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 3: Methodology

Introduction

The previous chapters set the context for this study. Namely, examining contemporary bereavement practices in palliative care, the theoretical discourse that has informed bereavement support and posited the importance of exploring receptivity factors that influence whether people access or utilise available support. This chapter will discuss the methodology used to conduct the research. Qualitative Descriptive (QD) research design within a Postmodernist paradigm set the framework for the study. Details of the methodology, which consisted of open-ended, semi-structured, exploratory, in-depth interviews with a purposive sample of research participants, will be discussed. The treatment of the interview data, including the transcription, coding, analysis and presentation will also be outlined. This study utilised Qualitative Description (QD) to prioritise the voice of bereaved participants as these were the largest cohort and the primary group in which receptivity was explored. Viewpoints from health professionals and Aboriginal health professionals were also sought and will be included throughout the findings chapters. The study is situated within a postmodernist theoretical framework.

Epistemological Framework: Postmodernism

A Postmodernist research framework aims to ‘give voice to the multiple perspectives’ of a phenomenon. By using a methodology of descriptive phenomenology, the researcher has endeavoured to remain close to the complexity and richness of participants’ narratives and reflections (Agger, 1991; Gergen, 2001; Tomso, 2009). Postmodernism recognises that discourses are often developed within a ‘discourse community’. Downs and Wardle (2011) describe a discourse community as a community that shares a common interest or public goals, has mechanisms to communicate between members, providing information and feedback, has defined purpose and features of one or more genres, shares specialised language and jargon and has enough members with content and communication expertise to ensure operation of the group as a community. As outlined in chapter two, the
bereavement discourse has predominantly been developed within the science-based professions – medicine, psychiatry and psychology (Olsson, 2008). Assumptions underpinning postmodernism include that meaning is socially constructed and that language is an inherent by-product of social interaction (Gergen, 2001; Olsson, 2008).

Casstevens (2010) posits that language is culturally bound and can act as a form of oppression. Current prevailing bereavement discourses may be considered as hegemonic discourses, perpetuating knowledge and power. As the science-based disciplines have provided much of the language of bereavement, this maintains their knowledge and power as being the ‘experts’ of bereavement experiences, effectively silencing or at the very least ‘muting’ the voices of the bereaved. Bereavement discourse in the psychological and medical sciences has led to a dominant approach of viewing coping in bereavement from a pathological perspective, rather than as normative experiences (Valentine, 2006; Ord, 2009). Bereavement discourse is discussed in further detail in Chapter Eight.

The narrow focus of medical and psychological discourse in bereavement may be attributed to the ‘blanket approach’ informing many bereavement programs with palliative care services.\textsuperscript{12} However, it will be shown in this research that the experience of bereavement occurs within the context of discourse constructs, both with bereaved individuals, health professionals and the general community and postmodernism is an approach that fosters a polyvocal perspective.

A Postmodernist theoretical perspective compels the researcher to engage in collaborative pedagogies\textsuperscript{13} with research participants and to maintain reflexive practice when

\begin{footnotesize}
\textsuperscript{12} The narrow focus refers to viewing bereavement through a physical-psychological lens whereas the broader bereavement experience of the person-in-situation is often not given as much consideration eg. the socio-political environmental factors that impact on the person’s experience.

\textsuperscript{13} Collaborative pedagogies occur through the inter-personal engagement between researcher and participant. The emphasis is that critical thinking occurs through this interaction and that there is an intention to learn by the researcher. Pedagogic research “…is systematic and sustained enquiry, planned and self-critical, which is subjected to public criticism and to
\end{footnotesize}
undertaking qualitative research. Postmodernism acknowledges the role of inter-subjectivity in research process and hence discursive practices (Parsons, 1995; Gergen, 2001). Utilising a qualitative methodology allows for the study of personal experiences, narratives and language in order to seek understanding and meaning about a phenomenon (Berglund, 2001). However, as Sandelowski (2000, p.336) asserts, “…qualitative researchers cannot insulate themselves from the data…”

**Descriptive Qualitative Research**

Qualitative description (QD) is a suitable method in healthcare research as it helps to focus research questions on the experiences of patients, families and professionals (Neergaard, Olesen Anderson & Sondergaard, 2009). QD studies are the least encumbered method of all qualitative approaches that has pre-existing philosophical or theoretical commitments (Sandelowski, 2000). Neergaard et al., (2009, p.2) assert that QD differs from other qualitative methods as it is “…thoughtful linkages to the work of others in the field and clinical experience of the research group…” They further differentiate QD from other qualitative methods as it is not thick description (ethnography), theory development (grounded theory) nor interpretive meaning of an experience (phenomenology) but is ‘rich, description of an experience or an event’ (Neergaard, et al, 2009, p.2). QD analysis enables researchers to stay closer to the data, describing participants’ experiences in language similar to their own. QD research is the preferred method when descriptions of phenomena are desired (Sandelowski, 2000).

It is acknowledged, however, that descriptions are influenced by the describers’ perceptions, sensitivities, inclinations and sensibilities.’ In QD, the presentation of the facts of the case are done in everyday language by the researcher. Sandelowski (2000, p.336) asserts that “…language is a vehicle of communication, not itself an interpretive structure that must be read…” Through language, the researcher portrays the stories of

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*empirical tests where these are appropriate…” (Stenhouse, 1985, pp.18-19; cited in Moron-Garcia & Willis, 2009, p.3).*
their participants using their own language as much as possible. The process of presenting the data in a useful and coherent manner is a significant part of QD research (Sandelowski, 2000).

Gathering data within QD research often utilises a purposive sampling approach to source cases that are deemed information-rich for the purposes of the study (Sandelowski, 2000). In conjunction with purposive sampling, QD often uses semi-structured interviews with open-ended questions. Strategies such as authenticity, credibility, criticality and integrity inform rigour. Integrity is the most important criteria when using QD and strategies include reflection on researcher bias, dual role clinician/researcher during the interview, dual role in the process of analysing, peer review and researcher triangulation (Neergaard et al., 2009). QD uses a slightly more structured interview guide which is iterative in that it is modified and transformed as themes emerge. The QD interview guide is often based on expert knowledge to focus on areas that may need to be further understood or are potentially amenable to intervention. QD is a useful method for exploring experiences in health care at the intersect of patient-professional experiences and helps to inform service delivery or models of care (Sandelowski, 2000; Neergaard et al., 2009). QD frames the methodology for this study in which the experiences of the bereaved in the context of palliative care services occur and includes the perspectives and experiences of the palliative care clinicians.

