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Exploring the concept of receptivity to bereavement support: Implications for palliative care services in rural, regional and remote Western Australia

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Chapter 1: Bereavement support in palliative care and receptivity of the bereaved

Introduction

This chapter will present an overview of the aim or purpose of the thesis and its genesis, including reflections of personal and professional influences of the researcher. The issue of receptivity in bereavement support explored in this study was identified through the researcher's clinical practice and also informed by personal experiences of bereavement. Perspectives of bereaved individuals and health professionals living and working in rural, regional and remote Western Australia inform the findings of this research. In order to remain close to the complexity and richness of participant's narratives and reflections, a qualitative descriptive research design was adopted for this study. Researcher reflexivity articulating values and assumptions and how these shape the study is a core component of qualitative research. The process of researcher reflexivity provided insights into how the research process was monitored and consistently re-oriented by the researcher (Dwyer & Buckle, 2009).

This chapter sets the scene of this research, with a dominant focus on researcher reflections. The 'voice of the researcher' and reflexive insights will be explored in this chapter by articulating the researchers' position within this study. As this chapter has a dominant focus on researcher reflections, the author will speak in the first-person voice. How findings from this research contribute to the broader field of bereavement will also be discussed, along with a chapter overview of the thesis.

Genesis of the Research

“...the effect we have on other people is in turn passed on to others, much as the ripples in a pond go on and on until they're no longer visible but continuing on a nano level. The idea that we can leave something of ourselves, even beyond our knowing, offers a potent answer to those who claim that

meaninglessness inevitably flows from one's finiteness and transiency..."
(Yalom, 2009, p.83).

It is this concept of 'ripples' that was the catalyst for this research. Unfortunately, people do not often feel the effects, or have gratitude for, the ripples of positive legacies left behind following the death of a significant person. This research only has the richness it does because of the ripples left behind from others who have died and from the bereaved, sharing their experiences of love, loss, grief and transformation.

My interest in bereavement support within palliative care¹ services arose from my frustration at trying to integrate clinical social work practice within current clinical system and practice constraints. In my role, I was provided with the 'bereavement program' which involved contact at specified timeframes post death, a phone call at two to four weeks, then again at three months, six months and a card and phone call at 12 months. The aim of the contact was to provide emotional support. At times, I felt I was being intrusive as some of the bereaved families I contacted were not known to me or sometimes those that were, I felt I was intruding into their grief. I also did not feel adequately equipped with the skills to provide bereavement support. I asked questions of my colleagues and managers about why the program was structured in the way that it was. The response was "because that's just the way that it is done". In my role, I did a lot of social work oriented activities for bereaved individuals and families related to providing information, or assisting with the practical matters after death, however this was never considered part of the 'bereavement program'.

Bereavement support programs currently adopt generic universal approaches to providing support within prescriptive timeframes. From my perspective, existing bereavement support programs seemed more about meeting organisational administrative processes.

¹ 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 (World Health Organisation, 2002).

These processes include completing bereavement risk assessment tools and demonstrating contact had been made with the bereaved within specific timeframes. However, these processes did not demonstrate meaningful and individualised approaches to supporting the bereaved. When I explored the genesis of current bereavement support practices in palliative care, there was no evidence that palliative care bereavement programs were informed by any empirical evidence base, yet the same program structure was, and continues to be, replicated both nationally and internationally.

Additional insights through my own personal experiences of bereavement, enabled me to understand the lived experience of bereavement. With my own personal experiences, I was contacted by palliative care services and at that time I felt that people were being 'intrusive' into my grief. I did not give people permission to contact me and felt that I would seek support if I required. Working in palliative care provided me with insights into how bereavement support was structured. If I was to change practice, I realised I would have to undertake further study and contribute to the bereavement research and ultimately, change practice.

