomes & Higginson, 2006; Kellehear, 2005).

The structure/agency tension.
With a focus on components and functions, the death system concept also provides a way to understand the social and cultural restraints on change. As it is a structural approach, little attention has been paid to the agency of deathworkers in the death system. Glennys Howarth's socio-historical work tracks the social changes within society's changing relationship with death, dying and loss (2007). She notes the structure-agency debate is also important in how we understand society's view of and relationship with death. Interactionists such as Giddens (1984) attempt to overcome this duality. His view is that structure and agency have a role in social change. Social structures are produced and maintained by people, and these structures also restrain and influence how much power an individual can exert on the system.
There are considerable tensions in examining the social approach which bring the structure/agency debate to life. In considering a social approach to deathwork I am interested in the social nature of practice and the how the deathworkers in this research respond to their social contexts. Having a social approach, when the dominant approach to death, dying and loss is a biomedical one, will bring with it constraints. The agency deathworkers bring to their actions will provide insights into the death system and how change occurs. As such I will return to the issue of structure/agency throughout this thesis.

**Deathworkers.**
The death system concept influences my use of the term ‘deathworker’. In this thesis, I define deathworker as a person who is working within the death system and is involved in the care of the dying person, the dead body and/or people after loss. I deliberately chose the term ‘deathworker’ for two reasons. First, I did not want to privilege the work of any one person or professional group and second, I felt it was more aligned with the death system framework. That is, the people who work in the death system can be considered deathworkers because their work contributes to the functioning of the death system as a whole. Up until now, the term deathworker has been used in conjunction with people who work with dead bodies such as coroners and funeral directors (Stadler, 2006; Walter, 2007). According to Kastenbaum (1972; cited in Corr, 2015) “in most previous societies, the symbolic and physical actions performed with the dead constituted the core of the death system” (p. 315). Traditionally, the term deathworker has however been
applied to the funeral industry and other professional groups who work with
death bodies such as coroners and police (Stadler, 2006, Walter, 2005).

The use of the term ‘deathworker’ was a deliberate decision taken as a
way to examine and acknowledge the breadth of deathwork occurring within
the death system here in Australia. I consciously choose and use language that
seeks to honour the stories shared with me. Some of the people who
participated in this research worked across multiple components of the death
system. To simply use a person’s job title would not fully capture the variety of
social practices in the death system. In hearing their stories and writing this
thesis, I have come to appreciate the simplicity of the term deathworker and all
the meanings and practices that it captures. Deathworker thus recognises the
role or ‘work’ of renegade deathworkers as less compartmentalised than is
widely recognised. Further, I did not wish to privilege the established and
mainstream language in deathcare by using health and medical terminology to
describe the work that people do. In palliative care that might mean ‘nurse’,
‘doctor’, ‘social worker’, and ‘volunteer’ for example, where each of these ‘roles’
comes with a pre-prescribed set of skills and qualifications. In choosing to focus
on social approaches to death, dying and loss, I was less interested in the
prescribed role people performed and more interested in their experiences
within this role as someone using a non-dominant approach to deathwork.

**Deathwork.**

I use the term deathwork to describe the work of deathworkers. Traditionally,
deathwork has been used to refer to the specialised work immediately
following a death (Walter, 2005). Walter also uses the terms barrier deathwork,
intercessory deathwork, and witness deathwork to delineate a number of other kinds of deathwork. I argue that in the modern death system, traditional ideas of deathwork have created structures that artificially restrict contact between the alive and dead body based on professional specialisation. People dying in hospitals are cared for by nurses, doctors and families while alive; once they die, their bodies are given to mortuary workers or funeral directors and body disposal workers in crematoriums and cemeteries. In such ways, professionalisation within the death system has contributed to the tacit knowledge of experienced ‘lay people’ being undervalued and viewed suspiciously.

Chapter Summaries

Chapter One – Setting the scene. This chapter outlines the context and theoretical framework for my research. This includes the current and changing social and cultural contexts of death, or death system in Australia.

Chapter Two – Death, dying and bereavement in Australia. Chapter Two provides a critical analysis of death, dying and bereavement in Australia. This includes an examination of current biomedical and social models. I examine the impact of medicalisation on death, dying and bereavement and review the public health approach to end-of-life care and the new social innovation models having an impact on the death system.

Chapter Three – Researching deathworkers. This chapter explains each component of my research design including the ethical considerations.

Chapter Four – Renegade Deathworkers. This chapter introduces the deathworkers who participated in the research. It explores the reason why
deathworkers do what they do, and the beliefs and values that give their work meaning. In this chapter the differences between institutional and community deathworkers starts to emerge providing a key finding for this research.

Chapter Five – Doing Deathwork: Renegade Practices. Actions are informed by values and beliefs and deathworkers were strongly influenced by their personal and professional experiences. Deathworkers use their knowledge to influence the components of the death system they work within. This chapter examines how deathworkers put the ‘social approach’ into action.

Chapter Six – Transforming the Approach to Death: Relationships, staying power and strategies for change. Deathworkers have critical awareness of the death system and they use this awareness to work strategically with other people and structures. They do this through leadership and advocacy work. This chapter examines similarities and differences in the practices of institutional and community-based deathworkers.

Chapter Seven – Doing death differently: Discussion and conclusions. This chapter synthesises the findings from the data chapters responding to my research questions about what shapes and influences ‘renegade’ deathwork.

Appendices. This includes the appendices of my research. This includes for example my ethics approval, consent forms and interview schedule.

Chapter Summary and Conclusion

In this chapter I have discussed the key concepts underpinning the subsequent chapters. The social model and the death system are my key theoretical frameworks. The death system provides a useful way to examine how and why a society’s response to death is shaped by people, places, and events, times and
structures such as the hospitals and funeral homes. The system has also been shaped by people and events over the past 120 years, significantly changing the way we interact with dying people, their carers, the dead and bereaved.

In the next chapter I will critically examine the key literature as it relates to social practices in the death system.
Chapter Two: Social Models of Dying, Death and Loss: Theory and Practice

A core task of any society is to manage the death of its members, a task involving both institutional arrangements and cultural resources (Walter, 2012, p. 123).

Dying well is a social issue, yet there is very little evidence that the social model has been incorporated into end-of-life care practices in Australia (Horsfall et al., 2013; Rosenberg et al., 2017; Urbis, 2016). This research is positioned in the social model of health and is influenced by Kellehear's (1999, 2005) formative ideas about how to translate social theories into practices that improve the end-of-life experience. These ideas helped me to develop my practices as a community worker and death educator.

This chapter examines how social theories, policies and practices are making a difference, or not, in a practical way in health services and communities in Australia. I do this by examining the research literature, multiple policy documents, and my own experiences as a deathworker in the death system. I take a pragmatic approach to the complexities of dying well in Australia by seeking out evidence of system change, reviewing tensions, and examining evidence from other sectors. I also review current social practices such as compassionate communities. With this in mind, I have structured this theoretical chapter as a series of questions: Why a social model of dying, death and loss? How can social practices transform the end-of-life experience for everyone? And what is missing from the research and practice?
Why a Social Model of Dying, Death and Loss?

Social models provide a way of defining and understanding the concept of 'health and wellbeing' that moves beyond the limitations and reductionism associated with the biomedical model (Yuill, Crinson, & Duncan, 2010).

Biomedical models focus on the identification, diagnosis and treatment of physical and psychological disorders. Health and wellbeing is therefore measured by the absence of disease. The goal is to treat and remove (or cure) the physical disease to return an individual to their pre-illness state. As such, health services are increasingly concerned with developing strategies to prevent, treat and manage chronic and terminal illnesses. Health literacy initiatives, treatment plans and 'just in case' end-of-life planning are increasingly promoted and incorporated into health care practices (Price & Cheek, 2007). An individual may be encouraged to develop the knowledge and skills they need to manage their condition by utilising the expert knowledge of healthcare professionals, while the patient remains a passive recipient of treatment. This frames the responsibility for health and healthcare decisions in terms of individual needs and rights (McNamara & Rosenwax, 2007), unnaturally removing the individual from their wider social context (Wilson, Ingleton, Gott, & Gardiner, 2013).

Table 3 provides an overview of the biomedical and social models in relation to the view about health, death, the role and function of care, the role of health professionals, a view of the ‘problem’, and examples of practice approaches and how outcomes of the approaches are understood or measured. This table is informed by the key literature and allows a comparison across the
key concepts and practices in the biomedical and social models. By using a table my goal was to condense this overwhelming body of work into the main components relevant to this research.

As can be seen in Table 3, the biomedical model of health focuses on the classification, diagnosis and treatment of illness and disease in individuals. In contrast to the social model, the concept of ‘health’ is viewed as the absence of disease in the human body. To rule out disease in the body, doctors order medical tests and use their technical knowledge about biological markers to diagnose illness (Walter, 1994). If a diagnosis is made doctors aim to provide medical treatments, such as surgery or medicines, to reduce or remove the disease from the body. If a person has dementia for example and there is no medical cure as such, the patient may be offered treatments to delay the development of the physical symptoms and ultimately delay death.

There is increasing acknowledgement of the limitations of the biomedical model. The biomedical model cannot account for the impact that social, cultural, and environmental factors have on the health and wellbeing of an individual as they are ageing and dying (Abel & Kellehear, 2016; Abel, Walter, Carey, Rosenberg, Noonan, Horsfall, Leonard, & Morris, 2013; Engel, 1977; Gisquet, Julliard, & Geoffroy-Perez, 2015; Grindrod & Rumbold, 2015; McDonough & Davitt, 2014; Timmermans & Haas, 2008; Wade & Halligan, 2004). Social models promote health and wellbeing as a holistic concept that acknowledges the relationship and interplay of human agency and social structures (Yuill, Crinson, & Duncan, 2010).
<table>
<thead>
<tr>
<th><strong>Beliefs about health</strong></th>
<th><strong>Social model</strong></th>
<th><strong>Biomedical model</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Health and wellbeing are socially determined.</td>
<td>Health is the absence of disease.</td>
<td>Emphasis on treatment of the physical underlying disease/dysfunction to ‘cure’ or prolong life.</td>
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<tr>
<td>The human body is simultaneously social, psychological and biological. It is much more than simply biology, physiology and anatomy (Giddens &amp; Sutton, 2014).</td>
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<thead>
<tr>
<th><strong>Beliefs about dying, death and bereavement</strong></th>
<th><strong>Social model</strong></th>
<th><strong>Biomedical model</strong></th>
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</thead>
<tbody>
<tr>
<td>A normal and expected part of life.</td>
<td>Death is a failure of medicine, to be avoided.</td>
<td>Dying is treated as a medical condition – biomedical criteria that involves diagnosis of and treatment of disease (Wade &amp; Halligan, 2004).</td>
</tr>
<tr>
<td>Dying is a social event with a medical component not a medical event with a social component (Kellehear, 2007).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People hold multiple views and experiences about dying, death, and loss. These beliefs are often gained via experience (Noonan et al., 2016).</td>
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<table>
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<tr>
<th><strong>The role and function of care</strong></th>
<th><strong>Social model</strong></th>
<th><strong>Biomedical model</strong></th>
</tr>
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<tbody>
<tr>
<td>The individual is not thought of as separate from their family or broader network (Abel et al., 2013).</td>
<td>Focus is primarily on the individual and their carer.</td>
<td></td>
</tr>
<tr>
<td>The dying person and their family has an existing network of family and friends.</td>
<td>Care is person-centred and based on the diagnosis of biological conditions and then treatment options and multidisciplinary teams provide intervention based upon this diagnosis.</td>
<td></td>
</tr>
<tr>
<td>Ideally care “builds upon the resources and networks already surrounding individuals” (Brown &amp; Walter, 2013, p. 1).</td>
<td>The dying person and their family are guided by experts – medical and health professionals with specialised training.</td>
<td></td>
</tr>
<tr>
<td>Social networks and social connection is positively connected to physical and mental wellbeing (Reeves et al, 2014).</td>
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<table>
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<tr>
<th><strong>Role of health and medical professionals</strong></th>
<th><strong>Social model</strong></th>
<th><strong>Biomedical model</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify and support naturally occurring support networks and fill in support where families and their personal networks are not able (Abel &amp; Kellehear, 2017).</td>
<td>Doctors have the technical skills and training required to diagnose diseases and ‘dying’ (Lupton, 1995).</td>
<td></td>
</tr>
<tr>
<td>Focus on capacity building, but in the context of working with and for not ‘on’ or ‘to’.</td>
<td>Curative care and end-of-life care has different specialties/teams and wards.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dying, death and bereavement requires multi-professional support and expert knowledge. Patients manage their conditions and plan for their dying by drawing on this expertise (McNamara &amp; Rosenwax, 2007).</td>
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</table>
| View of the problem of the current approach to death, dying, and bereavement | Despite improved symptom management people are still not dying in the place of their choosing (PCA, 2011). Dying people have agency. End-of-life carers actively navigate the health system in order to get the care they need (Brown & Walter, 2013; Horsfall et al., 2015; Rosenberg et al., 2017). The skills and knowledge of dying people, their families and communities go largely untapped and disconnected from formal service provision. Three key ideas (Sallnow, Tishelman, Lindqvist, Richardson, & Cohen, 2016):  
• Sensitise the community via an upstream preventative and early intervention approach.  
• The PHPC approach promotes the reorientation of health services toward this social approach.  
• Social network enhancement and mobilisation of family, friends and personal community. | Address carer burnout with volunteers and palliative care training programs for carers (Hudson, Trauer, Kelly, O’Connor, Thomas, Zordan, & Summers, 2014). Death awareness and education for the public to ensure they know about services and how to use them (health literacy) (Price & Cheek, 2007). ACP and directives help people get the death of their choosing. Caring and bereavement is a burden and people who are caring/bereaved need professional support. The government must invest in more palliative care specialists and training for health professionals in order to meet the needs of the ageing population. |
|---|---|---|
Accordingly, a social model holds that health can be both enabled and inhibited by the social context of an individual. The effect of having adequate social connections for example has been found to have comparable health effects to stopping smoking (Holt-Lunstad, Smith, & Layton, 2010). Social connections are also helpful when caring for people who are dying (Horsfall et al., 2013) and after death when families are grieving (Aoun, Breen, Howling, & Rumbold, 2016). Further social networks also have a role in disease self-management, with research indicating that self-management strategies are most effective when individuals are socially connected (Reeves, Blickem, Vassilev, Brooks, Kennedy, Richardson & Rogers et al., 2014).

A Social View of Dying and Death in Australia Today

The death system in Australia has developed to ensure it does not impose too much upon the everyday lives of the living and the biomedical model has provided a conceptual framework to normalise the distance between the living, dying and the dead. To understand this more, and examine how social models and social practices are being used in Australia, I have looked for evidence in research and policy documents for public health approaches to palliative care, including compassionate communities, health promoting palliative care, and other social research. During the period of this research (2011–2017) there have been a number of state and national end-of-life policy documents and discussion papers released, including the following:

- Supporting Australians to Live Well at the End-of-life: National Palliative Care Strategy 2010 (Commonwealth of Australia, 2010)
• Health System Reform and Care at the End-of-life: A Guidance Document (PCA, 2010)
• Palliative Care Australia National Palliative Care Consensus Statement and Call to Action (PCA, 2012)
• Advance care planning: Have the conversation. A strategy for Victorian health services 2014–2018 (Department of Health, 2014)
• Dying Well, Gratton Institute Report (Swerissen & Duckett, 2014)
• Conversations: Creating Choice in End-of-life Care (Bartel, 2016)
• Evaluation of the National Palliative Care Strategy 2010 Final Report (Urbis, 2016).

A close analytic reading of these documents (Weis & Fine, 2004) revealed four reoccurring themes or ‘problems’ with the experience of dying, death and grief in Australia: prolonged end-of-life, the need for professional support, the need to educate the public and health professionals about palliative care, and the notion that end-of-life planning is necessary to die well. These four problems serve here to structure the content of this chapter and to enable me to discuss the above-mentioned policy and practice documents with reference to the relevant literature. I will now examine each of these in greater detail in order to examine current social practices. My aim is to uncover the social processes and social structures that enable and hinder social practices in the Australian death system.
A prolonged end-of-life.

Dying is a slow process in Australia because we are living longer with more complex and chronic illnesses. In this sense, death is often viewed as unpredictable while at the same time occurring from a predictable chronic illness. As such, the trajectories or patterns of dying (Lynn & Adamson, 2003) are featured throughout the above documents to demonstrate how medicine and medical innovation has changed the patterns of dying in Australia. It is generally accepted there are four illness trajectories that end in death: sudden death (including trauma and suicide), terminal illness (which can include a period/s of wellness and then decline when the condition no longer responds to treatment), organ failure (can happen over many years of acute exacerbations), and frailty (steady and progressive decline) (ACSQHC, 2013). It is this last trajectory ‘frailty’ that is becoming increasingly prevalent because people live for many years with functional decline due to multiple chronic healthcare conditions such as dementia, and heart and kidney diseases. While ‘frailty’ is a way of describing functional decline and ageing, it is also viewed as a medical syndrome diagnosed based on a person’s activity level, physical strength, and overall fitness (Clark et al., 2017).

Frailty and prolonged dying is viewed in policy documents as a significant problem because chronic diseases such as dementia, respiratory diseases and heart disease account for 70% of the disease burden (PCA, 2010). Further, the death rates from dementia and Alzheimer’s disease are rising. In the last decade alone they have increased by 126% and are now the third most common cause of death (ABS, 2016). These multiple conditions make it more
likely that a person will die in aged care or in an acute hospital increasing the likelihood of institutionalisation in the final years of life (Swerissen & Duckett, 2014).

Increased rates of institutionalisation has increased medicalisation and dependence on the medical model. The past 120 years has seen this gradual shift toward institutionalised care; however the ‘problem’ of prolonged dying is a modern one. A century ago prolonged dying was less common with the family unit—usually women—taking on a significant amount of the caring and care of older people (Howarth, 2007). In modern societies, there is a dependence on institutions to provide care and this has over time reinforced reliance upon the biomedical model for end-of-life care (Walter, 1993). As such, this is reflected within the above reports and social approaches are referred to in a tokenistic way, as a way to provide education about palliative care or advance care planning (ACP). Social approaches are not viewed in any way as an alternate way to intervene or to create significant change toward de-institutionalisation.

Normalisation is presented a number of times as strategy for promoting good end-of-life care. For example, one goal of the 2010 palliative care strategy is: “To significantly improve the appreciation of dying and death as a normal part of the life continuum” (PCA, 2010, p. 11). To address this goal, the strategic action is stated as to “develop a comprehensive, evidence based, multi-modal and targeted national public awareness strategy to promote death as a normal part of living and promote the services and options available for people nearing the end-of-life” (PCA, 2010, p 11). Community awareness is viewed as a way to promote palliative care services and ACP, though there is conflicting evidence
that either of these strategies leads to better outcomes for dying or death (Lewis et al., 2017; Urbis, 2016). Further, the idea that palliative care normalises death and dying has been strongly contested (McNamara & Rosenwax, 2007; Rosenberg, 2011). Fifty years after the hospice philosophy was incorporated into mainstream healthcare as palliative care, the biomedical model remains largely unchallenged. In addition, it is this ‘good death’ discourse that continues to imply that a person must know they are dying, or have some forewarning to allow for a period of awareness and preparation.

**The need for professional support.**

The medicalisation and institutionalisation of dying is acknowledged throughout the above reports as problematic for dying well. Part of the response to this, suggested in these documents though, is to argue for more professional care and support for dying people, dead bodies and their carers. There is a tension, perhaps even a contradiction, inherent here as the types of supports and services suggested in these documents are those that are clearly located within the biomedical model. Place of dying and death needs to be planned for and awareness campaigns to promote ACP and to encourage people to access palliative care to ensure this choice. The report by Bartel (2016, p. 16) for example views ACP “as a precondition for delivering choice driven quality care”. Another example:

One of the major communication tools to emerge in recent years has been advance care planning. Advance care planning provides for an ongoing conversation between patients, their families and carers and the health care team that can be used as a mechanism to take control of decisions that affect an individual’s care. It is linked with the broader
imperative of raising community awareness about death and dying (PCA, 2010, p. 65).

However, it is becoming clear that awareness raising and increasing the uptake of palliative care services does not necessarily lead to meeting people’s emotional, psychosocial or even medical needs at the end of their lives. As noted in Chapter One of this thesis, Australians are increasingly dying in intensive care and acute hospitals, with approximately 30% of people receiving often intrusive futile care in the last months of life (Swerissen & Duckett, 2014).

Home death is now less common than it was 100 years ago, with less than 20% of deaths occurring in a private residence. While I do not want to ignore the significant social resources that are required to achieve death at home (Gott, Allan, Moeke-Maxwell, Gardiner, & Robinson, 2015; Horsfall et al., 2013) the rate of home death does provide some insight into the medicalisation and institutionalisation of dying and the social and cultural changes that have occurred in the death system. Ultimately, it is family, friends, and personal communities who actually make death at home possible (Gardner, Rumbold, & Salau, 2009; Horsfall et al., 2013; Stajduhar, Martin, Barwich, & Fyles, 2008) yet policies continue to focus on a professionalised response to end-of-life care. One way this occurs is through a focus on health care education about palliative care and ACP (PCA 2010). There is a significant emphasis on promoting services to the public about palliative care services.

There are a number of benefits to palliative care. Recent research shows that palliative care can lead to longer survival and better quality of life for people who have cancer (Temel et al., 2010) and decrease caregiver burden
(Casarett et al., 2008). The past decade has also seen the growth in social, spiritual and psychological programs in palliative care, including bereavement care for families. Palliative care teams have expanded to include multiple professionals: specialist nurses, social workers, psychologists, occupational therapists, physiotherapists, dieticians, speech therapists, art therapists, pharmacists, and volunteers including social and bereavement support groups, autobiography programs, and walking groups (PCA, 2005).

In 2014–15 nearly half of patients who died in a hospital in Australia received palliative care and one in six public acute hospitals had a palliative care unit (AIHW, 2017). The majority of this end-of-life care (52.3%) occurred when people were admitted as an inpatient and it was provided to people with a cancer diagnosis (AIHW, 2017). While up to 70% of people, when asked, say that they would like to die at home, very few, possibly less than 20% die in their own home (Productivity Commission, 2017). Despite the expert culture and the growing number of specialised health and medical professionals, people are not dying in their place of choice or receiving palliative care there. These statistics provide some perspective into the ongoing criticisms that palliative care has not delivered the reformist agenda of the modern hospice movement (Kellehear, 2005; Rosenberg, 2011; Walter, 1993).

Although palliative care sprouted from the hospice reformist movement, a number of authors argue that when it became a mainstream practice it created greater specialisation and expert knowledge in keeping with the biomedical model (Kellehear, 1999, 2005; Rosenberg, 2013; Walter, 1993). And this can be clearly seen in the discussion above where it seems the aim of such
policy documents is to engage the public to use services rather than transform services to provide the public with the care they need where they would like it. A tension exists therefore between the person-centered rhetoric and the institutionalised and medicalised reality of palliative care for a majority of Australians. The review of the national strategy for example notes “over-medicalisation at the end-of-life persists at all levels of health provision. Often this is because there is a lack of understanding that appropriate pain and symptom management can be provided without continuing aggressive treatment” (Urbis, 2016, p. 23).

Home and the dying person’s social context have “been replaced by institutional spaces” (Rosenberg, 2011, p. 16). Palliative care has professionalised care of the dying, intensifying community members’ reliance on healthcare and medical systems for end-of-life care and continually working, albeit perhaps not intentionally, to weaken the significance of community or ‘lay’ knowledge about dying and death (Gomes & Higginson, 2006; Kellehear, 2005).

In the biomedical model, preparation for the end-of-life is considered highly important and there are a new set of rules and expectations for both the patient and staff when a person is ‘dying’. Conformity to the norms of the institution is important, as is compliance to the expected routines because when either the individual’s disease is not conforming as expected on the trajectory, or the dying person is coping unexpectedly too well or too poorly (i.e. deviant/abnormally), the dying person will likely need to manage
themselves or the institutional response to this deviation from the norm to remain autonomous (Glaser & Strauss, 1967).

In their classic ethnographic study of institutionalised dying Glaser and Strauss (1967) noted four types of awareness of dying in the interactions between patients and staff members: closed awareness, suspected awareness, mutual pretense, and open awareness. Closed awareness styles, including suspected awareness and mutual pretense, were observed in situations where the person dying was not told directly by staff they were dying. This happened for a number of reasons including medical paternalism ‘my patient won’t cope’ and staff decisions to collude with family members to hide the truth from their patient. Glaser and Strauss (1967) noted that closed awareness was a difficult state to maintain for families and staff and it often caused significant anxiety for everyone, including the patient. Staff developed avoidance strategies to cope with the possibility that a patient might inadvertently talk about dying. Interestingly however, Glaser and Strauss (1967) thought there was functionality to these ‘conspiracies of silence’ because open awareness between patients and staff for example, could be disruptive in the busy ward environment.

There is very little acknowledgement in the policy documents about how these open and closed communication styles might impact professional support that is being advocated for. Recent Australian research has indicated that the term ‘palliative care’ is viewed by cancer patients as a euphemism for ‘death’ and that patients perceive a reluctance from care providers to talk directly about death and dying (Collins, McLachlan, & Philip, 2017, 2018). This research
provides insights into some of the complexities associated with the professionalisation of the death system. Health professionals are expected to both communicate about the pathways to palliative care and to provide end-of-life care. The existing knowledge and experience of patients and caregivers is rarely referred to in the policy and discussion papers.

The biomedical model also reinforces the professionalisation by ‘diagnosing dying’. This is a mechanistic and technical process (Engel, 1977). In order to achieve this ‘diagnosis’, the biomedical model objectifies the human body so it is “no longer a person but a constellation of objects subjected to medical scrutiny” (Foucault, 1973 cited in Walter, 1993, p. 13). Eventually all medical interventions and treatments for delaying death fail and a person is now ‘diagnosed as dying’.

This process of diagnosing dying provides an important view of the biomedical model in practice and how the argument for more professionalisation is promulgated through the above documents and expert knowledge. To illustrate this I will provide an example of how dying is diagnosed in Australian hospitals. Diagnosing dying is a medical assessment, sometimes referred to as a ‘holistic’ assessment of the signs and symptoms of pending death (Kennedy et al., 2014). These signs and symptoms include objective measures such as testing biological markers (such as changes in oxygen and calcium) and subjective measures (a rating by a doctor or sometimes a patient/family member).

One of the most common tools of measurement is the Palliative Care Outcomes Collaboration package (PCOC, 2016). It is broadly accepted as a
standardised clinical outcome tool that aims “to capture clinically meaningful information, at significant periods in a palliative patient’s disease trajectory” (n.p.). As such it is designed to:

- provide clinicians with the tools to systematically assess individual patient experiences using validated clinical assessment tools;
- define a common clinical language between palliative care providers to support assessment and care planning;
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking;
- provide regular patient outcomes reports and workshops to facilitate service-to-service benchmarking; and
- support research using the PCOC longitudinal database (PCOC, 2016).

The five assessment scales in the PCOC framework assess the ‘phase of illness’ (i.e. are they deteriorating or terminal?), the person’s level of functioning (i.e. are they bed bound and dependent on others for care?), and how severely the symptoms are experienced (PCOC Assessment Protocol, 2016). Each phase of illness progression (as noted in Table 4) has a clinical action attached that is based upon whether the phase is new or recurring.

Table 4 (below) clearly shows the phases of dying. The phases are styled as stable, unstable, deteriorating, terminal, and bereavement or post death support. It provides a set of clinical actions for phases when they are changing or when they remain the same. The phase ‘terminal’ for example, provides “discuss change with family” as an action to inform family members about a “change in condition”.

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Table 4: Palliative Care Outcomes (PCOC, 2016)

<table>
<thead>
<tr>
<th>Palliative Care Phase</th>
<th>Actions if this is a new Phase</th>
<th>Actions if Phase is the same as previous assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stable</strong></td>
<td>• Continue as per plan of care.</td>
<td>• Continue as per plan of care.</td>
</tr>
<tr>
<td></td>
<td>• Commence discharge planning if appropriate.</td>
<td></td>
</tr>
<tr>
<td><strong>Unstable</strong></td>
<td>• Urgent intervention and escalation required.</td>
<td>• Continue urgent action, adjust plan of care, refer, and intervene.</td>
</tr>
<tr>
<td></td>
<td>• Change plan of care.</td>
<td>• When no further changes to the care plan are required, change Phase.</td>
</tr>
<tr>
<td></td>
<td>• Urgent medical review and or allied health services.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Review within 24 hours.</td>
<td></td>
</tr>
<tr>
<td><strong>Deteriorating</strong></td>
<td>• Change in plan of care required to address increasing needs.</td>
<td>• Review and change plan of care.</td>
</tr>
<tr>
<td></td>
<td>• Referral to medical or allied health may be required. Family / carer support may increase.</td>
<td>• When deterioration plateaus, change Phase to Stable.</td>
</tr>
<tr>
<td><strong>Terminal</strong></td>
<td>• Commence end of life care (adjust plan of care if required).</td>
<td>• Continue end of life care as per plan of care.</td>
</tr>
<tr>
<td></td>
<td>• Discuss change in condition with family and those important to the patient.</td>
<td>• Communicate changes to family and others important to the patient.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• If patient not likely to die within days re-assess Phase.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• End the Episode of Care when patient dies.</td>
</tr>
<tr>
<td><strong>Bereavement or Post Death Support</strong></td>
<td>• Provide bereavement support to family and those important to the patient.</td>
<td>• If family require ongoing support, refer to appropriate service (family member becomes a client in their own right).</td>
</tr>
</tbody>
</table>

*Bereavement phase excluded from outcome measures

It is difficult to imagine the PCOC tool could exist without a culture of medicalisation. Medicalisation consists of defining a problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem or using a medical intervention to “treat” it. This is a sociocultural process that may or may not involve the medical profession (Conrad, 1992, p. 211). As can be seen in the above table however there are very few family led actions and PCOC has a strong emphasis on the clinician assessing how stable or unstable a person’s ‘condition’ is so they can communicate this with a family member. Conrad (1992) also identifies three levels of medicalisation: 1) conceptual, which relates to the language used to define problems; 2) institutional, which relates to how the adoption of medical
ideas are maintained by the non-medical staff, systems and processes of the institution; medical personnel need only function as gatekeepers in this medicalised system; and 3) interactional, in which medicalisation occurs directly within the doctor-patient interaction, when the doctor treats a ‘social’ problem with a medical form of treatment. Conrad’s (1992) analysis highlights the many potential ways that the PCOC tool might be misused because it relies solely on clinical judgment.

As can be seen in Table 4, the PCOC tool, reflecting the biomedical model, thereby constructs the dying person and their experiences as a set of symptoms and phases. The PCOC tool provides no information about the lived experience of the person who is dying. It does not tell us what the symptoms mean to the person or their family or if they feel safe or supported. Nor does it provide any information about why symptoms are getting worse or improving. Instead, the boxes are ticked and centrally compared to national benchmarks that measure the number of people who experienced a reduction in pain and other symptoms (PCOC, 2016).

So, while the tool can be used clinically, the comparison or ‘benchmarking’ does not occur at the bedside but is compiled by the PCOC research collaboration. Palliative care teams are also encouraged to use the tool to communicate at handover, for example, “Mr. Jones is in Phase 4”, which, according to PCOC, may or may not mean that the person is dying (PCOC, 2016). Further fitting with a biomedical approach to dying, specialised training is required to use the PCOC because it has its own jargon and is used to provide an evidence base that palliative care is effective. In such ways, the PCOC
normalises a medicalised bureaucratic approach to death, reducing dying to an objectified event, and providing an illusion of control to clinicians, giving bureaucracy a significant role in the maintenance of these biomedical practices in hospitals and other institutional settings. Zola (1983) writes that medicalisation “is the process whereby more and more of everyday life has come under medical dominion, influence and supervision” (p. 295). Additionally, Lupton (1995) argues these technical interactions reinforce our dependency on doctors to diagnose dying and further reinforcing the power/knowledge of doctors and medicine.

So while the PCOC tools were designed to show the effectiveness of palliative care treatments through monitoring and accountability (PCOC, 2017; Urbis, 2016) the pathway for the dying is a tool designed to improve end-of-life care. In addition to PCOC, the ‘pathway for the dying’ document is used across healthcare (not just in palliative care). The pathway, designed in the 1990s in the United Kingdom (UK) as a best practice tool, aimed to trigger comfort care and a ‘good death’ when people were in the final days and hours of life in hospital settings. It was also designed to enable better diagnosis and identification of the symptoms of dying and thus help clinicians in hospitals ensure that futile treatments such as CPR were not administered (Neuberger, 2013).

Watts (2012) argues that the end-of-life pathway process and documentation reflect “a particular conceptualisation of a ‘good death’, one which is akin to the hospice ‘good death’ ideal, yet where the dying process and resultant ‘good death’ is ‘managed’ within a biomedical framework” (p. 26).
This objectification of the dying process is dehumanising, even though the original intent of the pathway was to ensure compassionate care at end-of-life. In 2014, the pathway document was the source of a national enquiry because of reported abuses of power by medical practitioners made worse by the pathway systems (Knights, Wood, & Barclay, 2013). The subsequent report noted that 50% of people had been placed on the pathway without consent or without the knowledge of family members (Watts, 2012; Neuberger, 2013).

The dying person and their family are ‘in the hands’ of the medical profession at a time when they are highly vulnerable and overwhelmed. In these situations, the palliative care team may be called upon to ‘step in’ and provide holistic care to the dying person and their family; in other words, to humanise and demedicalise dying. The interactions between the institution, the dying person and family thus act to both empower and disempower the person dying and the people caring for them, because, according to Brown and Walter (2013), it “carries the clear message that dying is complex and requires skilled multi-professional support. In the very process of demedicalising dying, it further professionalises it” (pp. 4–5).

One reason hospitals and institutions have patterns and systems like PCOC and ‘care pathways’ is to help soften and contain the experience of dying and death for patients, families and staff (Mellor & Shilling, 1993). Rosenberg (2011) has argued that “The mainstreaming of palliative care retained a focus upon models of service provision, and although providing some important clinical benefits to ‘users’, demonstrated that many contemporary conventional models of palliative care do not adequately locate death and dying in the social
context of people’s lives” (p. 17). Paternalism, guided by the principle that doctors decide what is best for the patient (Weiss, 1985), holds that health professionals can act in the best interest of their patients even if it is at the expense of the patient’s autonomy. In order to take action, the doctor uses their knowledge of a patient’s values and wishes and makes an informed decision on their behalf. The Liverpool Care Pathway, as discussed above, is an example of how destructive paternalism can be when medical decisions are made without the patient’s informed consent.

