THE PSYCHOSOCIAL IMPACT OF FATAL CHILD DROWNING IN QUEENSLAND AND THE AVAILABILITY AND USE OF SUPPORT

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Abstract
This thesis examines the impact of fatal child (0-18 years) drowning in Queensland, Australia, and the supports available to parents following the death of their child. Using a social constructionist qualitative approach, two sets of participants were interviewed: bereaved parents and service providers. The key areas addressed in this research relate to the experiences of parents following their child’s death and the benefits and limitations of community and professional support available to them.

Bereavement and bereavement support related to an unintentional child death such as drowning have different elements to other child deaths. There is a dearth of literature that examines optimum support for families who experience a fatal child immersion.

Fourteen Queensland parents were interviewed about their experiences following the death of their child, the support services available to and accessed by them, and opportunities for improvement within these services. Seventeen service providers were interviewed about their experiences in dealing with parents of children who had drowned, and the support services offered. Data were thematically analysed. Participants highlighted how life changed forever the day their child drowned. Parents’ emotional, physical and spiritual states were compromised and some parents also experienced negative changes in their financial situation. Recurrent fundamental themes were expressed by participants in relation to their overall wellbeing. These were physical and/or emotional health; their sense of identity and the impact on their identity of their perceived failure as protector for their child, surviving children, and spouse; the nature and importance of ongoing relationships with immediate and extended family, friends and colleagues; the importance of continuing to honour their child; and the impact of their child’s death on work and finances. Service providers described their specific roles in providing services to parents of fatally drowned children, the professional challenges within those roles and the personal impact of providing this service. Themes include: the relevance of the unique geography of Queensland; resource and referral challenges for many organisations; training and education implications; and the impact of bereavement support work on the providers. A consistent finding for both parents and service providers was the limited understanding across the community and professional services regarding the support families require following an unintentional death such as drowning.
Attention to improved training and education across community and professional sectors, development of a specialised referral database and further research into school and workplace bereavement policies and procedures were key suggestions. Whilst the child drowning rate is decreasing in Queensland due to a number of intervention strategies, unintentional deaths from drowning continue to occur and impact irreversibly on families. Service providers, like parents, clearly articulated ways to improve available services. This thesis provides insights to offer guidance in improving support for parents following the death of their child due to drowning.
Declaration by author
This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my research higher degree candidature and does not include a substantial part of work that has been submitted to qualify for the award of any other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications during candidature
No publications.

Publications included in this thesis
No publications included.
Contributions by others to the thesis
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**Keywords**
Grief, loss, bereavement, stigma, child death, drowning, prevention, support.

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List of abbreviations

DSM    The Diagnostic and Statistical Manual of Mental Disorders
PTSD   Post-traumatic stress disorder
QLD    Queensland
WHO    World Health Organization
QISU   Queensland Injury Surveillance Unit
RCH    Royal Children’s Hospital
“It happened like this”– one parent’s story

Mum is in the kitchen making a sandwich, while her two-year-old is exploring his surroundings. His older sibling has just come home via the laundry door, accidentally leaving it open. The toddler has entered the backyard and is now 60 cm away from a broken pool fence panel. His mother is unaware that the pool fence is broken.

Since the age of six months, this child has been attending weekly water familiarisation programs at his local swim school. Every Friday, mum packs the swim bag and heads off for fun and learning games in the pool. Mum believes she is teaching her toddler about water safety. Only last week, he was sitting in his swim nappy, with his goggles and swim cap on, at the side of the pool. Upon hearing the cue – a particular song – the group of toddlers jumped into the water. Kicking and propelling themselves into mum’s arms, they then, with mum’s instruction and again with a cue from the instructor, propel themselves back to the side of the pool. He smiled and clapped at his achievement. This is where the joy of last week’s lesson ends, and something will go horribly wrong.

The toddler has found a gap of more than 10 cm, and he is able to fit through the bottom corner. It’s only been 15 seconds since the toddler was out of mum’s sight. The next 20 seconds will leave this family shattered forever.

As the toddler heads for the water, the lessons of last week will not kick in. He is now on his knees looking at the water. But today he is wearing a jacket, a T-shirt, a singlet, a nappy, a pair of corduroy jeans, shoes and socks. Most, if not all, toddlers will explore their environment; this is what toddlers do best. The toddler sees a leaf in the water and his ball in the middle of the pool. The toddler has now reached out with his hands. The next 20 seconds are the most crucial. There is no splashing, no screaming, nothing, not a sound. He is now fighting for life, but in sheer silence.

Mum is now calling bub’s name as she can’t hear him and she can’t see him. There are 360 degrees from where she is standing; which direction does she take?

Thinking that because the pool is fenced there is no danger, she looks around the side of the house, but the toddler is nowhere to be seen. Mum walks past the edge of the pool (still not in panic) and notices something unusual in the water. As she walks closer she
realises it's actually her child. She runs in a panic to the pool gate but remembers, horrified, that the key is on the fridge in the kitchen. Unable to climb the gate, not knowing how her child had entered the pool area, she simply screams and neighbours come running. One of the neighbours jumps the fence and grabs her son out of the pool. The neighbours start CPR, but by this time three minutes has already passed. Mum is now constantly screaming in panic, but is unable to move, frozen with emotion and shock. Neighbours assist the mother and call 000.
Chapter One – Introduction

Drowning is the third leading cause of unintentional injury death worldwide (WHO 2012). The WHO estimates that there are 388,000 drowning deaths each year but this is considered an underestimate, as different countries use different methods for recording and reporting data (WHO 2012). Each year over 300 people drown in Australia and approximately 20% of these are children 0–17 years (Australian Water Safety Council 2008). Consequently, child drowning is a major cause of preventable death in Australia. In fact, drowning is a leading cause of injury (Australian Water Safety Council 2008). Queensland data indicate that drowning was the most frequent cause of injury death in children 1–4 years (Royal LifeSaving Society Australia 2009) until 2011 when it was superseded by transport death (CCYPCG 2012). In Australia and Canada, the total annual cost of drowning is US$85.5 million and US$173 million, respectively (WHO 2012).

The death of a child causes intense grief, throwing parents into confusion and putting them at high risk in terms of mortality and morbidity (Murray 1999). Whilst acknowledging that any bereavement is difficult, researchers acknowledge that in a westernized cultural context, the death of a child is significantly harder to cope with than the death of an adult (Osterweis 1984; Weber 2001). Freeman (2005) suggests that due to the supposed order of life whereby children are not supposed to die before their parents, this bereavement is even more difficult to address: “The death of a child in our society is always viewed as psychologically unacceptable; it stands against the natural order of things that dictates the elderly should be the first to die” (Freeman 2005: 77). The situation can be further complicated if the death is sudden or due to unintentional injury such as a fatal immersion and where culpability may be implied (Reed 1998; Dyregrov 2003; Freeman 2005). In relation to child drowning, particularly a young child supposedly under the supervision of a parent/carer, the death may be viewed as negligence on behalf of the parent. This often results in disenfranchised grief (a situation whereby following a significant loss, social recognition implies that the person does not have a right to grieve and as a consequence, there is an absence of social sympathy and resultant support (Doka, Stroebe 2008). Blame and guilt are usually inescapable and relationships often become challenged as the blame is directed inward at oneself, or toward a spouse or other person with whom a significant relationship is present. Similar to parents coping with the suicide death of their child, this

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1Disenfranchised grief is discussed later in the thesis
blame and the attempt to cope with the felt and enacted stigma\(^2\) can further complicate the grieving process (Freeman2005; Feigelman; Gorman & Jordan 2009). When a child dies suddenly, the opportunity for preparation and support is absent and the loss can therefore be more difficult to handle than if prior preparation and support had been possible (Kamm 2001; Jiong, Dorthe Hansen et al. 2003; Knazik 2003; Copnell 2005). This is the scenario when a child suffers a fatal immersion.