As bereavement is a complex, individual and multifactorial phenomenon, Qualitative Descriptive Research (QDR) was the method intended to use from the outset. In acknowledging the complexity of bereavement, I wanted to explore the multiple experiences of the bereaved and also the health professionals in order to gain in-depth insights. Qualitative research gives voice to the multiple perspectives of a phenomenon. I wanted to explore if there were different ways of providing support and what support was meaningful. As the famous quote from movie, *Field of Dreams* says: "...if you build it, he will come...". It is not enough to design a service and expect people to engage in it. If palliative care services are to change the way bereavement support is provided, at the core of effecting change, is whether the bereaved are receptive to support.

The purpose of this study

This study explores the concept of receptivity in the implementation of bereavement programs by health and palliative care services in rural, regional and remote settings of Western Australia. As a clinician, I have predominantly worked in rural, regional and remote areas in Australia, Scotland and England and have an interest in the unique context of rural practice. I have an interest in the ‘culture’ of country people. I have a specific interest in bereavement.

Bereavement support by palliative care services is an important service to the community. However, features of bereavement programs that I was particularly concerned about include a) no consent process in place from the bereaved² to participate in bereavement support programs; and b) although bereavement support was available, many bereaved families I worked with did not utilise this support. Although there was access to bereavement support, there was little uptake. I became curious about what would make people more receptive to support. Exploring receptivity to support will provide a different perspective to inform service development and provision. For the purpose of this study, the following definition of receptivity was adopted;

“...the range of factors (individual, social and geographical) that affect an individual’s desire or ability to receive or engage with supportive care services designed to meet his or her needs...”

(McGrath, 2013, p.36)

The success of bereavement services depends in part on how ‘receptive’ bereaved family members and friends are to receiving support. Although palliative care services provide support services for bereaved carers and families, there still remains a discord between

² Bereavement programs currently adopt universal approaches of contacting the bereaved without prior consent. Filmer (2002) and Walsh, Foreman, Curry, O’Driscoll & McCormack (2008) highlight that unsolicited contact or advice can be intrusive. However, Breen and O’Connor (2011) argue there is an operating assumption by service providers that the bereaved are aware of their own need for help and that they are willing and are able to seek help.

what is delivered, what is needed and factors that deter or encourage a person's receptiveness to support. The aim of this research was to examine utilisation of bereavement support through the 'lens' of receptivity. The research question which is the focus of this research is: **What are the factors that influence bereaved individuals in rural, regional and remote Western Australia to be *receptive*, or otherwise, to bereavement support from palliative care services?**

What will this study contribute?

Questions of service utilisation and receptivity provide a fresh approach to analysing bereavement support, moving the focus from service-provider centric practices to consumer-centric reasons for engagement (McGrath, 2013, p.46). Although data from this research highlighted factors that influence receptivity, serendipitously, this study also surprised me and provided a new insight to understanding the lived experience of bereavement. Analysis of the findings revealed a new concept – attributed to the theme Diaspora.³ At the time of embarking on my PhD, diaspora was not a concept with which I had anticipated being a key theme in regard to the topic of my thesis. However, the more I listened to the stories of participants, the diaspora metaphor was consistently visualised in my mind.

I first became familiar with the concept of diaspora through an interest in history, particularly after watching the movie *Sophie's Choice* in the early 1980's. The protagonist of the story, Sophie, was a Polish woman interned in Auschwitz concentration camp and was given an unbearable choice, she was forced between choosing which one of her children could go with her and live, and which child would be left behind and be killed.

³ Academic constructions of Diaspora have changed over the decades. The use of Diaspora for the purpose of this research does not, in any way, have the intention of diminishing or disrespecting the historical etymology or origins of the term and the experiences of Diasporic individuals. The concepts and themes within the Diaspora discourse mirror many features of bereavement. Further details of the application of Diaspora in bereavement are discussed in chapters four to nine.

The story of Sophie was one of torment about her choice, of finding herself in a world in which she had no control, where she felt powerless, and in a world, that was foreign to her. This sparked my interest in the plight of the Jewish people, and introduced me to the concept of diaspora. I had gained further insights into this concept over the years from literature and film about Jewish diaspora. I also visited the Museum of Tolerance in Los Angeles and Verzetsmuseum, the Dutch Resistance Museum in Amsterdam in 2011.