Methodology

Purposive Sampling

This research utilised non-probability purposive sampling. This sampling technique enables the researcher to target subjects who typify the issue to be studied in order to achieve particular objectives (Henry, 1990; Coyne, 1997; Alston & Bowles, 1998). Non-probability sampling enables the researcher to seek participants that may provide a range of variations in, and depth of experience of, the phenomenon (Coyne, 1997). The purpose
of this study was to explore the lived experience of bereavement and identify the role of receptivity with regards to professional support. Letourneau and Allen cited in Whittlemore, et al., (2001, p.525) state “…critical multiplism encourages the critical and exhaustive study of a phenomenon from multiple perspectives.” As this research collected the views of both bereaved and health professionals regarding bereavement support, the focus was mainly on the views of the bereaved. The bereaved participant cohort had the greater number interviewed and the focus of discussion on the findings in relation to receptivity is predominantly on their perspectives and experiences.

**Ethical Considerations**

Ethical guidelines and principles specifically for conducting research aim to protect participants and researchers. Principles of non-maleficence, beneficence, autonomy, respect, justice, research merit and integrity all provide standards of how to conduct ethical research (National Health and Medical Research Council, (NHMRC), 2007). To conduct socially responsible research, researchers need to ensure that vulnerable groups are protected and that the research is conducted with integrity. The bereaved are considered a vulnerable group and this presented some challenges with obtaining ethics approval.

Ethics proposals were submitted to respective organisations in Western Australia, namely the WA Aboriginal Health Council, WA Country Health Service (WACHS), St John of God Health and Silver Chain. A National Ethics Application Form (NEAF) was completed online via the National Health and Medical Research Council (NHMRC) website and outlined all aspects of the study. The NEAF was used as a master document to submit to respective organisations in conjunction with their specific protocols. It was originally proposed to recruit participants across 13 different sites. Silver Chain did not approve progression of the ethics application at pre-submission review stage due to organisational priorities. St John of God Health required four clarification responses to the committee before ethics was approved, however there was no successful recruitment
of participants via this organisation. Ethics approval was granted by Griffiths University, the Western Australia Aboriginal Health Council WACHS (Appendix A: Human Research Ethics Committee Approval Documentation). All ethical and cultural issues were addressed in accordance with NHMRC guidelines for ethical conduct in Aboriginal and Torres Strait Islander Health Research. The researcher submitted an ethics proposal outlining the research to the WA Aboriginal Health Council Ethics Committee and was granted approval. As WACHS is comprised of seven (7) regional areas, all regions within WACHS approved access to recruit participants in their area.

The palliative care field in Western Australia is relatively small and many clinicians are known to each other or have ongoing working relationships. The researcher completed a conflict of interest form as part of the ethics submission for WACHS to acknowledge the researcher had existing collegial relationships or that some participants were employees of the same organisation in which the researcher is employed, the WA Country Health Service (WACHS). WACHS comprises seven (7) regional areas: Kimberley, Pilbara, Midwest, Wheatbelt, Goldfields, South West and Great Southern (Figure 1: WACHS Regions, page 69). This research was reliant on recruiting participants via established palliative care services in these regions. This was a mechanism put in place to minimise risk of harm in recruitment processes and was required as part of ethics approval by organisations.

The researcher discussed the research with Nurse Managers and Senior Social Workers of palliative care services in each respective region and provided information on the study. Each region adopted their own approach to recruitment and the researcher acknowledges this variability can lead to bias, however, in order to have access to participants, this was a strategy organisations required to ensure risk mitigation. Some regions did screen their bereaved clients and provided selected participants with the information whereas other regions provided all participants with the opportunity to participate. Health professionals working in health and palliative care services are often familiar with the potential participants, their mental health and physical health status and their capacity to participate in research or quality improvement activities. As Palliative care clinicians screened
individuals who are bereaved and were eligible or interested, participants were recruited at any time post death as long as they were assessed by the clinicians as having capacity to engage in the interview process. Health professionals were self-selected in response to invitations promoted by the palliative care services sent to health care services. The total number of invitations is unknown so ascertaining a response rate is not possible.

Previous studies that have recruited bereaved participants have recommended that recruitment should be done indirectly, such as through advertising or via third parties (Buckle, Dwyer & Jackson, 2009). Evidence also suggests that recommendations for recruitment is to allow individuals to decide for themselves if they feel they are ready to participate in research as there is not a clear consensus on the most appropriate time to initiate recruitment. Research has indicated that participants in bereavement research do not ascribe any importance to the length of time passed since the death of a loved one, but emphasise that the emotional impact does not change (Feigelman, Jordan & Gorman, 2008-2009; University of Haifa, n.d). It has been noted that there needs to sensitivity to avoiding special dates such as major holidays or anniversaries for recruitment of research.

One participant in this study (ID: B: 3112; F; 75; Sp; 13-18; R3) participated in an interview on what would have been her 55th wedding anniversary. The researcher was very mindful of the impact this may have on her psychological and emotional wellbeing and checked with her via email prior to the interview date, offering the opportunity to reschedule, however she declined. Transcript from the email communication:

**Participant:**

**Tuesday, 15 July 2014 2:12 PM**

“Hi Pippa

I don't believe this!! 25th July was our wedding anniversary - It would have been 55 years this year!! Perhaps it would be better on another day - I don't really wish to dissolve into a blubbery heap!!

Regards

[name]”
Interviewer:

Tuesday, 15 July 2014 6:38 PM

“Goodness me, [name]. I know anniversary dates are usually very difficult…please know I will be holding you in my thoughts and my heart next Friday. How do you feel about doing the following Friday on the 1st August?

Warm regards,
Pippa

Participant:

Wednesday, 16 July 2014 10:20 AM

“Hi Pippa
Let’s go for the 25th July - I'm sure I will be OK - it will be good to talk to some-one!!
Regards
[name]”

Prior to commencing the interview, the researcher clarified with the participant again if she was okay to do the interview on her anniversary and she advised she was fine to progress with the interview:

Interviewer:

“[name] I'm very mindful of what today is...your anniversary...so I just wanted to see how you are at the moment.”

Participant:

“I'm fine, Pippa...when you first sent the email I got sort of a shock and fell into pieces but I'm over it now, I'm fine.”

At this point the researcher reminded the participant of what was written in the information sheet that had been sent out to her prior to the interview and reiterated that:
“If at any point you want to stop, just let me know. If you want me to stop the tape recorder in particular, just let me know….even if you’re half way through a sentence and think ‘nah, I don’t want to do it anymore’. That's fine as well. You can just let me know and, if you just want to pull out, then what's been recorded will just be deleted.”

When nearing the termination of the interview, the researcher again re-visited that it was an anniversary day and checked in with the participant again:

**Interviewer:**
“[name], it is your, it would have been your 55th anniversary today?”

**Participant:**
“yep”

**Interviewer:**

are you doing anything in particular around it?