1.1 The research focus

There is a paucity of research on the needs of families who have experienced a fatal child immersion, the associated stigma, and their experience of support to help them cope with their loss. A disenfranchised death such as a young child drowning can have different grief consequences than a child’s death due to illness. This thesis examines the effect of a fatal child drowning on parents, identifies some of the professional (formal) and community-based support (formal and informal) available for bereaved families, and highlights the challenges often faced in providing and receiving support. The study explores the experiences of 14 Queensland parents whose child drowned between the ages of one and 11 years before the commencement of this research and also 17 service providers who provide support for parents bereaved by their child’s death.

A social constructionist, qualitative approach was undertaken to explore the experiences of the parents and an opportunity for the service providers to offer their personal and professional insights into the service they offered. This approach was consistent with the study intent; i.e. to understand the participants’ interpretation of their experience based on how they construct their own world within their social setting. Social constructionism is a approach which enables the opportunity to gain participants’ experiences through descriptions rather than explanations, through the eyes of the participants themselves (Savvidou, Bozikas, Hatziigeleki, Karvatos 2003). This study is based within a western cultural discourse of death and grief, which suggests the ‘order of life’, is based on the parent dying before the child, unlike other cultures where child mortality is higher than in the western world.

This thesis explores the experiences of bereaved individuals and their attempts to adapt to their circumstances, the supports available and the influence their grief has on their

\(^2\)Stigma is further discussed later in this chapter
personal, social and professional worlds (Patton 2002; Creswell 2007; Daly 2007). In so doing, the following four objectives were addressed:

- The impact of a child drowning death on parents
- The support available to parents bereaved by a fatal drowning
- Parents’ experience of social, organisational and professional support
- Factors that influence the delivery of support

1.2 Thesis map

The rationale for this research is provided in Chapter One, which also proffers the main research enquiry and the four main research objectives. This is followed by the literature review, which is divided into two sections (Chapters Two and Three). The first section of the literature review is a brief overview of fatal child drowning, drowning prevention strategies, and the impact of the drowning death on parents. The second section of the literature review (Chapter Three) is a summary of the range of supports available and needed by families. This chapter includes a critical examination of the efficacy of some of these services. It concludes with the four main research objectives, with a particular emphasis on the service and support gaps.

The methodology used in this thesis is described in Chapter Four. In this section, the research objectives are stated and the rationale for selecting a social constructionist approach is described. The process of selection and eligibility are described as well as the sampling techniques used to identify participants. The interview process and documentation are laid out, the analysis described and main questions for each of the two participant groups listed. Finally, the chapter addresses the ethical considerations for such a sensitive study, the rigour and validity, and also highlights some reflexive issues and study limitations.

The findings of this research are described in Chapters Five and Six. A brief overview of the first three days in the lives of families following a fatal child drowning is charted in Chapter Five. Immediate and longer-term changes experienced by parents in relation to physical and emotional health, relationships, and challenges to their identities as protectors (of drowned child, surviving siblings, and spouses), as well as impact on work, are described. In the second section of this chapter, the experience of parents with a
range of support are detailed, including suggestions from parents on how these services could be improved. Many parents spoke of the ‘pay it forward concept’ and therefore the final section of Chapter Five describes some of the activities parents engaged in to prevent or minimise the impact of such tragedies on others who may find themselves with similar grief experiences.

In Chapter Six, service provider participants discuss their roles as bereavement support persons, the roles of their organisations where applicable and the limitations and challenges to providing optimum support. Key issues included the geographical distances experienced in Queensland; challenges to service provision including access, training and funding; the nature of volunteer support; experiences of coronial support and the impact that such intensive work can have on the service provider. Suggestions provided by service providers on how support for bereaved parents could be improved are also included and reflect the socio-political posit of the service providers.

Chapters Seven includes a synthesis of the key issues raised by the participants and links the parents’ psychosocial experiences with current literature, identifying the similarities, differences and gaps between the literature and the current study. Issues directly related to a sudden child death are discussed, in particular the impact of stigmatisation, isolation, ongoing relationships, the role of religion, financial challenges and their experiences and needs with regard to social support and concludes with some of the parents’ altruistic approaches to their children’s death. This last section of the chapter identifies how some of the parents chose to make changes in their lives to support others going through similar crisis; how this altruistic approach is consistent with the literature relating to a child death, and offers new insights into some challenges facing volunteer groups and parents regarding when a bereaved person is ready to take on certain support activities. It highlights the positive and negative aspects of support available to parents; offers new information regarding the trajectory of support required from the moment of the drowning event through to the years of adaptation following their child’s death and discusses the scarcity of specialised training regarding sudden child death. Suggestions for further research into a number of key areas are discussed, including professional training, identification and coordination of services to improve referral processes, and re-examining of existing policies and procedures, particularly in the Emergency Departments.
Chapter Eight identifies some of the strengths and limitations of the research, concluding with key findings and recommendations for further research. Many of these recommendations are new to the literature; all are feasible and practical, and, most importantly, if implemented will validate the voice of the bereaved parents, and offer an improved, integrated bereavement service which will address the needs of parents and also assist health practitioners to manage their stressful workload and consequently offer an improved service.

Study participants reported a variety of experiences following their child’s immersion. In order to appreciate the possible trajectory of events post immersion, below is a flow chart indicating the possible pathways following a child drowning event.
Table 1 Flow chart to illustrate possible pathways post-immersion gained from participant interviews

CHILD DROWNING / IMMERSION OCCURS
- Medical personnel called
- Police arrive to take statements and/or begin investigations for a potential criminal act
- Media may arrive on the scene
- Patient transported to hospital or morgue

Child may be declared dead at the scene, transported to the morgue

Child may be declared dead on arrival or declared dead in ED

Child is taken to hospital via Ambulance or carer

Admitted/transferred to ICU

- If rural area, child may be transferred to a tertiary hospital
- ED transfers to critical care
- Assigned social worker (sometimes)
- May be offered opportunity to discuss organ donation
- Opportunity for family and friends to arrive and support parents.
- Opportunity to say goodbye to child
- May get opportunity for priest visit
- May or may not get opportunity for hand and foot prints etc.
- May receive opportunity for priest visit.
- Some families may be advised ‘someone’ will be in touch regarding funeral arrangements but usually child goes directly to morgue
- May or may not be given contacts for bereavement support
- May be asked about organ donation
- Autopsy to be arranged – at this stage no detail

Possible opportunity for hand and foot prints etc. in hospital

May or may not be assigned social worker

Child dies within three days

Asked if require a priest
- May receive pastoral support
- Family return home OR some unable to ever return to house where child drowned
- Police statement within 24 hours
- Media reports and possible requests to interview family members
- Identify a funeral home and make funeral arrangements – may need to seek charity support or donations to fund funeral
Chapter Two – Fatal child drowning and grief: literature review (Part A)

Introduction

In order to contextualise the literature, the literature review has been separated into two main chapters, the first addressing the epidemiology of drowning in Australia and a history of the concept of grief. Drowning is a significant contributor to Australian mortality and morbidity and whilst there has been a body of knowledge for many decades regarding prevention strategies, fatalities are still occurring in a range of environments. Recent Queensland legislation for domestic pool fencing has been a significant step toward reducing toddler drowning, but deaths in open waterways in the older age range are still a challenge regarding prevention strategies. This chapter therefore includes current drowning prevention strategies to highlight the development of understanding toward drowning events and offer context to the experiences of the participants later in the thesis.