The concept of diaspora provided a different perspective into the bereavement experience. It is hoped this perspective may enhance clinician knowledge and skills, and vicariously inform bereavement support services and clinical practice. A change in practice may also lead to enhancing receptivity by the bereaved to support. Receptivity to bereavement support, framed within a Diaspora concept, will contribute new insights to the empirical literature on bereavement.

Reflexivity: The voice of the researcher

Knowledge is inherently constructed and sustained by social processes. Reflexivity is integral to research in human sciences, recognising discursive possibilities that deepen our understanding of the lived experience of others. Researchers' reflexivity should acknowledge the interactions between the researcher and research participants, and recognise how this inter-subjectivity produces different versions of knowledge (Colombo, 2003). Within stories, there are a multiplicity of complex conceptual structures (Sarbin, 1986 cited in Colombo, 2003, n.p.). The researcher must position themselves so that they reflect on self-understanding and also in understanding others. Positioning themselves within and outside the research enables the researcher to note differences and similarities between researcher and participants. This can enhance the validity of the research as Whittlemore, Chase and Mandle (2001, p.532) state, "...reflexivity, open inquiry and critical analysis of all aspects of inquiry contribute to validity in qualitative research..." (p.532). Dwyer and Buckle (2009, p.55) highlight the paradox of the researcher citing Maykut and Morhouse (1994, p.123);

[T]he qualitative researcher's perspective is perhaps a paradoxical one. It is to be acutely tuned in to the experiences and meaning system of others – to indwell – and at the same time to be aware of how one's own biases and preconceptions may be influencing what one is trying to understand.

Qualitative researchers are not separate from the study as they are embedded in all aspects of the research process. Qualitative research is described as having a level of intimacy which does not accommodate true outsider perspective of the experience under study (Dwyer & Buckle, 2009). Sullivan (2002, n.p.) reinforces the influence of the researcher, citing Monk (2001, p.9) who discussed the work of Wittgenstein (1953) "...we have an inner life, that we have thoughts that we do not share with other people and desires that we deny even to ourselves..." Dwyer and Buckle (2009) assert that an outsider perspective might conceptualise an experience more adequately as this will reduce the risk of professionals or researchers who are enmeshed in their own experience, and are unable to distance their experiences from the experience of the client, or participant.

Roth and Breuer (2003) highlight that the research *per se* is inextricably tied with the researcher and recognises the biographical experiences of the researcher and how this shapes a research study. Researchers may identify contradictions in their study and this contributes not only to growth in knowledge but growth in the researchers' identity as well (Roth & Breuer, 2003). Sullivan (2002, n.p.) reiterates the role of the researcher and how "...our own perspective and experience enter into, transform or change the issue or area being investigated...". If researchers have experienced a similar phenomenon, such as bereavement, this may place them in a position of 'insider' but this does not mean they are a better or worse researcher, just a different type of researcher (Dwyer & Buckle, 2009, p.56).

I specifically chose Descriptive Qualitative Research as my methodology as I wanted to remain close to the voices of participants and their stories, in order to minimise the influence of my own beliefs and assumptions in interpreting results. Detailed reflexivity of my own assumptions and values and subjectivity within the research process required

disciplined bracketing in order to help reduce potential concerns regarding ‘insider’ membership (Dwyer & Buckle, 2009).

Bolam, Gleeson and Murphy (2003) posit that the debate on reflexivity in qualitative research is often targeted at the level of methodology however, they articulate how qualitative investigators can move from theory to research praxis. The role of the researcher is acknowledged in the development, process, interpretation and documentation, or write-up. It is imperative the researcher’s reflexivity throughout these processes is made transparent. Researchers are considered as being positioned as ‘insiders’ and ‘outsiders’ in the research process. For example, the author was positioned as an ‘insider’ in some respects in relation to shared characteristics such as experiencing bereavement and being a recipient of palliative care services. My own philosophical commitment to the study that led to qualitative methods and a desire to be as close to the voices of the participants *per se*, provided the framework in which I was positioned more closely as a ‘lay person’ rather than a position of ‘expert’ (Bolam, Gleeson & Murphy, 2003).