**Participant:**

“No. No, I've got friends up here. We're going out to lunch with the friends but not, not to celebrate that. No. It's, that's finished, over”

The researcher was cognisant throughout the interview of the significance of the date for this participant. Evidence demonstrates that many bereaved individuals welcome the opportunity to express or talk about their grief and although they are aware that discussion of their loss(es) may be painful, they are often not deterred by this (McGrath, 2003; Buckle, Dwyer & Jackson, 2009).

**Risks of the Research**

When participants first registered interest in participating in the study, they were provided with Participant Information and Consent Forms (PICF’s) outlining the nature of the study, the process of the interviews, the consent process, how the researcher would
maintain confidentiality and were provided contact numbers for telephone counselling lines for those who may have required emotional or psychological support after the interviews. PICF’s were administered via email or post. Prior to each interview, the researcher reiterated the process outlined in the PICF’s and continuously monitored participants’ wellbeing throughout the interview. (Appendix B: Participant Information Sheets: Bereaved & Health Professionals; Appendix C: Consent: Information Sheet Outlining Process: Bereaved & Health Professionals).

There are nuances in conducting qualitative research in which the researcher needs to maintain awareness. These nuances include working with ‘gatekeepers’ who can facilitate or hinder access to potential participants, participant recruitment (such as whether they were coerced by staff or family members), lack of insight on behalf of the researcher who may have a paternalistic viewpoint that the participant will benefit from the interview process per se and thus negating the potential harms that may occur as a result of exploitation or exposure to inappropriate questions or in divulging more information than they would have preferred. Participants from smaller communities may not realise that although anonymity will be maintained in reporting the research, participants may still be identifiable by others in their community by the very nature of their narratives (Rosenblatt, 1995; Mitchell & Irvine, 2008; Aluwihare-Samaranayake, 2012; Silverman, 2013).

It is important researchers ensure confidentiality is maintained and that individuals are not identifiable in any subsequent publications. Another responsibility of the researcher, outlined by Aluwihare-Samaranayake (2012), Rosenblatt (1995) and Mitchell and Irvine (2008), is managing the emotional and psychological risks wherever possible prior to the interview, when discussing a potentially emotional or distressing subject like bereavement. Researchers need to be aware of, and responsive to, participants’ distress and have strategies in place to manage this, such as allowing participants to set the pace and depth of the interview, ‘sitting with’ extended periods of silence, changing or diverting the subject, enabling participants to opt for time-out or to cease the interview and turning off the recording device (Mitchell & Irvine, 2008; Aluwihare-Samaranayake, 2012; Silverman, 2013).
Qualitative interviewing allows for consent to be an ongoing, mutually negotiated process that is integrated into the researcher and participant relationship. This allows for ongoing monitoring of participant wellbeing throughout the interview thereby minimising risk and is more effective than a single initial signing of a consent form at the commencement of the study (Buckle, Dwyer & Jackson, 2009). One recommendation made by the bereaved to qualitative researchers is that researchers have sufficient training to conduct the interview in a professional and supportive manner, with knowledge of the process and expression of grief (McGrath, 2003; Buckle, Dwyer & Jackson, 2009). Researchers need to be cognisant of the emotional risks experienced to their own personal agency and Finlay (2003) and Wojnar and Swanson (2007) highlight processes around researcher self-reflexivity through the utilisation of memoing, diarising, field notes, outsider verification and the use of supervision to continue to ensure the integrity of the research. Reflexivity of the researcher was discussed in chapter one. The researcher regularly engaged in supervision and diarised as part of their self-care throughout the research process.

Benefits of the Research

Evidence demonstrates that when bereaved participants are provided with a safe environment, or emotional space, that allows expression of their grief, they often do not see participation in research as a risk. Thus, even if some experience tears during interviews, this is not considered as a negative consequence. The bereaved expressed gratitude for having the opportunity to sit with a person who was willing to sit with them in their pain and that participating in research is neither distressing or invasive (McGrath, 2003; Buckle, Dwyer & Jackson, 2009). Qualitative bereavement researchers do not intend to induce pain but invite listening to the stories of others that are often shrouded in sadness (McGrath, 2003). Some participants did cry throughout the interview, but cited different motivations for participating in the research, whether it was;
To help others:\n
“I hope it helps you out. I didn't think I'd be as tearful as I was but I haven't really talked about it, like this until now.”
“It would be nice to see something come out of it.”
ID: B: 3072: F; 52; Sp; 6-9; R3

“I thought it’s the kind of thing that people say oh no, I don’t want to do that, or else they say oh yes, I suppose I, well…and they don’t get around to it, and then you’ve got people that don’t like doing surveys. So I thought oh you poor thing you need somebody.”
ID: B: 3391: F; 69; Sp; 13-18; R3

To help themselves:

“I got you, the letter that you were doing this research, I thought well, it might help others but it might also help me”
ID: B: 3072: F; 52; Sp; 6-9; R3

“I don’t think I should dwell on it anymore. That's why I've agreed to talk to you and I thought, this must be the final bit.”
ID: B: 2875: F; 81; Sp; 13-18; Rem1

“I will never ever pretend I am ok when I am not, and, I will be eternally grateful that a lady by the name of Pippa Blackburn came into my life who enabled me to put all of this journey into perspective.”
ID: B: 3388: F; 69; Sp; 13-18; R3

\footnote{Throughout this thesis, participants are represented by the following descriptor: ID: Cohort (bereaved/health professional/Aboriginal health professional) / ID Number / Gender / Age / Relationship to deceased / duration since death / RRMA status.}
Or as a precursor to see if they need counselling:

“*She [my neighbour] seeks counselling but she says I should do it. But I really don’t think at the moment - that’s why I’ve agreed to come down and do a face to face and sit down and talk to someone and see how I feel at the end of it.*”

ID: B: 3400: M; 70; Sp; 13-18; R3

There is a plethora of evidence regarding the benefits of the qualitative approach to research, particularly as it allows participants to set the pace of the interview and shape the focus, discussing what they are most comfortable with and what is relevant to them and their experience (McGrath, 2003; Buckle, Dwyer & Jackson, 2009). Participation in research by the bereaved has been explored in the literature and has demonstrated that the experience has been positive and therapeutic for participants as the bereaved appreciated the opportunity to tell their story and they felt that the research may also be helping others in some way. Although participants acknowledged that it can evoke distress, many of the participants reported it to be a positive experience (Cook & Bosley, 1995 cited in Buckle, Dwyer & Jackson, 2009, p.117; Dyregrov, 2004; Koffman, Higginson, Hall Riley, McCrone & Gomes, 2011). The research indicates that risks are minimalised and that participating in research may be more of a benefit as discussing issues can have a cathartic benefit - people feel listened to and the process of contributing gives them a sense of being able to make a difference to others. Benefits identified by participants in qualitative research included being able to release pent up emotional energy, having an important emotional space to reflect on and gain insight into their experience, normalisation of their experience (hearing about similarities and differences) which reduced the sense of aloneness; valuing the opportunity to educate others, a sense of empowerment in a life situation in which individuals felt very disempowered, providing help to others and contributing to a better understanding of grief issues (McGrath, 2003; Buckle, Dwyer & Jackson, 2009).
Recruitment