In order to place the drowning events within a psycho-social context, the chapter continues with a history of grief, illustrating the development and the current conflicts between health professionals regarding what grief actually is, and hence indicates potential confusion regarding appropriate support for the bereaved.

The second chapter examines some of the challenges in coping with disenfranchised grief (grief which is not acknowledged by society or judged in a way to be detrimental to the grieving parties), the potential stigma of a disenfranchised death and the supports available to bereaved families. It highlights the effect that grief can have on intimate and social relationships and introduces a range of support opportunities. Within these supports, the literature indicates some positive and negative experiences afforded by bereaved families, including health professionals, families, friends, schools and workplaces.

2.1 Fatal child drowning

In 2012/2013, 291 people (82% male, 18% female) drowned in Australian waterways, 43 (15%) of which were children, 0-17 years of age. Queensland had the second highest drowning rate, with NSW drownings being the highest in the country (Royal Life Saving Society – Australia, 2013). Swimming pools account for 61% of all drowning deaths in children under 5 and this same age group account for 44% of all swimming pool drowning deaths in the 2012/13 financial year. An absence of supervision was identified in 94% of cases. For the 0-4 year olds, the majority were male (65%) and in most cases
(81%), the toddler gained unintended access to the pool, and fell into the water. This pattern changed in the older age group with more than half of the children intentionally in the water prior to drowning, although males still dominated the statistics (89%)(Royal Life Saving Society – Australia (2013)).

Until 2011, drowning was the most frequent cause of injury death in Queensland children 1–4 years of age (CCYPCG 2012). For every toddler drowning death, there are several others admitted to hospital for an immersion incident – estimates range from 3–10 hospitalisations per fatal drowning event (Cunningham 2002; Royal life Saving Society 2009; Wallis et al. 2013), and one US study indicated that 14 non-fatal drowning events were treated in the Emergency Room for every fatal event (Wintemute GJ 1987). At present there is no capacity within routine data collection sources to follow these toddlers’ progress after they are discharged from hospital. Children who die in the months following the drowning event may not be recorded as being linked to the drowning event.

In a recent study using seven years of retrospective data on drowning events among children in Queensland, the authors found that location of drowning events was age-dependent (Wallis et al. 2012). The most frequent location for fatal drowning events for children under 5 years was a pool (56%), whereas static inland waterways (i.e. dam/lake) were the most frequent location for children aged 5–9yrs (26.7%), and dynamic inland waterways (i.e. river/creek/stream) were the most frequent location for older children 10–14yrs (44%) (Walliset al. 2012).

Some recent data indicate that the frequency of drowning fatalities among toddlers may be higher in newly purchased and rental properties than in other property types. (Queensland GovernmentDepartment of Infrastructure and Planning 2010). The potential risk period has been identified as within the first six months of moving into the home. Seventy-one percent of the drowning deaths among young Queenslanders 2000–2009 occurred on rented properties (Queensland GovernmentDepartment of Infrastructure and Planning 2010). As a consequence of this information, questions regarding rental or ownership status and the length of rental period and/or ownership of the residence are now included in the police report for drowning events that occur in residential properties in Queensland. This information was pivotal in altering the Queensland legislation to include inspection of pool fences on sale or re-rental (Queensland GovernmentDepartment of Infrastructure and Planning, 2010).
2.1.1 Drowning prevention strategies – a historical perspective

Whilst it is important to understand where and how children drown, the picture is not complete without an appreciation of drowning prevention strategies. Investigation into prevention strategies proffer a picture as to the complexity of fatal child drowning, including the realisation that with all the known strategies in place, children still drown and parents and society look to either blame or question how or why the drowning occurred.

As far back as 1977, Pearn and Nixon discussed improving the collation and reporting of a range of information to offer clarity around toddler drowning events (Pearn, Nixon 1977). In 1999, Mackie reinforced the need for improved reporting requirements. Both papers included the need for coronial information and police investigations of toddler drowning to include information on fencing and other details relevant to the drowning event; detailed studies of adolescent drowning; investigation of surveillance methods; support for advocacy of fencing of swimming pools; community education on the dangers of mixing alcohol with aquatic activities; and having mandatory first aid training for all pool owners (Pearn, Nixon 1977; Mackie 1999). Thirty-five years later, many of these suggestions have been implemented in Australia, including public awareness programs, the development of a database of pools in Queensland, a fencing inspection program and improved legislation and standards. In Queensland, amendments to legislation reflecting these improvements were introduced to state parliament in 2009 and May 2010 (The National Public Health Partnership 2004, Queensland Government. Department of Infrastructure and Planning 2010).

Key prevention elements which include, supervision, creating a barrier around the pool and swimming lessons, were noted over 30 years ago by Nixon and Pearn (Pearn, Nixon 1977). These elements have been repeated in numerous Australian and international public health and drowning prevention reports (Pearn, Nixon 1977; Mackie 1999; Rivera 2005; Australian Water Safety Council 2008; Barker 2008; Royal LifeSaving Society Australia 2009). Prevention strategies have been in the foreground of government and non-government initiatives over the last decade, and include: active supervision; restricting the child’s access to water; encouraging water familiarisation; and resuscitation. Injury prevention practitioners, researchers and legislators have collaborated and together their efforts have resulted in the introduction of pool fencing legislation, continued improvement to the Standards, public awareness campaigns, quality instruction for cardio pulmonary...
resuscitation (CPR), increased attention to the need for early introduction to water
familiarisation and swimming lessons and improving the understanding of the concept of
supervision. In addition, the Queensland Government established the Pool Safety Council
(Queensland Government 2010) in September 2010 to overview the training and practice
of Pool Safety Inspectors and make recommendations regarding best practice and
ambiguities in the application of the Queensland legislation.

2.1.2 Prevention strategies – the current climate

Given that there are known drowning prevention strategies, both passive and active, it is
important to try and identify the benefit of these strategies and to develop and appreciation
as to why these strategies alone are insufficient to prevent children drowning. The toddler
drowning rate in Australia has decreased in the last 15 years, possibly due to a number of
drowning prevention strategies. It is important to note that while the numbers of domestic
pool drowning almost halved between 1992 and 2004, the population of Queensland
children under 5 increased by 21.5% and the number of domestic pools tripled, hence
significantly increasing exposure (Barker et al. 2008). A significant policy change during
this period was the introduction and refinement of domestic pool fencing legislation as well
as public awareness campaigns that include the importance of supervision, water
familiarity, Australian Standards Approved fencing and knowledge of CPR. It is reasonable
to attest to some success from these strategies.