The policy documents above promote professionalism and community empowerment; the issue of paternalism is however unacknowledged. This tension is unacknowledged throughout the discussions of ACP, assessment tools, and in response to interventions that aim to ‘empower’ patients and families through person-centred care. However, there is one example of this tension worth mentioning from the evaluation of the National Palliative Care Strategy 2010 final report (Urbis, 2016), which noted the following:

One stakeholder commented that clinical staff and health professionals have an important role to play in delivering high quality care; however, they are not necessarily best placed to effectively drive community awareness activities. ...it's really, really hard for health and medical people to think in community development terms. So I think co-creation models are really important but there would be a priority need to help people develop an understanding of how to do co-creation in the community (palliative care advocate) (p. 23).

In the absence of any acknowledgement of paternalism, discussions about co-creation, professionalisation and community empowerment are
extremely difficult. Paternalism has been identified as a barrier to good care (Drayton, 2011; McNamara, 2004; Rosenberg et al., 2017) education (Kellehear, 2005) and it is also a barrier for health promotion and social approaches (Dempers & Gott, 2016; Rosenberg, 2007, 2011).

Rosenberg (2011) uses the term ‘benign paternalism’ in an attempt to align the paternalism in palliative care to a compassionate rather than a malicious intent. Illich (1976) has a more deterministic view of this kind of medical decision-making. He asserts that medicalisation creates the conditions that enable paternalism to be practiced and normalised in the medical system. Illich (1976) and others (Conrad, 1992; Conrad & Schneider, 1992; Zola, 1972) view medicalisation as a form of social control, making it possible for previously non-medical issues to be re-categorised as deviant. As noted by Conrad (1992), without medicalisation in a definitional sense, medical social control loses its legitimacy and is more difficult to accomplish. The development of a technique of medical social control may precede the medicalisation of a problem, but for implementation some type of medical definition is necessary (p. 216). Hence we can see that diagnosing dying, categorising dying and viewing death as deviant (as in the medical construction of prolonged dying) and taking the position that everyone who is dying requires palliative care, is one way of bolstering medical social control and reinforcing the legitimacy of the biomedical model.

Given that medicalisation gives medicine its legitimacy (Conrad, 1992) the notion that paternalism can be viewed as a benign practice is therefore a contested one. Further, end-of-life planning is commonly thought (by people within the medical system predominantly) to guard against paternalism. In
practice though, with so few ACPs being completed in the community, with “well” people, end-of-life pathway documents may guard against futile care, but the social benefits are less clear. While paternalism is important, my main point is that when viewed through a social lens, ACP is yet another tool for supporting medical dominance. This tension is again unacknowledged in the above documents. It might even be argued that ACP is almost universally accepted as a solution for preventing a bad death and futile care.

People need to be educated about palliative care and death.

Social changes are also acknowledged throughout the policy documents and associated literature. The public health and medical advances of the twentieth century transformed the social context of dying, death and grief. At the turn of the previous century, the average age of death was 41 and one in 10 infants died before their first birthday (Jalland, 2006). Death being so much a part of life was ‘known but not feared’ (Aries, 1974). In 2018, the majority of the population in countries such as Australia do not experience the death of an immediate family member until adulthood. Children, young people, families, and communities are now less likely to see end-of-life care, the dying process or the dead body as they did in the past. Yet death is regularly beamed into our lives via social and traditional media and popular culture. The ‘death positivity’ and death acceptance movements (Walter, 2017) have also had a revival in recent years, with new initiatives such as death cafes representing the emergence of a new cultural meme, one that promotes the individual contemplation of mortality while being an informed and expressive consumer within the death system.
I have talked about the normalisation of dying and death, but community education about palliative care has a different goal. Community awareness and community engagement activities have been growing in Australia over the past decade. The goal of community awareness is to improve public understanding and uptake of palliative care services. A number of population-based surveys have been undertaken that show that awareness in Australia has risen throughout the 1990s and currently about 70% of the population over 18 has a reasonable understanding of what palliative care is (PCA, 2010). Despite this increase, Australia ranks ninth in the world on public awareness of palliative care. That is, the Australian public is considered to have a “somewhat good understanding and awareness of palliative care services” (The Economist Intelligence Unit, 2015, p. 47). To further increase public awareness, numerous organisations (see AMA, 2014; AHHA, 2016; PCA, 2016) have called for a national government run awareness campaign about palliative care. Although this is yet to occur, there is a strong emphasis in Australia on public health campaigns that promote awareness of palliative care services. This is consistent with the prevailing approach that focuses on educating the public about palliative care and ACP.

Health education in medical settings has also been increasingly incorporated into the medical model and is directed toward changing the knowledge, attitudes and skills of patients and their families. Ideally, improved health literacy is the outcome of this kind of education process, which also has a strong emphasis on treatment compliance and improving the health of
individuals. In the end-of-life setting, training carers to provide end-of-life care (see Hudson et al., 2013) is one such intervention.

Traditional public health thinking promotes the idea that if medical and health experts can educate the masses, behaviour change will follow. This approach has been shown to have benefits and limitations for health and wellbeing at the population level (ACSQHC, 2013). Ideally, while improved health literacy is the outcome of this education process, a biomedical model “is socially and culturally constructed, public health and health promotion are socio-cultural products”. It follows therefore that “their practices, justifications and logic [are] subject to change based on political, economic and other social imperatives” (Lupton, 1997, p. 4). These points are evident in the current approach to raising community awareness that has a strong emphasis on patient compliance and improving the health of individuals. Further, public education can risk being paternalistic and heavy handed. Recently, for example, there were calls for ACP to be compulsory at 70 and for elderly people to be penalised if they did not comply by losing Medicare benefits by the age of 75 (Productivity Commission, 2017).

Death education about the human and emotional aspects of death is considered a key component of the public health and palliative care approach, as it has a role in the development of death-related knowledge and in promoting awareness about the death system. In Australia, the National Palliative Care Consensus Statement notes “all Australians must have access to education about dying and death” (PCA, 2011). While death education can be delivered didactically and/or experientially, it is most commonly associated
with training programs for medical and nursing students (Hegedus, Zana, & Szabo, 2008; McIlwaine, Scarlett, Venters, & Ker, 2007), grief counsellors (Doughty & Hoskins, 2011), and more recently public education initiatives about death and dying (Gallagher, 2001).

Community death education is generally less common in Australia, but it has increased over the past two decades with the rise of the public health approach. The public health approach to palliative care holds that death education is best delivered within the context of community development in equal partnership with community members (Kellehear, 2005). Within this definition, community development initiatives are focused on process and interpersonal relationships; it is more than informing or consulting with community members; it is about creating sustainable collaborations and partnerships (Abel et al., 2013; Sallnow & Paul, 2013). I will return to community engagement and community development activities later in the chapter.

**People need plans to die well.**

End-of-life planning has received considerable attention over the past 10 to 15 years (see for example Detering, Hancock, Reade, & Silvester, 2010; Lewis, Cardonia-Morell, Trinkle, Ong et al., 2016; Kaldjian, Curtis, Shinkunas, & Cannon, 2008; Lorenz et al., 2008; Mackenzie, Smith-Howell, Bomba, & Meghani, 2017; Sellars, Silvester, Masso, & Johnson, 2015). There are two planning tools commonly referred to in the above reports, these are ACP and care planning for the dying. ACP is defined by Advance Care Planning Australia (2017) as a “process of planning for future health and personal care, whereby
the person’s values and preferences are made known so that they can guide decision-making at a future time when the person cannot make or communicate their decisions”. ACP is a process designed to enable people to think about and plan for the care they do and do not want to receive when they are dying. An advance care directive is the documentation of these wishes. The distinction is important, although the terms are often used interchangeably. In Australia, there has been considerable investment and research into ACP because advance care directives are the primary healthcare document to indicate your end-of-life wishes in Australia.

As such, increasing community awareness about planning, as noted above, is a major strategy in public policy in Australia. The need for planning is seen by health bodies and professionals and advocates of ACP as a response to increasing rates of futile care. As such, ACP is viewed as:

Promoting the autonomy and dignity of an individual is an important part of providing high quality, person-centred care. Advance care planning is intended to enable individuals to make plans for their future care. The process encourages individuals to reflect on what is important to them, on their beliefs, values, goals and preferences in life, and how they want to be cared for if they reach a point where they cannot communicate decisions about medical care for themselves (Department of Health, 2017).

The benefits of ACP include improved communication of wishes between family members and reduced anxiety and depression in family members (Detering et al., 2010). When compared to family members who were not involved in ACP, family members with an advance care plan were more satisfied
with the experience of death (Detering et al., 2010). There is also evidence that having an advance care plan will improve the possibility that a person will die in the place of their choice (Detering et al., 2010).

Despite these potential benefits, only 14% of people in Australia have an advance care plan (White et al., 2014). Additionally, these benefits have been challenged. Robins-Browne, Palmer and Komesaroff (2014) argue that end-of-life decision-making is only partially captured when writing an advance care directive. Sociocultural contexts and family relationships of the person dying, for example, can never be fully captured by the process. Robins-Browne, Palmer and Komesaroff (2014) also argue that the central idea that ACP promotes patient autonomy is seriously flawed because ACP/ACDs rely on surrogate decision-makers to carry out and uphold the wishes of the person dying, challenging the underlying principle of patient autonomy (Robins-Browne, Palmer, & Komesaroff, 2014). Further a recent systematic review has also challenged the notion that ACP is effective in helping people to avoid futile intervention and die well (Lewis et al., 2016). This evidence appears to be strengthening the focus on values-based end-of-life planning (Lewis et al., 2016; McMahan, Knight, Fried, & Sudore, 2013). This continued simplification and medicalisation of end-of-life planning reinforces that the process of completing your ACD is a ‘procedure’ of the medical and health systems and therefore playing a part in the biomedical model as a form a medical control (McNamara, 2004).

In a recent study, oncologists and palliative care doctors struggled to balance patient autonomy and the structural and systemic norms of the ‘good
death’ ideal (Johnson, Butow, Kerridge, & Tattersall, 2018). The authors concluded:

While patients’ preferences for care are central to decision-making, professional norms, structural limitations to care and organisational interests in limiting treatment, all may problematise individual choice. Failure to acknowledge the institutional interest of ACP, or the constraints on patients’ preferences, offers patients a ‘false promise’ that is morally problematic. It also diverts individuals, policy makers and organisations from exploring and minimising the potential harms of bureaucratic ACP programs, which reduce ACP and patient autonomy to a ‘tick box’ exercise and may fail to enhance EOL care in any meaningful way (Johnson, Butow, Kerridge, & Tattersall, 2018, p. 573).

Values-based activities are deeply personal and meaningful, often involving reminiscing about past experiences with death and dying, and involve a high level of empathy and communication skills. In the current medicalised healthcare environment, there is a preference for care-based conversations over values-based ones. In my own work, I have felt and seen the tension expressed in the above quote. This tension between care-based and values-based conversations with people who are dying. Care-based conversations tend to focus on enabling access to services and on service delivery. By their very nature these conversations are more efficient in the short-term and can occur with or without family members. Values-based discussions on the other hand, usually occur over a number of facilitated conversations and may or may not be related to whether a person needs a service to be delivered for them.

Despite attempts to encourage community end-of-life planning, the ACP process continues to be an institutionalised activity carried out by or within
hospitals and other health settings. The focus up until now in Australia has been on the formal and legal procedures involved in making a directive. Although there is no legal requirement to complete a standardised ACD form, the NSW Government recently released an approved version of an ACD (NSW Ministry of Health, 2017). As such, end-of-life planning is what Sabatino (2010) calls the legal transactional approach that emphasises that individuals write an ACD. According to Sabatino (2010), this is the best way to ensure compliance from professional service providers with the end-of-life wishes of a patient. As noted above, this approach however has not improved uptake of ACD or the following of ones by health professionals which are complete, nor is there sound evidence for better end-of-life outcomes (Lewis et al., 2017).

As such, there is now movement toward a communications approach to ACDs in Australia, which is promoting family conversations and doctor-patient conversations about end-of-life preferences (Sabtino, 2010). This includes a broader emphasis on ACP in the community and using a community awareness approach that combines palliative care and ACP awareness. Palliative Care Australia, for example have recently released a ‘dying to talk’ booklet that uses a communication rather than a legal framework. It is worth noting however, that this shift toward using ACP as community awareness is not community engagement as defined by Sallnow and Paul (2013). Rather, it is yet another mechanism to get people to use the services provided rather than provide the services needed. Abel and Kellehear (2016) however have proposed that ACP can be used as a community engagement tool through the development of support communities and volunteers, although there is a risk that ACP will
dominate and become viewed as synonymous with the public health or social approach.

This argument by Abel and Kellehear (2016) might also be considered an example of what happens when the biomedical model co-opts the language of the social model. End-of-life planning with individuals is by definition a process with a limited social reach. However the language of the public health palliative care approach, or in general social approaches such as compassionate communities, is extremely appealing. The discussion paper by Bartel (2016) is the only report to detail social approaches such as health promoting palliative care and the compassionate communities movement. It has limitations though because it overlooks the evidence for public health approaches to end-of-life and advocates for “innovative” strategies that promote community conversations and community awareness. Like many of the other documents examined in this chapter there was very little critique of the biomedical model or biomedical approaches in Australian public policy. The need for innovation and to develop new ways of addressing the ageing population, medicalisation and poor understanding of the limits of medicine is acknowledged throughout.

As such, the end-of-life reform agenda in Australia is directed primarily at patients, their carers, and health professionals who are expected to change their attitudes toward dying and their behaviours when talking about death. The general public/citizens therefore must become more accepting that death is a normal part of life, plan better and understand the way that the health system works. In the next section I will examine how these traditional ideas are being resisted and challenged.
Challenges to the Medical Model

In discussing the current challenges to the medical model it is important to begin with understanding power and power relations, because, as noted in the previous section, there are a number of unchallenged norms that influence the practice of end-of-life and deathcare in Australia.

Traditional structural views of power emphasise the state having control ‘over’ people, with control being seen as hierarchical (Labonte, 1995). However, I have found that Foucault’s (1973) less structural analysis and discussion of the role of power/knowledge helpful in examining and making sense of the biomedical model in relation to end-of-life care and the role of deathworkers in the death system. Foucault (1973) uses the single term power/knowledge because he sees the relationship between power and knowledge as inextricable and inevitable. Experts, such as doctors, have a key role in this power/knowledge structure, however it is not as simple as the doctor exerting power over patients (as in Labonte’s view of power). Foucault instead views power as ubiquitous and in every moment of our social relations each of us enacts power. In this view, power can be both repressive and productive, although never benign. In the case of medicine, power is embodied and enacted in biomedical practices. These practices contribute to the ongoing production, social construction and dominance of the biomedical discourse. At the same time the past decade has seen the emergence of ‘lay experts’ and ‘new deathworkers’ and their voices are resisting and disrupting the biomedical model, potentially challenging its dominance.
Celebrity illnesses and deaths are one example of ‘lay experts’ who live their dying and death in the public sphere. Popular culture and access to information via the internet and mass media provides deeply personal stories and insights into illness, dying, death, and grief. Jane Goody for example, is a UK celebrity who was diagnosed with cervical cancer during her participation on a reality TV program. Goody’s use of social and mainstream media while she was dying provided her with the status of lay expert (Ashton, 2014). Her diagnosis, illness and death have been examined by a number of academics because they created a significant increase in cervical screening in Britain. This became known as the ‘Jane effect’ (Ashton, 2014; Kavka & West, 2010; Walter, 2010).

Another example of lay experts in the death system is death doulas, or end-of-life doulas. Death doulas, similar to birth doulas, journey alongside a person with a life threatening illness and their family providing non-medical support. Some death doulas describe their work as a return to a more ‘traditional’ view of dying at home, when a trusted and experienced friend or community member might provide support to a person dying and their family (Preparing the Way, 2018). Death doulas also refer to their practice as complementary to palliative care services. Although I was unable to find any academic articles about death doula work, there is evidence that death doulas and death doula training programs in Australia are increasing. While it is difficult to know exactly how many practitioners are working in the deathcare space, the end-of-life doula college estimates that 120 of their students are practicing (H. Callanan, personal communication, March 2, 2018). In the Australian death system, where the biomedical model regulates the behaviour
of dying people and their families in a number of key ways, a practice that is wholly outside of that system, and one that doesn’t rely on a specialist referral, is a practice of resistance for the normal relations of power and is disruptive.

Some authors assert that the growing consumer movement is also changing and challenging medical dominance. For example, Ballard and Elston (2005) argue ‘modern day’ consumers can both contribute to and resist medicalisation and assert that medical dominance and medicalisation are not synonymous. They argue that medicalisation can also arise through collaboration or collusion between the doctor and patient, suggesting that some patients are “passively duped into accepting doctor’s orders” while others pressure the doctor (Ballard & Alston, 2005, p. 234). One view is that medicalisation can be a process of oscillation between medicalisation and demedicalisation, or even a process of negotiation between the medical profession and their patients (Ballard & Alston, 2005). There is certainly evidence that ACP has, for example, been adopted and embraced by disease specific groups and advocacy groups such as Council on the Ageing (COTA, 2017), as a way to promote autonomy at end-of-life.

Medical authority and the recent consumer movement are also changing power relations (Lupton, 2012). At the beginning of this thesis I shared Jude’s story. I can see how Jude’s story is an example of a person actively engaged in their care. She was not considered compliant or following the expected rules of a dying a person—still drinking, smoking, and socialising with her family and friends, and she died at home. In fact, her body remained at home for three days after her death, which is a rare experience in Australia. Jude did however have
access to social and cultural resources that supported her choices and ultimately her experience of dying. These included gaining access to information about the death system via her friends who were nurses and through our conversations together. In this situation power/knowledge developed through the strategies we used to navigate a path of care that was acceptable to Jude enabling her to die at home (Lupton, 1997). Jude’s death is an example of how dying can be a social event despite the medical model, not because of it. Doctors and patients are seeking to make sense of and interpret each other’s meaning and assumptions to create a shared language and also negotiate authority (Lupton, 2012). The question of how the health and medical system manages this authority and power has been examined by health researchers (Blomqvist, Theander, Mowide & Larsson, 2010; Broom, 2006; Oudshoorn, Ward-Griffin, & McWilliam, 2007).

Broom (2006) in particular, notes that very little attention has been paid to understanding the complexity of medical dominance given the current sociocultural context. He notes that applying “previous structural notions of medical dominance or power” to the contemporary environment overlooks some of the challenges inherent in the lay/expert divide (p. 497). Broom’s research (2006) found that oncologists were seen to be developing, at least rhetorically, a more holistic model of care based upon patient interest in complementary therapy. The internet was also seen to be playing a role in this lay/expert interaction in healthcare and in the deathcare industry where information about how to care for people who are dying, how to care for the dead body and even how to arrange your own funeral are readily available. One
example of this in Australia is Flinders University conducting a Massive Open Online Course (MOOC) about death and dying (Tieman, Miller-Lewis, Rawlings, Parker, & Sanderson, 2018). There is evidence that some participants in the MOOC have reported feeling more positive and competent in relation to planning for death (Miller-Lewis, Tieman, Rawlings, Parker, & Sanderson, 2018). This course demonstrates the role internet-based learning can have in the democratisation of death and dying related knowledge.

Further, there is also emerging evidence that palliative care would benefit from separating patient contact that involves education with clinical care (Collins, McLachlan, & Philip, 2017). Collins, McLachlan and Philip (2017) found that patients wanted palliative care doctors to be more direct and avoid euphemisms. This is an important finding because of the pervasive idea that death is a “taboo” topic. Though there are now a number of community-based surveys that are challenging this belief that death is a taboo topic (Australian Seniors Insurance Agency, 2016; PCA, 2014, 2016b) with over 70% of Australians reporting they are comfortable talking about death and that they think talking about death is an important thing to do. While these are stable findings, positive community attitudes about death are not reflected in policy documents or the professional discourse about end-of-life planning and death education.

It is common for the concept of medicalisation to be used by the palliative care sector as a discursive device to communicate the urgent need to reform end-of-life care in Australia (PCA, 2010). The health system reform and care at end-of-life guidance document (2010) for example states there is
“significant concern that we have lost the notion of death as a normal part of life because it has been institutionalised and medicalised” (p. 36) and states that “high quality end-of-life care is not possible without adequate, appropriate and equitable resourcing” (p. 42). Further, this helps to explain how palliative care can simultaneously promote reform to counter medicalisation and promote the development of reductionist programs for diagnosing dying such as PCOC and care pathways for the dying. The absence of critique about the role of power/knowledge and how this constitutes and maintains medicalisation in palliative care also provides some understanding about why the uptake of social approaches in Australia has been so limited. Social approaches are often criticised and viewed as deviant, or are colonised and cherry-picked by palliative care services (Rumbold, 2016).

**How Can We Improve the End-of-life Experience for Everyone?**

If people are living longer, dying with multiple health conditions and have fewer people to care for them, how is practice following? In reviewing the above reports, and reviewing the literature four strategies are consistently recommended to improve end-of-life care in Australia: 1) health and medical professional training about palliative care/communication about end-of-life; 2) increasing the aged and palliative care workforce to ensure better access to palliative care; 3) increasing the uptake of ACP in the community, especially for those aged 75 and over; and 4) raising community awareness about palliative care, which also includes normalising the fact that dying and death are part of life.

Dying well, however, is a complex social issue that cannot be solved with
more education and training for health professionals and the general public alone. This idea of complexity is not new, however it is a paradigm that is only beginning to make its way into the health promotion discourse (Temblay & Richard, 2011). Complexity thinking acknowledges that solutions to complex problems are not reducible to simple thinking and program delivery. As discussed in this chapter, dying is more than a biological event that requires medical management; it is also a spiritual, emotional and social experience. The definition of palliative care has evolved to encompass a holistic view of the individual experience, while public health palliative care researchers and practitioners have been working to evolve the definition of palliative care in order to include some of this complexity (for example see Abel et al., 2013 for a discussion about incorporating palliative care and community development principles). Any attempts to move beyond the reductionist biomedical approach will need to acknowledge the limitations of the current biomedical approach. In the next section I will examine approaches to end-of-life care that developed from the social models of health.

**Social Approaches in Practice**

Social approaches have the potential to challenge and disrupt the process of medicalisation and medical social control.

Public health research and practice is not unlike palliative care, in that it emerged from the belief in “enabling people to increase control over, and to improve their health” (WHO, 1986, p. 1). The Ottawa Charter (WHO, 1986) was considered the beginning of 'new public health'. It signaled a move away from the narrow view of the biomedical approach to disease prevention. Early public
health strategies focused on the reduction of mortality and morbidity of communicable diseases and strategies such as better sanitation and nutrition, and did not address social determinants of health (Laverack, 2014; Lupton, 2012). In the late twentieth century, public health approaches were addressing the health and wellbeing of the whole population (Laverack, 2014). This included early intervention and prevention programs designed to modify the behaviour of individuals and change environments to enable health improvements.

There is no one definition of the ‘social approach’ that is accepted or used universally in the literature. However, it is generally agreed that social approaches can provide a framework to enable palliative care services to expand beyond the provision of clinical services into community engagement and non-traditional community partnerships that nurture and develop existing community capacity around death and dying. In thinking about social approaches to end-of-life I have adopted the language ‘top-down’ and ‘bottom-up’ for this section because it reflects my interest in practice and because it best reflects the role of the practitioner too. For example, top-down refers to health promoting palliative care approaches (Kellehear, 1999) that usually involve health organisations engaging with the public. While bottom-up is usually associated with community empowerment and initiatives led and implemented by community members (Kellehear, 2005; Sallnow & Paul, 2014).
Top-down Social Approaches

Community engagement.
Community engagement in end-of-life care is an umbrella term for a process that enables communities and services to work together to understand, build capacity and address issues to improve their experience of end-of-life and bereavement, and their related wellbeing. It exists on a spectrum of engagement that extends from informing through to empowering, depending on a range of factors such as the degree of participation from the local community and the intention of the work. Community engagement activities by end-of-life care services go beyond working in the community to working with the community to improve its experience of end-of-life care (Sallnow & Paul, 2013, p. 3).

Within a public health approach, as promoted by Kellehear (1999, 2005) and Sallnow and Paul (2014), community engagement between palliative care services and the general public is best achieved when working with and for communities. In Figure 1 Sallnow and Paul (2014) have developed a ‘spectrum of engagement’ in end-of-life care that is based on Arnstein’s (1969) ladder of participation, “This spectrum is designed to aid professional services and the communities they serve to embark on community engagement projects with an open awareness of the key components underpinning their success” (p. 5).

This hierarchical model provides an overview from low to high levels of community engagement. Low levels of engagement include informing and consulting with the community through leaflets and websites. This is a passive form of engagement and aims to raise awareness rather than involve
community members in the ‘work’ of end-of-life care. As expected, the other end of the spectrum is ‘empower’. This is where the community self-determine and self-organise the design and delivery of the work.

Figure 1: Spectrum of engagement in end-of-life care: developing community capacity (source: Sallnow & Paul, 2014; reproduced with permission)

Although community engagement leading to empowerment is an underdeveloped and under-researched area in relation to palliative and end-of-life care it has been applied to other social issues including mental health. Ife and Tesoriero (2006 cited in Talbot & Verrinder, 2014) offer four perspectives on empowerment, the desired end point of community engagement. They see empowerment as a process that equalises because disadvantaged groups can compete more effectively with other interest groups. Second, that empowerment is learning an ability to compete with political power. Third, that
structural inequality and oppression are major forms of power and empowerment can only be achieved by challenging structural disadvantage through social change. And finally, that power is expressed through discourse. Empowerment is achieved through validating voices other than those currently dominating.

The issue of power sharing is central to Sallnow and Paul’s (2014) engagement model. Sallnow and Paul (2014) note that the “degree of power sharing by an organisation and the capacity of the community to mobilise their skills and resources” is key (p. 5). In Australia, the majority of community engagement strategies are ‘top-down’ (leaflets, education sessions, online videos) and at the lower end. Talbot and Verrinder (2014) describe them as:

where organisations with power to direct policy and implement change identify priorities outside the context of the community. Practitioners with expertise and knowledge about a population develop policies and programs aimed at improving the lives of vulnerable groups without necessarily including members of those groups in the decision-making processes (p. 136).

Empowerment is often pursued rhetorically at the policy and management level of healthcare as opposed to direct care with patients or community members (Stajduhar, Funk, Jakobsson, & Ohlen, 2010) or as a set of relations and practices. It is not uncommon for health services to have empowerment as a core value, but to use the term in a tokenistic way that does not address inequality or disadvantage authentically. That is, initiatives ‘do to’ community members rather than ‘with’. Health and medical professionals when working with people who may be unwell, in pain, dying or bereaved, have
status and social control attributed to them because of medicalisation. Organisations working within an empowerment model of community engagement do not aim to ‘empower’ people, rather they work democratically within the community recognising that people and communities are the only ones who can empower themselves (Stajduhar et al., 2010; Talbot & Verrinder, 2014).

Power sharing continues to be a sticking point for the public health approach. If power is still viewed as something that the health system ‘gives’ to people who are dying and their families, this fails to recognise the ubiquitous nature of power. I think at this stage of the public health palliative care movement hierarchical models have the potential to initiate deeper analysis and challenging conversations about power and medical control. At the present time however, there is very little evidence that public health palliative care has moved into a deeper structural critique of professional power when engaging with the community about dying, death and loss.

**Bottom-up Community-led Initiatives**

I am particularly interested in approaches that can be initiated by communities and activities that function independently from healthcare services because they are more likely to focus on total populations and not just people ‘at risk’. This includes social network enhancement and development, community development approaches, and social innovation models. These have three principles in common: that dying, death and grief are primarily social events with a medical component; that community members and communities are and can be genuine partners, transforming the experience of end-of-life care
and bereavement; and finally, that dying is everyone’s business—palliative care and other institutions do not have a monopoly on caring for the dying. In the next section I discuss each of these commonalities with the aim to examine what happens when people and communities take steps to empower themselves through social networks and community development approaches.

**Social Networks**

Mobilising and strengthening networks lies at the heart of a social network approach as does the belief that human experiences such as loneliness, isolation, grief, and loss are best supported within communities, by family members, friends and neighbours (Brown & Walter, 2013; Rosenberg, Horsfall, Leonard, & Noonan, 2015). Where this is not possible, professional services have a role in helping to mobilise support (Abel et al., 2013). The current approach to end-of-life care in Australia manages gaps with services rather than recognising and supporting the development or growth of caring networks (Horsfall et al., 2013; Rosenberg et al., 2017).

Brown and Walter (2013) argue for a social model of care that addresses the issue of professionalisation not medicalisation. This emphasis enables health professionals (particularly social workers) to rethink how they work with families that have support needs to best mobilise existing family and social networks and strengthen ties without unnecessarily professionalising support. They encourage health practitioners to use self-awareness and advocate for the use of social networks to counteract hierarchical and disempowering control in health services.
Interestingly, as Brown and Walter (2013) point out, there is very little literature about how end-of-life carers are supported by their social networks. The literature that does exist acknowledges that social networks are mostly hidden from health professionals for two key reasons. First, palliative care typically does not work beyond the patient/carer/family (Burns, Abernethy, Dal Grande, & Currow, 2013); and second, family meetings in palliative care are focused on clinical issues and do not tend to include the social networks of the patient/carer/family (Brown & Walter, 2013; Rosenberg, Horsfall, Leonard, & Noonan, 2017).

In contrast, Abel et al. (2013) propose the circles of care model. This model invites palliative care services to rethink the emphasis on service delivery and use community development approaches to “restore the ability of families and communities to be able to look after their dying” (Abel et al., 2013, p. 6). Figure 2 presents the Circles of Care model, representing a way of thinking about the types of care and support a dying person has access to.

The inner and outer networks are the close family and friends who are likely to provide hands-on care while the outer circles relate to how services and policy can support the inner networks. This model is influenced by the Caring at End-of-life research project that I was involved in at Western Sydney University. Over six years we completed a pilot project and then a larger statewide study investigating the nature, role and effect of social networks at end-of-life. The research has provided key insights into what and how networks care (Horsfall, Noonan, & Leonard, 2012), the role of health professionals in mobilising care networks (Rosenberg et al., 2017), and how relationships
within the care networks develop over time (Leonard, Horsfall, & Noonan, 2013). This research has highlighted that palliative care policies promoting a public health approach had not translated into palliative care services with very few health professionals referring to public health or social approaches in their work. Social network research (Abel et al., 2013; Brown & Walter, 2016; Horsfall et al., 2013) has also provided insights into the role that community organisations, such as schools, sporting clubs, service clubs, and churches have in supporting people who are dying and their families.

Figure 2: Circles of care (source Abel et al., 2013)
Social network approaches also have a practical application. A recent example in the end-of-life space is the use of ACP to initiate social network development in clinical settings (Abel & Kellehear, 2016). This work has shown promise with one study in Frome in the UK revealing that increased social support can reduce hospitalisations in frail older people with multiple health conditions (Abel, 2018). Another program is the Healthy End-of-life Program (HELP), which uses a person-centred collaborative community planning tool to help people to identify existing social resources and then make an end-of-life plan for care based on this (Grindrod & Rumbold, 2016, p. 2).

Community development is one way to develop social networks. For Leadbeater and Garber (2009) the creation of social networks is the key to transforming end-of-life care in the UK. However, they and other authors argue that not all carers are equipped for their end-of-life caring role (Abel et al., 2013; Burns et al., 2013). Leadbeater and Garber (2009) note:

Our challenge is to help people to achieve what is most important to them at the end-of-life. That will require the creation of a network of health and social supports so that people can die at and closer to home, with the support of their family and friends, as well as professionals.

If we do not create this social network, then in the decades to come many hundreds of thousands of people will experience unnecessarily distressing deaths. We will die badly in places not of our choosing, with services that are often impersonal, in systems that are unyielding, struggling to find meaning in death because we are cut off from the relationships which count most to us.

In fact, social innovators such as Leadbeater and Garber argue that the health promotion strategy to reorient health services toward a social approach
will not create the kind of radical and transformational change needed to change end-of-life care in western societies. That is, to change end-of-life care in such a way that it aligns with the wishes of people who are dying and the wishes of their families. As social innovators Leadbeater and Garber align (2009) with a transformational discourse that eschews the reformation and improvement agenda so inherent in healthcare services. I will return to this later in the chapter and again in Chapter Seven when I examine how this relates to the much needed critique of power in this field.

**The ‘Compassionate communities approach’**.

Compassionate communities are communities that develop social networks, social spaces, social policies and social conduct that support people through the many hours, days, weeks, months and sometimes years of living with a life-threatening or life-limiting illness, ageing, grief and bereavement, and long-term caregiving (Wegleitner, Heimerl, & Kellehear, 2016. p. xiv).

**Community development**.

Community development is referred to in a number of ways in the literature. Kellehear (2005, p. 118) defines it as “any set of initiatives designed to develop the social resources of the community in order to enhance its quality of life”. Public health researchers assert it is a “process of working with people as they define their own goals, mobilise resources, and develop action plans for addressing problems they collectively have identified” (Minkler, 1991, p. 261 cited in Talbot & Verrinder, 2017). Feminist researchers describe it as “a political and social process of education and action to achieve self-
determination and social justice for marginalised groups” (Emejulu, 2011, p. 379). Further, I agree with Ife (2009), “Community development can be regarded as a way of thinking, as a philosophy of practice, rather than merely as a process for building stronger communities” (p. 29). The definition, utilised by a program or practitioner, is dependent on whether the approach taken is a top-down/bottom-up approach or a mixture of both (Ife, 2009; Talbot & Verriner, 2017).

Ife (2009) makes an important distinction between bottom-up and top-down approaches to community development. Bottom-up processes are based on the belief that the knowledge and skills of local communities are of central importance and should be “valued above top down wisdom and experience” (Ife, 2009, p. 30). Top-down approaches are common in Australia, and are usually designed and implemented by organisations ‘for’ a community identified as disadvantaged or in need of services. In the top-down approach, organisations must ensure that community participation is not tokenistic and partnerships are developed with community members. This sounds straightforward in theory but in practice community development approaches are challenging, especially in the dominant medicalised and bureaucratic model of end-of-life and deathcare in Australia.

My own experience with a bottom-up approach was first hand a decade ago when I was working for a community development program for end-of-life carers. The organisation held the belief that past carers were highly knowledgeable about end-of-life caring. The program was a way of harnessing existing community knowledge to complement the health and medical services
being provided to the person dying. At the time, community development in the context of end-of-life care was rare in Australia and the program caused considerable angst in the formal healthcare sector. Palliative care services refused to work with us and healthcare staff frequently sabotaged public meetings. Nurses from the local palliative care services would attend our public meetings and be openly outraged ("That's our job", "we already have services and volunteers to do that") that the mentoring program existed; some even threatened carers who were using the mentoring program. A number of services complained to our funders, arguing that the funding would be better spent on service delivery.