Participants were recruited via palliative care services currently operating in the WA Country Health Service (WACHS). Eligibility criteria for participants were:

1. People over the age of 18 years
2. Bereaved: People who have had a deceased loved one who was under the care of a palliative care service
3. Health Professionals: Professionals who provide support to those who are bereaved
4. People from rural, regional and remote areas of country WA
5. People who speak English
6. Between 0-3 months and five years post death

Health professionals were recruited via regional palliative care team members within WACHS. A promotional flier was sent to regional teams which provided information on the research allowing staff members to self-select or opt-in. Nurse managers and senior social workers from respective teams circulated the flier to their networks (both palliative care staff and bereaved families) to highlight the research project. All bereaved participants involved in interviews were identified by their involvement with palliative care services and who had a loved one cared for by the service. The research was communicated to patients via post, email or telephone and

Figure 1: WACHS Regions
recruitment processes differed for individuals and regions. Health professionals were tasked with ascertaining suitability of clients for participation. This was embedded as a protective buffer to ensure participants were not approached directly by the researcher. Regions did not feedback formally on processes of recruitment however anecdotally advised some sent letters to all bereaved and others were specifically identified by staff who believed it would not have a detrimental impact on the person’s psychological or emotional wellbeing to participate. Despite the fact that this may be recognised as having contributed to a level of bias within the study given the sensitive nature of the topic, a certain degree of pastoral care amongst service providers is expected. Experienced clinician/researchers advocate to let the bereaved decide when they want to participate in research as some feel ready shortly after a death, some may not be ready for a number of years and some may never wish to participate (Buckle, Dwyer & Jackson, 2009).

Palliative care clinicians screened individuals who are bereaved, were eligible for the study and interested in participating. Participants were recruited at any time post death as long as they were assessed as having capacity to engage in the process. Health professionals working in health and palliative care services are often familiar with the potential participants, their mental health and physical health status and their capacity to participate in the research study.

There was no set length of bereavement period before participants were enrolled. As recruitment was through palliative care services, existing clients were usually within their first year of bereavement. However, some services identified participants linked in with their service, who had been bereaved for longer. As the literature identifies that three to five years’ post death is a time where there is a change in the grief, or there are secondary effects from bereavement that impact on them, the time frame was left open to bereaved participants up to five years post death (Stebbins & Bountrey, 2007; Corden, Hirst & Nice, 2008; Feigelman, Jordan, & Gorman, 2008-2009; Rubin & Nadav, 2009; Chow, 2010). Evidence from research with participants soon after death indicate that less than 10% of bereaved individuals reported a great deal of stress from an interview (Emanuel, Fairclough, Wolfe & Emanuel, 2004).
As rurality was a focus of this study, participants were categorised according to the Rural, Remote and Metropolitan Areas (RRMA) Classification systems in which classifications are based primarily on population numbers as an index of remoteness. The aim was to have representation of participants from the following areas as classified by the RRMA:

1. Rural Zone
   - R1 - large rural centre (urban centre population 25,000 - 99,999)
   - R2 – small rural centres (urban centre population 10,000 – 24,999)
   - R3 – other rural areas (urban centre population < 10,000)

2. Remote Zone
   - Rem1 – remote centres (urban centre population > 4,999)
   - Rem2 – other remote areas (urban centre population < 5,000)


**Aboriginal and Torres Strait Islander Participants**

Aboriginal and/or Torres Strait Islander (ATSI) peoples were targeted as a specific sub-group. The initial aim was to recruit approximately five to eight ATSI participants to comprise this sub-group. This research is a pilot work looking at receptivity to bereavement support within Aboriginal and Torres Strait Islander peoples. As they are such an important group in WA, especially in relation to rural and remote areas, there needs to be inclusion, albeit small, in this research which can contribute to the evolving evidence base that will inform culturally appropriate and sensitive responses by health services in the provision of bereavement support.

The researcher has worked as a clinician with numerous Aboriginal groups and is familiar with the culture and practices of Aboriginal and Torres Strait Islander peoples. The researcher recognises the cultural distinctiveness of Aboriginal and Torres Strait Islander communities and groups and the methodology selected respects and acknowledges such
diversity. This research aims to highlight the voices of the bereaved to inform health services of their needs leading to enhanced bereavement support that can improve the health and wellbeing of participants and communities. Therefore, including the perspectives of ATSI peoples was an important part of this study as the focus is on country areas in Western Australia in which a higher proportion of Aboriginal populations live. Additionally, bereavement programs are developed by health professionals and there has been little to no contribution invited by ATSI peoples to providing guidance, knowledge and experiences to better inform culturally appropriate and responsive bereavement support. It is hoped that the research will contribute to the social and cultural bonds by recognising that bereavement support needs to include emotional, social, practical, financial, legal, family and other support.

As this research was a state-wide project, there was no specific Aboriginal community to be addressed, however written support was obtained by Aboriginal Liaison Officers within the WA Health Department. Aboriginal Liaison Officers (ALO’s) and an Aboriginal Health Worker within WA Country Health self-selected to participate in the research in their roles as health professionals who provide bereavement support and as they have had personal experiences of bereavement. Although the number of this sub-group within the health professional cohort was small, when compared to the percentage of Aboriginal people within the total population in Western Australia, information provided throughout the interviews was very informative and gave some diverse insights into receptivity to bereavement support from an Aboriginal perspective which will be discussed further in the following chapters of this thesis.

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15 There is no empirical literature that evidences involvement by ATSI peoples in the design of bereavement programs that the researcher could find as part of a review of the literature.
Data Collection

Additional data was collected on income amount and income source with bereaved individuals to ascertain if there was any link between the experience of bereavement and financial status (Australian Bureau of Statistics, 2012). The financial impact of death has only been examined in some depth in the past decade in relation to bereavement (Corden, Sloper & Sainsbury, 2002; Stebbins and Batrouney, 2007; MacDuff, 2013). There is a correlation between rurality and lower socio-economic determinants of health and wellbeing (Cheers, Darracott & Lonne, 2007). There is also a link between receptivity and perceived financial cost or burden (McGrath, 2013). As a result, socio-economic status of the bereaved was included in the data collection for this study.