Whilst fatal toddler drowning in domestic pools is decreasing, there is still an average of 11
drowning events per year in Queensland (Wallis et al. 2012). The circumstances of these
fatal immersions include a lack of effective barriers, reduced supervision, parental
understanding of a child’s water safety ability, and lack of CPR knowledge (Barker et al.
2008). In most toddler drowning cases, the parent or carer was not aware that the toddler
was near the pool. Little research has been conducted to ascertain parental attitudes
toward child supervision in regard to both an understanding of appropriate supervision
based on the developmental stage/age of the child, and the relevance with regard to water
safety. A consensus regarding what constitutes adequate supervision is still required, with
further research needed to both establish these parameters and to understand parental
attitudes and behaviour toward supervision (Bugeja 2012). Petrass et al. (2009) examined
the literature around the relationship between child injury and supervision and concluded
that most studies were inadequate and that greater attention to a rigorous methodology is
required (Petrass, Finch, Blitvich 2009).
Appropriate fencing of domestic pools is highly effective in reducing toddler drowning (Cunningham 2002; Northern Territory Water Safety Advisory Council 2002; Barker 2008; Royal LifeSaving Society Australia 2009). In the past decade there have been a small number of articles regarding the efficacy of swimming lessons as a preventive factor to drowning, though none have been conducted in Australia. In one study published nearly 20 years ago, the effects of training in swimming and water safety on young preschool-children's ability to recover safely from a simulated episode of falling into a swimming pool were researched. This study showed that improvements in water recovery and jump and swim skills were associated positively with changes in swimming ability (Asher et al. 1995). The researchers concluded that improvements to preschool age children’s swimming ability and safety skills may offer some protection for children at risk of drowning and that there was no indication that this program increased the risk of drowning (Asher et al. 1995). In addition, a study conducted in the USA in 2009 drew the conclusion that participation in swimming lessons provided an 88% reduction in the risk of toddler drowning (Brenner et al. 2009).

However, further comments on this study have advised treating this result with caution. Concern surrounds the interpretation of swimming lessons, water familiarisation lessons and the possibility that parents and children may develop a false sense of security based on the child’s ability in a controlled environment rather than unexpected and unfamiliar access to water. Ekchaloemkiet and Gerdmongkolgan (2012) investigated the efficacy of various styles of swimming lessons on swimming ability and survival in children in Thailand. They presented their unpublished data at the Safety 2012 conference in Wellington, New Zealand, and concluded that children who took part in a specific safety and rescue swimming course displayed greater ability than those who participated in a general swimming course (Ekchaloemkiet;Gerdmongkolgan2012). The interim findings from this as yet unpublished study may offer important insight into the protective factor of certain types of swimming lessons and perhaps raises more questions regarding what should be taught in the earlier stages of water familiarisation and safety classes.

One Canadian study offered further insight into parents’ beliefs in relation to children's swimming ability and drowning risk, as well as their judgments of supervision requirements for under five year olds as they accumulated experience in swimming lessons (Morrongiello et al. 2012). Results indicated poor parental accuracy in judging children's
swimming abilities. Supervision needs were underestimated and children's ability to keep themselves from drowning was overestimated. Furthermore, there was no discussion as to the coping ability if the child unintentionally fell in a pool, if the water temperature was cold or if the child was without the safety net of adult supervision or in unfamiliar surroundings. This may be a critical factor as yet unexplored. The study mirrored other drowning prevention studies which highlighted the importance of pool fencing and parental supervision as the most important strategies to reduce the number of fatal drowning in young children (Asher et al. 1995; Cunningham et al. 2002; Rivera, Blessing 2005; Australian Water Safety Council 2008; Barker et al. 2008; Royal LifeSaving Society Australia 2009).

Notwithstanding the increased awareness of drowning prevention strategies in Queensland, children are still drowning. Part of the challenge will always be the active component of prevention, such as supervision, knowledge of CPR and possibly swimming lessons for older children. The more passive interventions such as signage and fencing fall into the legislative and local authority arena. Both require continued refinement in order to understand the gaps which still result in fatal drowning as well as constant revision and education at a government and general public level. Given that there is so much drowning prevention knowledge in Queensland, when a child drowns, blame may be at the forefront of both the parent and society. Following a fatal child drowning, parents enter a world of horror, which will never be the same again. Navigating that world and attempting to adapt to their new life without their child involves the support of family, the community and health professionals. Grief dominates the surviving family members, yet reaching out for support in an environment of guilt or blame can create significant difficulties. Understanding how grief manifests itself in such circumstances is critical to offering appropriate and relevant support to bereaved families.

2.2 Drowning death and the need for support.

“It has been said that no parent ever gets over the grief of losing a child; it’s an ‘all wrong’ death; it goes against the rules.” (Weber 2001:142)

The death of a child has a permanent impact on the lives of families, with shifts in life values, connectedness, relationships, finances and sense of identity (Love 2007). Further complications occur when the child dies suddenly, posing additional challenges for the bereaved who may try to reconstruct meaning in their world (Neimeyer, Prigerson, Davies
When such a catastrophe occurs, some parents are ill equipped to cope and need to seek support in order to continue with their lives. Kubler-Ross asked pertinent questions regarding what the experience is like for the parent and where or from who do they seek help.

“When is it like to lose a child? Who helps whom during such a crisis? How can one be more sensitive to the needs of those who are faced with one of life’s greatest tests? How can parents who lose a child ever again resume a normal, happy life?” (Kubler-Ross 1985: 22)

When a child is diagnosed with a terminal illness, the family may have time to prepare for the death, arrange the funeral and possibly start the grieving process (Kamm, Vandenberg 2001). When this anticipatory grief is absent as is the case in a sudden death, parents may experience more severe and often complicated grief as the sense of shock and helplessness overwhelm them (Lang, Gottlieb 1993; Miller 2003). Further complications may arise when the death has an element of blame attached; a stigmatised death such as death by AIDS or drowning suggests that the person or the carer could have prevented the death in some way (Dyregov, Nordanger, Dyregov 2003; Freeman 2005; Wender 2012). This perception can be exacerbated or minimised depending on the responses from family, friends, the broader community and health professionals.

Bereaved families may need a range of support to help them adjust to a life without their child. In the case of a sudden death where complicated grief is commonly experienced, a range of support is often necessary (Dyregov 2005/2006). According to Stroebe and Schut (2002), complicated grief may occur when a person loses a significant other person from their lives, and has the potential to become more complex if the loss is sudden or traumatic. Whilst in many cases professional support is sought, social support is considered an integral part of the grieving process (Laakso, Paunonen-Ilmonen 2002; Dyregov 2005/2006; Roehrle 2008; Stroebe et al. 2008; Benkel, Wijk, Molander 2009). Breen describes social support as providing the opportunity for a person to feel cared for and valued (Breen, O’Connor 2011) and Wilkinson (2006) describes social support as influencing one’s self image in order to stay connected with society. Positive social support has also been linked to reduced stress and improved psychological states with the opposite occurring if support is not received (Piperet al. 2009). Social support may be sought from a range of sources including family, friends, schools, religious communities and the workplace. However, the support available may not meet the needs of the
bereaved family. This is an integral aspect of this research; an attempt to understand the needs of bereaved parents, their experiences with support and the experiences of those providing support.

Grief is a unique experience, dependant on many variables such as the circumstances around the death, the relationship with the deceased, access and availability of support and other socio-cultural factors (Breen, O’Connor 2007); yet there appears to be expectations from community members and some professionals on how people grieve and the length of time until they should move on (Rando1993; Brabant, Forsyth, McFarlan1995; Bath 2009). These expectations can contribute to parents' feelings of despair and complicated grief as they feel unsupported through their grief. Grieving the loss of a child often intensifies in the second and third year. For some parents, time heals and assists with the acceptance and adaptation (Parker, Dunn 2011) whilst for others the intense grief may continue for a lifetime(Schwab 1998) yet most people are unaware of the prolonged period of time and the numerous symptoms and behaviours involved in complicated grief (Wiles et al. 2002; Freeman 2005; Worden 2005;Walter 2005). Prolonged or complicated grief is more likely to occur if the death is sudden or unexpected (Harper et al. 2011; Lichtenthal, Neimeyer, Currier, Roberts, Jordan 2013).