On reflection, I can see that the bottom-up community development model was deeply perplexing to the health sector. We viewed the community mentors as knowledgeable and experienced citizens. They were autonomous people and our organisation was in many ways just facilitating a connection between a past and current carer. The connection and process almost seemed too simple. Further, the training program for mentors harnessed and built upon the existing knowledge and skills of the mentors. It did not look like a traditional eight-week training program. As such, the community development approach that we were promoting was viewed by the health service as inferior. Finally, our training program taught volunteers the skills they needed to be community builders and enhance the networks of carers they were supporting. This was a key part of the mentor role. Unlike traditional palliative care volunteer roles in Australia, mentors were 'knowledgeable friends' and they were network enablers—they normalised asking for and organising help. They
did not do housework or respite for example, but if there was a need for this kind of practical support the mentor could act as a sounding board and facilitate the mobilisation of the carer’s network.

At the time, although my experience told me that palliative care services viewed autonomy and self-reliance very suspiciously. I was completely bewildered by the response of palliative care services toward the community development program. I remember feeling a sense of helplessness about the interactions I was having within the sector because it did not matter how many questions or concerns I responded to, I was not able to reduce their anger toward the program.

Eventually we decided to reach out to other end-of-life organisations and services and that led to a partnership with the Motor Neurone Disease Association of NSW and other smaller not-for-profits. We started hosting community events about end-of-life planning as a way to find a neutral territory to re-engage with palliative care services. At one stage, there were over 100 volunteer mentors. It was not difficult to recruit people/past carers—as they deeply understood how the program addressed a need for social support for carers. They also had an understanding about how this would support the person dying and their family and friends.

The principles of self-reliance and autonomy as applied to communities, not individuals, is a key feature of community development and these were both the guiding principles and practices of this program. It is however a significant challenge to the controlling top-down managerial approach of health services (Ife, 2009; Kellehear, 2005). In many ways by doing bottom-up
community development we were challenging the usual relationship of power, and resisting the professionalisation and medicalisation dominance within the death system. We were both being renegades and disruptors in practices, not just rhetoric. But we did not fully understand it that way at the time.

The question of how community voices and lay experts can participate is an important one. I will return to this discussion in Chapter Seven. It does appear however that the palliative care volunteer, recruited, trained and managed by the sector is the only legitimate way a citizen, who is not a medical or health professional, can contribute to end-of-life care.

This experience gave me cause to reflect upon the way health services can respond to community development programs involving community members as volunteers. It was clear that palliative care volunteers in Australia had been professionalised and the expectation is that they function as an extension of the clinical teams (Kellehear, 1999). The mentoring program discussed above no longer exists in Australia, but it has inspired other programs in the UK (see McLoughlin et al., 2015). For example, it was influential in the early stages of the ‘Compassionate Neighbours’ program at St Josephs’ Hospice London, which is a collaboration between a palliative care service and a local community development agency ‘Social Action for Health’ (Barry & Patel, 2013; Richardson, 2011). Together, the two agencies developed a cross-disciplinary task group and out of this process a series of community-led initiatives were implemented. These initiatives included the development of community hubs where community members address issues about serious illness, death and bereavement together and request training and support from the hospice as
required (Barry & Manjula, 2013). The program is now widely viewed as a successful way to engage local community members through community development programs. Unlike our mentoring program however, the compassionate neighbours program was initiated and funded by the hospice, using both top-down and bottom-up approaches to navigate concerns about volunteer autonomy and risk management.

In India, the work of Kumar and colleagues has demonstrated how palliative care can be led by and delivered in partnership with community members and community organisations such as schools, police services, and college students (aged 17 to 24) (Kumar & Numpeli, 2005). The neighbourhood network program in India has led the way internationally as a program promoting bottom-up community development in palliative care. They have a highly autonomous and self-reliant model that effectively mobilises local communities. However, in the western context this program has been criticised for involving volunteers in patient care and for not maintaining patient privacy (Gupta, 2005). Though these criticisms emerge from a medical approach to dying:

I would contend that the palliative care as social mobilisation of the community model has the real danger of losing sight of its intended beneficiaries - the person dying with cancer and his/her immediate members of the family. Although one welcomes care providers gaining a sense of purpose and self-respect and a feeling of pride through helping neighbours, one must be careful that this does not become the raison d’etre for the model (Gupta, 2005, p. 93).
The self-reliance of communities is also a central feature of bottom-up community development. Ife (2009) argues that the principles of self-reliance and independence “become reconstructed within community development as values that need to be applied to communities rather than to individuals” (p. 32). These approaches, within the context of end-of-life care, can provide a framework to enable palliative care services to expand beyond the provision of clinical services into death education and non-traditional community partnerships that nurture and develop the existing community capacity around death and dying. It is this integration, the normalising of the connection between life and death, living and dying, that modern medicine and living in a modern society has changed significantly over the past 120 years.

A recent practice development is the co-design model, which is an approach to working with people to develop solutions they want to be part of (The Australian Centre for Social Innovation (TACSI), 2011, p. 4). An example is the Ageing Project by TACSI in Adelaide (2011). The methodology for the project centres on co-producing solutions to social problems with the people directly affected by and/or invested in change. In 2009, they began a body of work that identified ageing as an urgent social challenge that needed new thinking to create new solutions. These solutions challenge traditional service delivery models of aged care by re-focusing on bringing to life the strengths and abilities that currently exist within neighbourhoods and amongst groups of people who are socially or locally connected. This approach is unique in the Australian healthcare and aged care sector because the design process is not
focused on filling up perceived gaps with new or existing services. Instead it enhances what is already working for carers and older people.

**Leaning into Complexity**

Transformation is a radical approach to change. The *Dying for Change* report on end-of-life care argues there are four main types of social innovation: improve, combine, reinvent, and transform (Leadbeater & Garber, 2009). Many of the strategies for community engagement, as discussed above, aim to improve the end-of-life experience for people dying and their families. ACP is an example of both a personal and a policy level strategy to improve dying. The Liverpool Care Pathway was also considered a strategy to ‘improve’ end-of-life care. It is easy to see that ‘improve’ is the least disruptive type of innovation for health care organisations to implement, making it a popular choice for policymakers.

The ‘combine’ strategy includes reducing fragmentation by working to bring together well functioning aspects of end-of-life care, while ‘reinvent’ is an approach creating change by developing new institutions to do a radically different job. The most radical approach however is to ‘transform’ the experience of dying and death. This strategy aims to develop alternative approaches outside the current institutions. To create a completely new paradigm for caring for people who are dying, as Leadbeater and Garber (2009, p. 64) assert, “we need to go beyond improving, combining or even reinventing the services we have”.

Social approaches to end-of-life, can be considered innovative in the context of the current dominance of medicalisation and professionalisation in
the death system. Public health palliative care, given it is based on health promotion and undertaken primarily by and in health services would be viewed (as per Leadbeater & Garber, 2009) as an approach that ‘improves’ or ‘reinvents’. There is a body of palliative care and end-of-life care work that seeks to ‘improve’ care (see for example Lorenz, Lynn, Dy, Shugarman et al., 2008; Meier, 2010) but not transform it in the same spirit of social innovation.

In fact, there is very little evidence of a social change or social innovation discourse in public health approaches to end-of-life. One recent example of improvement in Australia was focused on using an arts-informed approach in residential aged care. Yalden, McCormack, and Connor et al. (2013) undertook an action research evaluation of what they called an “innovative and transformative” end-of-life care project, where they concluded that this work “led to a more integrated team, through enabling staff to be more fully engaged with family and carers and incorporating evidence-based palliative principles into the work of residential aged care” (p. 14). In the UK, where public health approaches to palliative care are the most prolific, there is a strong movement for social change in the National Health Service (NHS). A recent report Health as a social movement: The power of people in movements has a clear agenda (Del Castillo, Khan, Nicolas, & Finnis, 2016) to clarify and promote ideas about change and transformation in health. In particular, they contrast the dominant approach to change in the healthcare system with the emerging social change approach (see Table 5).
Table 5: Emerging themes in change and transformation (Source: Bevan & Fairman, 2014).

<table>
<thead>
<tr>
<th>Dominant approach</th>
<th>Emerging direction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power through hierarchy</td>
<td>Power through connection</td>
</tr>
<tr>
<td>Mission and vision</td>
<td>Shared purpose</td>
</tr>
<tr>
<td>Making sense through rational argument</td>
<td>Making sense through emotional connection</td>
</tr>
<tr>
<td>Leadership-driven (top-down) innovation</td>
<td>Viral (grassroots) creativity</td>
</tr>
<tr>
<td>Tried and tested</td>
<td>Open approaches, sharing ideas and data, co-creating change</td>
</tr>
<tr>
<td>Transactions</td>
<td>Relationships</td>
</tr>
</tbody>
</table>

As evident in Table 5, the dominant approach to innovation is based on traditional features of organisational and management structure. It is about producing control and predictability. The emergent approach however supports shared values and motivates people to take action toward urgent challenges together. Harnessing the tension created by these two approaches is considered a central task for leaders. Change needs leaders and Bevan and Fairman (2014) view activating “disruptors, heretics, radicals and mavericks” as a key enabler of change and transformation in healthcare. These are people who Bevan and Fairman (2014) see as the ones who can rock the boat and stay in it; these are the people who I wanted to talk with as part of this research.
Summary and Conclusion

The purpose of this chapter was to examine the dominant medical model and the emerging social models and social approaches to end-of-life, with particular focus on the potential role of community development and social innovation models in Australia. In reviewing recent policy and research, I have shown that social models continue to have a marginal role in the end-of-life sector in Australia. At the same time, there is emerging evidence of a growing dissatisfaction about end-of-life and deathcare practices in Australia, and awareness that the biomedical model has a limited role in promoting a healthy response to dying, death and loss. There is, for example, a significant gap between the death people want, and the institutional death that approximately 70% of Australians actually have.

Complementary social models and approaches are also beginning to gain traction in end-of-life care. Social innovation approaches, for example, have grown out of complexity theory and systems theory and are not a response to the biomedical model like public health palliative care (Leadbeater & Garber, 2009; TACSI, 2011). Public health palliative care provides a reorientation view of health, not the transformational change that social innovators and health activists are advocating for. Transformational change requires we develop complex in-depth understandings about the people who are doing change work and the methods they are applying to this change.

In this chapter I have referred to top-down and bottom-up approaches to systems change as a way to further understand current policy and practice initiatives. The health sector, as evidenced through the reports in this chapter,
has become quite fond of using the language used in community development approaches with little evidence that the concepts are fully understood. The phrase ‘Compassionate Communities’ for example, is applied to everything from compassionate care to community development projects (Paul & Sallnow, 2013). This appropriation of social language reflects the dominance of the biomedical model and biomedical practices in the death system. This adds little to understanding the practices and approaches of the changemakers who are on the ground doing the change work with/in the system.
Chapter Three: Researching Deathworkers: 
Methodology and Methods

Introduction

As a practitioner my aim for this research was to deepen the understanding about what shapes and influences socially oriented deathwork. I had an understanding that informal care tends to be marginalised and hidden (Horsfall et al., 2013) from the dominant systems and social processes, and I wanted to explore this further. The purpose of this chapter is to describe how I did this and provide an overview of my research methodology and methods.

Research Questions

Renegade stories is a qualitative study shaped by three research questions:

1. What are the stories of deathworkers in Australia?
2. How are these stories shaped and influenced?
3. How are the renegades working to make a difference?

Researching as a Critical Social Scientist

My primary aim in this research was to understand more fully the lived experiences of people using social approaches to death, dying, and bereavement, and how the dominant biomedical discourse is resisted and constructed by them (Foucault, 1967). As such, I chose to use a critical qualitative research methodology to explore the lives and experiences of deathworkers. Qualitative research is an interpretive approach to understanding social phenomena. This approach assumes that knowledge about social phenomena can be gathered through the exploration of people’s
reflections and understandings of their lived experiences. As such, I have used methods that are embedded within the social context of the phenomena being researched. I have used a critical approach to qualitatively research, informed by the critical social sciences (Fay, 1987; Freire, 1970; Habermas, 1985).

As a critical social scientist I am concerned with questioning dominant ideologies and taken-for-granted assumptions, and the need to give voice to alternative viewpoints (Eakin, Robertson, Poland, Coburn & Edwards, 1996). Critical social science takes the view that reality is constructed and shaped in “multiple ways through political, cultural, economic, ethnic and gender influences” (Higgs, Trede, & Rothwell, 2007, p 32). Key to the critical framework are the concepts of critical consciousness and praxis, which invite the researcher to critique and question the status quo (Fay, 1987). In doing this, the researcher explains the “social order in such a way that it becomes itself the catalyst which leads to the transformation of this social order” (Fay, 1987, p. 27).

Critical Social Science (CSS) holds that “humans are active creatures, that is, creatures who broadly create themselves on the basis of their own self-interpretations” (Fay, 1987, p. 47). It is not surprising then that CSS emerged from critical theory and developed from a desire to integrate theory and practice (Fay, 1987). As such, researchers taking a critical social science position are motivated not only by the examination of beliefs and practices, but indeed by seeking to understand the beliefs and practices needed to challenge the status quo and effect social change (Fay, 1987).
Research positioned in the CSS does not seek to measure human experiences. Instead, it seeks to develop a deeper understanding of experiences and social phenomena through an in-depth examination and critique of beliefs and practices (Fay, 1987). In this sense, research provides a way to access our understanding of the world. The process of reflection also extends to the researcher and their role as researcher (positionality) (Chavez, 2011).

There are several examples of critical qualitative research being used to understand deathwork and the death system. Glaser and Staus (1969) brought to life the process of dying in a palliative care ward using an ethnographic approach. Their work uncovered a hidden discourse about truth telling in palliative care. Other critical researchers have revealed new ways of viewing the role of women in the funeral industry (Watson, 2005), and the impact of working as a researcher in death (Woodthorpe, 2009).

I recognise that as a deathworker and clinical psychologist, this research is also a product of my own experiences working in the Australian death system. Throughout the research process I attempted to recognise and attend to my own positionality and the way my values and experiences have helped shape my research questions, data collection, and my analysis. I have journaled, kept personal notes, used the supervision process, presented to peers, and applied theory to practice throughout my candidature, as a way to stay present and reflexive.

Critical social science has an emphasis on practice and how theory is applied ‘in action’. Through action, researchers and research participants can form new insights. When new insights are developed, new actions can follow.
Critical social science argues that the role of critical inquiry is to foster the necessary and sufficient conditions for enlightenment, which then leads to transformation and change. This includes methods that support both self-knowledge and action (Schwandt, 2001).

Eakin et al. (1997) for example, have taken a critical approach to health promotion practice; they argue that CSS “reveals the ideological and therefore political nature of human knowledge” (p. 163), and that CSS provides a framework more suited to social change because researchers are also cognisant of the social conditions and structures that reproduce the status quo. Critique provides a way to both understand dissatisfaction and the actions that are taken (or not) to address this dissatisfaction.

Finding my Voice

I struggled at times with the question of legitimacy and my critical position. I constantly examined my values as a researcher and had numerous conversations with my supervisors about my critical position. On reflection, I am able to see that CSS challenged me and required me to declare my activist stance to both my research and my practice as a clinical psychologist. However, at the beginning of my research journey I feared that subjectivity and self-expression might make me appear self-indulgent, too radical and ultimately discredit any research I conducted; indeed all of the things that many participants in this research worried about too. There is no doubt that my training as a psychologist played a role in these beliefs. Psychology is so strongly ideologically aligned with the biomedical position but because my
psychological research days were long behind me, I thought it would simply be a matter of personally unlearning. It was not that simple of course.

Feminist researchers, such as Michelle Fine (2002) for example, have called the approach I am taking to research an ‘activist stance’. Fine asserts qualitative researchers can take three positions: ventriloquist stance, voices stance, and an activism stance. The activist stance seeks to “unearth, interrupt and open new frames for intellectual and political theory and change” (p. 220). Fine (2002) and Lorenzetti (2013) assert that when researchers declare their values, it has a profound impact on the development of research methods and the position of the researcher:

It took time for me to develop confidence and to apply reflexivity and emancipatory frameworks to my own self-expression and research writing. I struggled initially because I tried to write as if I was still a psychologist hiding behind scientific objectivity. Payne and Payne (2011, p. 153) describe objectivity as,

the principle drawn from positivism that, as far as is possible, researchers should remain distanced from what they study so findings depend on the nature of what was studied rather than on the personality, beliefs and values of the researcher...

The biomedical model that I was trained in requires that researchers hold an objective stance. CSS however, acknowledges the subjectivity of the researcher and the researched.

My understanding and my ability to self-reflect on the tension created by the subjective-objective ideologies was an important source of learning during
my candidature. My training in psychological research was helpful for my literature review and my interviewing skills helped me to interview people about sensitive topics. However the ideology of quantitative research was ever present and it created significant tensions for me as a critical qualitative researcher, when I was immersed in critical theories and developing a deeper understanding of critical social science. While this was a very intellectually stimulating and necessary period of my thesis, it seriously overcomplicated my writing and my thinking. I did not synthesise CSS concepts into my writing, I instead wrote long descriptive passages about CSS theory and practice.

As a psychologist, I am most closely aligned with the critical branch of community psychology (Laing, 2008). I practice as a clinical psychologist and have all the skills that I need to do that; assessment, diagnosis and treatment is the bread and butter of a clinical psychologist. What my professional training as a psychologist gave me was knowledge and experience about how to practice as a psychologist. The critical framework developed over time from participating in professional and personal development.

During my writing, I immersed myself in critical research and this time I took a different approach. I stopped writing notes about theory, facts and evidence and I listened deeply to the voices of my fellow critical researchers. It helped to know that a number of researchers have written about this tension in health, nursing, and medical research (Higgs, Titchen, Horsfall & Bridges, 2011; Rose & Glass, 2008; Horsfall and Welsby, 2007).

The resulting three key understandings have ultimately influenced my research voice and my thesis. First, that research is a political act. I have an
activist voice. I am a researcher who is interested in power, injustice and social change in the death system. The gap between how people want to die and how they actually die is unacceptable and change will not occur without challenging the status quo.

Second, research has a role in challenging the dominant ideas about the production of legitimate knowledge in the end-of-life space. Lived experience is an important research method (Koch, 1998). I am interested in alternate voices and lived experiences and I am aligned with a non-dominant paradigm in end-of-life care. Ways of knowing and telling that knowing are however not fixed. People develop ways of knowing in response to their environment and circumstances and there are multiple ways of knowing, experiencing and acting. As a critical social scientist, my thesis can contribute to end-of-life research that is socially oriented. Self-reflection and in my case writing about what influenced me was helpful to the process.

Third, boundary riding and crossing. Boundary riding is a metaphor for the ontological territory a researcher covers (Horsfall & Higgs, 2011). The term itself comes from farming, boundary riders are those people who check the boundary fences of large properties (Evans, 2014). Like many of the participants in this research I have multiple roles in the death system that impact on my approach to research and my self-expression. I work in a highly institutionalised end-of-life care environment in an acute hospital on a palliative care ward. My work as a clinical psychologist in this institution gives me a particular role in the care of people dying and their families. I am also a social researcher who has spent many years talking with people about home
death with a clear critical and social justice framework. I am a daughter and
daughter-in-law of ageing parents. I am a community death worker and death
educator who founded a charity whose mission is to disrupt community
conversations about death and dying. As a result I have worked in community
development in the arts with communities all over Australia; working with
people of all ages and backgrounds. As a critical social scientist, who
understands that boundaries are socially constructed, I have sought to
understand, challenge and critique my own boundaries and the way that
research boundaries are constructed to maintain the status quo (Evans, 2014).

Evans (2014) warns against doctoral candidates breaking boundaries,
even suggesting that it might be harmful. But I have come to accept that I have
multiple roles and experiences that make me both an insider and an outsider at
times. I am one of the renegades that Leadbeater (The GroundSwell Project,
2011) referred to. I am both participant and researcher and as such I have
included critical reflections to provide context for my values and motivations
for my research. End-of-life research does have disciplinary gatekeepers
(Evans, 2014). For example, by focusing on the burden of carers and caregivers,
the biomedical model controls the narrative and the solution for changing end-
of-life care. The act of boundary riding is important to the research process, and
I have found it a useful concept in the political act of researching death from a
social perspective.

I have also found it very challenging at times as someone who works in
palliative care to write about social control and medicalisation. I have noticed
that a tension exists in the literature too. Palliative care often reads like it is
trying too hard to be ‘scientifically accepted’ and at the same time provide reassurance that care is person-centred and holistic. Can it be both? The sociological critique of palliative care—in particular how enthusiastically palliative medicine adopted institutional routines and its increasing focus on symptom control—has even been accused of ‘sniping’ (Ahmedzai, 1993 cited in Maddocks, 2000). And here I am a clinical psychologist, social researcher, sometime community development worker, researching death, dying and loss from a social perspective. Does this make me a palliative care heretic? Possibly, however it seems that we will not make progress at all if we keep researching the medical model.

Researching social approaches when the medical model is so dominant requires an exploratory process. The following section is an outline of my research methods.

**Research Methods**

**In-depth interviews.**

In-depth interviews are one of the primary methods of data collection in qualitative research used to explore social meaning (Walter, 2006). This research used a semi-structured interview schedule enabling the exploration of the ‘social approach to death, dying and bereavement’. Interviews were designed to elicit stories about the lived experiences of deathworkers.

Qualitative interviewing is a distinct type of social relationship (Birch & Miller, 2000). As interviewers we need to attempt to suspend the belief that a more personal story reveals a more authentic story. We are responsible for co-producing such accounts, but can we ever be certain about the researcher’s role
in the production? This is especially difficult to assess in the unstructured interview, which is particularly conducive for gathering open, intimate stories (Birch & Miller, 2000, p. 200).

Because this was research with an exploratory focus I developed a semi-structured interview that was open ended and encouraged deathworkers to elaborate freely about their experiences and share their stories. For example I asked questions such as:

- How did you come to be doing this work?
- What does the social approach/health promoting approach to death, dying, and bereavement mean to you?
- Can you share a story that best captures the meaning of the social approach?

(see Appendix 3 for the full interview)

I chose a semi-structured interview, mindful of my status as both an insider and outsider in the death system. As noted above, my positionality shifted throughout the period of this study. At the time I was conducting interviews I was an end-of-life researcher and community death educator/worker. My main concern was that if the interview was too formal it might alienate and feel restrictive to participants not familiar with research interviews, and conversely if it was too informal my research colleagues might not feel like they were part of a ‘legitimate’ study (Chavez, 2008). The semi-structured interview however enabled the interview to be flexible and responsive and more like a conversation with purpose (Walter, 2006).
Further, I also needed to pay attention to ‘deferring responses’ such as “we’ve talked about this before” or “you know what I mean” (Chavez, 2008); and at each interview I reminded participants to “tell their stories as if I’ve never heard it before”.

... only those events which are significant actually bear on our identity and figure in the stories which are meant to reveal who we are; but what is and what is not significant depends on the perspective of the storyteller (Fay, 1987, p. 207).

As the key features of critical inquiry are critique and transformation (Higgs & Trede, 2010), my purpose in the interviews was not to seek one truth, but to illuminate and gain deeper insight into the lived and varied experiences of practitioners using a social approach to death, dying and bereavement. Acknowledging and giving voice to the multiple constructions of knowledge is important to me, because end-of-life research privileges the advancement of medical discourses and professional knowledge. I wanted to illuminate different stories and invite new voices, new ways of doing, and new knowledge to come to life (Higgs & Trede, 2010).

**Participants.**

As I have already shown in this thesis, research and practice in the palliative field is dominated by the production of medical and professional knowledge. Health professionals for example are rarely encouraged to speak to their own beliefs and practices in the sector, or speak with their own voices about death, dying, and bereavement practices. Likewise, there is very little acknowledgement given to ‘lay’ experts and deathworkers or non-professional
deathworkers in Australia. They are almost completely absent in the research literature despite their real life contribution and lived experience caring for the dying and dead in the general community. And this absence is what I sought to work against in my research by inviting deathworkers to speak about their own experiences and expertise, from their point of view.

Twelve people participated in this research, ten women and two men. Six identified as people working in institutions such as hospitals and universities. They were doctors, nurses, and researchers with clinical backgrounds in palliative and end-of-life care. The remaining six identified as community deathworkers they were death doulas, death educators, celebrants, and community development workers.

In order to protect the anonymity of my participants, in Chapter Four I have constructed vignettes to provide the reader with a more detailed overview of the institutional and community deathworker roles. As such, I have chosen to code data extracts with CDW1 to CDW6 for community deathworkers and IDW1 to IDW6 for institutional deathworkers.

**Procedure and Data Collection**

**Recruiting renegades.**
Ethics approval was obtained from the Western Sydney University ethics committee (Appendix 1; Approval number H9533) prior to beginning. Once approval was given recruitment letters were sent out via email to professional bodies and my own professional and community networks. This included the Palliative Care Australia newsletter, Social Networks newsletter at La Trobe University, and the Compassionate Communities network in Australia. I also
sent an email to my personal networks of people I knew to be working in the
death system. Invitation letters were all sent from my student email address.

Given that I wanted to explore the stories of people using a social
approach regardless of setting or professional group or workplace, my
recruitment letter made it explicit I wanted to interview people both inside and
outside of the palliative care sector. There are also people working from within
the community, outside the health and medical systems, providing end-of-life
care and after deathcare that is based on community development.

This research aims to explore all of these stories and experiences in the
death system. The death system is seen as shaping and guiding how we
interact with and act toward our dying, our dead and the bereaved. It is
my intent therefore, to look beyond the usual voices to those change
agents enacting the social approach in various aspects of the death
system. This includes people working in the funeral and celebrant
industry and community development (Recruitment email, 2012).

The participant information letter (Appendix 5) was emailed as an
attachment to the recruitment letter (Appendix 4). Participants typically replied
to my recruitment email via an email response. Three people wanted additional
information about the research to see if they were suitable. For example, a
surgeon, who had recently experienced the death of his mother-in-law and
heard about the research via a mutual friend. The death had sparked his
interest in how the health system had responded to his family and during our
conversation he decided that he was not suitable to participate.

In total 27 people responded to the recruitment letter. Twenty-one
(three male, 18 female) self-identified as working in the health sector as a
clinician or researcher, three were not suitable for the research, two were not interviewed due to scheduling issues, and four did not participate in the research when the sample size had been met. Six (four women, two men) health-based workers were interviewed. Two were interviewed via Skype and four face-to-face. Six women identified as community deathworkers. All six women were interviewed; four via Skype and two face-to-face.

**Preliminary analysis and recruitment.**

I interviewed nine participants and completed a preliminary data analysis. The method of this analysis is described in detail below, but I mention it here because I made recruitment decisions based on this analysis. Four findings to emerge from the preliminary analysis were:

1) There were differences in how participants talked about their deathwork. This included the way they discussed their social approach and the meaning they derived from their practice. This revealed that while all participants were motivated by social approaches to death, dying and bereavement the way they practiced was influenced by where they worked.

2) Institutional-based deathworkers were primarily working toward cultural change within their institutions, whereas community deathworkers were more concerned with social change.

3) Community deathworkers shared stories that demonstrated an extensive knowledge about medical and health systems. Whereas institutional-based workers rarely talked about community-based initiatives or workers such as death doulas.
4) This initial analysis also highlighted a gap in the academic writing about community-based deathwork in Australia. A quarter of the people who responded to the recruitment letter were practicing as community-based end-of-life workers, yet this practice appeared to be hidden from view.

Following this review I made the decision to interview an additional three people taking my total number of people interviewed to 12: six people each from the institutional and community settings.

**Interview procedure.**
All 12 participants were offered face-to-face, telephone or Skype interviews. As noted above, six participants chose Skype and six face-to-face. Skype provided flexibility and an inexpensive way to access participants.

At the time participation was confirmed I re-sent the information sheet and the consent form (Appendix 6). Prior to beginning the interview we reviewed the information letter and I invited participants to ask questions. In the case of face-to-face interviews I provided the consent forms and participants signed the form before we began the interview. For Skype, interviews participants either sent their forms back to me via post or electronically prior to the interview. The interviews lasted between 45 minutes and two hours.

As a researcher who is also an activist, I needed to pay attention to how I conducted interviews with people who had also come forward as renegades. While I had some insights into the challenges they faced I also deeply related to the experiences they shared. As noted early in the chapter, the insider/outsider stance meant that I needed to pay attention to deferring responses (Chavez,
2008). I addressed this directly at the beginning of the interviews, by reminding participants that I was interested in hearing all of their stories, even the ones I may be familiar with.

There were times during the interviews, for example, where participants challenged me about my insider status and what they perceived my role to be. One community deathworker said “I really don’t think it’s complex, it’s almost like, I know you’re doing your PhD, I’m doing all these studies, we’re all trying to convince everybody, but part of me laughs and goes you know it’s just not that complex” (CDW2). Another noted “I’ve got better things to do than a PhD” (CDW3). Institutional based deathworkers were worried about “ranting” (IDW4) and ensuring they were responding in a way that was helpful for the research (as noted below with transcripts). Having interview skills certainly helped in all these situations and in these moments when I needed to reassure participants or hold onto myself as ‘researcher’ I was grateful for my clinical psychology training.

Approach to Data Analysis

Transcripts.

Interviews were transcribed by the Transcript Diva's service within three days of the interview and returned to participants. I chose to have the interviews transcribed externally to ensure that I could return the interviews to participants for review in a timely manner. It was important to me that all participants were given the option to review the transcripts for accuracy and to change any aspect of the story that might compromise confidentiality or privacy (see Appendix 6 for the consent form).
Participants who volunteer for the in-depth interviews will participate in a 60-90 minute interview about their work. Interviews will be recorded and transcribed. Transcripts will be sent to participants to review for accuracy and identifying information. A brief 15–30 minute phone call will be made to participants as part of this data review process (Consent form, 2012?).

Some participants did not wish to review their interviews, while two people took the opportunity to change facts and identifiable information. One participant was particularly concerned about accuracy and after a week had not returned her transcript. When we discussed the research process, the participant revealed that she was reviewing and editing the file for grammar. Her concern was not about accuracy of the text as such, nor was it about confidentiality issues, instead she was concerned that the transcript was “a mess” and difficult to follow. She was concerned that it would not be useful to me and my research. Following our conversation she gave permission for the transcript to be used unedited.

**Methods of analysis.**

The methods of analysis I employed were informed by a critical and interpretive approach. The process was in-depth, iterative and creative and informed by thematic analysis which is a useful and flexible research tool for qualitative researchers. An inductive thematic approach outlined by Braun and Clarke (2006) was used to provide a guiding structure to the data analysis. This guide provides six phases of thematic analysis: data familiarisation, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.
As noted above, I completed an initial read through and analysis of the first nine interviews, which generated some preliminary findings and ideas that I presented at the 3rd International Public Health Palliative Conference in 2013. I used a similar method of analysis described in detail below. I used this review as an opportunity for feedback from my supervisors and also from my peers. As noted above this preliminary analysis revealed the emergence of four main differences in the stories of those workers in the formal and informal death systems.

To familiarise myself with the whole data set however I did two things. First I printed all 12 of the transcripts and did an initial read through underlining key points, taking notes about key ideas and any patterns that emerged. Second, I reviewed my interview field notes. These notes usually included a brief description of the participant and information about their work and approach. Following this process I developed a full description of each participant: the work they do, their values and beliefs, and the pivotal experiences influencing their deathwork. I reviewed all of these notes and descriptions, looking for any patterns emerging from the data. I used the question "What is the data telling me?" to focus my exploration of the data, and kept notes of repeating patterns across all of the transcripts. During this period of my data analysis I immersed myself in an iterative process of reading and rereading the transcripts, taking notes, making mind maps, and using sticky notes to tentatively develop and flag possible higher level themes. Alongside this process and guided by these patterns, I dipped in and out of the research literature, deepening my theoretical understanding of the stories and
experiences. I re-read the transcripts a number of times until I was satisfied that I was ready to begin generating initial codes.

Next I began the process of generating codes. To do this I used the online application 'Dedoose' to systematically code each transcript line-by-line. During this process I continued to keep written notes and I generated brief descriptions of each code. Twenty codes were generated during this coding process and then I began the process of reviewing the codes for higher level theme generation. To do this, I once again organised my data into mind maps and reviewed the initial themes with my supervisors.

At this stage I was aware that the codes generated both semantic and latent themes. I was seeking to know more about the deathworkers and their work (descriptive data), and also their experiences in the death system (data revealing broader meaning and implications). I reviewed the codes and organised the data into preliminary themes and sub-themes. The collated extracts that were now organised into the four themes loosely constructed as deathworker qualities, doing deathwork, system tensions, and strategies for renegade deathwork. I also had an additional group of extracts I labelled miscellaneous. These consisted of references to birth, changing culture and what the deathworkers defined as a 'social approach'. All of the coded extracts in each theme were collated, printed and read and reread to develop a thematic map of the data (Braun & Clarke, 2006). At this stage I reviewed the initial codes with consideration of these four themes. Finally, the individual themes were defined and reviewed. During this process it was clear that doing deathwork and system tensions were similar and they were combined into what is now
Chapter Five: Doing Deathwork: Renegade Practices. The data was reviewed to ensure there was consistency; however my goal was not to make all of the data fit neatly into categories, instead to accept the contradictions and paradoxes, consistent with my CSS approach.

These themes are the basis of the data presented in Chapters Four to Six.
Chapter Four: Renegade Deathworkers

I think that we are sort of renegades in a way, because we’re challenging the system to actually be more patient-centred, when the way the system is developed, is to be more system-based. It’s more... fact... well, production line even. People come in, get them out of hospital very quickly, get them back home. The idea is to not have them in hospital for too long, so their bed stay is as small as possible (IDW3).

Introduction

The purpose of this chapter is to introduce the deathworkers who participated in Renegade Stories. Twelve practitioners, six employed in institutions (IDW) and six deathworkers who identified as practicing in various community-based roles (CDW) shared their stories about having a social approach to their work. I wanted to gain a better understand about what shapes and influences the practice of deathworkers. I wondered *Why do people do this work? What does the social approach mean to them?*

This chapter also provides an overview of how professional and personal experiences shaped social and work practice and how this learning was pivotal in the way it informed this ‘social approach’ to deathwork.

Who are the Deathworkers in ‘Renegade Stories’?

Rather than present the individual stories of each deathworker I have used the data to construct two vignettes that provide the reader with a richer understanding of the similarities and differences that emerged in the stories of institutional and community deathworkers. This section provides an overview of how deathworkers think and feel about their work and professional
practices, setting the scene for the rest of the chapter, including *what it means to have a social approach*.