Data was obtained through in-depth semi-structured interviews and lasted between 37 to 143 minute’s duration. Depending on the location of the participant and the modalities available to parties, methods of collection varied and included face-to-face interviews, telephone interviews and interviews via Skype. Although Skype was only used for three interviews overall, there were issues with internet signals ‘dropping out’ leading to disruption to interviews. This did not have a significant impact on the content of the interviews however there was some transmission lag. Sedgwick and Spiers (2009) advocate for using a high-bandwidth connection when conducting interviews using video-conferencing as a medium.

Figure 2: Interview Modalities
As recruitment was driven by regional services, there is no information of how many individuals were invited to participate. Recruitment occurred within four of the regions within WACHS. Forty seven (47) people initially expressed interest to participate in the project and PICF’s were sent to all. A total of 37 interviews were completed. The cohort of Aboriginal participants interviewed as a group (n=4). Two of the health professionals preferred to be interviewed together and the remainder were interviewed individually. There was a total of nine health professionals interviewed. A total number of 24 bereaved participants were interviewed. Ten (10) participants who were not interviewed included three health professionals, four bereaved individuals and three Aboriginal health professionals. Of these participants, one was male and the other nine were female. One bereaved individual declined to be interviewed, instead forwarding a letter sharing her experiences of bereavement, providing a message for health professionals and others who have a loved one die. This was included in the data analysis.

**Description of the Sample**

The final sample for this study was a total of 37 participants, of which 24 were bereaved, nine (9) were health professionals and four (4) were Aboriginal health professionals. Bereaved participants comprised the majority of the total number of participants at 65%, health professionals 24% and Aboriginal health professionals (11%) respectively. Some health professional and Aboriginal health professionals shared some of their personal experiences of bereavement as well as their professional roles in providing bereavement support.
The Bereaved

The following section will discuss the demographic information of the bereaved. The total number of bereaved participants categorised by age is depicted in the following figure:
The youngest participant was 44 years of age and the eldest was 87 years of age. One (1) participant identified as being of Aboriginal descent.

*Figure 5: No. of Participants by Gender*

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<thead>
<tr>
<th>No. of Bereaved Participants by Gender</th>
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</thead>
<tbody>
<tr>
<td>19</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>Male</td>
</tr>
</tbody>
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Female participants comprised 79% of the total cohort (n=19) and ages ranged from 44 years to 87 years of age. Fifteen (15) of the female participants experienced spousal bereavement (79%), three (3) adult child bereavement (16%) and one (1) bereavement of a friend (5%). Males comprised 21% of the total cohort (n=5). Male participant ages ranged from 52 years to 73 years of age. Four (4) male participants experienced spousal bereavement (80%) and one male experienced adult child bereavement (20%).

*Figure 6: Relationship of Bereaved to the Deceased*
Time since death ranged from as early as 0-3 months up to 24 months’ post death. The majority of participants (42%) were 13-18 months’ post death followed by 21% at 7-9 months’ post death, 12.5% at 19-24 months and 10-12 months respectively, 8% at 4-6 months and 4% at 0-3 months’ post death.

Figure 7: No. Bereaved Participants & Time Since Death

There was representation from different rural zone classifications with the majority of participants (58.3%) being from Rural Zone 3 where towns have a population of less than 10,000 people. The next largest cohort (25%) were from Rural Zone 1 where towns have a larger population of between 25,000 to 99,999 people. There was 8.33% of participants from a Rural Zone 2 where the population ranges from 10,000 to 24,999 people. There was small representation 4.2% from participants living in Remote Zone 1 where populations are less than 4,999 people. One participant representing 4.2% from a Metropolitan 1 Zone which represents a capital city. Although this participant lived in the city, their deceased loved one was from a Rural Zone 3 (Australian Institute of Health and
Welfare, 2004, p.5). This participant spent a lot of time attending to practical matters in bereavement dealing with local agencies and services. She also accessed the local palliative care service and attended their local memorial service. Much of her experiences with coping in bereavement occurred in the rural context so she was included in this study.

Figure 8: RRMA Status: Bereaved Participants

Other demographic data was collected based on income amount and source (Australian Bureau of Statistics, 2012) and demonstrates 37.5% of bereaved participants received income via government pensions, 25% were earning incomes via wages or salary and 37.5% received earnings from businesses or other sources.
The majority of bereaved participants earned between $20,000 to $41,599 per annum however there was also representation from the extreme ends of one participant earning no income and another participant earning in excess of $104,000 per annum.
Based on the Melbourne Institute of Applied Economic and Social Research Poverty Lines: Australia Report (December, 2015), nine of the participants sit below the poverty line and potentially an additional five (5) participants sit below the poverty line depending on their earnings within category seven (7) of $21,200 to $41,599 per annum. Participants in this study represent 58.33% of total bereaved participants as being from a low socio-economic status.

**Health Professionals**

The following section outlines the demographic information of the cohort of health professionals. The total number of health professional participants categorised by their professional role is depicted in the following figure:

*Figure 11: Health Professionals by Profession*
The age range of health professionals was relatively narrow with the youngest health professional participant at 42 years of age and the eldest at 55 years of age. Forty-four percent (44%) of health professionals were between the ages of 40-50 years and 56% were between the ages of 50-60 years.

Figure 12: Health Professionals by Profession

Female participants comprised 89% of the total cohort and males comprised 11% of the total cohort.

There was representation from different rural zone classifications with the majority of participants (44.5.3%) being from Rural Zone 1 where towns have a population ranging between 25,000-99,999 people. The next largest cohort of health professionals (44.5%) was from Remote Zone 1 where towns have a smaller population of less than 4,999 people. There was 22% of participants from a Rural Zone 3 where the population is less than 10,000 people. There was no representation from health professionals living in Rural Zone 2 where populations range from 10,000-24,999 people (Australian Institute of Health and Welfare, 2004, p.5).
Figure 13: RRMA Status: Health Professionals

Aboriginal Health Professionals

Figure 14: Aboriginal Health Professionals by Gender and Age
Three (3) of the Aboriginal health professionals were Aboriginal Liaison Officers\textsuperscript{16} and one (1) was an Aboriginal Health Worker. As per RRMA categories, three (3) of the participants were from Rural Zone 1 and one (1) was from Remote Zone 1. The Aboriginal health professionals expressed a wish to be interviewed as a collective group and face-to-face.