Dwyer and Buckle (2009) argue that researchers occupy the position of both insider and outsider and that data collection and analysis is influenced by the intimate role the researcher plays in qualitative methodology. Insider researcher refers to researchers who conduct research with population groups of which they are members, hence share an experiential base, identity and language with study participants. The personhood of the researcher, a constant present aspect to the investigation, warrants that the researcher be aware they may be a part of the culture under study, but may not understand the subculture and this is where ‘bracketing’ of assumptions needs to occur. Dwyer and Buckle (2009, p.55) cite Rose (1985, p.77) who states “...there is no neutrality. There is only greater or less awareness of one’s biases...” In fully engaging in researcher reflexivity throughout the study, my values and assumptions were a ‘compass’ to which I consistently re-oriented myself throughout the research process, asking myself, what is ‘their stuff’ and what is

‘my stuff’?⁴ If I even thought there was an inkling I was looking through the lens of ‘my stuff’, I would repeatedly go back to the data to ensure ‘my stuff’ was bracketed.

I was cognisant of bracketing my own experience, knowledge and assumptions to ensure the participant’s voice was promoted. As Sullivan (2002, n.p.) reflects, there is a potential risk for “...qualitative researchers to become connoisseurs of the inner lives and narratives of others...” Reflexivity can help qualitative researchers achieve clarity about the interrelations between their work and personal life. If a researcher is heavily influenced by a particular theory which distorts the research processes, or the researcher lacks a sensitivity to the narratives of the research participants, this may lead to inconsistency in researcher reflexivity (Sullivan, 2002).

Reflective processes involve thinking about something more closely than usual to try and gain a fresh perspective or understanding of a subject. Although meaning is situated in the data, finding the meaning is an active and analytical process engaged in by the researcher who allows some meanings to emerge and others to diminish through the method used that serves as the lens. I was committed to ensure reflexivity was consistent in this research in order to ensure participants’ voices were represented honestly and accurately (Sullivan, 2002). In order to be reflexive as possible, it was essential to reflect on professional and personal factors that inform the research.

The professional

The importance of the therapeutic relationship has always been emphasised as an integral part of clinical social work education and practice, this has never been more evident than

⁴ According to Corey (2005), when counsellors engage in a therapeutic relationship, they must be aware of their own “...conflicts, needs, assets and liabilities...” (p.21). This is called counter-transference which describes the process of counsellors seeing themselves in their clients or over-identifying or meeting their own needs through their clients. I have used the vernacular of ‘stuff’ to encompass this notion of counter-transference. Awareness of counter-transference is just as important in researchers as it is with therapists and counsellors. The researcher needs to be constantly self-reflexive on what they are projecting on to participants. If they are using the research more for their own purposes than for being available to the participants and their stories, this becomes an ethical issue.

in my role working in palliative care. My clinical role in a regional Western Australian health palliative care service centres on the provision of interventions that aim to empower and equip families with the skills and resources to reduce stressors from all aspects of their lives. Working in palliative care, I use myself inter-subjectively. I bear witness and hold intimate spaces for those in their suffering, and I “companion” them on their journey. I companion those who are dying and their loved ones, both prior to the death and then in bereavement. The tenets of companioning are very much reflective of the positive therapeutic relationship and although these tenets have been applied to supporting those who are bereaved (Wolfelt, 2005), they apply to working with people who are living until they die. Companioning:

is about honouring the spirit, it is not about focusing on the intellect.

is about curiosity, it is not about expertise.

is about learning from others, it is not about teaching them.

is about walking alongside, it is not about leading or being led.

is about being still, it is not about frantic movement forward.

is about discovering gifts of sacred silence, it is not about filling every painful moment with talk.

is about bearing witness to the struggles of others, it is not about judging or directing those struggles.

is about being present to another person’s pain, it is not about taking away or relieving with pain.

is about respecting disorder and confusion, it is not about imposing order and logic.

is about going to the wilderness of the soul with another human being, it is not about thinking you are responsible for finding the way out.