Research also suggests that people do not know what to say or do when confronted by a child death and, as a consequence, often fail to provide support to parents (Dyregov 2005/2006; White, Walker, Richards 2008). Unmet support needs can result in emotional and physical symptoms, adversely affecting the bereaved parents' ability to cope with their new reality (Laakso, Paunonen-Ilmonen 2002; Miller 2003). This combination of factors has the potential to fracture nuclear and extended family relationships and friendship circles.

Support from schools and the workplace is an important factor in coping with loss (Rowling 2000; Cohen, Mannarino 2011). When surviving siblings return to school, offering flexibility in attendance and performance expectations and involving peers and teachers in the support process as part of a holistic community approach aids their re-entry into the community (Kraus 2005). Having a plan in place to assist the family will help the child adapt to their grief, experience less feelings of isolation and increase their sense of feeling safe (Samide 2002; Jenkins, Dunhan, Contreras-Bloomdahl 2011).
Similarly, parents re-entering the workplace require similar support to children returning to school. They need flexibility, a return to work program, the opportunity to talk about their child rather than ignore the situation and support from staff (Charles-Edwards 2009). Where these aspects are absent, a parent may experience difficulty in maintaining their employment.

A critical part of parents’ bereavement journey includes their experiences of support with health professionals. Experience of bereavement support from health professionals is varied. In the case of a fatal child immersion, initial contact is with the paramedics, followed by the hospital staff. Experiences with and support from these staff are critical factors in parents’ adjustment to life after their child’s death (Dent et al. 1996; Cook, White et al. 2002; Macdonald et al. 2005; Meert et al. 2011). Bereavement support is available for children admitted to hospital and for those in palliative care (Copnell 2005) but does not appear to be the case for those children who die in the Emergency Department (ED) (Knazik et al. 2003). This lack of support is a significant gap in medical practice and yet support in the ED has been identified as a necessary process toward helping parents cope with their loss (Merlevede et al. 2004).

In the case of a child drowning death, isolation and feelings of guilt and shame often result in parents experiencing stigmatised behaviour, affecting health and social interactions (Corrigan, Miller 2004; Link, Phelan 2006). Stigma occurs when an individual who experiences a certain set of circumstances is deeply discredited by his/her society and as a consequence, members of that society reject the individual based on the attributes afforded from those circumstances. It is the reaction of others which affects the individual and adversely challenges their sense of identity. (Goffman 1963). Similar to suicide death, the stigma associated with child drowning can result in disenfranchised grief, with families being unable to openly mourn, to receive acknowledgement of their pain or to receive social support (Maple, Edwards, Minichiello, Plummer 2013). Stigmatised grief can also manifest itself in physical symptoms such as somatic problems, physical pains and often chemical changes to the body resulting in a range of health issues (Freeman 2005; Link & Phelan 2006.; Buckley et al. 2012). The emotional trauma associated with a stigmatised death may result in parents avoiding seeking further professional help (Weiss, Ramakrishna, Somma 2006). When parents do seek help, the GP is often the first professional contact after leaving the hospital (Oppewal, Meyboom-De Jong 2001; Wiles et al 2002), yet GPs may not have the skills to support their bereaved patient
Sudden unexpected death can result in a more complicated grief requiring specialised knowledge with regard to support and referral options (Van der Houwen et al. 2010). However, there is a paucity of research into GPs’ confidence in dealing with paediatric sudden death.

Schut and Hoyt suggest that there needs to be a clear understanding between complicated grief and the natural healing process, as well as appreciating that grief can occur over a long period of time (Hoyt, Larson 2010, Schut 2010). In addition, there is some concern that in some instances, health professionals’ approach to grief can be more harmful than beneficial (Schwartz 2005; Black, Tufnell 2006). Combining appropriate therapeutic interventions may be the answer (Vlasto 2010) but it takes a knowledgeable GP and allied health professional to be aware of the patient needs and refer accordingly.

Support groups provide a specialised function in that people can relate to a similar lived experience. Support groups can help parents come to terms with their loss in a non-judgemental environment and may be combined with counselling to maximise the positive affect (Bouckaert 2000; Vlasto 2010). Research suggests that women attend support groups more than men due to their different coping mechanisms (Aho et al, 2011), another factor relevant for the GP when considering referrals.

This research therefore explored the experiences and support needs of parents bereaved by the fatal drowning of their child and highlight some areas for improvement within a social and professional context.

2.3 The history of grief as a concept

The concept of grief has altered over the past century, moving from a pathological malaise to recognition that grief is a natural response to death, to a combination of these definitions, depending upon the understanding of the health professional, and the circumstances surrounding the death. Therefore, in order to understand support available for people experiencing grief, it is useful to understand the development of grief as a concept. In particular, this understanding links to the relationship of grief as a normal, healthy response to a death compared to a response that can manifest ill health and negative outcomes. While Freud (1856–1939) was the first to introduce the concept of grief into the psychological lexicon, there are several pre-Freudian researchers who studied the phenomenon of grief within a relatively close paradigm to the social sciences,
hence recognising that grief is a combination of the experience itself, and societies response to that experience (Granek 2010).

As early as the 16th century, in his book *The Anatomy of Melancholy*, Burton argued that grief is a kind of transitory melancholy that affects everyone at some point in their lives. While Burton referred to grief as a “cruel torture of the soul”, he also emphasised the distinction between melancholy as a disease, and melancholy as a normal reaction to everyday events such as death of a loved one. He proposed that melancholy could either be found in disposition or in habit, the former referring to context specific melancholy, and the latter referring to a person who is habitually melancholic in character (Burton 1621; Brink 1979).

In the 17th century, grief was often viewed as potentially fatal, and it was widely believed that grief could make you mad and even lead to premature death. Rush described a list of emotional and physical symptoms characteristic of grieving people such as aphasia, fever, sighing, loss of memory, and the development of grey hair (Rush 1830). Rush offered a variety of remedies to “heal grief” that included using opium, crying, and in intense cases, bloodletting and purges.

The first study of the psychology of grief was written by A. F. Shand, in which he referred to grief as “the laws of sorrow” (Shand 1914). He described four types of grief reactions; active and directed aggressively to the outside world; depressive and lacking in energy; suppressed through self-control; and the fourth involved frenzied and frantic activity. Shand also identified other aspects of grief, including the need for social support, the continued relationship with the deceased, and the trauma associated with sudden death.

It was Freud’s psychoanalytic theories, however, that had the most impact on contemporary grief research within the discipline of psychology. There were two simultaneous trajectories happening within the psy-disciplines in the 20th century that helped introduce and popularise psychoanalytic thought in North America. The first trajectory related to the introduction of Freudian theories in the United States, the expansion of psychiatry in the 20th century, and the development of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM)\(^3\) that would become an essential guide for

\(^3\)The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) is the standard classification of mental disorders used by mental health professionals. It is intended to be applicable in a wide array of contexts and used by clinicians and researchers of many different orientations.
the discipline (American Psychiatric Association 2000). The second trajectory that coincided and developed in relationship to psychiatry was the expansion of psychological expertise into the everyday domain.