**The Interviews**

Participants are acknowledged as being expert informants and were invited to share their stories, in their own words, and at their own pace. Throughout the interviews, I engaged in active listening techniques, asking probing questions, clarifying and summarising points in participant narratives. Interviews for individuals who are bereaved were initiated by the following open-ended invitation: “Could you talk about your bereavement and the impact it has had on your life?” Additional prompt questions were included to provide a semi-structure for the interview. Questions exploring factors that encouraged or deterred receptivity to professional support included: who did they turn to for support? Did they feel the need for professional bereavement support? What experiences did they have with formal and informal support? These exploratory questions provided additional insights into bereavement experiences. (*Appendix D: Cohorts Schedule of Interview Questions*).

Interviews for health professionals who provided bereavement support were initiated with the following open-ended invitation: “Can you talk about your work in providing bereavement support?” and examples of prompter questions included, “What do you think the bereaved require for support?” “What are some lessons you have learned from the bereaved?” “Are there things that bereavement programs do not include that you think..."

\textsuperscript{16} An Aboriginal Health Worker (AHW) differs from and Aboriginal Liaison Officer (ALO) as AHW’s complete a Certificate III or IV in Aboriginal Primary Health Care via a tertiary institution or recognised training organisation whereas ALO’s do not have any formal qualifications required for the role.
might be helpful for the bereaved?” (Appendix D: Cohorts Schedule of Interview Questions).

Although these questions were the starting point for the researcher, interviewing participants was an iterative process. Qualitative interviewing techniques may lead to learning more about a subject and questions may be altered if they are not eliciting the necessary information. Therefore, the researcher needs to be flexible in the interview as digressions may be very productive in revealing rich information as the interviewee’s interest and knowledge shape the interview. Iterative processes in qualitative research allow for ‘reaching out’ to other participants who may be able to contribute further to developing descriptions or themes. Iterative processes enhance reliability and validity of the research and occur concurrently with data analysis as this informs data collection. This iterative process continues until the description is comprehensive and leads to a point where saturation occurs and no new themes emerge (Morse, Barrett, Mayan, Olson & Spiers, 2002; Polkinghorne, 2005; Dicicco-Bloom & Crabtree, 2006; Kuper, Lingard & Levinson, 2008).

Data Saturation

Mason (2010, no page) cites Bertaux’s (1981, p.35) guidelines for sample sizes in qualitative research and posits that within PhD studies, 15 participants is the smallest acceptable sample size in qualitative research and relates sample size to saturation. Data saturation occurs when there is ‘informational redundancy’ where no new concepts or dimensions for categories can be identified. It does not necessarily mean that nothing new can be found (Holloway & Wheeler, 2010). Mason (2010) advises that saturation is influenced by many factors and can occur at any point in a qualitative study. This study comprised 24 bereaved participants and 13 health professionals of which four of these comprised a sub-cohort of Aboriginal health professionals. This study had a total of 37 participants which were predominantly female and over the age of 44 years. The potential for further insights could be found with younger, male and more ATSI participants. The
researcher conducted all of the participant interviews and was thus ideally situated to identify when all issues of primary importance were identified and data saturation was reached.

**Data Storage**

Recordings and transcripts were stored on the QUADRANT website. All information collected was stored as an encrypted computer file on a secure, password protected Australian central server, the QUADRANT computer management package which was used for data storage and management. This is a password protected computer package where access to data can be limited to those nominated. User access was controlled only and solely by the researcher. Access to the server also required password protected and encrypted authentication processes. De-encryption is only possible for the users (investigators) defined by the researcher. The central server and access is professionally maintained and is physically secure and located in Australia. Encryption and access procedures use 256-bit shared public-private keys and are current best technology. Information collected will be stored for a period of five (5) years after the completion of the project to meet the mandatory time period for the Griffith University and Notre Dame Code of Conduct respective policies for data storage.

**Data Analysis**

*Rigour in qualitative research*

Morse et al. (2002) emphasise the importance of the researcher focusing on verification at all stages throughout the study to reduce the risk of missing threats to reliability and validity. In effect, qualitative research is an iterative process where the researcher moves back and forth between design and implementation to ensure congruence between formulation, literature, recruitment, data collection strategies and analysis (Morse et. al., 2002, p.17). Verification strategies enable the researcher to identify when to modify, stop
or continue the research. These strategies contribute to, and build, validity and reliability thus ensuring rigour, enhancing researcher responsiveness and constantly reminding researchers to take responsibility and be proactive. Verification strategies included:

- **methodological coherence** where there is congruence between the research question and components of the method
- **appropriate sample** of participants who represent the research topic
- **collecting and analysing data concurrently**, an iterative process between data and analysis
- **thinking theoretically** where ideas emerging from data are reconfirmed in new data, checking and re-checking
- **theory development** moving between micro perspectives and macro conceptual or theoretical understanding.

(Morse et al., 2002, p.18)

Consultation between the researcher and supervisors can encourage probing questions which may help highlight researcher preferences and biases, promoting refinement of methods, greater explication of research design and strengthening of arguments (Shenton, 2004). Researcher reflexivity around these, alongside impressions of data, will reveal patterns emerging from the data which can play a key role in the monitoring of the researcher’s developing constructions. Guba and Lincoln (1989, cited in Shenton, 2004, p.68) refer to this process as ‘progressive subjectivity’. Ongoing discussion with the primary supervisor enabled the researcher to refine analysis processes and the overall study design. According to Shenton (2004, p.70) boundaries of the study should be documented and include:

a) the number of organisations taking part in the study and where they are based
b) any restrictions in the type of people who contributed data
c) the number of participants involved in the fieldwork
d) the data collection methods that were employed
e) the number and length of the data collection sessions
f) the time period over which the data was collected
g) geographical area (as the results of qualitative research must be understood within
the context of the characteristics of the organisations or geographical area in which
the study was conducted)

and for any reason during the interview (Shenton, 2004).

Mays and Pope (1995, p.110) advocate that researchers need to “…ensure rigour is
systematic and self-conscious in research design, data collection, interpretation and
communication...” Strategies that can promote rigour include researcher transparency
about the method so that another researcher could analyse the data in the same way and
draw the same conclusions. This is achieved through clearly articulating assumptions and
methods, particularly with regard to data analysis. When a researcher can present the study
in such a way that the reader can distinguish the data, analytic framework and
interpretation, this can minimise researcher bias in the presentation of results (Mays &
Pope, 1995, p.111). Rigour is also achieved through sampling techniques that identify
specific population groups that possess characteristics that reflect the phenomenon being
studied. In qualitative research, as data is often collected in relatively unstructured forms,
such as recording or transcripts of interviews, meticulous records of interviews and
documenting the process of analysis in detail also promote rigour. Collection of data from
different sources provides validity to the data collected as referencing multiple sources
can potentially help to identify patterns of convergence between data sources (Mays &
Pope, 1995). This is the underlying reason for including representation from three
different cohorts within this study.