(Alan D. Wolfelt, 2005)

This notion of companioning and the importance of therapeutic relationship underpin my core practice values. In my current role, I recognise significant challenges of working within current frameworks and guidelines for bereavement services, or programs that are situated more within a medical or psychological model. In my experience, these perspectives adopt pathologising and deficit based approaches to working with those who

are bereaved. As a social work clinician, I prefer to adopt a strengths-based approach and a person-in-environment perspective that views the individual and their multiple environments as an interactive and dynamic interdependent system, each component simultaneously affects, and is affected by, the other. This approach recognises the individual in the context of all the systems in which they have reciprocal relationships, the environment in which the individual is placed, and all the mutual inter-relationships that occur between the various subsystems with the individual (Harris, 2009-2010). This approach integrates medical, psychological, spiritual, social and anthropological aspects.

Contemporary bereavement theories often do not incorporate all factors impacting an individual's life. The challenge I face as a clinician is trying to practice within contemporary policy and practice modalities whilst reconciling these with clinical practice. This tension led me to co-develop a framework to help guide clinicians to deliver bereavement support that is holistic and contemporary (Blackburn & Dwyer, 2016). I draw on best practice research, however my clinical practice wisdom and personal experience has provided insights that have helped shape my practice and inform my work in this field.

The personal

My first introduction to palliative care and bereavement was following the diagnosis of a rare brain tumour in my daughter, Mia. Mia was diagnosed when we were living and working in the UK and given a short prognosis of weeks to live, she died 40 days after diagnosis. In a whirlwind, we returned to Australia, had nowhere to live, no source of income, no jobs and chaos reigned around us. I was paralysed with terror. I was powerless to protect my baby and support my family in their grief. The story of Mia is a long one and I doubt I would have the verbal language that could adequately portray the devastation of the loss of my child, my experience, and that time in my life, and yet my six-year-old daughter poignantly told me one day what dying was like for her: "*Mummy. I feel like I'm crying hard inside my heart.*" She knew she was dying, she knew we were devastated and

that we would be sad for the rest of our lives (portrayed in the stories she wrote). The devastation of her loss continues to have an impact, ten years later.

On the anniversary of her death, her final hour plays through my head vividly over and over again. From the moment she started making noise, to gently bathing her and turning her over when she opened her eyes. It was the first time she had opened her eyes in two days, she looked straight into my eyes and was making a sound. Her eyes were so clear, a clarity I had not seen for over a week, a clarity that indicated she was trying to tell me something. Perhaps that it was her time to go? She once told me during her illness that she would tell me when the angels would come to take her to heaven. Despite never talking to her about God or Jesus, she also asserted one day “*Mummy, Jesus will be there waiting for me you know.*” In the last minutes of her death, we turned her on to her back, her eyes flicked opened, I could hear the sound of the first school siren in the distance (we lived near a number of primary schools). Her pupils grew gradually larger and larger; her brain was dying. Her heart was so strong, it continued to beat, with the final beat of her heart stopping to the distant sound of the second school siren. These images, return over and over in my head with vivid clarity, every anniversary, of every year.

I held her gently as the light left her exquisite blue eyes, whispering words of love the whole time “thank you sweetheart for the years you’ve given us”, “thank you baby, for being such a beautiful daughter and sister”, “we’re going to miss you”, “it’s ok to go,” ”you’ll be ok” and “we’ll see you again” – all the while my inner essence, my core, the depths of my soul was exploding, shattering, obliterating, splintering, into infinite painful particles simultaneously to the background of the metronomic scream in my head crying “don’t go, DON’T go, DON’T GO!”.