A ‘social approach’ was a unifying concept for practice, the most influential factor however was found to be place of practice. As noted in the previous chapter this finding emerged during the data collection process and it is a major finding I examine throughout the remainder of the thesis.

**Vignette one: The “small a activist”**.

*When Sam was an undergraduate medical student she knew she wanted to specialise in palliative care. “Palliative care was an opportunity to really delve into being holistic in the care I was providing” (IDW3). She was and still is passionate about end-of-life care and supporting people to die well, and she takes pride in getting to know her patients, their stories and families. Sam is 49 now. She has had a number of different roles in the health services as a doctor. She has worked in New Zealand and in remote parts of Australia.*

*She did not expect that she would need to fight for and advocate for her patients’ needs in the healthcare system. On a daily basis she might be advocating to admit a patient, or to send one home or be debating with a colleague from another specialty about why an increase in morphine is justifiable. Despite this, Sam uses her professional standing as a doctor and a palliative care specialist to create change in the hospital where she works.*

*Sam’s current role is ‘palliative care specialist’, and while this gives her authority in the community palliative care team, she knows her colleagues in other medical specialties are regularly confronted by her approach to illness,*
dying, and death because they can be actively dismissive of her medical recommendations. On occasion they are publicly aggressive and angry.

There have been times she feels unsupported by her medical colleagues in the hospital setting because of the work she does in palliative care. She believes that the care of the dying is a skill every medical professional needs, that not everyone survives curative care, and not everyone wants proactive life-saving treatment. Sam knows this because she has time to have conversations with her patients and their families to learn what their wishes are. She cares deeply about how people want to live before they die. Sam believes that many more people could benefit from palliative care and is frustrated by the myths that her colleagues reinforce by not referring earlier to palliative care.

The work Sam does often involves ‘working around’ the health system, and sometimes her colleagues, to get things done. This attitude of getting things done despite the system is a key approach to practicing in the health system. She believes that small and sustained changes in the delivery of care in an institution can ultimately create cumulative change. Sam has seen the positive impact that comes with patients making informed choices about their medical treatments. At times this has included patients choosing to stop curative treatments such as chemotherapy, which can emotionally and physically affect patients and their families.

Sam has had personal experiences with illness, dying, and death. She has had family and close friends and colleagues die. Her professional experiences of dying and death though significantly outnumber the personal. Every day at least one of her patients die. In over 20 years of palliative care practice, this is literally
thousands of people. Sam is also a source of support to family members and members of the multi-disciplinary team she works with.

After 20 plus years of working in end-of-life care she is realistic about how long change takes. She helped to lead and implement a number of policy and practice changes. Sam has had to develop ways of managing herself when these have been challenged and criticised by other staff members or by executive teams. She applies her knowledge of systems and cultural change theory, and draws strength from her ‘old school’ mentors to keep chipping away at changing the system. Sam is also keenly involved in the next generation of doctors, teaching medical students to work on influencing new medical practitioners about palliative care.

Sam is not sure if this work constitutes activism but she is definitely an advocate for her patients and their families. She is a palliative care doctor first though. On reflection, Sam calls herself a small ‘a’ activist.

The institutional-based deathworkers interviewed in this study, like Sam, came from a variety of professional backgrounds including social work, health promotion, medicine and nursing. They worked in places such as acute hospitals, universities, community health services, and not-for-profits. Two had previously worked in a ‘health promoting palliative care’ role and were engaged directly in public health activities. A social worker with many years’ experience working in bereavement, said her current role enabled her to provide leadership to a team of case managers, while a palliative care doctor said that participating in the research was a way to give voice to the work she does advocating for the dying in an acute hospital.
Vignette Two: Committed to my Community

Fran is 47 and she has worked in a community centre for over 10 years. Her job involves being a jack of all trades, from managing volunteers to working the community garden and local arts festival. She describes herself as deeply engaged and involved with the people in her local area. She identifies as someone who works in community development. She is deeply compassionate about her local community.

Over the past decade Fran cared for both her parents as they died from cancer. Her father died first. He had lung cancer and brain tumours that were diagnosed very late. He was referred directly to palliative care and died in a hospice. Three years ago Fran’s mother (Pat) was diagnosed with breast cancer, then a short time later a scan revealed a tumour in her ovaries and liver. Pat was in her late 70s but chose to have chemotherapy, which helped for a while; and then Fran, her partner, their two teenage children, an aunt and two close family friends all pitched in to support Pat so that she could die at home. This was the first time Fran had been involved in the intimate care of someone dying.

While Fran was caring she began to think about the way death and dying was experienced in her local community and broader society. Her experience with the local hospital was challenging because services were not available as she had expected and her learning curve about palliative care was very steep. Overall, the end-of-life care services her mother received were adequate, and ultimately they got by because of family and friends. After six weeks at home, Pat died in the front room of her home. It was an experience Fran describes as good enough. The experience she had with the local funeral director was surprising. They were
paternalistic, acting as if she was incapable of decision making and treated her as a vulnerable person. She grew increasingly frustrated as they made it difficult for her to carry out her mother’s wishes. Fran remembers the experience as distressing. She was left wondering if an educated, middle class white woman, has had such a difficult experience caring and planning a funeral, how was the experience for other people in the community?

Fran believes that death is a part of life. She has no great fear of dying and has since cared for a number of friends and family members through their dying and death. She has become an educator and regularly advocates for people who are dying and their families so they can access healthcare services on their own terms. She believes that healthcare needs to integrate dying, death, and bereavement experiences, instead of creating silos to separate out these experiences. Fran has always been an activist, only now she is using these skills to improve the experience of death.

Her mother’s death was the catalyst to start her own death doula and death education business. She works with carers, family members, and the dying person. She describes her work as holding a space for people so they can make informed choices about how they die. She also describes this deathwork as community cultural development. She advocates, empowers and informs so that people can make more informed decisions about end-of-life care and body disposal.

As an activist, she feels like it is a fight to be heard at times—the community gets it but there are professionals and structures in the death system that are resistant to change and unsupportive. Fran spends a great deal of time
educating both professionals and the general public about the death and healthcare system. She draws upon her leadership skills, her feminism, and her understanding about social change to enable and enrich her work.

Fran says she is a realist. She thinks the best way to make change is to connect with the hearts and minds of people in the community. She knows she can contribute to creating this change because of her personal and professional experiences so far.

Community deathworkers had various ways of defining their deathwork practices. For example, they referred to themselves as death doulas, death educators, celebrants, visual and sculptural artists, writers, community development and community cultural development workers. All of the community deathworkers practiced their 'deathwork' in an independent financial arrangement or a social arrangement that was negotiated directly with each family they worked with. At least two community deathworkers were providing their services in a voluntary capacity, as a way to maintain their ability to do the work. One community deathworker had worked for a number of years as a celebrant while developing her end-of-life services. She (CDW4) talked about her work as carving out a little bit of space within the death system to practice supporting and equipping individuals and communities to know-how to meet their life passages. Like other community deathworkers she did not hesitate to describe her work as activism.
Social Approach: “It takes a Village to Nurture People out of this World” (IDW2)

Defining a 'social approach'.
As noted in Chapter One, there is no one definition of the social approach to death, dying, and bereavement. However, what is generally agreed is that social approaches to death, dying and bereavement aim to build the knowledge, capacity and resilience of the whole community (Kellehear, 2005). In practice however, social approaches can and do encompass a wide number of community-based initiatives (Paul & Sallnow, 2012). Given that all of the deathworkers who came forward to participate in this research identified as having a social approach, I wondered how deathworkers conceptualise the social approach idea and how it informed (or not) their practice. As such, I asked deathworkers an open question “what does the social approach mean to you?” during the in-depth interview (see Appendix 3).

The main idea to emerge from the data was that having a social approach is connected to the view that death is part of life. This was expressed in three ways:

1) a social approach normalises death as part of life through conversations,
2) it promotes mutual support and equal partnerships, and
3) it recognises existing community knowledge and experiences about death and loss.
Social approaches normalise death as part of life through conversations.

All deathworkers, regardless of work setting, felt that death was a topic that should be ‘normalised’ and more present as a topic in the community. One institutional deathworker (IDW5) said “a health promoting social approach” is an accessible way for people to have the conversations:

I guess at a basic level it’s just having a part of the conversation that we have in life in general you know that we can talk about dying, that it’s something that is not hidden away… (IDW5).

For another institutional deathworker (IDW4), a social approach was about creating opportunities for intergenerational conversation:

On one hand, I think that we’ve sort of removed the everyday talk about death and dying, and so in terms of the social approach and health promotion, I think about that in terms of right back to children in school. Talking to children about death and dying…where you sort of bring young people together with older people and you have extraordinary conversations using methods like drama (IDW4).

Whereas a hospital palliative care specialist viewed health promotion as enabling conversations in palliative care:

...health promotion is enabling conversation in palliative care about death and dying that are ongoing conversations that people can, you know, at different stages in their life... but that they’re constantly thinking about it but not in a dreading way... (IDW1).

IDW1 also added that health promotion conversations are the most authentic community conversations because they:
...happen at football fields, in the coffee shop, in the school canteen, in the mothers’ group, in the office... So health promotion that promotes real understanding and reflection, to get understanding you need to reflect and you need to be prepared to change your views.

The type of conversation, was also viewed as important:

...part of me laughs and goes you know it’s just not that complex, we just have to sit with people and go “oh right when people die they find it hard to breathe, when people die their heart stops, you know when people die they get cold”, and those are very ordinary things we have got no experience of, so we find that traumatic (CDW2).

All of the participants in this research viewed normalising death, dying, and loss through conversations to be a key feature of the social approach. This includes being free to have a conversation in any setting (sporting clubs, schools), at any age and regardless of your health status. They believed that to be most effective these conversations should be genuine and truthful, simple and uncomplicated. Further, participants did not view health professionals as the ‘rightful’ initiators or the facilitators of these conversations, which is at odds with public policy in Australia. A community deathworker (CDW2), for example, states it plainly when she says it’s “not complex”, and asserts that the increasing professionalised approach to the conversation about death and dying is unhelpful. This is consistent with a recent advance care planning article that argues for an “upstreaming” of end-of-life conversations (Prince-Paul & DiFranco, 2017). Like the deathworkers in this research, Prince-Paul and DiFranco argue that end-of-life conversations are becoming an overcomplicated
and technical process that alienates the people who may benefit most from planning for their end-of-life.

In Chapter Two, I argued that the dominant approach to end-of-life planning in Australia is legal and technical with a preference for standardised forms. Members of the public are increasingly told to talk about their end-of-life wishes and to write an advance care directive as a way to avoid futile treatment at the end-of-life. Institutional deathworkers are familiar with the health system approach to end-of-life planning, so it is in some ways not surprising they emphasise the need for end-of-life planning conversations to occur in social settings outside of health institutions. Further to this, no deathworkers in this research referred to the topic of death as ‘taboo’, despite this being a common marketing message by health-based institutions invested in advance care planning. This is consistent with the social research and public health proponents, who for decades have been providing evidence and arguing that death is not a taboo topic within the general community (Kastenbaum, 1977; Kellehear, 2005; Rosenberg, 2011; Walter, 1991).

The deathworkers in this research had a preference for community-based conversations that build capacity, are meaningful and social. At its best, advance care planning can be this, however we need to take care that it is not conflated with the public health approach to end-of-life (Paul & Sallnow, 2013). In a recent example of a health promoting palliative care approach, advance care planning and directives are used to help build and encourage the development of care networks (Abel, 2017). This uniquely addresses concerns
public health proponents have about using advance care planning as a 
community engagement strategy (Sallnow & Paul, 2014).

**Promoting mutual support and equal partnerships: 'Partnerships, 
community, let’s all get in there, there’s not one expert, let’s all share our knowledge... (CDW5).**

The next way deathworkers in this research defined the social approach was 
through an emphasis on mutual support and partnerships. A key value 
proposition of a public health approach is the focus on collaboration and 
partnership. Deathworkers considered this to be a central tenant of the 
approach.

To me, the social approach is about a partnership, a genuine, mutual, 
reciprocal partnership, between people who are experiencing illness 
that will end their lives, and services that can provide support for that 
(IDW6).

... social approach to me would mean that, there’s not some expert on 
death who is old school lecturing, but it’s more about, let’s get involved 
and let’s use our strengths and build skills and take a more community 
approach... (CDW5).

While both promote equality, connection was also important to all of the 
deathworkers in this research. The above examples highlight how institutional 
and community deathworkers are shaped by their contexts, for example, IDW6 
views a social approach that promotes partnership between the dying person 
and their healthcare team, while CDW5 does not want community members to 
be “old school” lectured by health professionals.
The community deathworker quoted above was inspired to work as a death doula after the death of her father. She values her practical knowledge and practical understanding of what it takes to be an end-of-life carer. Her father died in hospital after significant attempts to get him discharged from a hospital setting to her home. CDW5 now works directly with families despite her own anxiety about being ‘qualified’ to work with the dying. Eventually she came to realise that her community development experience was an invaluable guiding framework for her deathwork. IDW6 views partnerships as an essential part of the social approach; however, the partnership dynamic he refers to is between palliative care service providers and the dying person. As a nurse and a researcher, he has a different experience of partnerships. It is more aligned with the professional/health service relationship and the person-centred care approach. This is a topic I will return to in Chapter Five.

As noted in Chapter Two, community development, because of its focus on mobilising community and capacity building, is considered an important social practice in the field of public health. Community development can be delivered as a top-down or bottom-up strategy. Health professionals can also work in their traditional nursing or medical roles and have a community development approach (Talbot & Verrinder, 2017). The view of participation is the same, that is, community members and health professionals ought to be equal; however, the mode of delivery can be different. For health services community development can be a means to an end, for example promoting palliative care in the community:
How to reconnect not only with communities, but also with each other, I think that’s an interesting way to promote palliative care, within that… (IDW3).

This is again consistent with research in the UK suggesting that public health approaches to palliative care are not always social approaches but instead marketing opportunities for palliative care services (Barry & Patel, 2013). As such, community development was considered an important model of partnership development and was mentioned by a number of community deathworkers,

...irrespective of whether it’s death, or drug and alcohol, or whatever. So, you know, it’s about the pooling of resources, using expertise, and really creating something through a community (CDW5).

The community is the expert (CDW4): Recognising existing community knowledge and experience of death and loss.

Finally, a social approach was seen as recognising the existing community knowledge and experience about death and loss. A community-based deathworker emphasises both normalising mutual support and legitimising the social actions that occur within the community:

...it’s more a community model that you could you know ask Jo Blogs over the back fence so what do you reckon you know, and there’s information in the community that is alive and you know it’s really how people, it’s like you know people gave birth for years without medical intervention and sometimes medical intervention is a really great thing and sometimes it’s not, and there was a lot of knowledge in the community about what to do and what a labour would be like and what you need you know what you’re going to need, food and how are we going to make that happen and, so there’s a lot of knowledge in the
community. For me the best way of building community and building knowledge and empowering people is to, is that this knowledge just be part of our culture, not something that we are separated from or that is looked on as being sort mysterious or scary or medical... (CDW2).

An institutional-based deathworker in a health promotion position talked about the role of community building:

I can see, now, from personal experience, that encouraging people to encourage the one approach. I often think of it now as this is about gathering the village, that it takes a village (IDW2).

She added:

It’s taught me the importance of that compassionate community of caring people helps you get through, helps you travel the journey. Whereas I think before my involvement with this personally, I would’ve just clammed up and thought, “oh this is very private. No one would want to know about this. I’ll just do it on my own” (IDW2).

Overall, there were very few direct references to specific public health practice models such as health promoting palliative care or compassionate communities. In fact, institution-based deathworkers were the only participants who mentioned ‘health promoting palliative care’ and ‘compassionate communities’. One community deathworker commented:

...health promotions people may think “far out, how can death be health, you know, how can it be health promotion, how can... those two words go... three words go in the same sentence”. But, you know, it’s about resilience and mental health, and our capacity to deal with challenges... (CDW5).
Another community deathworker was slightly frustrated with my question about a social approach and the labeling of practice said:

...the really important thing is to see that this is not anything new, this is just a return to the traditional way that it was before other people came along and created an industry around it. So it’s not new, it’s not alternative, it’s traditional, full-stop, and people really need to sit with that thought and from that place they see that everybody has that capability and they have a choice whether they want to do it or not (CDW3).

I was surprised by how infrequently participants referred to public health approaches such as health promoting palliative care (HPPC) or even community development. I even wondered if I was interviewing the right people. I had expected that HPPC would feature in most of my conversations because I had assumed it was synonymous with the term social approach. While there was evidence that deathworkers knew about HPPC, it clearly was not important to all deathworkers in this study. I found little evidence that community-based deathworkers were utilising health promotion principles or the public health research, instead they focused on community development and other social practices.

So why is this? And does it matter? One explanation is my interview questions focused broadly on ‘social approaches’ rather than asking directly about health promotion. As a result, it is possible that this information simply did not emerge from the data. I suspect part of the problem was my expectations. I was highly familiar with HPPC and I simply over-estimated its reach beyond palliative care and institutions. This has caused me to reflect
greatly on the language in the field. It is confusing and technical. If a practitioner is to develop a public health approach, is an understanding of the Ottawa Charter (WHO, 1986) required?

Since their inception public health approaches have been challenged by poor definitions, confused use of public health terminology, and poor conceptual clarity (Dempers & Gott, 2016b; Rosenberg & Yates, 2009; Sallnow & Paul, 2014). At the time I was conducting my interviews there have been very few health organisations leading the way with health promotion activities in the end-of-life sector. In 2008–09, the UK appeared to embrace the more intuitive ‘compassionate communities’ term according to Barry and Patel (2013), and since then public health approaches appear to have grown exponentially. One institutional deathworker noted:

I think community development is probably one of the bits of language that we could use more effectively. If you say health promoting palliative care, anyone who has heard of it says, oh yes, that’s Allan Kellehear – where is he now? You know. Whereas if you talk about community development or you talk about death literacy, it doesn’t belong to any one person, or it’s not identified as any one person... (IDW6).

In Australia, the term ‘compassionate communities’ has had a recent revival, and in 2017 a national ‘compassionate communities symposium’ was held. Unfortunately in Australia, this terminology has not really solved the conceptual congruity issues. If anything, the words compassion/compassionate are strongly associated with service delivery and ‘care’ models. To add further to the confusion is the development of the ‘compassionate city charter’ (Public
Health Palliative Care International, 2017) (Appendix 9), which draws upon the principles of the Healthy Cities concept (WHO, 1996) outlined below.

A Compassionate City:

- Has local health policies that recognise compassion as an ethical imperative.
- Meets the special needs of its aged, those living with life threatening illnesses, and those living with loss.
- Has a strong commitment to social and cultural differences.
- Involves grief and palliative care services in local government policy and planning.
- Offers its inhabitants access to a wider variety of supportive experiences, interactions and communication.
- Promotes and celebrates reconciliation with indigenous peoples and memory of other important community losses.
- Provides easy access to grief and palliative care services (Kellehear, 2005, p. 46).

The present research findings are consistent however with the Barry and Patel, (2013) findings:

The case studies given illustrate the breadth of approaches and interpretations of the vision being currently applied across England. In keeping with Kellehear’s concept, there was a broad range of groups, organisations and individuals involved. Some of their work had been inspired by Compassionate Cities as well as by the models found in Australia, Ireland and Kerala, in India. Others were developing their own interpretations of the approach (p. 7).
However, unlike the deathworkers in this research, two-thirds of the 32 people who responded to Barry and Patel (2013) were aware of Allan Kellehear and the compassionate communities approach. Interestingly however, they found that there were new interpretations of the public health approach where there is “a balance to be struck between a loose interpretation of Compassionate Communities and the need for authenticity of approach, guiding principles and clarity of context” (Barry & Patel, 2013, p. 7).

Social approaches designed for dying, death, and loss are marginal even in palliative care circles (see Abel et al., 2013; Brown & Walter, 2013; Horsfall, et al., 2015). In the UK scoping study (Paul & Sallnow, 2013), it was apparent that health and palliative care services had invested resources into public health initiatives. I did wonder if the poor investment in public health approaches in Australia have contributed to just a lack of familiarity with social approaches. As expected, CDWs were more likely to talk about community development or community cultural development as a practice they are engaged in.

One IDW who had previously worked as a health promotion officer notes:

Well there was no way for it to be prescriptive I suppose because it’s new, on the edge. No one’s really written a constraining “you’ve got to work in this area”. Maybe they will rein it in, but no one’s quite sure what area to work in, so it’s fairly open. But I guess health promotion work’s a bit like that. Well it’s more community development work’s a bit like that, in that you’ve got a shape of how you behave but what it’s going to look like is all to be – that’s the best part about it I think is
you’ve got an end in mind but how it’s going to look maybe depends on who you’re working with, who you engage with and involve (IDW2).

Institutional deathworkers did demonstrate this conceptual blurring at times. For one participant, a hospital doctor, a social approach was framed within social or community care. For him this meant ensuring his clinical practice was thoughtful about the social impact caring can have in our modern societies:

I think from a social perspective, it’s more of a community-based approach. I think that communities over the years have been eroded by the fact that the world is now one big community. People are flying off to... sorry, children are flying off... the rest of the family are left in places they are. Not many people are growing up and living in the same places they grew up. So those communities have changed, rather from being people that know each other as friends, that have grown up together and stayed there, those communities are changed by other people coming in, and those differences. Having to work around those differences to actually live together is one thing, but actually in terms of palliative care, and social supports within that, I think that’s an interesting area to try and rebuild communities.

I think that within cities, we’ve lost some of those communities, and in the rural areas, you see that a lot more. So how to reconnect not only with communities, but also with each other, I think that’s an interesting way to promote palliative care, within that... (IDW3).

This demonstrates some of the tensions that institutional deathworkers experience while implementing community development approaches. Will I be reined in? The process feels chaotic! Ultimately, community development workers accept contradiction and chaos (Ife, 2009). However, work within institutions is characterised by hierarchical service delivery that is designed to
reduce unpredictability and control chaos. This makes community development a challenging undertaking for anyone employed by an institution to deliver ‘expertise’ to their patients. The institutional deathworkers in this research certainly experienced this pressure; and I will discuss this further in Chapter Five.

Community capacity building was also described by all deathworkers as an important part of the social approach. This included having the goal to bring to life or unearth existing community knowledge:

I think the social approach really means that the social frame can just hold so many potentially contradictory or simultaneously contradictory needs, or different faith and different cultural bases. It can actually be a space in which a lot of different beliefs, methodologies, ideologies can meet, because it’s such an amenable and responsive and plastic frame. So I think the social frame also means it’s the space in which, as individuals and community, we can begin to reclaim knowledge that’s been professionalised, because everybody, regardless of their level of professional skill or being an expert, and there’s a lot of the culture of the expert in death and dying particularly, so the social frame actually equips community members as experts in their own context (CDW4).

This community deathworker (CDW4) was one of the more experienced practitioners to participate in the research. As a death doula with a long-standing and well-respected practice, she described the challenges she has faced working in an invisible field of practice. Her work with dying people, their families, and communities was rarely acknowledged by mainstream deathcare professionals and palliative care professionals. In spite of this, she developed a lean and flexible approach enabling her to work effectively alongside
mainstream healthcare with dying people, their families/communities. In this quote, CDW4 gives us insight into how she has managed to practice as a deathworker in the margins. Her approach is structured and framed by a social approach because it is a model that provides her with an inclusive and flexible frame. This makes it possible to manage competing agendas and needs. In this research, it was clear that CDW4 and other community deathworkers have a positive view of how a social approach can contribute to social change in the death system.

Overall the responses to the question what does the social approach mean to you? revealed a number of shared beliefs about normalising death and building community capacity. Some important differences between community- and institution-based deathworkers began to emerge. Firstly, institutional deathworkers tended to have a focus on service delivery. They were more likely to refer to research literature and definitions from the literature. Community deathworkers did not conform to any one way of talking about a social approach. They tended to refer to capacity building and assets-based approaches, which have four foundational ideas (Kretzmann & McKnight, 1993; Mathie & Cunningham, 2003). When a community focuses on assets and strengths instead of problems and needs, it tends to identify and mobilise individual and community assets, skills and passions. It is a relationship-based process. One institutional deathworker reflected that health professionals must also “trust that communities will be able to look after themselves if you have given them some encouragement to do it, but it won’t just happen on its own” (IDW2).
**Pivotal Experiences with Death: Experience Shapes Practice**

This section provides an overview of the reasons why the deathworkers have adopted a social approach, contributing to the understanding of what shapes and influences deathwork practices.

The deathworkers who participated in this research all described a ‘pivotal’ personal and/or professional experience that helped to shape and influence their social approach to deathwork. Pivotal experiences represent a turning point and are described as moments in time that serve as a focal point for reflection and meaning making (Banks-Wallace, 1998; Carter, 1995; Chinn & Kramer, 2008; Grassley & Nelms, 2009). The experiences described here occurred during key developmental periods: childhood, early adulthood or during early career development. Two sub-themes emerged from the data: social experiences of death and dying with family and friends; and institutional experiences. The institutional experience sub-theme has both personal and work related experiences.

**Friends and family: learning about death for the first time.**

All participants identified the death of a close family member or friend as influential in the way they approached their deathwork. Deathworkers revealed that exposure to death either at a formative time (i.e. first employment) or during childhood/adolescence continued to have an influence on their deathwork today. Family, being the primary place of socialisation is where we learn the rules of engagement with the broader society (Kastenbaum, 2007), and we are exposed to cultural norms, including those related to death.

Therefore, family experiences were formative and normalised the experience of
death and loss in a meaningful way. These experiences were still painful and difficult, but they were not described as traumatic.

“I was treated like an adult”.
When death and loss occurred in adolescence, the deathworkers in this research reported the experience was normalised within their family and social contexts. Often deathworkers talked about the experience as a touchstone for their professional work in later life. One institutional deathworker shared a story about the death of her best friend:

I had my best friend die when she was twelve, she had leukaemia...and in those days the treatments were horrible and I went through that process with her and she blew up and had to wear wigs and as a thirteen-year-old, and my mum was just superb in the way she handled it because nobody talked about it of course, but my mum used to pull me aside for chats, and I think she set me up really... (IDW5).

She reflected further about her mother's response:

... she treated me as an adult, she understood when I got upset... she was a working class person, she didn't have any [training] but she just was comfortable (IDW5).

She reflected even further about the impact of this significant death.

...so my twelve-year-old self experienced something that a lot of people don't experience until they're much, much older, so perhaps that gave me that emotional maturity around death and dying, don't know (IDW5).

A community deathworker described a similar response to experiences in her childhood:
When I was a child my grandparents were the caretakers of the cemetery... I used to go and visit them until I was about ten... my grandfather would be digging graves or whatever, so I would just run and play with him, and it all seemed very normal.

...then when I was 14 my best friend died...and between 14 and 16 I probably went on this little spiral of thought which was oh my god it’s so random but it sort of isn’t and it’s, I could be dead, my plan for the future could be dead by the weekend. And so it really was an interesting time, but when I popped out of that at 16 I was sort of like okay I get it... (CDW3).

The experience of death in childhood or adolescence is rarely considered a positive experience. Much of the psychological research highlights poor health outcomes and increased vulnerabilities for certain deaths, including sudden death, and death of a parent (Strobe & Strobe, 2007). The stories in this research have not followed this script; if anything they suggest that experiencing loss might be helpful for future attitudes about death. In particular, the normalisation of death and loss as a family event or an expected, though difficult, life event may also have a protective factor. This is consistent with other research on resilience and continuing bonds following loss (Boerner, Wortman & Bonanno, 2005; Bonanno, 2008; Breen & O’Connor, 2010; Rosenblatt & Wallace, 2005).

Seeing death: “that was the real part...” (CDW1). Another important experience shared by deathworkers was seeing death and spending time with the dead body. One community deathworker experienced the loss of her grandparents when she was in her early 20s. At the time of her grandmother’s death, she had been studying death practices and deathwork in
Australia. It was her grandmother’s death that provided her first deeply personal and hands-on experience with the rituals associated with caring for people who are dying and caring for the body after death. In fact, this experience transformed her attitudes about working with the dead body. She said:

...for my grandma it was putting on her favourite perfume, and...that was the real part, that was...I feel like I’m dealing with her death, she’s right here and she is dead and I am caring for her. And that was it for me, that that was my grieving. That was me coming to understand that this is a body that she is gone from, we’re going to dress this body and we’re never going to see it again. (CDW1).

Here CDW1 is also reflecting on the reality of death through experiencing the dead body of her grandmother. In Australia dead bodies are usually hidden from view and the care of the dead body is primarily a professionalised practice (Howarth, 2005; Walter, 1993). Caring for her grandmother’s body after death was deeply significant, but it was not encouraged or supported initially by either the health professionals or the funeral directors. The experience of having the ‘battle’ with professionals provided this deathworker with some of the motivation for pursuing a career in deathwork. At the time it was happening:

... it became more and more apparent that this was a moment where something could be done, that the family could be brought in to do it... (CDW1).

This was the catalyst for what CDW1 needed to develop a service that would enable families to be more involved in the care of the dying and the dead.
Profoundly personal experiences like this one served as turning points in the career trajectories of a number of deathworkers. In reviewing these stories, it started to become apparent that in deathwork the personal and professional are intertwined.

**Becoming “acquainted” with dying and death.**

For one community deathworker it was her caregiving role and the grief she experienced during the AIDS epidemic in the 1980s and 1990s that changed her career path. As a volunteer she learnt about caring for people who were dying. As a friend, a neighbor and community member she experienced what it was like to be a member of a care network. Solidarity and connection was extremely important for the gay community who were so extremely disenfranchised and shamed by the stigma associated with HIV and AIDS. She recalls how heartbreaking the funerals were. Recalling that there were many funerals that were conducted completely at odds with the character and wishes of the person who had died. Many people had to hide their sexuality, identity, and the cause of death. She recalls:

> For a white middle class girl in the twenty and twenty-first century, I’m much more acquainted with death and dying in my early twenties than most other people (CDW4).

While these experiences were formative it was the death of her parents, a few years apart, that significantly transformed her deathwork:

> In my life, the two experiences that I see as foundational in this practice, was the death of my father, and ten years later the death of my mother, and in between that and before that a lot of other deaths. Those two ones gave me experience— on one hand with my fathers’ death, which was a
sensational dying, and just the most unbelievably impotent funeral, that we had no—we were just on this trip. I was in my twenties, so we just in good faith called up the funeral industry and took what they offered us, and it was a full-on debacle from go to whoa, and nothing happened (CDW4).

This learning was invaluable to how she then approached the death of her mother:

...when my mother died, I had enough nous and enough maturity and my hand on enough things to go “hey we’re going to do this differently”. And the quality of my grieving and my family and everything was so different (CDW4).

Nous as it is referred to here, corresponds to the concept of ‘death literacy’ (Noonan et al., 2016). Death literacy is the practical know-how a person gains through the experience of caring at end-of-life. The development of this context specific knowledge is evident throughout the stories of deathworkers. First-hand learning experiences such as organising funerals, holding a family vigil, making a coffin instead of buying one were all critically significant learning experiences that featured in the stories of both community and institutional deathworkers. While the learning for this deathworker (CDW4) was clearly “on the job” or experiential, the shift to becoming “a deathworker” was not accidental. To continue with CDW4’s story, she says she “consciously and wholly” stepped into deathwork:

So probably I had gone to, you know, fifty or sixty, seventy funerals, by the time I was in my twenties, and I just watched and witnessed from afar, sometimes closer in but sometimes from afar, the enactment of our funeral rites. And then over the next decade, before I consciously and
wholly stepped into this work, I continued to observe how the efficacy of the funeral rites was in direct proportion to the quality of peoples’ grieving, and that whatever did or didn’t happen at those times were like sticking points.

CDW4 continued:

OK, I’m in my early thirties, I’m ready to find my life’s work now...I’m ready to take what I’ve learned here out into the world. I know it’s really valuable. I know I have something that’s of immense value to people. In which places and how do I offer that? And it all came from there really, came from my friend dying of stomach cancer and asking me to MC his funeral just two weeks after my Mum died.

I share this story in detail because it powerfully captures the impact of experiencing dying and death in a non-professional role. This was not uncommon; all of the CDWs shared varied stories of transformation in their views and practices about death and dying.

Institutional and medical experiences of death.
Medicalisation is a multidimensional concept, which refers to the processes by which social phenomena come to be perceived and treated as illnesses (Ballard & Elston, 2005). Medicalisation is a feature of modern dying in Australia (Howarth, 2005) and deathworkers shared a number of painful and difficult stories about the effects of this. These experiences were formative, providing a catalyst for the deathwork they currently do.

One institutional deathworker (IDW6) shared a story about being on a student-nursing placement in an Intensive Care Unit of a major hospital. He recalled:
...a 93-year-old man was brought in from theatre straight into the ICU with a Pacemaker put in. After he was sufficiently awake, the surgeon came in looking very pleased with himself. He patted this guy on the head and said, “there you go, you’ll live forever now”. This poor old man, and now I would say this diminished man, looked up at this doctor with almost this despair, and said, “but I don’t want to” (IDW6).

This deathworker is now a researcher, and despite working in palliative care for over 25 years he described this moment witnessing the vulnerability of his patient as one of his strongest motivations for using a social approach. In a similar story, community deathworker (CDW6) described experiencing a number of family deaths in a community setting. However, it was the death of her brother-in-law in intensive care that had the most significant impact on her choice to work as a community deathworker. She said:

... I mean my brother-in-law died in intensive care ... the difference between that and the other experiences is so phenomenally different that... and people will never know this until they find themselves on that very last stretch. And I don’t want people to have to go through that. I do not want anybody to have to experience the pain of that when they can have it so different (CDW6).

Likewise, CDW5, a community deathworker, cared for her terminally ill mother at home. She describes experiencing a number of challenges with palliative care services in her area. This was her first experience of caring intimately for a dying person and she was acutely aware of how reliant she was on the guidance of healthcare professionals. She said:

...we wanted mum to die at home but it just, in hindsight it could have happened, but the system just wasn’t supporting us enough to do that,
and...So I think, just making it easier to bring our dying and dead home because that is our right (CDW5).

Sometimes the pivotal moment was simply a perspective changing conversation, in this case that enabled an IDW (IDW3) to reflect upon his practice and change his career from oncology to palliative care,

I thought I’d do oncology, and I was doing my oncology post, and there was a palliative care nurse who at the time, came up to me and said “Did you know that this person wants to go to a wedding on the weekend? Did you know they want this or that?” It made me think about how holistic I was being in my care. I always thought I was quite holistic, but when she said that to me, I realised I wasn’t actually scratching the surface (IDW3).