In 1913 Freud published *Totem and Taboo* (Freud 1913) in which he outlined his main ideas on grief that he later expanded in *Mourning and Melancholia* (Freud 1917). Freud proposed that the mourner had the task of detaching their libido/emotional energy from the deceased and sublimating it into other areas of their lives. Freud’s essay has often been interpreted to mean that those who failed to do their “grief work”, a term that has evolved into an ingrained Western psychological concept, could end up with a psychiatric illness that resulted from their pathological grieving (Genevro, Marshall, Miller 2004).

The idea that unmanifested grief is as pathological as chronic grief is one of the underlying assumptions driving contemporary psychological research and practice. While Freud never claimed that grief becomes pathological if it goes on for too long or is too intense, Deutsch legitimised the concept of pathological grief by claiming that another type of dysfunctional grief is the kind that is absent or unexpressed (Deutsch 1937). She thereby introduced both concepts into the psychological discourse. Deutsch also expounded the theory that unmanifested or repressed grief will resurface in other ways if not brought into consciousness and treated (Deutsch 1937). She stated: ‘The process of mourning as a reaction to the real loss of a loved person must be carried to completion. As long as the early libidinal or aggressive attachments persist, the painful affect continues to flourish, or vice versa, the attachments are unresolved as long as the affective process of mourning’(Deutsch 1937: 187). Deutsch’s ideas were pivotal in the process of grief becoming psychological. Her idea that pathological grieving can manifest in either intensity and chronicity or in the absence of any symptoms introduced the concept that all grieving people are potentially ill and need to be monitored for the process of their grief work. Second, the notion that grief work must be done or else it will resurface somewhere else puts the onus of responsibility on the grieving person to self-monitor or risk becoming ill or psychologically unbalanced.

The development and use of the DSM and the focus on the scientific status of psychology both contributed to the shift of thinking about grief as a psychoanalytic concept on a continuum, to a more distinct diagnostic pathology to be treated by mental health professionals. In 2013 this has caused contention amongst health and allied health
practitioners with a focus on diagnosing depression early in the grieving process (Rando 2012).

2.4 Understanding grief

Grief is a unique experience, and consequently the impact of grief and its effective management may differ based on a variety of reasons. The word ‘bereavement’ means ‘to be shorn off or torn up’ (Despelder and Strickland 1987) and highlights the experience of a severance of someone from your world, which was totally out of your own control (Terry 2012). Gender differences as well as religious, cultural, socioeconomic and educational level may impact on individual grieving processes (Dewees 2005; Worden 2009). Grief occurs with the loss of symbolically important connections and involves intense emotional reactions and changes to individuals’ experiences of self, the world and the future. Factors such as personality and life history, social context and cultural practices, and the symbolic magnitude of the loss will shape the individual responses to this severance between the deceased and the living (Love 2007). This is consistent with a social constructivist model that recognises that grief is managed within a social and cultural framework as well as a private and psychological framework (Hung, Lim, Jamaludin 2011; Neimeyer, Klass, Dennis 2014). The environment and social aspects of community cannot be separated from one’s sense of self (Hung, Lim, Jamaludin 2011).

Grieving can be a relatively slow and uneven process, so applying prescriptive stages or goals to individuals’ experiences can be unhelpful. However, a number of researchers have suggested stage and/or phase models of grief, which provide a framework for the health worker/therapist and the grieving person to make some sense of their emotional stage (Freud 1917; Westberg 1962; Kubler-Ross 1969; Bowlby 1980; Walter 1996; Parkes 2001; Parkes 2006). Kubler-Ross’s (1969) five stages of grief (denial, anger, bargaining, depression and acceptance DABDA) is perhaps the best known, but possibly also the most misunderstood (Friedman, James 2008; Terry 2012). From her observations with anticipatory grief in the dyeing, she identified denial, anger, bargaining, and depression, followed by acceptance as the emotional journey experienced by the person dyeing Kubler-Ross (1969). There are two critical issues with these stages that have caused misunderstanding. First off, these stages were initially postulated as processes experienced by the person dyeing, not the person grieving post death. Second, Kubler-Ross was adamant that a person may not go through all these stages, and that being the case, the term ‘stages’ may be inappropriate (Friedman, James 2008) in addition, Kubler-
Ross never intended for these stages to be seen as linear; rather as aspects of the grieving cycle that could be experienced at various stages and to differing intensities (Kubler-Ross, Kessler 2005). The confusion and even harm over the application of these stages from a therapeutic perspective can cause additional stress for the bereaved if a therapist or member of the public expects the bereaved person to behave within these linear parameters (Friedman, James 2008; Terry 2012).

As a complement to identifying stages, Worden (2009) offers insight into various tasks in the mourning process and discusses a concept labelled the ‘duel process of mourning’. He acknowledges the importance of recognising either phases or stages, but suggests this is a passive approach to mourning and as such proffers a more active, task oriented model. The first of the four tasks involves accepting the loss, facing the reality that the person is not going to return. The bereaved may vacillate between belief and disbelief. Rituals such as funerals assist with this task, and those who do not attend the funeral may have to find alternate ways to accept the reality (Worden 1996). The second task is to process the pain and it is this process, which is essential in order for the bereaved person to move forward. This pain is both emotional and physical and affected by internal and external (social) interactions (Worden 2009). Bowlby (1980) suggested that if people avoid dealing with the pain, it may manifest in depression later in life and become more complex to address.

The third task suggested by Worden is to adjust to a world without the deceased. This adjustment may be dependent on the relationship the bereaved had with the deceased. Neimeyer (1999) linked this adjustment to the ability to ‘make meaning’ from the person’s death. The more difficult it is to understand and accept the death, the more challenging this third task. The fourth task leads into a continued relationship with the deceased, a concept of continuing bonds. Klass (1999) researched ways in which people stayed connected with their deceased family members and recognised that by maintaining a bond creates a new relationship with the deceased that allows the bereaved to find a place for that relationship in their new life without that person physically present. Worden suggests that for many, this fourth task is the most difficult and if it is not accomplished, the person may stay stuck in a life where they feel they are not really living and do not have the ability to love.

Although most people are resilient in the face of loss and do not require special interventions, health professionals can contribute by empathic use of communication skills.
to facilitate the grieving process. This communication includes words and tone used to grieving parents, feeling comfortable in silences as well as continued communication as bereavement follow-up (Meert et al. 2011; Das 2012). A minority will struggle with their grief and experience prolonged, intense or problematic reactions (Love 2007). Love (2007) states that this is particularly the case when the death of a child is experienced and potentially more so when the death was sudden or unintentional. Psychiatric co-morbidities including depression and anxiety disorders, can occur as elements of grief and a distinct diagnosis of complicated grief disorder has been proposed (Love 2007). Health professionals can identify complicated grief reactions and ensure patients receive specialised treatment, including intensive grief therapy and medication, where indicated. Assessment methods are available to assist health professionals in providing a continuum of care for those who are grieving to minimise the onset of disorders.

The concept of grief has altered over the centuries, with current understandings contradicting much of the previous beliefs and hence current approaches to managing grief.

### 2.5 Understanding and managing grief: the health professional’s approach

“Grief is best defined not as an exclusively medical problem, but it is an individual and societal event with potential medical implications” (Centre for the Advancement of Health. 2004: 503).