(Personal journal entry, 9/6/16 on the 10th anniversary of Mia’s death, forever 6 years old).

The death of my precious six-year-old daughter launched me into a world that was so very foreign to me, I lost who I was, who we were as a family, our security and safety in the world. I lost who I was going to be and I lost so much of my future. So much of me died

that day, a light extinguished forever, a piece of my heart and soul irrevocably lost. My time since has been of rebuilding a life, supporting my family and trying to change the way clinicians understand and work with bereavement. I have studied dying, death, grief, loss and bereavement for nearly ten years and have learned there is a name for almost all types of grief or loss but the death of a child is so profound, there is no label, except that of 'bereaved parents.' Mia's death has led me, albeit serendipitously, into the field of palliative care and bereavement.

During my PhD candidature, I experienced another devastating loss, the loss of my sister, best friend and confidante. I had been working in palliative care for some time then, so knew what to expect and used my skills to be a companion and clinician. The death of my sister re-affirmed my motivation and desire to understand bereavement, what makes people receptive to support and how this can contribute to informing the development and delivery of bereavement support.

I was privileged to do dignity therapy with Terri and an excerpt describes below her thoughts about life after death and what she has left behind;

I don't know where I will be going to, I really don't. That's what makes it a big adventure... Stepping off into the unknown....and you hope...you hope...that what you have always believed will be there, WILL be there. In fact, you know it will...you just don't know in what form it will be. I know something will be there because it's too profound not to have a continuation...far too profound. Just as everyone leaves a legacy on your life, you hope you have left some kind of legacy on theirs.

(Terri Davidson, Dignity Therapy session, 11th March 2013)

Terri died a little over one month later after completing her dignity therapy. Both Mia and Terri have left profound legacies on my life. Although my work and my PhD is Mia's legacy, both Mia and Terri have shaped me and helped me become the woman and clinician that I am. The world has been a far more beautiful, love-and-laughter-filled world because they were in it - and blessed my life. My life has been richer, happier, compassion-

filled and humbling because they made sure I felt, and knew, I was worthy of their unconditional love. I could not think of greater gifts to bestow on another human being than the gift of wholesome, absolute and pure love. This is their ‘ripples’.

There are two key lessons I have learned from Mia and Terri, humility and wisdom. It is through my work, I feel they continue to leave their footprints on the world, I honour them in my work and in my personal life. As Steve Maraboli (2009) said;

I don't want my life to be defined by what is etched on a tombstone. I want it to be defined in what is etched in the lives and hearts of those I've touched.

I only hope to continue to touch the lives and hearts of my friends and family, my colleagues and my clients in a positive way. In the time I have on this earth I would like to leave a legacy of compassion, love, laughter and wisdom on others, honouring the love Mia and Terri brought into this world and my life. These will be my ‘ripples’.

Although my personal experiences have been the primary motivator for this research. My desire to provide meaningful and individualised bereavement support based on my clinical experiences are concurrent motivators for undertaking this research.

Making the unconscious conscious: Assumptions and attitudes

Examination of my own assumptions enabled me to reduce my own ‘researcher angst’ of interpreting results based on my own assumptions and values and not being truly attentive to what participants were saying. The process of ‘bracketing’ my own assumptions began with asking myself some pertinent questions. How did I make the unconscious conscious? By identifying my own assumptions and values I have about bereavement, support in bereavement and factors that may influence receptivity, I was able to orient myself to analyse the data as objectively as possible. I asked myself “What is the participant saying?” “Is it really what they are saying, or am I putting my own interpretation on it based on what I think they are saying, or based on my own assumptions?” “What are the assumptions I hold about the research topic?” Another question I asked myself as part of

engaging in researcher reflexivity was “What are my values and life experiences? How do my values and experiences shape how I read and interpret the data?”