The next story demonstrates this too. An institutional deathworker (IDW5) shared a story that challenged her view of “doing right” in the health system. As a junior social worker she happened to be on-call when the son of her colleague was brought into the hospital mortuary. The son had died suddenly in an accident and the trauma had caused significant disfiguring injuries to his body. In the mortuary there was heated debate about whether or not it was appropriate to allow the mother (IDW’s colleague and fellow social worker) to view her son’s body:

She was angry at us because we hadn’t pushed for her to view her son – she didn’t care what he looked like. Her son was going to be her son and just the impact that that had on me...I think she felt we could’ve pushed more for her in her grief (IDW5).

A viewing in a sudden death can be an important part of the healing process. There are a number of reasons for this, including that it can provide access to
the ‘reality’ of a sudden death. In the 1990s viewing dead bodies was still not standard practice but this experience challenged her viewing practices when supporting people after a traumatic death and particularly in the situation involving a disfigured body. Soon after she began working in the maternity section of the hospital becoming a strong advocate for the rights of mothers and families to spend time with their deceased babies and fetuses. This practice was pioneering and it became the benchmark for other hospitals and maternity ward social workers.

**What do we Know About the Deathworkers in this Research?**

Firstly, they all had vivid memories and personal experiences of death, dying and loss that they had reflected on, learnt from and made meaning of. Given the personal nature of end-of-life caring and community deathwork, it is not surprising that all of the research participants identified the death of a close family member or friend as an influential reason for how and why they do deathwork. This was particularly true when the personal experiences occurred during key developmental periods such as a first experience of death in childhood and the experience of a death in early adulthood. For institutional deathworkers, it was not always a personal experience, but a professional one, early in their training that fundamentally changed their views about dying and end-of-life care. These pivotal experiences were often described in vivid detail. One community deathworker for example spent school holidays living next to a cemetery seeing grieving families and interacting with gravediggers. Another deathworker recalls the last time she saw her best friend. These were emotionally connected moments.
These experiences of death and loss seemed to have been normalised by family or other social contexts. I would say that there was an element of socialisation too for those deathworkers who experienced death as a child. These experiences changed their view of death. For some it changed the course of their lives as they decided to become deathworkers; for institutional deathworkers it very often revealed the harsh reality of institutionalised dying and death. I have suggested this learning has some synergy with the concept of death literacy because deathworkers experienced a transformation in their ‘nous’ (CDW4) or know-how about death. I will return to this idea of death literacy in the next two chapters to discuss how this learning might be related to consciousness raising and to the emancipatory ideals that deathworkers held as part of their vision for the social approach to death, dying, and loss in Australia. Overall, these personal transformations made it possible for deathworkers to see things about the death system they were previously unaware of and I will examine the impact of this transformation on practice over the next two chapters.

**The Influence of Place of Work: Does it Matter?**

The simple answer is yes. Table 6 provides a summary of the key similarities and differences to emerge from the data about institutional- and community-based deathworkers. In the next two chapters I will continue to examine how place of work, (i.e. institution or community) influenced the practices of deathworkers. Institutional deathworkers were more likely to be working toward cultural change within their organisations, while community deathworkers talked more often about social change and for a few, being part of
a social movement for change. This was further reflected in the view of the problem. Both agreed medicalisation is a contributing factor; community deathworkers also talked about the impact of professionalisation and institutionalisation. As ‘lay experts’ community deathworkers often have to fight for legitimacy in the death system.

There was for the most part a shared set of assumptions about what it means to have a social approach to death, dying, and loss. There were some notable differences in terminology and language; for example, institutional deathworkers had a more academic or theoretical framework, whereas community deathworkers were more interested in describing a social approach through talking about community-based practices such as community development. Both groups advocated for normalising conversations in the community about death and dying. The next difference between the two groups is how the practice of deathworkers is defined. CDWs do not have a traditional job description like an IDW. Their work often occurs within their local communities, with people who are known to them or their social group. Often the work is guided by a social transaction and is voluntary, but not always. Practice is often related to ethics, especially for health professionals who are bound by their professional duties and boundaries. CDWs use experience and common sense to guide them. Health professionals working in institutions, even those who are working as researchers, use their ethics, institutional policies, and supervision to guide their practice.
<table>
<thead>
<tr>
<th>Social approach</th>
<th>Institutional DW</th>
<th>Community-based DW</th>
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<tbody>
<tr>
<td>View of the problem</td>
<td>Overall – uniformity in what it means to have a social approach</td>
<td></td>
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<tr>
<td></td>
<td>Normalise, partnerships, dying is everyone’s business</td>
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<td></td>
<td>Consistent with literature</td>
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<tr>
<td>View of the solution</td>
<td>Dying is medicalised</td>
<td>Dying medicalised</td>
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<td></td>
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<td>Illness, dying, death and bereavement are professionalised and institutionalised</td>
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<tr>
<td>Social approach in practice.</td>
<td>Normalise conversations about death</td>
<td>Normalise conversation about death</td>
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<td>(Chapter Five)</td>
<td>Person-centred care</td>
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<td>Tasks</td>
<td>Expressed via doing cultural change – inward looking</td>
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<td>(Chapter Five)</td>
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<td>Community activities</td>
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<td></td>
<td></td>
<td>And through client work</td>
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<td></td>
<td></td>
<td>Client work intensely focused on individual wants/needs of person dying and family</td>
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<tr>
<td>Relationship with person dying and</td>
<td>Defined by the institution via having a job description</td>
<td>Depends on/defined by the family/patient</td>
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<td>family (Chapter Five)</td>
<td></td>
<td>Adaptive: changes to adapt to the response of the institution they are working</td>
</tr>
<tr>
<td>Who pays for the service?</td>
<td>Defined by professional role and job description.</td>
<td>Defined relationally</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social transaction</td>
</tr>
<tr>
<td>Ethics</td>
<td>The institution pays the deathworker</td>
<td>Primarily a social transaction.</td>
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<tr>
<td></td>
<td>Professional awards define duties</td>
<td>Paid and voluntary</td>
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<td></td>
<td>Clear hierarchy based on pay rates and professional status</td>
<td>Status is derived by the social currency attributed by the community</td>
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<td>No professional body</td>
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</table>
IDWs work in hierarchical structures, where jobs descriptions, pay rates and duties are demarcated based on qualifications, and experience. While community deathworkers viewed knowledge or death literacy as a key way to respond to medicalisation, institutionalisation, and professionalisation, institutional deathworkers focused on improving clinical care through person-centred care.

Chapter Summary

...dying is the business of whole communities, and not just of the services that provide support (IDW6).

The purpose of this chapter was to introduce the reader to the deathworkers who participated in this study. I did this by constructing two vignettes designed to capture the essence of the institutional and community deathworkers. I was surprised during the data collection of the emergence of the 'place' theme, but once I made the decision to listen to what the data was telling me, the data revealed several important insights about what shapes and influences deathwork in Australia. Consistent with research in the UK and New Zealand, deathworkers described a variety of social practices (Paul & Sallnow, 2013; Dempers & Gott, 2016). This included but is not limited to death cafes, death midwifery, community funeral practices, community-based ceremony and ritual, advance care planning training, walking programs, arts programs, traditional death education and education for end-of-life carers about home caring. Overall, there was a degree of uniformity in the way that deathworkers viewed the meaning and definition of a ‘social approach’ and all had
experienced a significant personal and/or professional experience/s that was so pivotal it acted as a key turning point, shaping their deathwork.

This chapter lays the foundation for the next two results chapters that explore the interaction between theory and practice and provide a deeper understanding about what shapes and influences the practice of community- and institutional-based deathworkers.
Chapter Five: Doing Deathwork: Renegade Practices

I love it. I really love it. It’s like...like I feel like my soul says thank goodness we've come home. I know that sounds ludicrous but...and I sometimes think about it because I really did think for a while, if I am so focused on death and dying, is there some morbid and dark and miserable thing to do, but actually it’s kind of the opposite (CDW2).

Introduction

Working with people who are dying is a profoundly meaningful and transformative experience for the deathworkers who participated in this research. As discussed in the previous chapter, renegades come to be ‘doing’ this work, not just with technical or professional knowledge, but also with practical knowledge based on personal experiences with and in the death system.

The purpose of this chapter is to present the research findings and analysis about the practices associated with being a deathworker with a social approach. Having a ‘social approach’ is both a way of thinking about dying, death, and loss, and an approach to practice (Brown & Walter, 2013). This chapter focuses specifically on what that practice is and how practice is transformed by experience. Experience has helped deathworkers to develop the personal and system awareness they need to understand and ultimately disrupt the social norms in the death system. As previously discussed in this thesis, the idea of ‘renegades’ working in end-of-life care was inspired by an idea expressed by social innovator Charles Leadbeater (The GroundSwell Project,
2011). He had noticed that a group of so-called renegades could be influential change-makers because they held positions both inside and outside the health system. This chapter also provides some insights into this position.

**Deathwork is Lifework**

When describing what they do, deathworkers tended not to create rigid boundaries between their professional and private lives. Instead, they felt they were being shaped by their work and the personal experiences.

> And I feel compelled to do it. I believe it’s my soul and not only do I believe that our soul speaks to us in the creative stuff that we do (CDW6).

Renegade deathwork is not considered a job, it is more akin to a social practice.

> I don’t have a separate life practice, I mean it’s my life, so my work practice is my life practice, so I don’t have a separate life (CDW2).

For institutional deathworkers who already have their prescribed job descriptions, having a social approach is a critical mindset informing the way they carry out their professional duties. Community deathworkers have fewer boundaries between their working and non-working life, as evidenced in the above quote by CDW2. In the previous chapter, formative experiences were shown to influence both the values and practices of renegades and their work; however, some deathworkers consider their practice similar to a personal ‘calling’ and inevitable. As one CDW says:

> To be honest I don’t think I have much of a choice but to do this work. The conditions of my conception, birth, my upbringing, my particular placement in time in my early twenties in the middle of the AIDS
epidemic, my twenty years as an artist and as an artist involved in experimental processes – all of that really equipped me with a deeply embodied understanding and affinity and resonance with loss (CDW4).

And another:

On a logical level again it would be madness because it doesn’t follow the road of making lots of money and being seen as someone really important in the world or any of those sorts of I suppose what I would suggest are requirements to live in the culture that we do. In fact there are those against that. I’ve asked myself this question a lot, why am I doing this? And I feel compelled to do it (CDW2).

This sense of vocational calling featured more strongly in the community deathworker stories. Whereas some institutional-based deathworkers believed they had ‘accidentally’ found they were suited to end-of-life work:

How do any of us get here? – I don’t know?... never planned to spend most of my career working with people who are dying... (ICD5).

Institutional-based deathworkers were also more likely to connect their personal strengths and their professional identities:

I’ve been very blessed that I found a niche in medicine that suits my personality (IDW1).

A nurse of over 20 years who also draws upon her cultural heritage to make sense of the experience:

It’s embodied as part of who I am, and I really don’t know where that comes from. I think part of it is cultural, you know? I think it is partly a sort of Irish thing, but then my parents aren’t like that. My sister’s not like that. I don’t know. Is it nursing? (IDW4).
“It Changes You”: Critical Awareness of the Death System

In our increasingly secular society in the twentieth century, we threw the baby out with the bathwater to some degree, and I want to reclaim that (CDW4).

Deathworkers were highly critical of two key issues in the death system. First, of bureaucratic practices that overly manage the care of people who are dying and the care of dead bodies. And second, of the paternalistic behavior of health and death systems and staff. The concept of paternalism relates to both the general pervasiveness of paternalism in the death system, as well as the behaviour of other deathworkers toward the patients and families.

Bureaucracy: "The conveyor belt" (IDW1).
Deathworkers in both institutional and community settings viewed end-of-life care and deathcare as highly rigid and overly managed.

...the last thing I want is a whole lot of tick boxes people have got to tick, and I remember one man saying to me what I really like about our client adviser was, you know they were the only people who didn’t come in with a tick box, and that really sticks with me... (IDW5).

And it’s no longer going to be appropriate for funeral directors to just offer a one stop shop that is, you know, everything is in boxes and this is what you can get. Because we’ve got a whole generation of baby boomers coming up who have always done it their own individual way and they’re going to want to do this their own individual way. And so there has to be the opportunity for people to be able to do that (CDW6).

A one-size fits all approach was strongly resisted by deathworkers:
Personally I think what I do is I swim upstream, try to take people off conveyor belts and jump into their box rather than try to put them into the boxes that the health system puts them into (IDW1).

...we end up with what we think is one answer fits all. One funeral is going to answer everybody’s funeral requirements. One medical answer to an issue is going to answer everybody. It doesn’t (CDW6).

Those deathworkers with frequent contact with the funeral industry also viewed it to be restrictive and experienced that a standardised service restricted the choices some people have access to:

...at the end of the funeral he said to me I just want to say to you that what you did with your mother was exactly what we did with our father. We didn’t embalm, we just left him as he was. And I went, I said wow why would you do that, he said because that’s the right thing to do. And I said well why don’t you offer that, he said because that’s not what people want. So it’s like the tail’s now wagging the dog – that’s what I think (CDW2).

As in the health system, deathworkers are also advocating for families to have full access to their legally available options. A community deathworker described the frustration associated with trying to advocate when families want more than the ‘standard’ services offered by funeral directors,

“I just want to spend more time with my family member once they’ve died”, or “I just want to make my own coffin”, or “I just want to be able to have the ceremony in my backyard or bury my person where ever”, these things that seemed like very simple requests, when I started to go “OK, how do we do that and what does it mean? How do we make that happen?”, then I just encountered this century-old entrenched business model sense of disempowerment of families (CDW4).
She goes on to say:

Some people just feel hamstrung by their roles, and the funeral industry, by and large feels anxious and disapproving (CDW4).

Community deathworkers like CDW4 were highly knowledgeable about the death system and the legal options available to families. Their role often involved advocating for families and then navigating the system to enable families to access their legal options and ultimately their end-of-life wishes. Institutional deathworkers were less likely to express concern about the options available to families outside the health system. They were alarmed when the health system limited the end-of-life care options of their patients. Institutional deathworkers viewed this as poor care, putting at risk the wellbeing of people dying, and ultimately their bereaved carers and families. This included the lack of advance care planning and end-of-life planning pathways within the health system.

A common experience articulated here by a community deathworker (CDW4), is that service providers and other deathworkers were often reluctant and fearful about offering flexible services to dying people and their families. This inflexibility puts the service provider in a position of power:

They don’t want their staff picking up bodies that have been there for two or three days, and they don’t like the fact that I’ve got more authority than them, that I’ve stepped into a space that they normally step into. They don’t like the fact of having to meet families on their terms and not the terms of the funeral directors. They have a long history of working with families when they’re dazed, confused, inarticulate and vulnerable (CDW4).
The role of power and knowledge in the death system is evidenced in these statements. Community deathworkers, such as CDW5, centre their practice on the needs of people not systems. In order to practice in such a way, community deathworkers need to be death literate. Death literacy was defined in Chapter Two as the know-how needed to plan well for death. This includes knowledge about how the functions and components of the death system work together to both help and hinder end-of-life and deathcare practices in institutions and the community. Without this knowledge of the death system, it is not possible for CDW4 to advocate for her clients as a death doula.

The stories that deathworkers shared with me were peppered with frustration about the rhetoric promoting individual choice in the death system while in reality, the social actions involved in ‘patient-centred care’ are disruptive because the death system functions best when people follow the social norms, which in Australia means dying in an institution and then hiring a funeral director. The concept of person-centred care is an approach seen to promote the empowerment of patients and their families and yet empowerment is based on “the assumption that to be healthy, people must be able to bring about changes, not only in their personal behaviour, but also in their social situations and the organisations that influence their lives” (Feste & Anderson, 1995; p. 140). This view of “empowerment” where expert knowledge is transferred to the patient when applied to end-of-life care is overly idealistic, and problematic. The deathworkers in this research had a more cautious view because they personally witnessed and experienced the consequences of non-compliance (McNamara, Waddell & Colvin, 1994; Rosenberg, 2011).
Compliance was observed to be further enhanced because people typically engage with the death system when they are traumatised, bereft, and overwhelmed. Community deathworkers often used their knowledge to work with people who needed an intermediary with the death system (Walter, 2005). Having knowledge of the public health regulations about keeping a dead body at home AND enabling a family to enact this deathcare in the home, CDW4 disrupts the balance of power between the funeral director and their ‘customer’. Patient choice it seems, it not always aligned with the practice of end-of-life care (McNamara, 2004).

Further, institution-based deathworkers were concerned that end-of-life care is framed as holistic, yet this is not the case in practice:

Normally when you’re in medical training your main focus is around diagnosis, and we talk about holistic care, we talk about patient-centred care, but we really don’t practice it, I don’t think (IDW3).

A common view emerged from their stories: getting access to person-centred or holistic care means you are going to need to break the rules.

One of the most important things to this lady was her dog and this respiratory physician gave the ok for the dog to come into the acute hospital respiratory ward...I thought it was extraordinary because I couldn't imagine any specialist doctor breaking the rules for a dog... (IDW4).

We know there’s lots of red tape, but if we can bend the rules slightly to help someone because we know that a lot of the red tape is ridiculous, then we’ll do that. Now that’s one side. That’s sort of general healthcare professionals. But I think within palliative care, you’ve got that extra incentive (IDW3).
This idea of having an ‘extra incentive’ or breaking the rules when someone is dying was acknowledged by other IDWs too. There was a general belief that when people are dying, palliative care has a responsibility to respond to final requests of patients and families. For some IDWs, this was a justifiable reason to break the rules or at the very least stretch institutional policies that were considered unreasonable or restrictive. Though, it is worth noting that the death of a child was mentioned by a number of deathworkers as a time when the death system became flexible in the face of death:

...as you may know, the one place in death and dying land and in funeral land where things become much more malleable and softer these days is in the death of a child. Everybody goes above and beyond... (CDW4).

Community deathworkers displayed a fierceness in how they approached their end-of-life advocacy. The experience CDWs have gained over many years of working in the community with the process of dying, dead bodies and body disposal has resulted in a practical knowing that comes with exposure to the space that belongs to informal care. This informal space is described by community deathworkers as having a slower pace and is more personal, ‘you know people and they know you’. This has some synergy with the caring at end-of-life research that describes the importance of place to people dying, their families and personal communities (Horsfall et al., 2013, 2015, 2018). Community deathworkers are often involved in caring as an ‘activity of relationship’ instead of a system that an end-of-life carer needs to manage as part of their caring role. I will return to this concept of practical knowing later in the chapter.
**Paternalism.**

Deathworkers talked directly and indirectly about the role of paternalism on the delivery of end-of-life and deathcare. Paternalism defined as “interference with a person's liberty of action, justified by reasons referring exclusively to the welfare, good, happiness, needs, interest or values of the person being coerced’ (Dworkin, 1972; p. 65). Medical paternalism is when a doctor substitutes his or her own judgment for that of another person and decides in place of that person for his/her best interest (Meier, 2010). An IDW provided the following observation:

> The paternalism that I see in the palliative care sector, and by that I mean the service provision sector, is benign. There's not maliciousness in the palliative care sector that I've encountered. But sometimes well-meaning paternalism is still not the best approach (IDW6).

He adds:

> ...in the services we are so nice about what we do, and it is so well received and so appreciated that we are so nice. And we have drawers full of thank you cards that prove just how nice we are. But any paternalism, whether benign or otherwise, erodes or diminishes the opportunity for a balanced partnership (IDW6).

The deathworkers in this research were also concerned with systemic paternalism in the end-of-life and palliative care sectors.

We get taught really early on that professionals know better than we do and so we end up giving up our intuitive knowing and we become lazy in our ways of approaching the world. So therefore we end up with what we think is one answer fits all. One funeral is going to answer
everybody’s funeral requirements. One medical answer to an issue is going to answer everybody. It doesn’t (CDW6).

In another example, a CDW recalls a funeral director responding to her presentation at a conference:

There was a funeral director in the audience... and he was shaking his head. He was like “you can’t expect the family to see that”, you know, “we need to do it behind closed doors and then just present them nicely”, but... “it would be really traumatic, they won’t be able to cope with it”, and the thing is that if someone’s chucked into that situation without any preparation, without knowing what to expect, then of course they’re going to be traumatised (CDW1).

It was not uncommon for community deathworkers to have to reassure funeral directors that dressings and viewings were a normal part of the family and community ritual.

Because I was going to be seeing her naked, moving her around, that I wasn’t going to be able to cope with that, and I sort of said, you know, I’m going to be able to cope with this, if you embalm her I’m going to be really pissed off (CDW1).

Deathworkers were also concerned about the current policy emphasis on end-of-life conversations and planning,

And I’m thinking “is that really normal? Is that what people want?” I mean, Palliative Care Australia has got this logo “let’s chat about dying”. Well, I’m really not sure about that anymore. I think that people are living, and I know from my own reading that, for example, when you ask people, older people with say advanced heart failure and so-on, not everybody wants this “let me prepare for my own dying. Let’s sort it out. Let’s get everything arranged...I want it to be over quickly”. And so my
thinking sort of evolves all of the time around this, and I’m not sure, particularly around things like advance care planning. I think it’s good to be thinking about those things, and then to maybe box them and put them aside, but certainly in terms of writing a whole lot of stuff down, it’s out of context. It’s out of temporal context, so I worry that it lets people off the hook in a way, to have the conversations in real time, in context of what’s happening. I’m worried that it has the unintended consequence of letting people off the hook when the conversation’s actually mapped out, rather than bringing people to a point of talking about... (IDW4).

We spend billions prolonging life, which means that as human beings, we must think life is incredibly important. But the value surely is only as a human being in that life. So why stop treating people like human beings and extending their life? It doesn’t…it just makes no sense to me (IDW1).

And in end-of-life research:

And we want to take peoples’ voices away from them. So even in research, we say these people don’t have a voice. So we call them dying instead of living and we say well they’re dying and vulnerable, so they have nothing to say and we need to protect them. And so not only do people have this experience of care, or poor care, in hospital, but we don’t let them speak about it because they’re dying and we need to protect them (IDW4).

The concept of ‘benign paternalism’ was discussed in Chapter Two. This example has some synergy with the Glaser and Strauss (1965) concept of closed awareness, where staff engage in a “dance of mutual pretense” about dying with a family (Timmermans, 1998). By not acknowledging that dying is occurring and death is imminent, health professionals attempt to ‘soften the blow’ for family members. When families are left out of the decision making, the doctor
and patient are not truly partners. Deathworkers in this research viewed paternalism as a barrier to good care, again connecting it to the good death/acceptance ideal. Another IDW for example, shared a story about working as a community nurse:

...I remember even back as a McMillan nurse, sort of fitting into this discourse of people talking about their dying and, for want of a better word, some kind of acceptance, providing this holistic care model. Now I see it very much about meeting people where ever they’re at, and if that is where ever they’re at decides they don’t even want to ever talk about dying, that’s fine for me (IDW4).

And this:

So if you’re not, you know, talking about your dying for example, or putting things in order, then you’re outside of the norm and you’re not going along with the discourse. So what I’m about is pushing things to be different, pushing palliative care to be different, pushing care in hospital to be different, pushing research to be different (IDW4).

The acceptance discourse is often a feature of a broader view about “the good death”, which is deeply embedded into the philosophy of palliative care (Kring, 2006; McNamara, 2003). In end-of-life and bereavement care research, there have been numerous theoretical and practical approaches developed to facilitate acceptance. Acceptance is considered essential to a good death because it involves awareness of dying, which involves at some point medical and health professionals fully disclosing to a dying person that they are indeed going to die (Zimmerman, 2012). This in turn enables the dying person to make emotional and spiritual peace with dying and their pending death. As noted below, acceptance though implicit to the philosophy of patient-centred care, is
not essential for good care. Ultimately however, paternalism is a threat to patient autonomy (Weiss, 1985) and at odds with the idea of empowerment and thus the social approach.

**Empowering/empowerment.**

When you’re talking to patients and families, you empower them, so hopefully they’ll be empowered to demand what they are due in their healthcare (IDW3).

The concept of ‘empowerment’ is prevalent in healthcare and health promotion. As noted in the previous section, an empowered person is knowledgeable about the death system but the practice of this knowledge can be limited by numerous pressures in the system, including the attitudes of other workers. Empowering people or ‘empowerment’ was put forward by deathworkers as a response to paternalism. In the literature, empowerment is a complex concept and has been defined in a number of ways including as informed choice, shared decision-making and patient participation (Piper, 2010). It also has a broader definition referring to the emancipation of individuals through consciousness raising (Laverack, 2013) and ‘empowering’ people to improve their health (Labonte & Laverack, 2001).

The deathworkers in this study expressed both of these views of empowerment. Institution-based deathworkers wanted to see power transfer from the health system to the patient:

Stopping long enough to listen to the family story so that you can, as a clinician, respond appropriately to this situation. Instead of slipping in and saying – not even saying, but operating out of a set of assumptions about, this is the system and this is the way it works best. And it may be
that clinically that's true. As I said about the orthopaedic surgeon, I actually want established practice to be practiced upon me if I'm in that situation. But how that's navigated seems to matter. How that's navigated seems to be the difference between acts of diminishment and acts of empowerment (IDW6).

And the ‘system’ enabling people to take appropriate action on caring:

For people to be aware of what they need to do, and to be able to feel that they can do that, they need to be empowered by health professionals to say “Look, you can do this. We’ll be there to support you.” But, this whole medicalisation of death and dying, just like medicalisation of obstetrics…this is a natural process, this is a life process, and we should be there to support people, and empower them to do the things...if they want to be at home, we should empower them to be at home (IDW3).

Community deathworkers were concerned with the impact of the broader death system:

And then you’ve got the, so you’ve got the medical, you've got the legal, you’ve got the funeral industry which is then profit driven and disempowering and they’re doing it all and they’re making money on that. And then you’ve got religion and the religious industry which also disempowers people to say that you are not capable, you cannot have a direct link to the sacred, to the divine, to life itself – you have to go through us. So I think those four industries are very disempowering against a natural process (CDW3).

Empowerment is a contested and complex concept in the literature, and the deathworkers interviewed in this study were also grappling with this complexity. The above quotes about caring provide some insight into how empowerment and ‘helping’ can be used interchangeably by healthcare
workers. As noted by Piper (2010; p.176) the helping (rather than empowering) relationship can be “disabling, exploitative and actually reinforce rather than reduce the power base of HCPs”. Further, IDWs are often in a position where they are exposing truths or difficult information to families.

Often when we [palliative care] come in...we prompt a family meeting to open up the dialogue between family and the teams to actually realise that things aren’t going right. The family have known this for a long while, but on one’s actually spoken to them (IDW3).

These quotes also highlight a tension that exists for deathworkers about the mechanism for social and cultural change. This tension arises because the deathworkers in this research tend to talk about both individual behavioural change (i.e. educate people) and structural change (culture in institutions, policy change). For example, community deathworkers want to know they can rely on the healthcare and deathcare system to have the knowledge and skills to support empowered people:

We need people in the system, I think we need some, funeral directors onside, we need people with some pull in the system to actually be allies to have a sort of coordinated approach really I think. Because, this is our legal right, but there’s no point when you’re in the midst of grief because your loved one’s just died, you don’t want to have fight the system to get them home, you just want to hold up the paperwork and they say “on your way”(CDW5).

CDWs also discussed the importance of structural or policy change,

We just need to in every level of society get better at talking about death, better at doing it. We need to see it more, we need to be more real about it. But if we just do that, and the system doesn’t change, then there’s just
going to be that tension. So, I guess that the system needs to mirror the changes that are coming from the community and vice versa somewhat and for there to be a meeting somewhere in the middle. So, it would need to be policy...policy changes coming top down, it would need to be government, it would need to be health practitioners, community service providers, it would need to be an overarching new policy that says that ok, enough, we’re going to do it differently, here’s how we’re going to do it better (CDW5).

Because the system can still disempower structural changes may be helpful but not enough:

My thing's about empowering people because the industry disempowers people, but we’re all, the industry is just people working but everybody has the capability to deal with death and dying, and if you are supportive and helped rather than disempowered and disenfranchised in that, the benefit at the end of that experience is much greater and I see that over and over again. But part of what I find really important is, so when I’m speaking, like I’ve just done a couple of big public talks where I’m giving it to them but as part of that I am saying but you now have that, so you need to go and ripple that out to everyone you meet so that everybody has, not just the people who are lucky enough to be here – it’s your job now to ripple that out because the more people that, even a tiny, tiny piece of knowledge can change your whole experience (CDW3).

As noted by community deathworkers:

A lot of our death and dying knowledge is professionalised, and I want to reclaim that as actually the birthright of community and family, and it always has been that, and find a place where there can be a renegotiating of the status of people having these conversations (CDW4).

Communities go everywhere, they are everywhere and they’re having conversations with everyone we are coming up against these structures
and I think the thing is to be affirming of people's rights and responsibilities and empower them to when they go into a medical model to take their whole selves there and to have an impact in that you know (CDW2).

Health professionals are often working to improve the health of their patients by helping patients change their behavior through education and motivation (Laverack, 2013). Behaviour change needs systemic support through strong policy and increased participation from community members (Laverack, 2017). So while IDWs want to empower patients and families by providing good care and minimising the impact of any systemic barriers that challenge patient autonomy and choice, CDWs are frustrated that the system does not support their work or the ‘empowered’ clients.

Top-down approaches rarely promote critical awareness or resistance. As noted by Laverack (2013) “empowerment implies resistance and struggle to bring about a change in the political order and to challenge the very agencies that often fund and support health programs” (p. 45). While IDWs use the language of empowerment, the examples they provide appear more aligned to individual capacity building (Labonte & Laverack, 2001) as opposed to working in such a way that patients themselves are ‘resisting’, as noted above by Laverack (2013). This finding is consistent with other research that has found that public health initiatives continue to be focused on changing the behaviour of individuals (Laverack, 2013; Sallnow, et al., 2016).

As noted in Chapter Two, community development has an important role in a social approach to death, dying, and loss. Community development initiatives are focused on process and interpersonal relationships, it is more
than informing or consulting with community members, it is about creating sustainable collaborations and partnerships (Abel et al., 2013). In this research, it was only community deathworkers who talked about using community development as a guiding framework. Institutional deathworkers continued to advocate for cultural change, with this comment from an institutional deathworker expressing a common view about how services can work better together for change:

Part of what has to happen here is that the dialogue between services, mainstream services and advocates of the social approach, need to acknowledge the valid contribution that exists in the mainstream. It’s not all right or all wrong. It’s not one or the other. It has to begin with an acknowledgement that the mainstream offers certain things that are extremely valuable (IDW6).

This institutional deathworker goes on to say:

Who is going to do the stuff that needs to be done in order for palliative care to become health promoting? You need to have things like, at the top level, buy-in from the governance body and at the director’s level. There needs to be an articulation of, this is what we need to do (IDW6).

Community deathworkers are again less restrained by convention and they have experience in community development work. They did not have the same fears about having an activist role or seeing their work as social change work.

I want to really reclaim the access to this information, and the community, and the currency of this knowledge and understanding and literacy, to use my friend and colleague’s phrase, within the community. I want to reclaim that for people (CDW4).
As noted in the previous chapter, CDWs see themselves as activists, while those in the health system are more comfortable with advocacy, particularly where it applies directly to being an advocate for patients and their families. One way to interpret these findings relates to the tactics that deathworkers use to create change. Having allies and staying connected to other workers and colleagues in the death system is important, and IDWs are fearful their position in the system will be undermined if they are considered ‘too radical’. One way this tension is managed by IDWs is by using their leadership skills and this will be discussed further in the next chapter.

**Having Knowledge of the Death System: Being Death Literate**

If you have the knowledge anything is possible. But you shouldn't have to go and try and bang on a door to get that, someone should give it to you, it’s common knowledge it’s everybody's right to be able to have that social process for their dying, their dead and for their bereavement (CDW3).

If you say health promoting palliative care, anyone who has heard of it says, oh yes, that's Allan Kellehear – where is he now? You know. Whereas if you talk about community development or you talk about death literacy, it doesn't belong to any one person, or it's not identified as any one person (IDW6).

The funerals are very expensive and there's, and I think there's a lot of mystery and mystique around funerals and what actually, what's going on behind those walls in a mortuary, and the trick is not that much is actually really going on, like it's not that mysterious, and we don't you know embalm people in this country unless we're going to travel them or, and you know look I do think it's for people, I do actually think there's
a real role for a really good mortician if there's been a terrible accident, there is that, I think that it’s very important (CDW2).

In Chapters Two and Four I discussed death literacy as the practical know-how needed to plan well for end-of-life and death. Death literacy has been called a form of ‘practice wisdom’, because within the context of researching home death, it was found that carers and their networks were actively engaged in a critical learning process to develop the knowledge and skills required to care for a person to die at home (Horsfall, et al., 2013). Health promotion initiatives aim to create health education activities and health literacy in the end-of-life sector (Sallnow, Kumar, & Kellehear, 2012). It is only in recent years that the term ‘death literacy’ has been used to describe the knowledge and skills an individual has about the death system. Horsfall et al. (2015) found evidence that the act of caring at home for a dying loved one provides a learning experience that develops knowledge and skills about the death system. Further, death literacy has been viewed as a resource that “individuals and communities can use for their own benefit strengthening their capacity for future caring” (Noonan, et al., 2016; p. 31). As such, people with death literacy have ‘capacity’ enabling them to care at end-of-life.

The concept of death literacy has been influenced by critical public health approaches and critical health literacy (see Eakin et al., 1996; Noonan et al., 2016; Nutbeam, 2000). Of significance is the idea that death literacy (knowledge, skills, experiential learning, and taking action) is not professional knowledge but knowledge that belongs to everyone:
...we get taught really early on that professionals know better than we do and so we end up giving up our intuitive knowing and we become lazy in our ways of approaching the world (CDW6).

The findings in this research are consistent with previous research that noted that despite the medical model, caregivers have the ability to “do it their way” and step outside of institutionalised dying (Horsfall et al., 2013). In the Bringing Our Dying Home report (Horsfall et al., 2013), caregivers demonstrated time and again that they could seek out information and learn the complex physical and emotional end-of-life caring skills. Death literacy, conceptualised this way, viewed caring at end-of-life and participating in deathcare as transformational.