Trustworthiness is a term introduced by Guba and Lincoln (1985, cited in Morse, Barrett,
Mayan, Olson & Spiers, 2002) in the and refers to credibility, transferability,
dependability and confirmability. Specific methodological strategies within these aspects
for demonstrating rigour include “…audit trails, member checks when coding,
categorising, confirming results with participants, peer debriefing, negative case analysis,
structural corroboration and referential material adequacy…” (Morse, et al., 2002, p.14).
It is essential that the investigator remain open, to be willing to relinquish ideas that are
poorly supported within the data (Morse et al., 2002). Researchers might begin with pre-
existing coding systems and these are often modified in the course of analysis or may be discarded in favour of a new system to ensure best fit to the data (Sandelowski, 2000). Some initial codes in this study were modified to ensure accurate representation of the data following re-review of codes to ensure they were developed within the language of the participant and not the researcher. For example, ‘closing out the world’ was a code created by the researcher but on further review and discussion with the supervisor, this code was changed to ‘building a protective space from others’ when it was determined the individual was not closing out the world as an avoidance or pseudo-pathological behaviour but rather, as an intentional ‘psychological bracing’, so that when people did or said perceived harmful things, they felt some resilience in being able to manage these difficult situations.

Whittlemore et al., (2001) highlight the tension between rigour and creativity and discuss criteria (standards) and techniques (methods) to diminish threats to the trustworthiness of the research. As this research utilised a descriptive methodology, the researcher engaged in the process of ‘bracketing’ which draws from the phenomenology literature. Husserl, (2001, cited in Wojnar and Swanson, 2007, p.173) describes the process of bracketing as transcendental subjectivity in which the researcher consciously and successfully “…abandon(s) his or her own lived reality and describe the phenomenon in its pure, universal sense…” In essence, the researcher consciously puts aside a priori knowledge and personal bias so they do not influence the description of phenomena from participants. Strategies the researcher utilised to enhance rigour in this study involved re-reading transcripts and confirming in-vivo codes were representative of participant narratives and reflected the open code to which they were assigned. The researcher also engaged in peer debriefing with the supervisor to confirm process and thematic analysis.

Qualitative research is characterised by fluidity, uncertainty and emergent ideas. Authenticity involves the portrayal of research that reflects the lived experiences and the meanings ascribed to these experiences by participants. Authenticity is essential criteria for validity in qualitative research. Accurate representation of the multivocality of interpretive perspectives of participants is important to ensure the researcher stays true to
the phenomenon under study. Acknowledgement of the influence of the researcher can
influence authentic representation of participant voices and requires conscious attention
to this influence by the researcher (Whittlemore, et al., 2001). Congruence is a secondary
criteria of validity and is evident between the “…research question, the method and
findings, between data collection and analysis, between the current study and previous
studies, and between the findings and practice…” and methodological congruence and
theoretical correctness (Whittlemore et al., 2001, p.532). Sensitivity where research is
implemented in such a way that is sensitive to the nature of human, social and cultural
contexts, representative of the multivocality of perspectives and voices. Techniques
employed by the qualitative researcher needs to evidence the linkage between thought,
technique, philosophy and research question.

Exploring negative instances,¹⁷ alternative hypothesis and examination of biases are all
components of criticality that seek to enhance integrity at each phase of inquiry, a
recursive and repetitive process of interpretations. Themes emerging from the data in this
study demonstrated alternate and negative instances and contradictory experiences of
bereaved participants. Threats to validity in qualitative research include investigator bias,
not giving consideration to alternative understandings or not paying attention to discrepant
data (Whittlemore, et. al., 2001). Researchers need to be open about their own beliefs
underpinning decisions made, methods adopted and reasons for favouring one approach
over another and this should be documented within the research report (Shenton, 2004).
Researchers using descriptive qualitative research are compelled to maintain a critical
self-awareness and consciously ‘bracket’ their own subjectivity, assumptions and vested
interests on how these impact on the research process and to be open to the ‘other’ to see
the phenomenon in a fresh and different way (Finlay, 2009).

¹⁷ Negative instances are where findings contradict findings. When the researcher includes
negative instances, this enhances rigour of the study as it demonstrates the researcher has
considered supporting and negating evidence. Evidence of negative instances helps to guard
against error as research is developed within the construct of researcher perspective (Whittlemore,
et al., 2001).
**Transcription**

A total of 33 interviews that were digitally audio recorded. The size of transcripts ranged from 11 pages to 45 pages, depending on length of interview. There was a total of 758 pages of transcribed interviews. The shortest interview was of 37 minutes and 17 seconds duration and the longest interview was of two hours and 23 minutes’ duration. The total number of hours of transcribing was 334 hours and 35 minutes. All interviews were transcribed verbatim and included incidences of non-verbal language such as pauses when crying or when laughter occurred. Transcription was done using NVivo 10 data analysis software developed for qualitative research.

From the transcribed conversations, patterns or experiences were identified by quotes or the paraphrasing of common ideas. The process of thematic analysis is a descriptive strategy that enables the researcher to identify, analyse and report patterns, or themes, within data. These themes capture salient points in the data that relates to the research question and represents patterns of meaning or responses within the data set (Buetow, 2010). All participants were de-identified when coding and will be referred to by ID references which include:

- The cohort they belonged to – bereaved (B), health professional (HP) or Aboriginal Liaison Officer/Aboriginal Health Worker which will be under the one auspice of Aboriginal Health Professional (AHP)
- ID No. generated to de-identify participant
- Gender of participant
- Age of participant
- Relationship to deceased eg. spouse, child, friend
- Time since death eg. 0-3 months; 4-6 months, 7-9 months, 10-12 months; 13-18 months, 19-24 months and 24+ months
- RRMA status
Throughout this thesis, the bereaved participants will be represented by the following descriptor: ID: B / ID Number / Gender / Age / Relationship to deceased / duration since death / RRMA status. Health Professionals will have a descriptor as follows: ID: HP / ID Number / Gender / Age / RRMA Status. Although one of the Aboriginal Health Professionals is an Aboriginal Health Worker which distinguishes them from an Aboriginal Liaison Officer by the formal training they have undergone to receive the qualification, Aboriginal participants are identified by the following descriptor: ID: AHP / ID Number / Gender / Age / RRMA Status.