Potter and Wetherill (1987, p.33-34), cited in Colombo (2003, n.p.) use an analogy of construction that depicts processes of reflexivity. A researcher and participant bring to the research pre-existing experiences, assumptions, knowledge and values which are representative of the bricks and beams which form the foundations of a building. As the building is constructed, some resources are omitted and some included. This represents the ‘filters’ of the researcher and participant in terms of what is paid attention to, what is shared or not shared in the narrative or interview process. The final notion of construction is viewed as the consequential nature of accounts ie. the finished building. Similarly, the research study findings and implications are revealed or ‘constructed’ following analysis of the data (Colombo, 2003). Meek (2003, n.p.) states “unconscious mental processing is a necessary part of qualitative research, lying under what we call ‘reflective processing.’” As part of reflecting on my role and how it might influence the research, I stayed committed to my own personal values of taking the individuals’ lead, being invited into their story and acknowledge that they are the experts of their experiences and that I have a lot to learn from the stories of others. I want to authentically represent the ‘ripples’ of participants and their deceased loved ones. The findings based on the stories of participants are discussed over six chapters.

Overview of the thesis

This thesis is discussed over ten chapters. The introduction chapter (1) frames the genesis and background to the research question. I have outlined my personal and professional interest in the topic and reflected on assumptions. The introduction provides a brief overview of the chapters, discussed below.

Chapter two (2) provides in-depth discussion into the evolution of bereavement theories over the decades and how this has informed bereavement programs in the palliative care

setting. Palliative care and bereavement support will be discussed within state-wide, national and international contexts. To conclude this chapter, an overview of the concept of receptivity will be discussed.

Chapter three (3) discusses the methodological procedures undertaken for the data collection, analysis, ethical considerations, limitations of the study and includes a profile of the sample demographics and an introduction of the core findings. This chapter also references *Appendices A to D* which provides the documentation for ethics approval, patient information sheets, consent process and interview schedules for each of the participant cohorts.

The following chapter four (4), discusses the findings from the data in-depth and provides an overview of the core theme, *Bereavement Diaspora* and how this has subsequently been conceptualised. Insights from the bereaved, health professionals and Aboriginal health professionals will be discussed.

Chapter five (5) discusses the concept of *Existential Diaspora* and how concepts of the diaspora and existential literature provide insights from the voice of participants of the psychological, emotional and spiritual impact of bereavement.

Chapter six (6) discusses coping as it relates to the Diaspora and the multiple ways the bereaved cope with their experience and how staff cope in working in this field.

The next chapter, seven (7), explores the role of relationships and how they influence the Diaspora experience. Data from the bereaved and respective health professional cohorts will provide insights into the role of relationship in bereavement.

As language and discourse is such an inherent process of how people interact with their world, the discourse as it relates to bereavement and what evolved from the research will

be discussed in Chapter eight (8). The influence of discourse on receptivity will be explored.

Receptivity issues that emerged from the data, will be discussed in Chapter nine (9) and these will include enablers and barriers of receptivity that emerged from the data. This chapter also references *Appendix E* which provides an overview of receptivity issues from chapters five to eight that have been examined through the lens of diaspora, *Appendix F* which outlines desired characteristics and technical skills of health professionals and *Appendix G*, which provides a table of receptivity enablers and barriers to bereavement support.

The final chapter, ten (10), concludes with implications for research and practice and recommendations.

Conclusion

In this chapter, the personal and professional background which informs this research project was discussed. As this research adopts a descriptive qualitative research design, researcher reflexivity is a critical part of engaging in the research process. The voice of the author in this process was discussed in reflections on the personal and professional ‘self’ of the researcher.

The issue of receptivity in bereavement explored in this study was identified within the researcher’s clinical practice, and also informed by personal experiences of bereavement. The concept of receptivity is the foundation of this research and is a new area of scholarship to bereavement. The findings from this research identified receptivity factors however revealed another perspective of exploring bereavement, through the lens of Diaspora. This is a new contribution to the bereavement discourse.

In the following chapter, further contextualisation of the research through the exploration of bereavement theories and models which have informed palliative care bereavement programs, and a discussion of receptivity as it relates to help-seeking behaviours will be discussed.