Lindeman was the first to present an empirical study of bereaved patients as a scientific and objective approach to documenting the grieving process (Lindemann 1963). Lindeman interviewed 101 recently bereaved patients and claimed to produce a systematic, objective and accurate representation of what the grieving process entailed. He argued that psychiatrists could and should play a role in aiding the mourner in their grief work (Lindemann 1963).

Lindemann’s study revolutionised the concept of grief by establishing several assumptions about the nature of the grieving process that have remained central to psychology today. First, he established that grief was a medical disease (or, in contemporary terms, a psychiatric/psychological disorder) that fell into the purview of psychiatry (and subsequently modern clinical psychology) and described the process of grief as a disease
with an aetiology that could be predicted, managed, and subsequently treated by professionals (Lindemann 1963). He also acknowledged normal and abnormal grief symptoms and that grief symptom may occur immediately after the event, be delayed, be exaggerated or even appear to be non-existent.

Given that grief is such a complex phenomenon ranging from a natural state to a pathology of various dimensions, the challenge is how to determine the type of grief one is experiencing and then to predict what some of the determinants are for a manageable and healthy outcome. This in turn can inform appropriate intervention strategies. There are a diversity of approaches regarding the optimum way to manage grief, ranging from medical intervention, professional counselling, psychology, psychotherapy, narrative therapy, peer group support, pastoral support or possibly using no external intervention and relying on rituals, ceremonies, family and community support (Freeman 2005). However, Lindemann argued that psychiatrists could, and should, be involved in the management of grief since they were experts in the field and knew the right techniques to help the patient with their grief work. He stated:

Proper management of grief reactions may prevent prolonged and serious alterations in the patient’s social adjustment, as well as potential medical disease. The essential task facing the psychiatrist is that of sharing the patient’s grief work, namely, his efforts at extricating himself from the bondage to the deceased and finding new patterns of rewarding interaction. It is of great importance to notice that not only overreaction, but under reaction of the bereaved must be given attention, because delayed responses may occur at an unpredictable moment and the dangerous distortions of the grief reaction, not conspicuous at first, may be quite disturbed later on (Lindemann 1963: 8).

Thus, Lindemann argued for the explicit intervention of psychiatrists in the grief process. He believed that psychiatrists should not only treat grief like a medical and psychological disease, but that patients should also be monitored for grief reactions to see if they were doing their grief work properly. Furthermore, patients should also be monitored for not showing enough grief.

There are three key considerations not taken into account by Lindemann. The first is that given the range of variables that affect each individual’s grief journey, some people may not require any intervention beyond their existing support structure. The second consideration is that at the time of Lindemann’s work, other modalities such as counselling
and psychotherapy had not developed. Therefore the pathology and ‘illness’ orientation toward grief rather than a natural cycle of life is not included in Lindemann’s theories. The third is the changing focus of grief management from the traditional model of separating oneself from the deceased, to the current model which suggests a relationship should be maintained with the deceased, and a new life structure built which involves a new but critical continued relationship with the deceased (Davies 2004). The bereaved can acknowledge that the relationship is changed and that they “must move on; but they do not let go” (Murphy et al. 2003: 364).

Parkes’s clinical studies are credited as the beginning of a firmer empirical basis for the description of grief and are largely concerned with atypical patterns of grief (Archer 1999). First, he provided a further rationale for the pathologisation of grief and set in motion an explosion of research into the ‘illness of grief’. In his 1964 publication, Parkes claimed that the notion of grief as an illness was supported by his interviews with bereaved psychiatric patients who were found to be suffering from variants of typical grief (Parkes 1964). His second major contribution to the field was in justifying the use of psychiatry to treat this illness and claimed that medical students should be trained in the psychology of bereavement (Parkes 1964).

Parkes’s third major achievement had less to do with content and more to do with methods. Parkes’s studies were considered by the psychological and psychiatric communities as sound description of grief that was evidence based. As such, he provided information about the processes of grief as well as an empirical method in which future psychologists could begin to study the phenomena. In all his articles, Parkes referred to grief as a complex process requiring professional intervention. In this way, he firmly established grief as a psychological kind within the discipline by offering both the “problem” (pathological grief) and the “solution” (psychiatric intervention).

The view of grief amongst many professionals for the past 20 years proposes that grieving is a debilitating emotional response that is seen as a troublesome interference with daily routines, and should be worked through as quickly and efficiently as possible (Lunbeck 1994). The belief that grief is intrinsically traumatic and causally pathogenic is generally accepted among psychologists who study grief today. The pathologisation of grief is part of the widespread phenomena of turning everyday problems into psychological disorders to be managed and treated by mental health professionals (Lunbeck 1994).
This pathologisation has occurred with other phenomena aside from grief. Some clear examples include the transformation of mild malaise and general unhappiness into MDD (major depressive disorder) (Horwitz, Wakefield 2007), or the shift in thinking of shyness and introversion as social anxiety disorder (SAD) (Lane 2007). This suggests that grief moves from a difficult but necessary condition of living into a psychological disorder that can be observed, diagnosed, and treated (Granek 2010).

Whether one views grief as a pathology or natural order, the focus of this study is to share the experiences of those who are grieving, and those who support the bereaved. This thesis reflects the interpretive constructivist paradigm where individuals create their own reality based on their own experiences and the reaction from those around them (Williamson 2006). As a consequence, the following definition will be used as the basis of understanding the response to grief. It reflects the challenge people have with accommodating to their world without their deceased child, attempting to merge the assumptions that they had for their child’s life prior to his or her death, with the reality of realising these assumptions for their child, and hence them as parents will never be realised. Families experiencing such intense grief resulting from the untimely loss of their child, struggle to assimilate the new reality and in particular, the interactions between their own sense of their old and new self, family members, friends, health professionals and their community impact on how this accommodation takes place. Finally, incorporating this new sense of self within a forever -changed world is highly dependent on the assumptions made by the bereaved person’s immediate social supports and extended culture. In the case of a young child drowning, adapting to a world of blame and guilt may be a lifelong challenge. The definition below reflects the individual’s state, the changes following death in terms of a new reality and the relevance of other people’s opinions and responses to the bereavement based on their own assumptions and/or experiences.

“Grief can be defined as the psychic energy that results from tension created by an individual’s strong desire to

1. Maintain his or her assumptive world as it was before the loss
2. Accommodate to a newly emerging reality resulting from his or her loss
3. Incorporate this new reality into an emerging assumptive world”.

(Doka, Martin 2011:18).

How this energy is managed reflects how an individual will work through their grief.
2.6 Working through grief

As discussed, a number of researchers have identified various grief processes (Lindemann 1963; Engel 1964; Bowlby 1969; Kubler-Ross 1969; Doyle 1980; Parkes, Weiss 1983; Worden 2005; Stroebe, Schut 2010). They are termed differently, but they generally all involve the following stages: numbing; yearning and searching; disorganisation and despair; and reorganisation (Australian Institute of Professional Counsellors 2002). Westberg described ten common experiences for people suffering grief, and these experiences can manifest themselves to varying degrees throughout the stages (Westberg 1962). They include: shock; emotional release; depression; physical symptoms of distress; anxiety; hostility; guilt; fear; healing through memories; and acceptance. Hobson interviewed widows from a small town in the Midlands of England, and found that physical symptoms in the grief process involved migraines, ulcers, asthma, chest pains, and skin complaints as well as a general feeling of fatigue, and a sense of being removed from reality (Marris 1958; Hobson 1964).