There was a significant amount of data and this was initially overwhelming for the researcher. However, by immersing themselves in the data, the researcher initially reads the transcripts and familiarises themselves with the material and with repeated revisiting of the data, new material and ways of understanding begin to emerge. This repetition enables the mind to process the material in different times and in different ways (Meek, 2003). Meek (2003) discusses Bollas’ (1995, p.28) perspective of reflective processes where the researcher oscillates between condensing disparate information, synthesising thoughts and ideas with dissecting and deconstructing things into component parts. In effect, the processes of condensation and deconstruction are highly demanding intellectual and cognitive processes. Qualitative research entails active and high intellectual application. The processes of learning about the phenomenon and meta-learning, learning about context, requires a level of cognitive sophistication.

Namey, Guest, Thairu and Johnson (2007) recommend that when dealing with copious amounts of information, a system to identify large pieces of text on broad topics can provide a mechanism for indexing or grouping initially. Delineation of data in this study occurred by grouping the data separately where bereaved, health professionals and Aboriginal Health Professional participants were grouped respectively. Data was further grouped into pre-death and post death groupings however themes relevant to receptivity that occurred pre-death were included in the data analysis.
**Thematic Analysis**

As the focus of the research was on receptivity of the bereaved to support, there is a strong focus on discussing the findings from the data of this cohort throughout the following chapters (chapters four to nine). Data was examined within a framework of how discourses operate in society and influence experiences, meanings, realities and events, in effect, enabling analysis that reflects participants’ reality while simultaneously unravelling the surface of ‘reality’. According to Braun and Clarke (2006), key phases of thematic analysis include:

1. The researcher familiarising themselves with the data
2. Generation of initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report.

Thematic analysis is not linear and the process may even commence during data collection when the analyst “…begins to notice and look for, patterns of meaning and issues of potential interest in the data…” (Braun & Clarke, 2006, p.86). Analysis is a recursive process which entails moving back and forth between the data and it is in the early stages that the researcher commences writing notes about ideas or potential coding schemes and this continues through the coding and analysis process (Braun & Clarke, 2006; Buetow, 2010). The interview question schedule for both bereaved participants and health professionals were amended throughout data collection based on iterative process of themes emerging from the data.

Thematic analysis is to identify and describe implicit and explicit ideas. Codes are developed to represent ideas or themes and are linked to raw data. This helps to provide summary markers for later analysis. The researcher adopted a data-driven approach for thematic analysis as it compels the researcher to read and re-read the data, identifying
keywords, ideas, trends or themes and helped to provide an outline to inform analysis (Namey et al., 2007).

Participant comments were coded into ‘free nodes’ whereby reading through the data several times led to the creation of tentative labels for chunks of data that emerged from participant narratives. Categorising themes became easier as participant descriptions of their experiences provided the themes or categories to organise the prolific amount of qualitative data. The Rashoman effect describes the process of analysing and coding data where themes begin to emerge and the researcher arranges data where the same event is described from the perspective of more than one participant (Sandelowski, 2000) which led to the development of parent nodes and child nodes. ‘Parent nodes’ were created that reflected key ‘bigger picture’ themes that emerged from the analysis, with the creation of 13 (bereaved), eight (8) (health professionals) and eight (8) (Aboriginal health professionals) parent nodes created respectively. Further coding occurred in vivo, using the participants’ own language as much as possible to stay within the philosophy of qualitative descriptive methodology. Simultaneous coding also occurred where the researcher applied multiple codes to the same text (Holloway & Wheeler, 2010). A total of 416 ‘child nodes’ were created within the 13 ‘parent nodes’ for the bereaved (B). A total of 218 ‘child nodes’ were created within the eight (8) ‘parent nodes’ and a further two (2) sub-nodes created under the relevant ‘child node’ heading for the health professionals (HP). A total of 95 ‘child nodes’ were created within the eight (8) ‘parent nodes’ and a further two (2) sub-nodes created under the relevant ‘child node’ heading for the Aboriginal health professionals (AHP). A helpful analytic technique is to look at frequencies of individual participants who mention a particular theme as this is an indicator of thematic importance than the number of times a theme is expressed and coded (Namey et al., 2007). The number of sources (participants) and references (statements) varied between the cohorts and there were different nodes ranging from one to 24 sources (AHP), one to 54 sources (HP) and one to 206 (B) respectively.
Themes

In listening to the voices of the bereaved and the health professionals who provide bereavement support and being aware of one’s own values and how this can influence the research process, the researcher continuously had dialogue with the data. Findings that emerged from the data with bereaved individuals resonated with tenets from the postmodern and the Diaspora discourse which encompasses experiences of an individual’s inner and social world from the multiple perspectives of gender, culture, class and other group affiliations (Agger, 1991). Existential, coping and relationship experiences were core themes in the data and characteristic of the lived experience of Diaspora. Conceptually, findings from the research demonstrate:

1. The bereaved experience existential distress that reflects the profoundness of the diaspora lived experience.
2. There is a myriad of ways in which individuals cope.
3. Relationship is an integral component to how people make meaning of their experience and mediate their bereavement.
4. Language is a central feature that constructs experiences and connects the individual with their outside world; it is also a discourse created by professional lens.

These four domains are all reflected in the Diaspora literature. Diaspora can be viewed as an existential state (Chen, 2015) and can also be viewed as an all-encompassing experience which comprises individual, relational and social factors and will be discussed in detail in subsequent chapters. The findings have thus been conceptualised in the following way:
This conceptual diagram provides the framework through which data emerged and these domains were identified as key areas influencing receptivity to bereavement support. Throughout the interviews in this study, use of language to describe experiences was diverse and contradictory and not only highlighted the multiplicity of experience but also highlighted that language and the ways in which a person conveys their experiences may be an important factor underpinning a person’s receptivity to seeking and engaging in support.

**Limitations**

Limitations of this study include that bereavement experiences were explored only within the context of individuals who had been under the care of a palliative care service. The methodology entailed utilising third parties ie. regional palliative care services for recruitment of participants however there was no insight in to how respective regions did
this ie. advise all previous clients or selection bias based on staff assessment in communicating the research study to all parties. The cohort of bereaved participants were over the age of 44 years and were predominantly from the perspective of spousal bereavement. Younger participants and participants of varying relationships to the deceased could provide broader insights. Depending on where participants are in the life cycle, bereavement experiences could vary as a result of specific generational health and psychosocial developmental influences. There was only a small sample size of Aboriginal participants who engaged in the process as a professional who provides bereavement support. There was only one bereaved participant who identified as Aboriginal.

Conclusion

In this chapter, the methodology which operationalised the exploration of bereavement experiences and receptivity to bereavement support has been discussed. This chapter provides an overview of the iterative procedure used throughout this study including purposive sampling, data collection, the demographic profile of the sample participants, data analysis, ethical considerations, limitations of the study and an overview of the core theme that emerged from the data, Diaspora. The core concept of Diaspora will be discussed in the following chapters.