Table 7 presents a summary of the key differences between community- and institution-based deathworkers in relation to knowledge about dying, death, and loss. The community deathworkers in the research embody the idea of practice wisdom and have knowledge about the death system. Community deathworkers used their knowledge by supporting, educating and advocating for people who are dying and their families. And they viewed their work as a way of being able to share this knowledge in their community through education and with people dying and their families. Having knowledge of the death system is an essential aspect of their work:

So I’m positioned in this very slippery place where I have a certain amount of knowledge, and my knowledge or information and resources and access and skill, so I’m not just coming into the families as a community member, because this is my livelihood (CDW4).
Table 7: The role of knowledge: key differences and similarities between community deathworkers and institutional deathworkers

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<th>Institutional deathworkers</th>
<th>Community deathworkers</th>
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<td>System knowledge</td>
<td>Health system</td>
<td>Death system</td>
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<tr>
<td>Type of knowledge</td>
<td>Professional and explicit</td>
<td>Social and tacit</td>
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<td></td>
<td>Influenced by formal learning</td>
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<td>Influenced by personal experience</td>
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<tr>
<td>Purpose</td>
<td>Improve end-of-life care of patients and families</td>
<td>Death literacy is the CDW currency</td>
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<td></td>
<td>Improve end-of-life knowledge amongst colleagues and other health professionals</td>
<td>Raise awareness in the general community</td>
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<td></td>
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<td>Improved end-of-life care</td>
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<td>Improved deathcare</td>
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<td>Equity of access</td>
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<td>Goal</td>
<td>Amelioration of symptoms</td>
<td>Transformation of how dying and death are viewed by the wider community</td>
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<td></td>
<td>Improve the experience of dying for patients and families</td>
<td>Self-actualisation</td>
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<td></td>
<td>Influence colleagues exposure to social approaches</td>
<td>Improve the experience of dying for patients and families</td>
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<td>Role in the system</td>
<td>Health professional</td>
<td>Activist and advocate</td>
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<td>Advocate</td>
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All of the institutional deathworkers in this research had completed tertiary education and some had completed postgraduate and doctoral studies. These qualifications are essential for their professional roles and work in the health system. It also provides legitimacy when advocating for patients and families. As expected, IDWs were extremely knowledgeable about the health system and were orientated to the policies and procedures that guide their
clinical practice. While all talked about the philosophy of palliative care, each person interpreted that and enacted that philosophy based upon their working setting. An acute hospital and a community palliative care service, for example, are vastly different service delivery models with the same philosophy. Community palliative care for example happens in the home of a patient and not a hospital or hospice. Institutional deathworkers believed they had a role in exposing their colleagues to social approaches even though this was challenging:

They say, I’m so busy being a clinician; I don’t have time to be a social worker too. Or that whole, it’s all very well to go and do public forums but we’ve got to do it in our own time because we’re busy clinicians and we’ve got all these things at night (IDW6).

It was however an unexpected finding that IDWs demonstrated very little knowledge about the non-medical functions and components of the death system. This includes funeral directors, death doulas, and death educators.

I have been enculturated in lots of ways, even though I’m something of a heretic. I have been enculturated into the worldview that is held by the dominant, mainstream health system. It is so easy to forget that people who come into that system as patients or as family members or carers of patients, have no idea, often, what those assumptions are, that are operating within the health service system (IDW6).

As noted earlier in the chapter, IDWs are working toward cultural change within the organisation. It is not surprising however, that many of their stories revolve around service delivery and improving the care of their patients. I have already presented a number of examples of IDWs advocating for better
care through symptom relief, truth telling or ensuring the patients’ wishes about place of death are respected. This is frustrating work for IDWs because they have access to insider information about the health system and they have a critical understanding of how the health system maintains the status quo, for example:

So it’s that balance between when are you colluding and when is it wise to just quietly stay there and keep chipping away at the block? So that can be hard because if you keep ranting no one listens to you either. So it’s finding the right moment to influence things a bit (IDW1).

But they have good reason for maintaining their focus on cultural change:

Hospitals are focused towards curing, getting people in and out, and yet our ageing population tells us that most people that are admitted to hospital, they’re over 60, and most of us are going to die in an institution or a hospital, so we need to flick the whole thing round and say “OK, for those who are not able to be looked after at home, then let’s look at how we care for people in hospitals”. So my own work tells us that unsafe care is just normalised (IDW4).

IDWs did however talk about positive experiences with death and dying outside of their roles in the health system. For example, one set up a website aimed at supporting trainee health professionals. Another attended a dinner event that included performances and artworks about death. A nurse talked about her experience during bible study when her group talked about life and death.

In contrast to the IDWs in this research the CDWs, have gained their knowledge about the health system from primarily personal experience as compared to academic learning. In the next chapter there are numerous
examples of CDWs learning from other deathworkers such as funeral directors, nurses, and doctors. This learning is best characterised as informal on the job learning,

I don’t have an intellectual approach to it, I have a, I’m sitting, I’m in it with everyone. And I see that, I mean there are much more capable people than me, much more articulate people than me and, but I’m just giving it my best and somehow or other it works, I don’t know what that magic is but it works (CDW3).

Some community deathworkers gained additional knowledge and legitimacy in the health system by becoming a palliative care volunteer or other status building strategies. The primary role that CDWs had in the death system is to be activists, working to raise the consciousness of their clients and the community about the health system. They do this as a way to prepare people for the enablers and barriers to good care in the system. Community deathworkers are however aware of their marginalised status:

When you demarcate information and knowledge and turn it into a professional realm, then that means that some people have access to that knowledge and can claim that as their own and others don’t, and a lot of our death and dying knowledge is professionalised, and I want to reclaim that as actually the birthright of community and family, and it always has been that, and find a place where there can be a renegotiating of the status of people having these conversations (CDW4).

These findings suggest that deathworkers are “knowing and doing in context” (Higgs & Tichen, 2001, p. 3). In Chapter Six, I will examine how deathworkers maintain the pressure associated with this knowing and doing
and the tension they experience while doing it. This includes examining how place of work impacts on leadership and other tactics used to create change.

**Chapter Summary and Conclusion**

The deathworkers who participated in this research are deeply passionate about working with people who are dying and their families, and they draw upon and they are guided by their personal and professional experiences (Chapter Four). Most of the deathworkers in this research had over 20 years of experience, and during this time they had developed a critical awareness of the impact of paternalism and bureaucracy in the death system. Empowerment was put forward as an antidote to these challenges; however, this is a contested concept that had different meanings for IDWs and CDWs.

Overall, institutional and community deathworkers had different ways of dealing with paternalism and bureaucracy. Community deathworkers were more focused on the legal rights of people who are dying and their families and how to deal with these restrictions. This was linked to education and empowerment. Institutional deathworkers framed paternalism and bureaucracy as a threat to good patient-centred care and they were prepared to 'break the rules' when necessary to support the wishes of their patients and families. These findings have highlighted a tension between individual needs and system needs and this will be discussed further in the next chapter.

Death literacy was the final idea discussed in this chapter. The discussion about death literacy has emphasised further key differences between community and institutional deathworkers. These were outlined in Table 7. Knowledge about death, dying and loss had unexpected boundaries. In practice,
this translated to community deathworkers having a particular focus on supporting people after death, while institutional deathworkers care in the lead up to death. I will again return to this discussion in the next chapter and in Chapter Seven.

The next chapter presents the data related to what deathworkers do with their knowledge, their social actions.
Chapter Six: Transforming the Approach to Death: Relationships, Staying Power and Strategies for Change

I’m not interested in the fringe: I’m interested in the mainstream. So it’s about how do we take it from the fringe to the mainstream (CDW2).

We’re caught between the new style of palliative care, and the old guard leaving palliative care, with the old vision of what palliative care is. So there are lots of people in palliative care who still believe that it’s all about death and dying, and giving them morphine, and giving them midazolam, and holding people’s hands. Yes, that is part of what we do, but there is a much broader way of doing things. If you get to know people early on in their illness, you’ll get to know them really well so that you can do the best by them (IDW3).

Introduction

There are significant challenges for both institutional and community-based deathworkers in terms of effecting social and cultural change in the death system. The deathworkers who participated in this research, have a critical awareness of the death system and they are motivated by creating change to improve end-of-life and deathcare. In order to create this change, they have developed a number of strategies and tactics to enable them to face the challenge and function effectively as change-makers in the death system.

There were a number of similarities and differences in their approach to change. Working within an institution meant that IDWs were more likely to be involved in formal leadership and mentoring programs with the aim of changing the culture within the organisation. Community-based deathworkers had an emphasis on practices that created broad social change and death literacy such as death education and mobilising community knowledge and care.
The danger is also that you might spread yourself too thinly, because you’re covering not only that activism side, but you’re also doing your professional work. You’re also doing all the research, and the education, and trying to have a family life. So, that’s the other flip side. You need to motivate other people around you so that they can jump on board and run with you in terms of trying to change things (IDW3).

This section provides a deeper understanding of what taking action looks like when you are a deathworker with a social approach. The data highlights some of the key differences in the way deathworkers influence and support their peers. First, in the health system leadership is more established and legitimate because the system has an established hierarchy. These institutional norms promote the status of doctors and in some situations researchers. The hierarchy amongst medical specialties also played a role in this research because the palliative care workers felt disenfranchised by the ‘curative’ focused specialties such as oncology. However, medical and health practitioners working for change have developed skills so they can maintain relationships while simultaneously working to change practice. Relationships were the key to change in large health institutions.

In the community, however, deathworkers are participating at the margins of the health system and components of the death system such as funeral services barely recognise their contribution to end-of-life care. Many have responded to this by mapping the formal sector, developing their death literacy, and attempting to develop relationships with the formal system. I have previously called this a “one-way street” (Noonan, 2013) and there does appear to be some evidence for this. Community-based deathworkers are leading through community engagement and community development. Here the idea of ‘shape shifting’ came to life. This is the ability to maintain your values while adapting your style of communication to the environment you are
working in.

**Staying ‘in’ Relationship**

I’m interested in producing social change through bonding and affinity and, you know, in that classic strengths-based approach. So I want to meet the people I talk to. I want to meet them. I want to listen to them. I want to really feel what their fears are (CDW4).

All of the deathworkers in this study displayed a preference for working ‘in’ relationship with other workers and other institutions. They do this in a number of ways, including by nurturing relationships and staying flexible by being a “shape shifter” (CDW4). As leaders they choose connection and “small r revolutionary” (CDW4) actions when disrupting the system.

**Nurturing despite resistance.**

For me it’s so not about a revolution, it’s so not about that, it’s really just about it being so gentle and so that we don’t even realise it’s changed and it’s already changed (CDW2).

As noted in the previous chapter, the deathworkers in this research have developed a critical awareness of the system and they are highly critical of paternalism and bureaucracy. Social approaches may be an antidote (of sorts) to medicalisation but relationship building provides a way for deathworkers to manage resistance to change.

We have two main drives: we either bond or defend. It’s in us. It’s how we survive. We bond to it or we defend against it, and my revolution is a small r and much gentler and it’s much more about bonding, because often we think of a revolution or a change as really about storming the barricades (CDW4).

These community deathworkers view relationship building as an essential strategy for enacting change. Deathworkers are aware that the work they do can be unsettling for
the system and for the people who work in it. Sometimes they drew upon their understanding of psychological theory to frame this:

...when you come into a relationship with another person, something happens that goes beyond just two people meeting, so that has an impact on you as well as them, producing something greater I think. And transformational I guess is the word. So transformational for not just that person but for me as the clinician. But if I shut myself off to that by blunting down and not going there, and going along with detached concern, then I’m putting myself at risk as well. So I think that by opening up, I can retain myself in the encounter. By retaining myself in the encounter, then I open myself to being transformed in terms of learning and growth as well as that other individual (IDW4).

And others focused on making the conversations meaningful:

I think the key is always to think about making the discussions you have ‘personable’, or make it have an impact for that person, make it mean something to them (IDW3).

Another spoke about a feminine leadership style:

The feminine way is inclusive. It doesn’t... it doesn’t push people out and the old patriarchal way is very exclusive and it’s about the few owning the most and everybody else can just...they just have to make do. Whereas I think that the feminine way is to say there’s enough on this planet for everybody. There’s enough for us all to survive well and there’s enough for us all to do this well together (CDW6).

These are examples of deathworkers exerting ‘soft power’. Unlike ‘hard power’, which is power over individuals and groups, soft power is about cooperation and usually involves long-term actions (Laverack, 2013). Soft power, when exerted by deathworkers, aims to avoid conflict. It does not completely avoid tension though. One of the ways that deathworkers manage this tension is what they call chipping away (i.e.
small actions over the long-term). One IDW talking about her work in bereavement, described her approach as:

> The smallest way you can affect change is by not saying it’s okay for the sake of that’s what everyone else is saying. Equally, you know, I’m not out there chaining myself to the razor wire. I think it has to happen in both places (IDW5).

Community deathworkers also viewed relationships as a strategy for change:

> I really believe that is actually how change happens, it happens one relationship at a time and the more people having those conversations the more it changes and it, but of course that only happens if it’s an authentic thing that is, that speaks directly to people because I’ve never had that conversation with people and at the end of it they haven’t gone yeah right, that’s great. Like people are not saying to me I don’t want to talk about this, well I don’t think one-on-one it’s never happened (CDW2).

And this:

> If I’m literally carving out new spaces and inhabiting these liminal spaces, these grey zones, and building bridges between places where there’s been straight lines, and I’m making horizontal leaps, then I’ve got to make a connected affinity. I’ve got to build something. I’ve got to build rapport; otherwise it’s too exhausting (CDW4).

And for institution-based deathworkers it meant they could be less visible, and with strong relationships with people in the health system their work is less likely to be undermined or undone.

**Leading by example in institutions.**

Institutional deathworkers developed a number of strategies for creating change in their place of work. Leading by example was discussed by all of the IDWs and they considered this is an important part of their role. This occurred in the hierarchies that exist in healthcare settings, for example teaching junior staff:
You can have that effect on the younger people coming through. If we're getting to talk to the junior staff, nursing, medical, whoever, as they're learning, then hopefully we'll have more of an impact. At the moment, they come out at the end, and we get them for a little bit at the end, and that's not really how it works. You hope that the movement is going to help people (IDW3).

And it also happened through education provided to colleagues and other health professionals. Leading via formal education, teaching, and mentorship all played a pivotal role in how IDWs were able to enact cultural change in their organisations.

"It’s about breaking the rules" (IDW4).

I'm not a rebel. I'm not an angry sort of assertive person. But, you know, I've always felt that you do something because you've worked out that that is the best thing to do in that situation, not because the rules tell you you have to do it (IDW1).

As noted in the previous chapter, deathworkers also acknowledged that they were often pushing the boundaries or explicitly breaking the rules and norms in their institution.

**Radical but not too radical.**

Institutional deathworkers felt conflicted about the tension that inevitably occurs when they are breaking the rules:

So if I'm too radical, then I can't tinker away at the conventional, if I separate myself out as radical. So for me, I've got to interface with the conventional to start to influence it slightly. But make sure that I have enough supports outside of that (IDW4).

So whilst I articulate particular views about services and what they're like, that can be pretty confronting and offensive to the people who work in them and do their best, and are very good at what they do. If what we're saying as part of the social approach is that we need to have partnerships that are mutual, then we need not diminish the value of what's provided by clinical services. But we do
need to rethink our attitudes, or the attitudes within services, towards the people that they support (IDW1).

These quotes show that institutional deathworkers have a difficult choice to make. They can be radical change agents, speaking out, disrupting the system with direct forms of resistance or they can take this ‘small a’ activist role and remain employed by the system. As noted in the previous section, deathworkers are mindful not to collude with poor practice, however most choose to stay in the health system and exert their ‘soft power’. They do seem ambivalent about how to exert their influence though:

And I think the other thing is that you’ve just got to go for it a bit and really be very respectful of people and go, and get out of your own way sometimes, go I don’t know, I don’t know, what should we do, what do you think you know, not be the expert just be a human being, because I don’t think it is about being an expert (CDW2).

I wasn’t doing what was expected of me. I was expected to be toeing the line, gathering up scans, coordinating care, but what I was doing was being like a sort of radical innovator, and that doesn’t sit well in the system. So you have to tread the line (IDW4).

Institutional deathworkers report feeling restrained by their workplace structures and policies. Workplaces with cultures built around a top-down and centralised environment are not designed for people who tend to challenge the status quo. In order to generate change it is important that change-makers are aware of the impact institutions have on their work. Previous research, for example, has shown that proximity to policymakers made it difficult for environmental activists to overestimate the risks associated with their campaigning (Bevington, 2009 cited in Maney et al., 2012). While I did not ask institutional deathworkers directly about this, there does appear to be evidence in the data that they regulate their behaviour to ensure they can
continue to have influence while maintaining their professional standing. IDWs trade-off a more radical activist approach because they view cultural change about death and dying in institutions as:

excruciatingly slow, and there are a number of reasons for that. One of the reasons is that there’s a reason why there’s a dominant paradigm, and that’s because it’s dominant. It’s very powerful. The mainstream is very powerful. It’s very highly populated. Whereas I think that advocacy by the social approaches group is a smaller voice (IDW6).

People working in the health system struggled more with the terms ‘activist’ and activism. They were tentative:

I think the benefits are that you can hopefully motivate people. Part of my role is not only as an educator but also to try and make people be more aware. I suppose there is that sort of ‘activist’ side...so in that, you're educating, but you’re also trying to give people ideas and views about what they’re doing, to give them a framework so that they can say “Yep, I’m really happy about what I’m doing...or I need to change what I’m doing to have the meaning that I’m looking for” (IDW3).

This self-regulation, though frustrating for the deathworkers (and for myself as the researcher reading their stories), does appear to have an important function in the system, particularly in regards to policymaking. Another IDW viewed their role as an influencer in the ‘second wave’ of change.

To me, the complete renegades are the ones who are at the very front of that wave of change. They are the ones who are really doing the confronting part of this work, and the accidental renegades that sit behind them saying, that was a good idea and I believe it too. I can't make any claim to be a forerunner who is slashing and burning my way through the jungle of paternalism. But I hope I'm hammering away at it in a way that ultimately might have some impact (IDW6).
Another IDW put it this way:

IDW2: I always thought activists were right out-there people, but I think I am a bit of an activist, mild activist maybe.

KN: You seem reluctant.

IDW2: I guess I've surprised myself over the years about what I can and can't do, you know? I've been able to do things more than I ever thought I could. What I've done in this work – I've grown as a person, you know? Doing health promoting work has helped me grow as a person, because I've been able to try things and do things not everyone gets to do in their work. My work enables me to be really creative, innovative, try out new things and it wasn't a proscriptive job, so that's pretty damn good I reckon. You can have a job experience like that, where you got to do things that are new and different and have added in to a growing area, to a new area people are looking at. And having people from other countries coming to visit you and talk to your team. That was amazing.

Community deathworkers had no such hesitation:

I would say I was an activist because I'm an activist in every aspect of my life, but I think there's a danger that people, the fascination of death and the cutting edge can be captivating and can make you feel that you're more important than you are, and that because you're touchingly profound and it's like a drug (CDW3).

**Staying Power: “You’ve got to Keep Chipping Away” (IDW5)**

Challenging norms causes disruption, and deathworkers spoke about how they develop staying power to be an effective change-maker. As noted above, deathworkers need ‘staying power’ to nurture relationships with other workers in the health system.

Deathworkers also need to have a long-term strategy for motivating, inspiring, collaborating, and communicating with other deathworkers (Laverack, 2013). In this sense I see ‘chipping away’ as an adaptive leadership strategy (Heifetz, Grashow, &
Deathworkers create a holding environment to ensure they can keep being a change agent. It takes resilience, self-awareness and system awareness.

This ability to keep practicing in the face of stress and opposition from the death system was evident throughout the interviews. IDWs were particularly aware of the need to be persistent and they held a view that change will take time to achieve:

Hopefully the next generation won’t be as scared and frightened...kids going to cemeteries, and school trips to the crematorium...those things will help, but the other thing we have to bear in mind is Irvin Yalom’s ‘talking about death is like staring at the sun’. You can’t stare at it for too long, so people have to know it’s there, but if you start forcing their head to look at the sun all the time… (IDW3).

A longer-term vision for social change was common and often referred to as ‘chipping away’ in a number of stories from workers in the health system:

So it’s that balance between when are you colluding and when is it wise to just quietly stay there and keep chipping away at the block? (IDW1).

This idea of chipping away is also a helpful practice strategy as it maintained the connection with the people and systems they want to change:

So it was just little chipping away in different little ways where you can – I call it disruptive innovation, you know, where you just shake the tree a little. But then the other side of that is when you’re too radical, and you’re seen as a radical, then you’re not accepted (IDW4).

One IDW for example, a palliative care physician, described the behaviour of her colleagues from another medical specialty following a presentation about the palliative care service in the hospital, she said:

They were very aggressive and angry towards me. I had to…you know, going bright red in the face…I had to calmly stick my ground (IDW1).
She then goes on to explain her motivation for remaining calm:

You see I've never seen it as a dismissal of me personally. I think when people dismiss something or ridicule something, I often recognise that's because it's challenging them in some way. You don't ridicule something that doesn't challenge you (IDW1).

And...

I had that light bulb moment of thinking "Yes, you know, you can make a difference by just keeping at it slowly" (IDW1).

'Staying power' is mentioned by community deathworkers too:

I'm going to build that bridge. So that's really what I do, but what really fuels it, underneath it all, at any time I might be a community end-of-life worker, or a home death and dying practitioner, or a life rites practitioner or a bereavement counsellor, whoever I'm talking to, whatever I need to be...like I said before, if I knew how deeply embedded into our culture these conversations are, you know, I may not have started ten years ago (CDW4).

This is where the language and context for health-based and community-based deathworkers diverges. Health workers talked about burnout and boundaries between their professional and personal roles and experiences:

But there's a tension for people like me when I am needed to be a son or a husband or a father of a sick person, rather than being the nurse in the family or the nurse that is in our home or whatever. It's a bit of a dynamic state to be in, and there are times when – because I also have enduring power of attorney for health decisions of my father. So there are times when I act as the nurse in the family, the youngest son, or the enduring power of attorney. So different roles are taken on. What I would do with this personal experience is kind of extrapolate it out to the experiences of the hundreds and hundreds of families that I've journeyed with over the last few decades around the end-of-life (IDW6).
And their emotions:

Why shouldn’t you see a patient and be moved by that? It doesn’t mean you need to go mad. You reflect on it, and say “Why does this touch me?” How do you maintain that professional relationship, but also be open to being human at the same time? (IDW3).

Staying personally connected to the work was revealed as important. (IDW1) states this clearly when she says:

I’m a lot wiser but I don’t feel like, you know, a lot of my colleagues, you talk to them, they’re so disillusioned. I don’t feel disillusioned.

And in this example:

I’ve never found...other people get really personally upset about that. I think "Oh well, we’ve tickled a nerve here." So there’s room for a conversation (IDW1).

And another IDW makes the point that emotional blunting in response to deathwork actually puts you at increased risk of burning out:

If you try and remove yourself, I think it might be that that burns you out. When you blunt yourself out of it, and you have to put on the face, the professional mask, that’s when you become a risk for yourself as well as others (IDW4).

Ultimately though three of the institutional-based deathworkers decided they were unable to compromise their own personal values and left employment in the health system:

IDW4: The system that you work in has an underlying, underpinning notion that is about cognition, reasoning, objectivity. So it doesn’t allow for, or it tries to get rid of, intuition, connection...

KN: In favour of...?
IDW4: In favour of an objective, reasoned, rational, guideline-protocoted approach. So it tries to tick box everything, to take away those things.

KN: So, how do you exist then within that system?

IDW4: Well I think it’s very difficult, which is why I’m not in it. I think that the people who do remain in it, and are able to do it well, are able to filter that out...

IDW4 also gave the example of a colleague who was reprimanded for ‘over-relating’ to patients, she said:

Well, the point of the story is that she bucked that. She had something in her, a resilience, that enabled herself to say “that’s not right. I’m going to continue doing what I’m doing”. I don’t know what the difference is between someone being able to do that and someone not, but I think it’s partly by that thing of retaining oneself in the interaction, that it actually sustains you rather than burns you out (IDW4).

The issue of 'burnout' and vulnerability also featured in relation to the workload of institutional deathworkers:

I don’t necessarily believe that burnout is about the workload. I believe it’s about your ability to give what you feel you need to give, and if you’re so busy that you’re unable to...so it’s like being spread too thinly with no depth to what you’re doing. If you’re like that, then you’re likely to be stressed because you’re not actually giving what you feel you should give. It can be quite a lot of work, but if you’re giving the depth to everyone that you’re seeing...that you need to, then I think that you can continue. You’re getting fulfilment from what you’re doing whereas if you’re spread too thinly, you’re not really doing those things, then you don’t get that fulfilment. I suppose that Brené Brown...the work of Brené Brown around vulnerability, and opening ourselves up to be vulnerable when we’re seeing people, and being open with them, is a big part of the area that I work in as well (IDW3).
Burnout was not raised by community-based deathworkers; instead CDW4 talks about the personal cost associated with being a change-maker:

If you look at a lot of social change-makers, they often pay with their life. It’s often a very draining and exhausting thing, and I realised that I alone can’t make this thing happen. What I need to constantly do is to be able to move. So the whole way that I’ve talked about what I do is very much about flow and dynamic and being able to shape shift and put on that hat and be this, and yield and relinquish and go “OK, there’s lots of barriers there. I’m going to change direction over here”.

There are two aspects of this comment that seem important here. Firstly, the personal cost of activism is acknowledged and second the ‘shape shift’ are both strategies consistent with an activist approach. These will be covered in more detail in the section on strategies and tactics for change.

**The anxiety of other deathworkers and colleagues.**

Deathworkers were aware that having a social approach was disruptive and they developed strategies to comfort other workers in the death system. This skill enabled them to practice in what would otherwise be a difficult environment. CDW4 for example, talks directly about "holding anxiety”:

...well I’m just going to hold the anxiety of this, whoever it is, funeral person or doctor or whoever, at bay while I try and equip this family with some muscles and something in their kitbag, to get what it is they’ve identified they want”.

In this example, CDW4 shares a story about how she actively supported both the funeral directors and the family to negotiate a way forward:

She [a client] wanted to die holistically and consciously at home. She wanted to stay at home. Her partner definitely wanted her to stay at home between death and the funeral. They had a lot of kids in their lives, so they wanted to be able to
create a sense of beauty. And they wanted to be able to create a community support network that was theirs, and that they could create the language and aesthetics for. And my job was to lead, follow, improvise, guide them in that, and where necessary to make the funeral industry do what we wanted, to soothe their anxiety, to hold them at bay, to protect them.

In another example, CDW3 describes how she supports bereaved families by managing her own response to their grief:

I’m just walking with them, I’m walking alongside them, and sometimes I’m not even holding their hand in it – I’m just accompanying them in that journey.

This critical self-awareness provided deathworkers with a way of managing the competing emotions or tensions involved in navigating the medical and social models. Over time deathworkers developed both interpersonal and intrapersonal skills for managing this tension.

**Support from peers and allies.**

The importance of having support was acknowledged by deathworkers throughout this research. In this section, deathworkers talk about how trusted allies support their work.

Community deathworkers had allies both in the formal system:

I’ve been gathering allies, you know, the GP who contacted me, he’s just all over it. As I said he’s found people in the system already who want to change, you know, nurses, people in ICU who just don’t like it how it is and are happy to support...you know, researchers who are saying I’m a researcher, I’m unemployed, what do you want me to research for you, and but I just can’t get there yet (CDW5).

And informal:

So I learn through people you know when I talk to you, when I talk to (colleagues) you know or when I talk to the parents of the children who I know who have died, or when I talk to the funeral director who’s working with me
doing my mother-in-law’s funeral, all of those things teach me something and
yeah, so that’s how I learn things, yeah (CDW2).

Institutional deathworkers were looking for colleagues in the formal health system they
could trust and unburden to:

I’d pick out my resources, who to trust, who not to trust, allies. I’d look for allies, similar minds. For example, I worked in a big Sydney hospital, and I’d find another couple of senior nurses, a social worker, a dietician, who were my allies and who sustained me in the midst of this big unwieldy medical model centre of excellence (IDW4).

Further, IDWs were also focused on relationships that would improve the care of their patients and change systems:

So you get people together to think about “Well, how did this happen? How can we make it better? What was this person thinking?” There were lots of rules and regulations around it, but we managed to have a dialogue that meant that things were done in the right way from that point onwards (IDW3).

Having an ally was also seen to facilitate self-reflection about practice. Peer influence and key learning came from multiple places: colleagues and mentors, patients and families, other deathworkers, the writing of clinicians and academics, writers and supervisors. Most of this learning was via informal networks, private learning, and for a few IDWs from within their workplace.

Formal and informal learning between peers was highly valued by deathworkers:

I think the biggest influences have been the quiet colleagues around me ... who have just steadfastly worked in a decent way with people their whole careers and they’ve never lost their decency. For me, you know, that surely ... I mean that, to me, is just incredible, that people can do that. They’ve been huge (IDW1).
All of the deathworkers I interviewed had a positive experience with a peer, a manager, or a colleague who has supported their practice. Institutional deathworkers all shared stories about supervisors and managers and community deathworkers about peers and people who inspired them. For example, institutionally-based deathworkers often talked about observing their colleagues work:

I think there have been some key people who I've looked to, both direct colleagues, you know, and I could name them you know, early on. They sort of stand out. The first McMillan nurse I worked with, x… would have friends who might be the bereaved husbands of patients that he’d cared for. So he’d be off hill-walking with some bloke that he’d met through his work, and at the time I had this notion of that as sort of somehow dodgy professional boundaries, and he was going to burn himself out. But then I look back and I think “hang on a minute. Here’s a man who’s been doing this job now for twenty-five years or something… he’s getting something right there is that he’s seeing and connecting with people as people (IDW4).

Notably, these formal relationships were often hierarchical and provided structure:

My latest manager has been extraordinary in really helping you being my encourager…she really understood how to manage me and what I needed to be encouraged myself. She’d give me good guidance and supervision around what I was doing (IDW2).

All deathworkers interviewed in this research reported that sources of inspiration came from people who have written key books and articles. They focused on big picture people who have inspired them with a theory or framework or who were good at navigating the system to encourage better end-of-life care. These included academics Tony Walter (2003), Allan Kellehear (1999, 2005), Viktor Frankl (1984), Eric Gazelle, Bruce Rumbold and Glennys Howarth, physicians Elizabeth Kubler-Ross, and Michael Carney.
I mean, you read people like Eric Gazelle, Viktor Frankl. You read all of that. It just orientates you in a certain direction for a while. Then you read something else and that’ll reorientate you (IDW3).

Those fundamental principles around presenting diminishment and entering into partnerships and providing expertise in a way that isn't framed up by benign paternalism. These are the sorts of principles now that drive my thinking around death and dying. Trying to find a framework to hang that on intellectually, so that I can explain what it is that I believe... (IDW6).

When I read Compassionate Communities, or as best as I could read it, that’s probably when I could see – when he was naming things like whether you’re an activist or what kind of role you might take on, and I could see myself as one of those, a bit of an activist doing – “oh, that’s what I am. I’m one of those”. So I could see that I had a place (IDW2).

One of my key influences, who I never actually met but had a strong influence on me early on, was a palliative medicine doctor, Michael Kearney, who’s an Irish guy. He’s remained a key influence in the PhD, so both clinically and academically (IDW4).

Community-based deathworkers also had unique learning experiences in relation to developing a business model that would suit their work in the community. This learning was fast paced, action orientated and on the job. In this situation other deathworkers were the key source of learning:

I met a great funeral director who gave me all the information I needed in half an hour and we, he was incredibly generous and I honour him every day by being as generous with others as he was with me. And I can't tell you how, what a great lesson he was because it's the perfect lesson – he gave it to me and because he gave it to me he changed the whole face of death on the north coast, much more than he could've done on his own. And so it's my role to also keep feeding that out to change everybody's opportunity. So I'm just following his example really (CDW3).
Well look I did some work in the US with this great funeral director...and I took a lot of their modeling...they have a shop front, like I’d like to have a coffin shop and just a place for people to come and talk and you know do their... you know write down what they’d like to have for their funerals and they also, they are funeral directors, so they’re very hands-on as well, but they’re very, it’s very, they’re a business so it’s very eclectic (CDW2).

These learning experiences are common when people are literally learning ‘on the job’ which was the experience for community-based deathworkers. Since beginning this research a number of death doula and midwifery programs have developed. However, these were not well established when I conducted the interviews and practitioners needed to make the most of their informal support networks for technical advice. Two of the community deathworkers I spoke to were in the early years of their businesses and practices, and every work transaction felt new and had the potential to be disruptive in their community.

Given that social approaches are not part of the dominant biomedical approach, these active learning experiences were encouraging and normalising. One IDW was working in health promotion when her health service invited Allan Kellehear to provide an in-service to her team. She views this to have been a crucial professional opportunity:

...we wanted to see if we could involve volunteers, and that’s how we connected with Allan Kellehear. At that stage, when he was heading up the palliative care unit at La Trobe University, we arranged an opportunity to meet with him over in Bendigo, and he just stood in front of a whiteboard and mapped out a little vision he had for how we could set up sort of trying to find champions for palliative care through a resource team approach. And so we sat there looking at this board and going “oh my God, how are we going to do that”? So he had this little theory idea that we could have a resource team of interested people who
would come together and they would try to be champions I guess, and instigate health promoting work in the region (IDW2).

Role models were often a person considered a pioneer or a leader in their field. For example, Allan Kellehear who developed the initial writing and work in the public health palliative care field was often mentioned by institution-based deathworkers,

The thing that happened for me was that I was working away as a clinician. This is about probably the year 2000. Working away as a clinician with this growing discontent or this growing disquiet about the nature of relationships between services and the people they supported at home. I came along to Allan Kellehear's lecture…Health Promoting Palliative Care (IDW6).

But, you know, Elizabeth Kubler-Ross, what an amazing woman, she was the first deathy [sic] that I really came across, you know, 16 years ago or whatever it was, 15, 16 years ago, and I used to want to be Elizabeth Kubler-Ross (CDW5).

Institutional deathworkers were strongly influenced by colleagues working in their field, for example:

Yeah, I think early in my career I was very lucky to work with a guy called Michael Carney…A lot of his writings as a palliative care physician. He’s also written a whole load of books…We’ve maintained…It was initially sort of a more of a mentoring relationship. I’d say now a peer relationship (IDW3).

Professionally though, I think Rod McLeod has been a big…has been a mentor really, in some respects…When I first got introduced to palliative care…I was given a little green book, which just had some guidelines and ideas and things in it…and that was Rod McLeod’s book when he was in…probably ten years before me. He developed that book with another colleague. Now from that…that was updated, and updated, and updated. I got an updated version when I was working in the UK…It probably got me into palliative care (IDW1).
If a deathworker was employed by the health system, a supportive system and manager was considered essential to practice within a social framework. IDW2 for example, who talked earlier about her work with Allan Kellehear identified her manager as a key enabler of the social approach:

And I think JJ certainly had a great understanding, as my manager at that time. She was my manager, and she’s got a very good strategic vision, and so she sort of had the vision and wrote up the initial project and then it was me being the project worker activating it on the ground. But you had to go in with enthusiasm, “we can do this and be encouraging” and doing all those – being an encourager and trying things out. Being an encourager of people having a go (IDW2).

IDW2 describes the impact this support had on her practice:

What has really helped shape me has been, as a worker, working in a team and being part of a management structure, having a manager who also operates from that framework. And even though I’ve worked in a community health service which operates under a social model of health, not everyone gets it and understands.

Clinical supervisors were also considered important role models for IDWs, though only one community-based deathworker talked about the role of professional supervision in her practice.

I think, on another level, what enables me to do this practice is I have a supervisor, a woman that comes from social work, so these days, in a way I think my – I work with someone that works in the not-for-profit, into the business sector and a supervisor, and so they’re my two anchors at the moment that support me to build up my interpersonal muscles, to continue to front up for this and to work out how I take it to the next level (CDW4).
In a hospital setting where the medical model dominates, these enablers of innovation appear to function in a slightly different way. There are also challenges with not having a role model:

...if you have managers in a palliative care unit, they have to understand what you do, and where your motivation comes from. To support the staff in that sort of field, you have to really listen to what they're saying to you. I think a lot of managers have their own view about managing the actual service, without really...it's a 'top down' management approach...(IDW3).

For those working in the health system, a role model gave deathworkers access to a legitimate framework for social support. This was considered relevant to both the medical and social model of care, providing deathworkers with the evidence they need to create change. They can perhaps safely recommend a book or a research paper knowing that it will be sufficiently ‘medical’ to introduce colleagues to a social approach.

Deathworkers in the community draw upon personal experiences to inform their practices initially and then seek our more formal frameworks and supports. Community deathworkers also refer to community development, community cultural development, and community capacity building but from a practice rather than theory based perspective.

**Strategies and Tactics for Change**

If you want to bring your dead mother home you can do it, you have every right to do it, this is how easy it should be, and if you have any problems phone me and I will come and advocate for you and kick some arse (CDW5).

For some deathworkers, activism and advocacy are uneasy pathways to change. It is perhaps unsurprising though that those working in the margins have an affinity for
activism, while those in the health system were more comfortable with advocacy, particularly when it applies directly to being an advocate for patients and their families.

In the previous sections, deathworkers experience the tension of wanting to take action and create cultural change and staying in relationship with people and institutions. Taking action is also a key part of leadership and because deathworkers are motivated to change practice they do need to lead by example. This means taking action despite the risks involved opening up their practice to public scrutiny. Closely related to this is mobilising and networking.

...I actually wanted to do like a skills audit, a regional skills audit, and pull all the people who...I’m not talking just interested in sitting down and having a cup of tea and talking about death, I’m talking about the people that this is actually really meaningful for them and they cannot not do this work, they’re the people that I’m talking about, actually getting them together (CDW5).

Community deathworkers often need to read carefully and respond to the situation as they go. They are regularly treading new ground,

But also I could articulate what it was that I did that was different. And that’s really been the core creative, not make-it-up-as-you-go-along, but that’s my sort of social larrkinism part of it, you know? That’s the dress-up part of it. That’s the part of it that comes from my practice as a fearless experimental practitioner in culture, or in creating culture (CDW4).

This was not always easy, however:

I thought this’d be brilliant, we could do stuff together. But she was positively rude. She was unbelievably...I just went whoa! Other than that, everyone that I’ve spoken to in the funeral industry have been delightful (CDW6).

Community deathworkers have an interesting position in the death system. They are positioned to have a classic activist role, to be trailblazers and rebels, instead their
work was viewed suspiciously and sometimes, like in the example above, with contempt.

“Activism with a small a”.

The other challenge associated with leadership in this space is what IDWs referred to as ‘small a activism’. There are two parts to this. Firstly, IDWs did not want to appear too radical or as expressed here:

IDW4: And I think they saw me as a troublemaker that wouldn’t fit into that. Yeah, I’m pretty sure actually.

KN: What do you make of that?

IDW4: Well, I’m not real sure. I think it’s sad, because I think—it is because it’s safe, because that’s the way it’s done? You know, instead of seeing a potential innovation and transformation, maybe that’s the threat, you know? We like convention, we like the order, we like to imagine—maybe that’s the overarching threat—we like to imagine certainty and order, and I think this is about uncertainty, all of this.

People working in the health system struggled more with the terms ‘activist’ and activism. They were tentative:

I think the benefits are that you can hopefully motivate people. Part of my role is not only as an educator but also to try and make people be more aware. I suppose there is that sort of ‘activist’ side...so in that, you’re educating, but you’re also trying to give people ideas and views about what they’re doing, to give them a framework so that they can say “Yep, I’m really happy about what I’m doing...or I need to change what I’m doing to have the meaning that I’m looking for” (IDW3).

They are balancing actions for change and relationship:

There are some people who...they’re not going to change. They’re not going to change at this moment in time, however you keep working around them, and you
keep saying the same things that you say. Then something happens to them on a personal level, whether it’s their mother, their father, their wife, their husband; whatever. Something happens to them on a personal level, where they see the benefit of palliative care coming in, and after that experience, if that happens, they’re generally your biggest advocates (IDW3).

You have the conversations. You appeal to people’s humanity. They start seeing what they’re doing. You don’t appeal...you don’t affect change by showing graphs. I don’t believe you do. We love showing graphs but actually you affect change by having conversations (IDW1).

**Having a more radical researcher or clinician in the field was helpful because:**

You need somebody like Allan Kellehear to grab people's attention in this very big and busy and noisy mainstream (IDW6).

**And because they can provide a less radical and risky path for IDW working in conservative organisations:**

There are two ways of convincing to your point or persuading people to your point of view. One is to gently bring them along, like being caressed by a feather. Allan, on the other hand, uses the whole chicken. This sort of chicken hurling smack across the head approach that he uses, this is the role of the innovator. The early adopter, like me, who comes along on the second wave behind the innovator is able to say, all right, well we’ve all gotten over the shock of being hit over the head with a chicken. Let’s start pulling that apart and trying to understand better what we mean when we say we want to strengthen community action, or we want to reorientate health services. Any of those elements of health promoting palliative care. Once the shock has worn off, of the initial idea, then at a systems level I can begin to work with the sector to say, here are some ways of thinking about this that might be better (IDW6).

**Institutional deathworkers recognised the role these radicals have and they have observed the actions and behaviours of these early leaders and modified their own**
behavior accordingly. Second, by having an understanding of their professional role and how this role gives them power and status in their workplace they are able to be an advocate for change, in particular, for patient-centred care.

**Pushing back on paternalism and bureaucracy.**

Institutional deathworkers are in positions of authority even if they use a social model to inform their work. I have already noted they tend to build relationships and avoid conflict, however the interviews also revealed examples of IDWs actively resisting paternalism and bureaucracy. For most it included being mindful of how they can use (and misuse) their professional power, as is evidenced in this example:

I'm thinking about a family ... they were trying a whole lot of alternative treatments. Put somebody in hospital, and you can’t use many complementary or alternative therapies. But at home they could. I was confronted by this man’s wife, who said, don’t think for a moment that you’re going to stop us with these treatments. I was able to say to her, I will do everything in my power to support you in providing the care that you believe your husband needs. There was a whole discussion going on outside of that, outside the mainstream, that mattered immensely to them. And prevented that man’s diminishment in the face of his dying. He was very pleased to have me come and be part of the team of care. I would come in and make suggestions about symptom management and physical care and family coping. All of the things I did as a clinician, because she knew that I wasn't secretly disapproving of the stuff they were doing which was outside that mainstream (IDW6).

In this example, the family member reminds the deathworker they are indeed a visitor in their home and that the family is using complementary therapies. To provide good care in this situation, the IDW needs to suspend their own judgments and any beliefs the institution they work for may have.
The Caring at End-of-life Research Team (Horsfall, et al., 2015; Rosenberg et al., 2017) that found carers and their networks often needed to be assertive with health professionals in order to have their needs met. Further, Broom's (2006) work on medical power found that the interface between lay/expert knowledge is a complex interaction and he rejects the binary view that professionals exert ‘power-over’. When the medical interaction is viewed as holistic by the health professional, outcomes can be shared rather than led or dominated by the ‘expert’.

There was evidence in the data that IDWs were able to use the social approach to identify paternalism and clinical interactions that were at risk of being dominated by the medical system. This ‘pushing back’ or resistance on behalf of the IDWs demonstrated an ability to negotiate and share power. This resistance/willingness to share power is for some simply ethical practice (Rose & Glass, 2008).

**Shape shifting.**

The deathworkers in this research were adaptive and “shape shifters”. As such I have mentioned and provided examples of this shapeshifting throughout this chapter. Community and Institutional deathworkers respond to challenges in their workspaces. It is an adaptive leadership tactic that helps to “turn the heat down” when a situation becomes stressful (Heifetz, Grashow, & Linsky (2009)

For me this is not about fashion or a fad or the next great new thing, and so it will for me it’s about cultural shift in our culture of just take, putting people’s hands back on this right and you know if that takes ten years, fine, you know, if it takes twenty years, fine, it’s not going to happen because of anything I do, it’s not going to happen because of your PhD or what I’m doing or what, it’s going to happen because the community, it’s the right thing and the community
feel it’s necessary at everything we do, you know the fact that you’re doing it, I’m doing it, we know a lot of people who are doing this work (CDW2).

if we’re talking about Betty on the phone at the council, and a family want to have a funeral outdoors in the same place that one of them got married and they have now died, then I’ve got to get in the front door, and Betty’s the door-bitch, right? So I’ve got to charm my way in (CDW4).

The IDW’s in this research are motivated by improving end-of-life services for their patients and their families. So some of the IDW’s a social approach provides a lens for viewing end-of-life services that does not stray far away from amelioration and service improvement. This is one of the ways that community deathworkers and institutional deathworkers diverge. Community deathworkers view the social approach as transformational whereas IDWs first and foremost saw it as good care.

Shape shifting also facilitates the way deathworkers pivot to respond to opportunities to create change in the system. Influenced by Foucault I can see this occurs “in the cracks” of the death system. The cracks being the spaces between the formal structures or components of the death system. In Kastenbaum’s (2004) model, the functions and components of the death system provide a useful way to bring awareness to the visible and tangible moving parts and structures of the death system. Social innovation in the death system, as discussed in Chapter Two, has a cumulative effect, and the deathworkers in this research seem to be doing most of their work in the messy and more complex liminal spaces and working with/in the transitions. This is a point that I will return to chapter seven.
Managing the consequences of innovating.

There were both positive and negative consequences for being a change maker for both IDWs and CDWs. Deathworkers experienced exclusion:

I’m not popular with the funeral directors. There’s a fair amount of having to stand my ground. It’s not all sweet-talking. I encounter a fair amount of, at times, abuse. There’s certain funeral directors in Sydney that don’t want my work anymore, particularly now since I’ve had the cooling bed, and they are so freaked out at bodies staying home for a couple of days that there’s one of them that just says “we don’t want your work. Don’t ring us up” (CDW4).

They also worried that their efforts would be negatively labeled:

The downside is that you’re always railing against the system, and people will label you as being someone who is always going to moan about the system (IDW3)

As noted previously some IDWs choose to leave the health system, rather than work in a way contrary to their personal ethics:

I found myself increasingly unable to work in a system that had no room for the lived experience of people who were in the care of that institution. I certainly rubbed a few people up the wrong way along the way, because it would be very – an institution might be very inflexible about how a person should be part of their system. If I think back to difficult patients, in inverted commas, they were the ones that were saying, I’m sorry, I’m not going to do it that way. I’m going to do it in a way that is meaningful to me, and you as a provider of care need to fit in with me – not the other way around (IDW6).

And positive outcomes through their work resulting in policy change and additional funding for their services:
Over the years it’s been such a battle. It’s now... the surgeons when they were asked to prioritise, they prioritised a 20-bed palliative care unit ahead of opening the 60 ICU beds. There’s been a shift (IDW1)

**Chapter Summary**

The participants in this research experienced tension between the medical and social models. A recurrent tension for IDWs with a social approach is the rhetoric of person centered care. IDWs are working with/in institutions with little structural critique of medicalisation and professional power, and this is most evident in person centered clinical encounters. IDWs demonstrated resilient and strategic approach, which at times involved managing the anxiety of other deathworkers. The data also highlights some of the key differences in the way deathworkers influence and support their peers. In the health system, leadership is more established and legitimate because the system has a natural hierarchy. These institutional norms promote the status of doctors and in some situations researchers. Interestingly however the hierarchy amongst medical specialties also played a role in this research because the palliative care workers felt disenfranchised by the ‘curative’ focused specialties such as oncology.

This chapter has provided insights into of how deathworkers practice leadership by paying attention to their professional power and in institutional settings. It also provides a deeper understanding of what deathwork looks like in action and in relationship to other deathworkers and institutions in the death system. The main finding again related to workplace; is that community-based deathworkers are focused on the death system and institutional-based deathworkers are focused on cultural change in their workplace, although this chapter also identified some of the tensions in the formal and informal systems. The next chapter will discuss the overall findings of this research.
Chapter Seven: Doing death differently: Discussion and Conclusions

This research provides an insight into the practices of a small group of deathworkers who identified as using a social approach to death, dying, and loss. These practices were shaped and influenced by their workplace setting (i.e. institutional or community), which in turn was influenced by a lifetime of personal and professional experiences and learnings about loss and death (death literacy).

All of the deathworkers in this research work with/in a death system where the ‘siloing’ of health and death in Australia creates a fragmented system of care for people who are living with a life threatening illness, dying, caring, and grieving. This fragmented care, however also creates a transitional space between the silos. It is in this transitional space that institutional deathworkers were most active in developing relationships, gathering allies, and chipping away with cultural change practices. The work of community deathworkers is for the most part invisible to the formal healthcare and deathcare systems. The community deathworker is almost always in ‘activist’ mode because a great deal of their work revolves around advocating for the legal rights of their clients and families. CDWs therefore work across these so-called silos of care, with/in and through, with institutional deathworkers work primarily within their specialty area.

These findings demonstrate some of the challenges and tensions inherent in socially oriented practice for both community and institutional
deathworkers. I will discuss these challenges and tensions in relation to policy and future practice; in particular, how it relates to the continued efforts to develop and implement public health approaches, such as compassionate communities, in the Australian context.

Deathworkers are working to change fragmented care while navigating the social and medical models of the health and death systems. This research has helped to develop a deeper understanding of how deathworkers do that.

**Addressing the research questions.**
The aims of this research were to investigate the lived experiences of deathworkers who practice using a social approach. I deliberately used the term ‘social approach’ so that those people coming forward for interviews would identify with public health approaches to death, dying and loss, in particular Allan Kellehear's work (1999, 2005). In seeking out people who were by definition renegades in a system dominated by the biomedical model, my intention was simple: to gain a deeper understanding of what this change work looks like, and to examine what emerges from the collective learning of deathworkers. As a result, my research questions were designed to be open and exploratory:

- What are the stories and experiences of deathworkers who have a social approach to death, dying and loss?
- How is this deathwork shaped and influenced?
- How are the renegades working to make a difference?
Overview of the research findings.

In chapter four I introduced the 12 deathworkers who participated in this research providing an in-depth understanding of how deathworkers interpret a social approach to death, dying, and loss, and the experiences (both personal and professional) that influenced their work. The research participants had various roles in the death system including those based in institutions (doctors, nurses, researchers) and community-based deathworkers (educators, community development workers, and end-of-life doulas/midwives). All IDWs were employed by an institution such as a health department or university.

CDWs were engaged privately by a fee-for-service model directly by community members (clients). The CDWs also provided unpaid work in their community including advocating for people dying at home, community education, and other events such as festivals/markets. They did not necessarily define this as volunteer work, as it was often part of a reciprocal or social arrangement.

Additionally, IDWs had multiple roles in the health system. These roles were primarily informed by their work role and job description. For example, a palliative care physician and director of a palliative care service was also an educator, researcher and clinician. Having a social approach provided principles that informed his practice with patients. As noted in Chapter Three, similarities and differences between IDWs and CDWs began to emerge during the data collection process and I summarised these in Chapter Four. Discussion of the similarities and differences continued throughout the data chapters making place of work a key finding of this research. Deathworkers did however agree on the meaning of a social approach, in particular normalising conversations,
working in partnership and acknowledging existing strengths and knowledge in the community, giving the finding about place even greater potency. I will talk more about this later in the chapter.

Over time, and with increasing experience, deathworkers in this research grew increasingly critical of the health and death systems. In Chapter Five I examined how the social approach used by deathworkers provided a way to manage and cope with the competing and complex challenges in their work. Deathworkers were particularly critical of paternalism and the bureaucratic structures that made it difficult for people to die at home and access good end-of-life care. Institutional deathworkers viewed paternalism and bureaucracy as barriers to good person-centred or holistic care and the effect was disempowering and diminishing on all involved. IDWs were regularly working to raise awareness, educate, support and change the behaviour of their medical colleagues toward earlier referral to palliative care services. Whereas community deathworkers provided death education in and with their local communities about a variety of topics from palliative care to advance care directives.

Place of work (i.e. community/institution-based) also emerged as a major theme that informs both knowledge (death literacy) and knowledge about practice. Institutional deathworkers recognised the need for community wide interventions to raise awareness about palliative care and encourage better end-of-life planning conversations; however, they made virtually no references to community-led practices such as death midwives or non-health professional death education or care and disposal of the dead body. Community
deathworkers were extremely knowledgeable (death literate) about multiple components of the death system, of which end-of-life care is only one. This knowledge was important because CDWs move between both advocate and activist roles, navigating around barriers and amplifying the strengths within the system as needed.

Chapter Six provided insights into the strategies and tactics used by community deathworkers to create change. They needed to be adaptive, flexible ‘shape shifters’ to be successful at navigating the health and death system. Institutional deathworkers are also ‘shape shifters’, and they influence change though education and leadership and through a combination of soft and hard power. The health system is resistant to change so IDWs gather allies and colleagues to help maintain and sustain their efforts over the long-term. All the deathworkers in this research see change as a slow process, so allies and support are particularly important while they are ‘chipping away’.

**What does it mean to be a ‘renegade’ deathworker?**

One inspiration for the research, that I return to here, was the idea that change-makers or renegades can have ‘a foot in both camps’ of the formal and informal end-of-life care systems (The GroundSwell Project, 2011). The findings revealed very little evidence of this phenomenon.

Institutional deathworkers focused and practiced primarily in the formal systems of care. They used a social approach to improve end-of-life care through the delivery of formal services and to change the culture of end-of-life care within their institutions. As noted in Chapter Six, IDWs are ‘leading by example’ in their teams and ‘breaking the rules’ of their institutions when
needed. Institutional deathworkers frame these social actions within the relationships they have with their colleagues and patients. As such, IDWs attempted to gently encourage their colleagues toward attitude change and less paternalistic and mechanistic end-of-life practices.

Community deathworkers are highly aware of formal service provision in both the healthcare and deathcare systems; however, community deathwork hinges primarily on an intersection of informal care and knowledge of the death system or death literacy. In Chapter Five I discussed the impact of being death literate and how community deathworkers used their knowledge. Their social actions focused on improving death literacy in the community and amongst their clients and their carers. Community deathworkers demonstrated knowledge about the formal structures and institutions in the death system because they regularly advocate for their clients and provide education within their communities about these structures as part of the death literacy work.

Further, the community deathworkers who participated in this research provided examples of navigating between the formal and informal systems, at times almost acting like an interpreter for both their client and the health system. These actions could be seen as loosely aligned with Leadbeater’s version of a ‘renegade’; however, community deathworkers are invisible in the formal system so their work is largely marginalised. There was evidence that CDWs perceived that their role working with people dying was poorly tolerated by institutional deathworkers and their perception was the formal system viewed their work as an annoyance – at best. When a family hires a community deathworker, there is no way for the formal system of care to recognise this
relationship. They do not have a legitimate/legal relationship status such as the next of kin or ‘person responsible’, nor are they a family member. There were numerous examples of CDWs having to assert themselves with institutions. In these situations CDWs used their death literacy and legal knowledge to assert their authority. Likewise, there were a number of examples of IDWs using their authority as a health professional to advocate for the rights of patients and their families. In these situations the authority of the healthcare workers was assumed.

There is very little recognition about community deathwork in Australia and this has implications for the uptake of a public health approach to end-of-life care in Australia. As discussed in Chapter Two, public health approaches are concerned with social efforts and partnerships across organisations to improve the health and wellbeing of people dying through to bereavement (Karapliagkou & Kellehear, 2014). Although national palliative care policies have included elements of the public health approach, these have not translated to standard practice within palliative care services (Horsfall et al., 2013; Mills & Mills, 2016). One explanation is that palliative care services are already under-resourced and unable to meet the clinical demands of the ageing population in Australia (PCA, 2010; Rosenberg, 2007). There have also been considerable efforts to educate health professionals about palliative care and upskilling people in the ‘palliative approach’ to ensure that greater numbers of people with a terminal illness have access to good end-of-life care. The informal space where over 90% of end-of-life care occurs is however undervalued and significantly under-mobilised in Australia.
How might community deathwork become more visible? Given the findings of this research, one approach would be to develop policies and practices that provide opportunities to connect the formal and informal systems. There were examples in the data of community deathworkers benefiting from relationships with institutional deathworkers such as funeral directors and health professionals. These interactions were always initiated by CDWs and there were no examples of IDWs contacting CDWs. In most cases, community deathworkers had positive learning experiences with IDWs because the interaction developed their knowledge and skills contributing to their death literacy. Communication with the formal system was a challenge for community deathworkers when it involved direct care of a shared patient/client or the interaction focused on advocating for a service on behalf of a patient/client. In these situations, community deathworkers were required to activate their knowledge about the death system and to 'shape shift' to work around resistance from the formal system. An example of this was discussed in Chapter Four, when a community deathworker described having to convince a funeral director to ‘allow’ her legal right to wash and dress her grandmother.

A more challenging option to improve this visibility would involve institutional deathworkers taking an active role in engaging with community deathworkers. This might include seeking out death educators and doulas, informal carers and other community deathworkers in their local communities. However, given that IDWs are often negotiating a space that is ‘radical but not too radical’, it may be too risky for IDWs to endorse community deathwork directly and openly.
It is however important to acknowledge that there have been developments in the death system since 2011–2013, when I was conducting my interviews. In the past two years the informal and community deathcare space has grown considerably. There are now at least five death doula/midwife training programs, including one course that is run by a retired palliative care specialist. Further, the National Compassionate Communities Symposium in 2017 had a diverse program of speakers including doctors, natural funeral directors, end-of-life doulas, artists, health promotion workers, community development workers, and academics. This event was a significant moment for institutional and community deathworkers, sharing the stage together to talk about public health approaches to end-of-life care. The possibilities for formal and informal connection was modeled further through the conference partnership between The GroundSwell Project and the national peak body Palliative Care Australia. Finally, and perhaps the most significant development in the health sector, was the announcement in late 2017 of Department of Health funding to support the development of compassionate communities programs in the Primary Health Networks in Australia (The Department of Health, 2017).

There are 31 Primary Health Networks (PHN) across Australia working to improve the delivery of primary health services to people at risk of falling between the cracks of fragmented healthcare (The Department of Health, 2017). The PHNs work closely with both formal and informal care providers developing programs on local need. This funding opportunity was announced as
promoting a “greater choice for at home palliative care” through a number of strategies including:

inclusive community approaches, such as Compassionate Communities, to enhance the informal care networks of people requiring palliative care, and identify ways to connect both the formal health care services, information and social supports (Department of Health, 2018).

Connecting formal and informal groups is not a new concept in health promotion or health. In the UK, ‘health connectors’ and ‘community connectors’ are utilised to bring together formal and informal supports (Abel, 2017; Health Connections Mendip, 2016). This program has had a positive impact on health and wellbeing and social capital for people with multiple health conditions and at risk of social isolation (Health Connections Mendip, 2016). Although there are volunteers who have a valuable role in end-of-life care in Australia, the positions that connect formal and informal groups are often professional roles such as case managers. There are hopes that this new funding development for the health sector may provide additional opportunities for connecting the formal and informal spaces over the coming years.

Further sector developments include the compassionate communities program developed by Palliative Care Queensland (Palliative Care Queensland, 2018) and Palliative Care Tasmania being funded under a palliative care policy framework to develop and deliver public health initiatives. (Department of Health and Human Services, 2017) The public health approach is in an exciting period of development having been reinvigorated by the combination of these recent events.
Creating change

The ‘renegades’ in this research may not have demonstrated having a ‘foot in both camps’ but they believed their actions did disrupt the status quo. Institutional deathworkers are chipping away at cultural change by developing relationships and key allies within their organisations, and community deathworkers are ‘shape shifters’ with death system awareness and death literacy. As such, the actions of deathworkers have been shaped by their ‘social approach’ and also the setting where they practice. In the next section I will examine this further and discuss the next finding: renegade deathwork is shaped and influenced by the fragmented end-of-life and death systems.

‘Renegade’ deathwork is shaped and influenced by the fragmented care in the end-of-life and death systems.

The deathworkers who participated in this research were not satisfied with the care provided by mainstream healthcare and deathcare. Through their personal and professional experiences they observed end-of-life care to be fragmented, overly bureaucratic, and paternalistic. This fragmentation or ‘silos’ within healthcare services is a well-documented barrier to good healthcare (ACSQHC, 2013). One example of fragmented care in my workplace is the way cancer care is divided into ‘tumour streams’, with teams specialising in different cancers such as breast, ovarian, prostate, and head and neck cancers. This vertical disease model is not based on best practice patient care (though that is the intended goal) but upon funding models reinforced by a federal–state funding divide (Urbis, 2016). Over the past decade policy frameworks have attempted to develop a more integrated system of end-of-life care (ACSQHC, 2013) but it
continues to be a significant challenge since palliative care was mainstreamed into public health services in the 1980s and 1990s (PCA, 2010; Rosenberg, 2011). In examining the findings of this research, I can see these silos of care might also provide a way to examine this fragmentation on social practices. First, I am interested in how the patient journey and the silos in healthcare/deathcare reveal opportunities for change. In particular, IDWs and CDWs in this research appear to have a different relationship to structures in the death system.

To examine this more closely I have constructed a journey (Table 8) based upon the stories of my own patients in the hospital system. This is an abbreviated version of a patient journey, attempting to capture some of the major transitions that occur; although I note there are still 25 steps here. As a clinical psychologist in a palliative care team I would rarely see a patient or their family before step 19, by that stage end-of-life planning has been done via the pathway document discussed (Neuberger, 2013) in Chapter Two, and the social and care networks around the person dying are often anxiously rallying but unsure how to help. The patient, their immediate family and carers have spent many weeks institutionalised and removed from their informal social and cultural environments. In these situations hospitals and the hospital rooms usually become the new normal for patients, families and their social networks.

This example I detail involves a general practitioner, and at least six other medical specialists and their teams including nurses, social workers, physiotherapists, and occupational therapists. The patient experience in the health system is mentioned a number of times by the both the institutional and
community deathworkers in this research. IDWs were frustrated by the poor referral to palliative care and the lack of acknowledgement of dying for example. In this research, the involvement of institutional deathworkers was regularly limited to the last few weeks of a person’s life. This journey has been described extensively in the literature as a mixture of poor communication skills and paternalism (Meier, Issacs & Hughes, 2009; McNamara, 2004; Schofield, Carey, Love, Nehill & Wien, 2006; Woods, Craig, & Dereng, 2006).

Table 8: A Journey Through the Health System

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1</td>
<td>Person notices a pain or symptom</td>
</tr>
<tr>
<td>2</td>
<td>Visit General Practitioner</td>
</tr>
<tr>
<td>3</td>
<td>Diagnostic imagery for x-ray and CT scan</td>
</tr>
<tr>
<td>4</td>
<td>Pathology visit for blood tests</td>
</tr>
<tr>
<td>5</td>
<td>Initial diagnosis given GP (primary care)</td>
</tr>
<tr>
<td>6</td>
<td>Referral to cancer service – appointments made</td>
</tr>
<tr>
<td>7</td>
<td>Visit medical oncology specialist</td>
</tr>
<tr>
<td>8</td>
<td>Referral and visit to surgeon</td>
</tr>
<tr>
<td>9</td>
<td>Referral for radiotherapy</td>
</tr>
<tr>
<td>10</td>
<td>Referral and visit to cardiac specialist for clearance to surgery for pre-existing heart condition</td>
</tr>
<tr>
<td>11</td>
<td>Hospital admission</td>
</tr>
<tr>
<td>12</td>
<td>Surgery</td>
</tr>
<tr>
<td>13</td>
<td>See physiotherapist for support post-surgery</td>
</tr>
<tr>
<td>14</td>
<td>See Occupational Therapist because bed causing discomfort post-surgery</td>
</tr>
<tr>
<td>15</td>
<td>See surgeons for post-surgery review</td>
</tr>
<tr>
<td>16</td>
<td>Moved from acute medical ward to oncology ward</td>
</tr>
<tr>
<td>17</td>
<td>Start chemo in hospital because of findings from the pathology report</td>
</tr>
<tr>
<td>18</td>
<td>Social work team involved because of carer stress due to poor prognosis and now 3 week hospital stay due to infection post-surgery</td>
</tr>
<tr>
<td>19</td>
<td>Oncology team refer to palliative care for pain and symptom management</td>
</tr>
<tr>
<td>20</td>
<td>Palliative care ‘take over the care’ of the patient</td>
</tr>
<tr>
<td>21</td>
<td>Patient moved to palliative care bed/ward when available</td>
</tr>
<tr>
<td>22</td>
<td>Multidisciplinary team – medical team, nursing team, physiotherapy, dietician, speech therapist, social worker, psychologist, diversional therapist, volunteers</td>
</tr>
<tr>
<td>23</td>
<td>Patient dies 3 weeks later in palliative care ward</td>
</tr>
<tr>
<td>24</td>
<td>The body is transferred to the mortuary</td>
</tr>
<tr>
<td>25</td>
<td>Bereavement follow-up within 1 month</td>
</tr>
</tbody>
</table>
There are a number of patient journeys (see Appendix 7; Grampians Regional Palliative Care Consortium, 2013) and frameworks (see Appendix 8; Department of Health, 2016) that provide examples of how people move through multiple healthcare silos. Notably, all of these models provide insight into the routines associated with end-of-life care in the healthcare system captured by the biomedical model of care. These routinised actions are designed to help institutions to manage dying and death and also to provide a sense of predictability for staff (Rosenberg, 2011; Zimmerman, 2012). The day-to-day repetition of care routines and patient journeys also helps to maintain the reproduction of the cultural norms that support the healthcare institution to continue admitting and discharging people into and out of care. These institutional machinations were not, according to the institutional deathworkers in this research, enablers of good patient care and were often experienced as highly medicalised.

However, end-of-life experience of a patient cannot be fully captured through examination of the institution or its structures alone. Patients and families bring their own intricate social networks, social lives, and experiences with them to the institutional care experience. The social approach of deathworkers is one way of acknowledging the larger part of dying, caring, and bereavement that occurs in the informal lives and relationships and social spaces. As such, one outcome of this research is to suggest that there is merit in continuing to investigate these under acknowledged social experiences in the transitional or liminal spaces that exist between, around, and even within, the silos in the death system.
These findings are consistent with evidence that informal care is a hidden resource in the healthcare system (Horsfall, et al, 2012; Lewis, et al., 2013). The individual patient journey, the policy journey, and the clinical journey do not refer in any significant way to informal care, informal community-led end-of-life care or other supports that occur beyond the health institution. With support from family and friends people living with a terminal illness live at home for long periods independent of the healthcare system. As noted in Chapter Two, over 90% of end-of-life care is provided in communities by family members and informal care networks (Gardener, Rumbold & Salau, 2009). There is now a body of research providing greater insights into this informal care – the practical assistance, medical care, assistance with childcare and petcare, emotional support, and respite (Burns et al., 2013; Horsfall, Noonan, & Leonard, 2013; Horsfall et al., 2018; Rosenberg, et al., 2015).

**Structures and spaces.**
The stories of the deathworkers in this research also revealed the roles they occupy, and move in and out of in these informal and transitional spaces. For the deathworkers in this research, having a social approach—an “amenable and responsive” frame (CDW4)—did provide a way to manage their dissatisfaction with the biomedical model and respond to its dominance, and also gave them room to move between structures and systems although it was mainly the CDWs who took this up. A social approach was particularly important for institutional deathworkers who were employed by healthcare organisations and were conducting their work within the healthcare ‘silos’. In contrast, community deathworkers were working in relationship with people (such as
other deathworkers, clients, family members, community members).
Community deathworkers practice across, within, and around all of the silos of care. Unlike institutional deathworkers their practice is social and relational, and they can and do, respond to requests from people receiving care at any stage of their illness, this includes working with families post-death in preparation for funeral and burial. In this next section I turn my attention to understanding how deathworkers using a social approach participate between and with/in structures and spaces.

To examine this finding in more detail I have created the figure below. This figure represents the silos in healthcare and after deathcare as described in the data by deathworkers in this research. I have included the continuum of care, beginning with the diagnosis of a life limiting illness, the time of death and through to bereavement.

![Figure 3: Place of work and the transitions of care](image)

**Figure 3: Place of work and the transitions of care**
Transition one: Curative treatment to end-of-life care. The transition between curative treatment and end-of-life care has been researched widely, particularly in cancer care (for example, MacArtney, Broom, Kirby, Good & Wootton, 2017; McClement & Daeninick, 2006; Scholfield, Carey, Love, Nehill & Wein, Thompson, 2006). Curative care usually occurs following the diagnosis of a life-threatening illness such as cancer. Other illnesses, such as heart disease and dementia, are immediately a life-limiting illness from diagnosis because there is no cure and only medical interventions such as surgery and medications may extend life expectancy. As noted in Chapter Two, early referral to palliative care is a key public health priority because wellbeing and good end-of-life care is enhanced for the dying person and their families. Institutional deathworkers in this research were frustrated by poor referral processes and delayed referrals to palliative care. The transition to end-of-life care was enhanced when there was open communication between medical practitioners and the person dying regarding their diagnosis and treatment options.

This transition is often dominated by medical decision making and the manner in which these decisions are communicated is central, making paternalism and medicalisation significant barriers to people with a terminal illness accessing appropriate care and support in the last months of life. As noted already, this can be a time when people continue to be highly engaged in work and social activities. Medical input is important when symptoms interfere with these daily activities of living. In this research, community deathworkers were marginally involved in this transition and when they were they provided support and advice to people who were preparing for their end-of-life.
Community deathworkers had a role in educating the community about the range of formal and informal options available and as noted in the previous section, institutional deathworkers are rarely involved until the last months or weeks of life.

*Transition two: End-of-life care to time of death, is the* next major transition for people who are dying and their families. Death occurs the majority of the time in an institution in Australia, yet 90% of this care is provided by family members in community settings (Gardener, Rumbold and Salau, 2009). The transition between the final months of life and the time of death is enabled by good communication and acknowledgement of dying to allow for preparation for death. Barriers to dying well include poor access to palliative care and poor acknowledgement of the dying process by both health professionals and family members. This was a space that both IDWs and CDWs practiced in and talked about throughout the interviews. Notably, it was during this transition that IDWs broke the rules to ensure the last wishes of their patients were addressed.

Time of death in an institution signifies the end of medical care, and though bodies are washed and prepared for viewings this care is hidden and under acknowledged by institutions (Bloomer et al., 2013; Glaser & Strauss, 1968; Quested & Rudge, 2003; Sudnow, 1967). The findings of this research are consistent with these studies. Institutional deathworkers only refer twice to the dead body, once in relation to the importance of telling families about moving the body out of a ward and secondly when an IDW refers to the importance of viewings. Community deathworkers however talk a great deal about the dead
body and its significance in social life, linking it to healthy rituals and supporting the grief experience of both families and communities.

This finding is a reflection of the biomedical model and its dominance with/in the death system. That is the dead body is no longer ‘a patient’ under the control of the medical system (Quested & Rudge, 2003). The expertise of medicine ceases once the patient has died and a doctor issues a certification of death. In a community setting, community deathworkers can be extremely active after death working to facilitate social and community rituals. The primary role of the institutional deathworkers in this research was in the care of the dying, while community deathworkers facilitated non-medical and social supports, facilitated body disposal and supported the rituals associated with mourning.

**Transition three: Time of death to funeral and body disposal.** This is a transition usually managed by healthcare and funeral professionals because the large majority of people die in institutions. As noted in Chapters One and Two, hospital policies about bed management and mortuary services can inhibit the access a family has with their deceased family member, as can professional attitudes (paternalism) about who should see a deceased person and why. In some hospitals mortuary viewing rooms are understaffed or patients are encouraged to view the body at the funeral directors. As such, this transition was rarely referred to by IDWs, whereas community deathworkers frequently practiced in this space. The findings of this research suggest this transition provides a space where the tension and struggles between community and institutional deathworkers can be high. This tension is experienced when the
dying body, which is usually under medical care, transitions to being a dead body needing care. The body is now subject to a new set of public health policies and laws, and as such ‘the body’ is typically handed over to the care of the funeral industry. In this space however families can literally ‘reclaim’ their family member from the health and death systems, dramatically changing the power dynamic between the death system and family.

The community deathworkers in this research were deeply committed to facilitating the care between families and their dead. Community deathworkers spoke at length about working with healthcare professionals, funeral directors and facilitating body disposal (i.e. cremation/burial). In one example, a hospital refused to release the body of a deceased family member, and in another a funeral director refused to allow a family member to dress a family member. In these situations the institutional policies were often contradictory to the law or legal rights of a family member (Larkins, 2013). Community deathworkers used their knowledge of the death system to facilitate the options available to their client. For example, they might email copies of the public health policy to the mortuary workers in a hospital and work with hospital management to have the body released from the institution. When hospital policy and law is contradictory, IDWs do two things: they start ‘chipping away’ at the system to create policy change and they shift their focus onto patient-centred care. In this research there were a number of examples of patient-centred care being seen as a key action for change. That is, the institution might be rigid, but clinical care does not have to be.
Transition four: The transition from funeral and body disposal to bereavement. As noted in Chapter Two, the need for professional intervention following a death has been greatly over-estimated until recently with less than 10% of people needing professional bereavement support (Rumbold & Aoun, 2014). Supporting natural resilience though social supports enable the transition from death through the period of early bereavement and ongoing. Institutional deathworkers are only involved in this transition when bereavement is complicated. Community deathworkers are often highly active in this transition because they are often involved in organising funerals and facilitating the body disposal process (i.e. cremation, burial).

The institutional deathworkers in this research were most effective when they worked with/in the informal structures building relationships, mentoring, and connecting with others. Challenging the institutional structures directly was rarely experienced as effective nor did it help IDWs with their reformist agenda. Changing institutional policy is a good example of this. It takes considerable interpersonal skills and time to change operational policies in a hospital setting. The institutional deathworkers seemed to do both—chip away at policy and when warranted use their position and power in the system to try and transform the experience of an individual from a fragmented and impersonal experience to a more holistic/person-centred one. IDWs provided numerous examples of fragmented patient care experiences influencing their pursuit of policy change. In these situations, IDWs focused on patient-centred care and helping the person die well to attempt to buffer the patient and family from this fragmentation.
The difference between how and where IDWs and CDWs can support people and families through these transitions is stark. Community deathworkers can support a person with a life threatening illness from the moment they are diagnosed, through dying, and then continue to support the family members after death, for deathcare and mourning rituals. Institutional deathworkers are most engaged in transition three when a person is dying. Despite this unique offering, community deathwork is invisible to health professionals and under-recognised by the formal system.

**Is it possible for community deathworkers to have greater recognition and connection to formal healthcare services and healthcare practitioners?** Community development theories and practices, which underpin the Compassionate Communities and Compassionate Cities movement, could have a greater role in improving the connection between formal and informal systems. Compassionate Communities at end-of-life, for example, address the fragmentation of care by creating supportive environments around dying, death, and grief and shifting the focus toward personal networks and broader social networks (Abel, 2017; Karapliagkou & Kellehear, 2014; Leonard, Horsfall, Rosenberg & Noonan, 2018).

To achieve this in any meaningful way, efforts to promote a better understanding of public health approaches to end-of-life are needed, with a focus on community development and death system capacity building. A central tension seems to reside in the theoretical framework used by the individual deathworker, service provider, policymaker or researcher. Dempers and Gott (2016b) noted three such frameworks in the literature: health promotion,
which is about community networks and assets; a population-based approach focused on epidemiological and population-based methods; and a third 'WHO approach' referring predominately to palliative care service delivery efforts in whole populations. I have similar concerns as Dempers and Gott about conceptual clarity (2016b). However the purpose of this thesis is related to practice.

When recruiting the deathworkers in this research I used the term social approach to align my research with the social model of health and with social practices. The findings have revealed that deathworkers can be philosophically aligned with a social approach, and be a clinician at the coalface of clinical practice. The IDWs in this research managed this by being critical of the reductionist medical model.

It is important to acknowledge that despite policy imperatives, there is very little evidence of palliative care services and public health units collaborating in Australia. As discussed in Chapter Two, scoping studies have identified a range of terms, approaches and views about the public health approach (Barry & Patel, 2013; Dempers & Gott, 2016; Paul & Sallnow, 2013). These studies, for example found that the terms community engagement and community development are often used interchangeably, yet they are not irreducible; while advance care planning workshops and public awareness campaigns about palliative care were viewed as health promotion activities. The majority of literature over the past decade has focused on developing theory, or descriptions of how to implement a social approach. Rosenberg’s (2007) thesis for example was a mixed methods case study of a hospice in
Australia. It provided the field with a practice example of some of the challenges of implementing the approach and contributed by providing additional clarity about how public health and palliative care can work in conceptual unity. It is worth reflecting on these recent developments in light of the practice examples that previously flourished in Victoria (Gardner, Rumbold, & Salau, 2009).

**How might this understanding about the social approach develop more fully into practice?** The findings of this research have revealed that institutional deathworkers have an adaptive leadership style and are perceived as well regarded by their colleagues.

However, health systems will, if not checked, revert back to the status quo of service delivery. The IDWs were under constant pressure to maintain the status quo. Community deathworkers are not acknowledged by the formal system, so they have different systemic pressures. Both IDWs and CDWs, for example, developed a ‘knowing’ about and an awareness of how their actions effect the death system (Giddens, 1984). This practical knowing is important but not enough to create change. Deathworkers must also keep taking action or ‘chipping away’ and be strategic about how they channel their energies.

Structural norms therefore, only go part of the way in explaining the maintenance of the status quo in the death system. In Chapters One and Two I discussed the structure/agency tension in relation to the role of change-makers and social innovators in the death system. Institutional and community deathworkers demonstrated their role as change agents despite the constraints in their social environment. One way in which agency was demonstrated was via the active process of ‘shape shifting’, which enabled deathworkers to be
persistent and have a long-term approach to change. As the institution responds so does the deathworker and this research has highlighted how institutional deathworkers tend to use strategies that avoid conflict in preference for relationship building. Giddens (1984) uses the term “practical consciousness” to describe how this structural awareness is incorporated into social action. Institution-based deathworkers have a knowing about how far they can push a change agenda and they have adapted their approach accordingly. This adaptive style or ‘knowledgeability’ is helpful because institutional deathworkers are also employees of the system they are attempting to change.

The health and death systems need change-makers on the inside, who are able to create this kind of holding environment while the system re-orientates (Snowden, 2011). Moyer (2001) has developed a useful way to view the roles and contributions people can have to social change movements; they are: citizen, rebel, social change agent, and reformer. Citizens are people who can articulate the vision of the movement. These are people, regardless of profession or role in the system, able to talk about the principles and practices of Compassionate Communities, for example. They have a role in ensuring that any attempts to water such approaches down or discredit them are met with evidence or efficacy, for example. These people are champions and able to spread the word about the work being done in their communities or workplace.

**The rebel** helps put a social issue/movement on the agenda. They turn the heat up and cause tension by highlighting the gap between what is and what should be. They are often empowered to use information from the movement to
take action in their own community or contexts. They may be involved in direct action, but are more likely to support and facilitate.

*The social change agent* promotes alternatives and paradigm shifts, and nurtures and develops new cultural practices. In Compassionate Communities, this person could equally be the community development worker or a clinician. A social change agent brings new language and actions into a system. They do this by acting as an ‘open system’ sharing information and promoting dialogue between the system and the community/public. And finally, *reformers* change policy, and lead change within institutions by working with powerbrokers and acting as an interface between a social movement and the public. While change-makers are seen as encouraging awareness of a social issue through open dialogue, reformers are using their nous to lobby for change in institutions and systems. There is evidence that both groups of deathworkers moved in and out of these roles as part of their ‘shape shifting’.

**How are Renegades Working to Make a Difference?**

*Working toward change: amelioration and transformation.*
Community and institutional deathworkers work in the structures and spaces of the death system in unique ways. Institutional deathworkers are employed by the dominant institutions providing end-of-life care, but when they are using a social approach they are taking action in the transitional spaces between the structures. They make use of their professional authority “I’m the doctor” (IDW3) and they actively avoid conflict in favour of building connections and relationships within the system. Institutional deathworkers know these relationships with other health professionals will ultimately enable them to
stretch the rules and even break rules for the sake of patient care. They have long-term goals to change policy and practice, but they do not bring this structural change agenda into their practice with patients and families. Their primary focus, albeit using a social approach, is the amelioration of symptoms that cause suffering and pain.

Community deathworkers work outside the formal structures or silos but often they are directly managing information, facilitating relationships, and attempting to influence the behaviour of structures and systems. Likewise, CDWs do this because they are motivated by the possibility they can activate a range of choices and options for people who are dying, their families, and communities. They are activists and they are working for transformation in the death system and for the people and communities they work with.

As a deathworker I see that I am regularly moving between transformation and amelioration. I can see now however, that a critical social science frame, whether in a clinical or grassroots setting underpins my actions. This understanding, or perhaps declaration that I am a critical social scientist, has been an important part of the journey for me as a researcher, practitioner and activist. Critical theories have influenced my view of the death system, which have in turn strengthened my practice as a deathworker. This experience has been deeply iterative enabling me to put theory into practice and to also learn about and reflect on my practice. Ultimately, CSS has enabled me to function as a more reflexive activist and a practitioner.
Conclusions

You cannot buy the revolution.
You cannot make the revolution.
You can only be the revolution.
It is in your spirit, or it is nowhere.


The dominant medical approach to death can only account for part of the experience in our death system. A social approach constantly reminds us there are thousands of people living with a terminal illness being cared for and supported by friends, families, neighbours and community members in the last months of their lives. This research has highlighted how institutional and community deathworkers contribute to this network of care, and in particular how informal caring is invisible to the formal care system. Community deathwork in this research was found to be marginalised and hidden, yet the breadth of personal and professional experience, and death literacy shown by community deathworkers was extraordinary.

In Australia, the majority of the 160,000 people who die each year spend at least the last few days of life in institutional care. Then, once they have died, they are picked up from the hospital mortuary and transferred to the funeral director, where they are prepared for burial or cremation. Each transition has a bureaucratic procedure that reinforces the need for professionals and specialised knowledge. To promote any deviation from these deeply embedded cultural and systemic practices is too risky for institutional-based deathworkers. They employ long-term strategies and tactics for policy change,
but they rarely break institutional rules. For some, this ensures their long-term survival in the health system, while other deathworkers I spoke to removed themselves from their clinical positions to change the system in other ways. Without leadership opportunities within the health system we risk losing more of these change-makers with a clinical role (i.e. nurses, doctors) to burnout or to research programs where critical ideas are more freely encouraged and supported. There is a need for our end-of-life services to support deathworkers who are change-makers and healthcare activists.

In the past two years the sector has witnessed a growth in community deathwork and an increasing awareness of end-of-life doula/midwife practices. While it continues to be a marginal practice in the end-of-life space, I have witnessed that in my own network there is a growing community of practice developing and flourishing. Another sign social approaches are making an impact is that healthcare professionals are beginning to take notice. Just recently a research group contacted me to ask about the best way to access community deathworkers. Though worryingly I have also heard rumours about government departments ‘unofficially’ directing their funding recipients to not work with end-of-life doulas.

I am hopeful this fear might be a sign of systems responding to change. New paradigms, such as Compassionate Communities are disruptive and threatening to the dominant biomedical approach. It is important to remember that the current resurgence of Compassionate Communities is here because the previous revival was systematically defunded, while public health principles continued to ‘live on’ rather innocuously in state and national palliative care.
policies.

At the very least, new funding and interest in public health approaches is a sign that health services are tentatively looking beyond formal service networks toward the informal social networks within the community (Rosenberg et al., 2017). Over the past two years, I have observed that health professionals who are unfamiliar with community deathwork tend to compare it with palliative care volunteering, which is highly regulated in Australia. With the volunteer model as their only frame of reference, health professionals label community deathwork as a ‘danger’ to dying people because it is viewed to be ‘unregulated’. Yet palliative care services are also struggling with the professionalisation and over-regulation of palliative care volunteering. Recent research suggests palliative care volunteers are increasingly dissatisfied by the unnatural restrictions placed on their relationships with patients, families, and community members (Gale, 2017). This is consistent with the experience of at least two of the community deathworkers in this research who had trained and volunteered with palliative care services. It will be important to find ways of ensuring that community deathwork is not professionalised in the same way other informal care in the death system has been. As someone who has participated in both the medical and social models of end-of-life care, I view community deathwork as similar to a (social) movement toward reclaiming the community-based traditions about end-of-life, dying, and death. Community deathworkers could continue to act as a resource for reclaiming this knowledge within their communities.

It is difficult not to see the synergies between community deathwork and
the goals of Compassionate Communities and other capacity building approaches to end-of-life. As such, the question of how palliative care services can and will adapt to the broad implementation and growth of public health approaches in Australia needs urgent attention. How will service providers respond to grassroots-initiated compassionate communities work? Are service providers and healthcare services ready and able to participate in “genuine partnerships” with community members? (Kellehear, 2005). Service providers, such as the institutional deathworkers in this research, already have significant authority in the end-of-life space. If public health approaches to palliative care develop into a social movement, transformative practice, and emergent leadership is needed.

**Allowing knowledge and practice to flourish in communities.**

A colleague of mine, recently shared a story with me when we were discussing this research and the Compassionate Communities work that we have seen grow in the past 12 months,

My father, he said to me, was doctoring when there were no antibiotics. As a result, when he would attend to a person ill with an infection there was no treatment to offer. The family however, had usually implemented a remedy of some sort to support the wellbeing of the person. This might have included the types of food given to the person, herbal remedies, and hot towels and steam. When antibiotics became available this changed. A doctor now had a treatment and even a cure to prescribe. So whether an infection was bacterial or viral, doctors would and could prescribe antibiotics.

This change in practice, he said, altered the way families cared for their sick. Soups or balms infused with everyday wisdom used for generations
were now considered worthless and the role of medical practice
delegated to the primary source of care. It also changed the way newly
trained doctors viewed the remedies that families had used to care for
their sick. They were trained in ‘evidence-based medicine’ and there was
"no evidence" for such remedies and practices.

Families stopped practicing and passing on their knowledge to the next
generation. The same has happened with how we care for our dying
family members. Once we cared for people until they died at home, and
families and communities had access to this knowledge about how to
care for each other when we were dying, dead or grieving.

This tacit knowledge about dying and death still exists in some families
and particular communities in Australia in 2018. It is however deeply under-
valued and under-recognised by the dominant medical paradigm. We need a
way of acknowledging the people who ‘hold’ this tacit knowledge about the
death system, and indeed a greater acknowledgement that it even exists. This
idea faces significant difficulties in the face of the professionalised death
system; however, as Sallnow, et al., (2016) and others (Abel, 2017; Rosenberg,
et al., 2007) have demonstrated, community development approaches can
coexist providing positive outcomes for the dying person, their family, and local
community. The health service can also benefit through reduced healthcare
costs and more meaningful connection between the institution and local
citizens.

I would like to see future research further explore and unearth
traditional deathwork practices in communities across Australia. Future
researchers would benefit as would the formal end-of-life care sector, from
actively seeking to understand more about the role and function of community
deathwork in the lives of people who are dying, their carers, and families. Those of us with a social approach and an interest in Compassionate Communities would also benefit greatly from understanding more about those individuals and groups who have maintained their traditional practices despite the dominance of the biomedical model. This includes some Indigenous Australians and the numerous culturally diverse groups around Australia.

The stories shared with me have been a catalyst for my community work, my work as a psychologist, and as an end-of-life researcher. The research findings have informed numerous presentations to my peers and has inspired new projects and new research with The GroundSwell Project. I have talked about my findings, shared ideas, and used critical reflections in consultations and media interviews. I have felt challenged and surprised that institutional deathworkers in this research demonstrated very little awareness about community-based dying and deathcare. Again, I had assumed that people working within a ‘social approach’ meant that institutional deathworkers were more actively connected to deathwork in the community.

In this environment, the risk that social approaches are treated as a ‘threat’, causing mainstream practices to take up a less effective modified version of a social approach, or action to preserve its own dominance is high (Eakin et al., 1996). End-of-life research in Australia rarely examines social change or seeks to understand the conditions that enable the kind of paradigm shift it genuinely seeks in policy documents (PCA, 2010). We tend instead to fund ‘innovative research’ but there are few government or philanthropic initiatives that invest in social innovation to transform practice. Given that it
can take more than a decade to translate innovative research into new practice, this approach is not sufficient to transform practice before 2025 when Australia’s death rate will be higher than our birthrate.
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Appendices
Appendix 1: Ethics Approval

UWS HUMAN RESEARCH ETHICS COMMITTEE

16 April 2012

Associate Professor Deborah Horsfall,
School of Social Sciences and Psychology

Dear Deborah,

I wish to formally advise you that the Human Research Ethics Committee has approved your research proposal H9533 “Renegade Stories: Social Approaches to Death, Dying and Bereavement in Australia”, until 1 March 2015 with the provision of a progress report annually and a final report on completion.

Please quote the project number and title as indicated above on all correspondence related to this project.

This protocol covers the following researchers:
Deborah Horsfall, Rosemary Leonard, Kerrie-Lee Noonan.

Yours sincerely

Dr Anne Abraham
Chair, UWS Human Research Ethics Committee

d.horsfall@uws.edu.au
98487543@student.uws.edu.au
Appendix 2: List of Referral Resources for Participant Support

Renegade Stories – List of referral resources for participant support

De-brief with your friends and family

Talk to your clinical supervisor or mentor

Book an appointment with your massage therapist

Talk to your staff counsellor

Talk to your General Practitioner and if needed get a referral to a Medicare provider such as a psychologist.

Find support through a counsellor:

- The Australian Psychological Society has a referral service call 1800 333 497
- The Psychotherapy and Counselling Federation of Australia has an online search here: http://www.pacfa.org.au/
Appendix 3: Interview Questions

What is your current work and how would you describe it?
What does the social approach/health promoting approach to death, dying and bereavement mean to you?
How did you come to be doing this work?
What are your experiences using the social/health promotion approach in your workplace?
Can you share a story that best captures the meaning of the social approach?
How has your work been shaped by these experiences?
When you think of the social approach, what has helped shape your work in death, dying and bereavement? (prompt – experiences, research, literature etc.)
Appendix 4: Recruitment Letter

Is your work informed by the public health approach to palliative care and deathcare practice?

Are you working to build the capacity and knowledge of the community in care of the dying and after deathcare practices?

In 1999 Allan Kellehear wrote 'Health Promoting Palliative Care' which highlighted the role that the whole community has to play in the care of the dying. The health promoting approach calls for palliative care services to look beyond service provision of palliative care and find ways to engage the general community in death, dying and bereavement and look at dying as a social and community event. This work has since influenced public policy in Australia and resulted in an increasing number of services implementing health promotion. There are also people working from within the community, outside the health and medical systems, providing end-of-life care and after deathcare that is based on community development.

This research aims to explore all of these stories and experiences in the death system. The death system is seen as shaping and guiding how we interact with and act toward our dying, our dead, and the bereaved. It is my intent therefore, to look beyond the usual voices to those change agents enacting the social approach in various aspects of the death system. This includes people working in the funeral and celebrant industry and community development.

Please read through the information that is attached to this email. The information letter describes what is involved. You are welcome to email me
on 98487543@student.uws.edu.au or call me on 0439 040 499 if you have any questions.

This project is part of my PhD in the School of Social Sciences and Psychology at The University of Western Sydney and it has Ethics Approval (HREC No. 9533).

Yours sincerely

Kerrie Noonan

PhD Candidate

School of Social Sciences and Psychology

University of Western Sydney
Appendix 5: Participant Information Sheet

Participant Information Sheet (General)

An information sheet, which is tailored in format and language appropriate for the category of participant - adult, child, young adult, should be developed.

Note: If not all of the text in the row is visible please 'click your cursor' anywhere on the page to expand the row. To view guidance on what is required in each section 'hover your cursor' over the bold text. Further instructions are on the last page of this form.

Project Title: Renegade Stories: social approaches to death, dying and bereavement in Australia.

Who is carrying out the study?
Kerrie Noonan is carrying out the study. She is a PhD candidate in the School of Social Sciences and Psychology.

This research will form the basis for the degree Doctor of Philosophy at the University of Western Sydney under the supervision of Associate Professor Debbie Horstall.

What is the study about?
The purpose of the study is to investigate the stories and experiences of death workers who are using a social and health promotion approach to death, dying and bereavement in Australia.

What does the study involve?
This qualitative project involves gathering information about the experiences of people using a social approach to death, dying and bereavement in Australia. Participants can choose to be involved in this research in one of two ways - focus groups or interviews.

1. Focus Groups: 6-8 people will participate in focus groups as part of a 3 day digital storytelling workshop held in Sydney. The workshop will enable each participant to make their own digital story and a focus group will be held at the beginning, end and 3 months following the workshop. Focus groups will take 2 hours and be audio recorded, transcribed. Transcripts will be shared with participants for review and then analysed by the researcher.

2. Individual interviews will occur in a place convenient to the participant and will last between 60-90 minutes. Interviews will be audio recorded and transcribed. Transcripts will be returned to participants for review and then analysed by the researcher.

How much time will the study take?
Interviews will take between 60-90 minutes and 2 hour focus groups will be conducted as part of a digital storytelling 3-day workshop and occur before, after and 3 months following the workshop.

Will the study benefit me?
The study will provide an opportunity to reflect on the social approach to death, dying and bereavement and how this approach informs your work in the community. It also provides an opportunity to connect with other people working in the field.
Will the study involve any discomfort for me?
It is not expected that the study will provide any discomfort, however it is important to acknowledge that talking about death and dying can be distressing or stressful. Please find attached a list of suggested supports if this happens.

How is this study being paid for?
The study is part of the requirements of my Doctor of Philosophy degree. The university reimburses my travel and fieldwork expenses.

Will anyone else know the results? How will the results be disseminated?
All aspects of the study, including results, will be confidential and only the researchers will have access to information on participants. Results will be disseminated via a thesis, presentations and journals. Results and information about the research will also be available on the research website.

Can I withdraw from the study?
Participation is entirely voluntary: you are not obliged to be involved and if you do participate you can withdraw at any time without giving any reason and without any consequences.

Can I tell other people about the study?
Yes, you can tell other people about the study by providing them with the chief investigator’s contact details. They can contact the chief investigator to discuss their participation in the research project and obtain an information sheet.

What if I require further information?
When you have read this information, Kerrie Noonan will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact me at k. noonan@uws.edu.au. You are also welcome to contact my supervisor Assoc. Prof. Debbie Horsfall on d.horsfall@uws.edu.au or 02 47360023.

What if I have a complaint?
This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is H9533.

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form.
Appendix 6: Participant Consent Form

This is a project specific consent form. It restricts the use of the data collected to the named project by the named investigators.

Note: If not all of the text in the row is visible please ‘click your cursor’ anywhere on the page to expand the row. To view guidance on what is required in each section ‘hover your cursor’ over the bold text.

Project Title: Renegade stories: social approaches to death, dying and bereavement in Australia.

I, consent to participate in the research project titled Renegade Stories: social approaches to death, dying and bereavement in Australia.

I acknowledge that:

I have read the participant information sheet [or where appropriate, ‘have had read to me’] and have been given the opportunity to discuss the information and my involvement in the project with the researcher.

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I consent to participating in an interview that will last 60-90 minutes. I understand this interview will be digitally recorded and transcribed for analysis.

I understand that transcripts will be returned to me, and that I have an opportunity to comment on their accuracy and change any information to ensure my privacy.

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher now or in the future.

Signed: ____________________________

Name: ____________________________

Date: ____________________________

Return Address: k.noonan@uws.edu.au

This study has been approved by the University of Western Sydney Human Research Ethics Committee.

The Approval number is: H9533

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix 7: Patient Journey Chart (Grampians Palliative Care, 2018)

<table>
<thead>
<tr>
<th>STATE</th>
<th>Reasonably well</th>
<th>Unwell</th>
<th>More unwell</th>
<th>Dying</th>
<th>Dead</th>
</tr>
</thead>
<tbody>
<tr>
<td>Condition</td>
<td>Healthy; or may have chronic illness</td>
<td>Acutely ill</td>
<td>Progressive disease</td>
<td>Rapidly deteriorating</td>
<td></td>
</tr>
<tr>
<td>Events</td>
<td>Life-threatening illness/injury</td>
<td>Reversal/failure of treatment</td>
<td>Dying</td>
<td>Death</td>
<td></td>
</tr>
<tr>
<td>Outlook</td>
<td>Years</td>
<td>Years</td>
<td>Months – Years</td>
<td>Days</td>
<td></td>
</tr>
<tr>
<td>Treatment type</td>
<td>Preventive</td>
<td>Curative/Restorative</td>
<td>Palliative</td>
<td>Terminal care</td>
<td>Bereavement care</td>
</tr>
<tr>
<td>Goals of care</td>
<td>Maintain reasonable health</td>
<td>Return to reasonable health and independence</td>
<td>Management of symptoms including pain</td>
<td>A comfortable death</td>
<td>Care of family and friends through grieving process</td>
</tr>
<tr>
<td>Clinician planning</td>
<td>Preventive health care plan and/or disease specific care plan</td>
<td>Disease specific care plan</td>
<td>Palliative care plan</td>
<td>Terminal care plan</td>
<td></td>
</tr>
<tr>
<td>Living arrangements</td>
<td>Home and independent engaged with community</td>
<td>Home, hospital or aged care facility, engaged with health system</td>
<td>Home, hospice, palliative care ward, aged care facility or hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACD</td>
<td>Knows about; may complete; may retain a form in case</td>
<td>May lead to appointment of Substitute Decision Maker and/or discussion with family and health care providers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ACD records</td>
<td>SDM and sometimes values and life goals</td>
<td>May add values, life goals and circumstances to avoid</td>
<td>May add specific directions for SDM, and preferred outcomes</td>
<td>May add specific interventions refused</td>
<td></td>
</tr>
<tr>
<td>Completes</td>
<td>Independently or with legal advice</td>
<td>Independently, with legal advice or within an advance care planning program</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 8: End-of-Life Framework by Western Australia

### Department of Health

<table>
<thead>
<tr>
<th>Stages*</th>
<th>Triggers</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong></td>
<td>1. Would you be surprised if the patient died in the next 6-12 months?<strong>&lt;br&gt;Advancing disease</strong></td>
<td><em>Known advanced cancer or chronic disease</em>&lt;br&gt;<em>Evidence of disease progression and/or symptoms</em>&lt;br&gt;<em>Patient/family expresses concern about the future</em>&lt;br&gt;<em>Would you be surprised if the patient died in the next 6-12 months?</em> **&lt;br&gt;<strong>Consider:</strong>&lt;br&gt;<em>Advance Care Planning</em>&lt;br&gt;<em>Palliative Care consultation</em></td>
</tr>
<tr>
<td><strong>2</strong></td>
<td>2. Would you be surprised if the patient died this admission or in the next month?<strong>&lt;br&gt;Increasing decline</strong></td>
<td><em>As for Stage 1 plus:</em>&lt;br&gt;<em>Increasing frailty</em>&lt;br&gt;<em>Increasing symptom burden</em>&lt;br&gt;<em>Increasing psychosocial support needs</em>&lt;br&gt;<em>Not responding to treatment or non-adherence with treatment</em>&lt;br&gt;<em>For hospital inpatients, would you be surprised if the patient died this admission?</em> **&lt;br&gt;<strong>Consider:</strong>&lt;br&gt;<em>Referral to palliative care for ongoing care or palliative care consultation and/or shared care partnerships with palliative care</em></td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Irreversible clinical deterioration, life expectancy one week or less**&lt;br&gt;Last days of life**</td>
<td><em>Irreversible clinical deterioration</em>&lt;br&gt;<em>Team decision of diagnosis of dying.</em> **&lt;br&gt;<strong>Commence:</strong>&lt;br&gt;<em>Best practice care of the dying, e.g. Care Plan for the Dying Person</em></td>
</tr>
<tr>
<td><strong>4</strong></td>
<td>Death and bereavement**&lt;br&gt;Death of patient**</td>
<td><em>Death of patient</em> **&lt;br&gt;<strong>Consider:</strong>&lt;br&gt;<em>Bereavement follow-up needs</em></td>
</tr>
</tbody>
</table>

*The stages are provided as a guide and are not intended to be prescriptive – each patient’s circumstances will be different and care should be provided accordingly.*
Appendix 9: Compassionate City Charter (Source: www.phpci.info)

THE COMPASSIONATE CITY

- CHARTER -

People who live with life-threatening or life-limiting illness, their caregivers, and the bereaved are segmented social groups, forced to experience lifestyles that are commonly socially hidden and disenfranchised from the wider society. Outside of the health services that deal specifically with their immediate problems, these populations suffer from a range of other troubles that are separate but linked to their health conditions or social circumstances – loneliness, isolation, job loss, stigma, depression, anxiety and fear, or even suicide. These populations also suffer from a range of other debilitating health problems often caused by their social and psychological troubles - insomnia, cardiac arrhythmias, chronic fatigue and headaches, hypertension, and gastrointestinal disorders.

Compassionate Cities are communities that publicly recognize these populations, and these needs and troubles, and seek to enlist all the major sectors of a community to help support them and reduce the negative social, psychological and medical impact of serious illness, caregiving, and bereavement. A compassionate city is a community that recognizes that care for one another at times of health crisis and personal loss is not simply a task solely for health and social services but is everyone's responsibility.

Compassionate Cities are communities that publicly encourages, facilitates, supports and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care. Though local government strives to maintain and strengthen quality services for the most fragile and vulnerable in our midst, those persons are not the limits of our experience of fragility and vulnerability. Serious personal crises of illness, dying, death and loss may visit any us, at any time during the normal course our lives. A compassionate city is a community that squarely recognizes and addresses this social fact.

Through auspices of the Mayor's office a compassionate city will - by public marketing and advertising, by use of the cities network and influences, by dint of collaboration and co-operation, in partnership with social media and its own offices - develop and support the following 13 social changes to the cities key institutions and activities.

- Our **schools** will have annually reviewed policies or guidance documents for dying, death, loss and care
- Our **workplaces** will have annually reviewed policies or guidance documents for dying, death, loss and care
• Our trade unions will have annually reviewed policies or guidance documents for dying, death, loss and care

• Our churches and temples will have at least one dedicated group for end of life care support

• Our city’s hospices and nursing homes will have a community development program involving local area citizens in end of life care activities and programs

• Our city’s major museums and art galleries will hold annual exhibitions on the experiences of ageing, dying, death, loss or care

• Our city will host an annual peacetime memorial parade representing the major sectors of human loss outside military campaigns – cancer, motor neuron disease, AIDS, child loss, suicide survivors, animal companion loss, widowhood, industrial and vehicle accidents, the loss of emergency workers and all end of life care personnel, etc.

• Our city will create an incentives scheme to celebrate and highlight the most creative compassionate organization, event, and individual/s. The scheme will take the form of an annual award administered by a committee drawn from the end of life care sector. A ‘Mayors Prize’ will recognize individual/s for that year those who most exemplify the city’s values of compassionate care.

• Our city will publicly showcase, in print and in social media, our local government policies, services, funding opportunities, partnerships, and public events that address ‘our compassionate concerns’ with living with ageing, life-threatening and life-limiting illness, loss and bereavement, and long term caring. All end of life care-related services within the city limits will be encouraged to distribute this material or these web links including veterinarians and funeral organizations

• Our city will work with local social or print media to encourage an annual city-wide short story or art competition that helps raise awareness of ageing, dying, death, loss, or caring.

• All our compassionate policies and services, and in the policies and practices of our official compassionate partners and alliances, will demonstrate an understanding of how diversity shapes the experience of ageing, dying, death, loss and care – through ethnic, religious, gendered, and sexual identity and through the social experiences of poverty, inequality, and disenfranchisement.

• We will seek to encourage and to invite evidence that institutions for the homeless and the imprisoned have support plans in place for end of life care and loss and bereavement.
• Our city will establish and review these targets and goals in the first two years and thereafter will add one more sector annually to our action plans for a compassionate city – e.g. hospitals, further & higher education, charities, community & voluntary organizations, police & emergency services, and so on.

This charter represents a commitment by the city to embrace a view of health and wellbeing that embraces community empathy, directly supporting its inhabitants to address the negative health impacts of social inequality and marginalization attributable to dying, death and loss.

A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other’s company, in schools, workplaces, places of worship and recreation, in cultural forums and social networks anywhere within the city’s influence, even to the end of our days.