These stages of grief and associated symptoms can occur for varied periods of time, and reoccur often without warning. The period of shock associated with grief often lasts about four to six weeks, though for some this is much longer, depending on a range of factors such as self-protection from painful feelings, the significance and attachment of the relationship that has been lost and whether the death was sudden or anticipated (Neimeyer, Prigerson, Davies 2002; Love 2007). It is for this reason that at this stage, non-medical intervention may be redundant as the individual is likely to be incapable of any conscious understanding of the loss.

Working through these stages is different for each individual and is not a linear process (Love 2007; Worden 2009; Terry 2012). Some people stay stuck in the earlier stages of grief; some manage to work their way through to readjustment over time. Many move back and forth between stages. In every case, the need for support will be dependent on a number of variables such as age of and relationship to deceased person, gender, previous mental health conditions, existing support structures, relational support and previous losses (Love 2007). Grief expresses itself in many ways: physical, psychological and spiritual. These are all normal parts of grief but some people are unable to transition through to a healthy, manageable adaptive stage and need to seek professional help to achieve this (Freeman 2005; Worden 2005). People move between stages, which often
causes them to consider that they are ‘back to square one’. For some bereaved individuals the need to ‘be still’ is part of the process to become consciously able to handle the immense loss (Westberg 1962).

In acknowledgement of the struggle between accepting the loss and adapting to life after the loss, Stroebe and Schut (2010) considered the various stages of grief and identified grieving patterns that did not appear to be fully explained with the existing grief approaches. Their dual process model (DPM) reflects a combination of dealing with the loss itself and the re-orientation or acceptance of that loss in order to manage life after the deceased. They describe this process as dynamic and oscillating, with individuals coping differently at different times depending on internal and external variables. Unlike previous models, the DPM distinguishes between stressors and coping mechanisms, recognises that the process is not linear and as a result, offers greater insight into management of complicated grief.

2.7 Defining complicated (prolonged) grief– a psycho-social phenomena.

The process of defining grief embraces both medical and social frameworks. It is manifested by a combination of pathological and social reactions, the former being a bodily response to the grief, the latter, which may also manifest itself in chemical and physical dis-ease, is exacerbated by the impact of societies response. The constant interplay between the medical and social status have a profound effect on an individual’s ability to adapt to their new situation. Walter (2005) argues that as grief can be chaotic and undisciplined, creating ‘dis-order’, then the attempts to create order are challenging.

Complications following bereavement are not confined to complicated grief. Prigerson (2004) stresses the importance of recognising other psychiatric disorders such as depression or Post Traumatic Stress Disorder (PTSD), which may manifest themselves in the grieving person but are not complicated grief. In her early work, Prigerson et al (1995) conducted longitudinal empirical research to identify differentiations between complicated grief and other syndromes such as anxiety and depression. They argued that complicated grief is a unique disorder, which in turn would require specialised treatment. They concluded that those suffering complicated grief may not have been suffering depression or anxiety. Rather, they were struggling with attachment disorders and making meaning out of their mourning (Stroebe et al, 2000; Neimeyer, Klass& Dennis 2014). Prigerson also
suggests that unlike other behaviours that may suggest delayed grieving patterns, complicated grief is relentless in intensity, with no delayed onset. People experiencing complicated grief are typically stuck in their mourning, unable to concentrate, often feeling disconnected with even their closest family members and friends, resulting in feelings of isolation, self-pity and a sense of being totally stuck.

A number of researchers have identified specific symptoms that can help diagnose complicated grief (Doka 2002; Lichtenthal, Cruess & Prigerson 2004; Prigerson, 2004; Walter 2005; Stroebe & Schut 2006). These symptoms include chronic and persistent longing and heartache as a key element, with four of the following eight symptoms occurring daily: trouble accepting the death; inability to trust others; excessive bitterness or anger related to the death; uneasy about moving on; numbness, detachment; feeling that life is empty nor meaningless; feeling that the future is bleak and feeling constantly agitated (Prigerson 2004).

Working through the many manifestations of complicated grief, there is recognition of the combined social and psychological support requirements for the bereaved. A number of researchers argued the case for a revision of the DSM-IV categorisation to separate normal grief and complicated grief (Lichtenthal et al 2004; Horowitz, Bonanno and Holen 1993). Advantages and disadvantages to citing complicated grief include the potential limitations of pathologising the phenomena, the risk of pathologising what is otherwise a normal trajectory of grief, cultural differences and responses to bereavement, classifying complicated grief as a mental disorder, and finally, concern regarding continued refinement and understanding of the phenomena once it has become standardised (Lichtenthal et al 2004). However, to counter those concerns, advantages considered included prevention of related psychological and physical health problems, early intervention into suicidal ideation and minimising the risk of reduced physical health and mortality. The DSM-V did not identify complicated grief as a separate category (http://dsm.psychiatryonline.org/book.aspx?bookid=556).

Walter (2005) identifies the multi-faceted and multi-dimensional phenomena of complicated grief. He describes complicated grief within a social constructionist framework, offering possible ways to understand the condition but suggesting that there is no precise answer; Walter acknowledges the psycho-pathology experience of each bereaved individual as described by Prigerson (2004) and Prigerson et al (2005) in which
impaired performance in the daily lives of the bereaved is evident as a result of the internal dis-ease, often exacerbated by lack of social support. His second premise links with the historical context of psychiatric disorders, in which Western psychology attempts to normalise and pathologise. This leads to his third suggestion that health professionals require a diagnosis in order to access resources.

Moving away from the diagnostic, pathological approach, Walter acknowledges the social and cultural aspect of complicated grief, recognising the challenges within cultures to mourn in a certain way, and within a set time frame. If the individual does not or cannot meet these ‘norms’, complicated grief may become evident. This can be further complicated when confusion reigns within individual families in regard to their different grieving styles, often creating behaviour which attempts to bring the mourner into a ‘normal’ pattern of mourning, creating a further sense of isolation.

Some researchers suggest that if a person experiences stigmatisation, their bereavement experiences may be significantly complicated (Feigelman, Gorman, Jordan 2009). Stigmatisation can be subtle or overt, ranging from direct negative social behaviours to people avoiding talking about the deceased. They also suggest that in Western society, the absence of social norms in terms of how to relate to someone bereaved by a sudden unexpected death may contribute to people experiencing stigmatised behaviours.

Complicated grief encompasses larger societal and global influences, often challenged by society, which has a need to label and order behaviours and struggles with the disorderly outcomes. Social constructionist model in that many members of society, researchers, clinicians, doctors, organisations, family members and the wider culture all have an interest and need for interpretation of this disordered mourning. Complicated grief is at the very least, multi-faceted in nature, affected by the social construct in which the mourner lives (Walter 2005). Consistent with this thinking, continued debate will occur regarding two key elements of grief and mourning; the debate between the scientific and social construct of complicated grief, and the tension between combining mourning and meaning (Neimeyer 2005).
2.8 Bereaved parents' symptoms of grief following sudden death

Families often report common symptoms and behaviours when experiencing unresolved grief (Hannah’s Foundation 2009). Hensley and Rogers reported a 12% increase in the rate of depression for bereaved parents over the general population and Rogers identified a PTSD rate three times higher than the general population (Hensley 2006; Rogers 2008). The following symptoms were reported by many of Hannah’s Foundation members following the loss of their child to a fatal immersion: depression, family dysfunction, post-traumatic stress disorder (PTSD), complicated grief, anxiety, financial burden, isolation/ostracised, social fatigue, cognitive disturbances, somatic disturbances, psychosocial issues, development of phobias such as fear of water, agoraphobia etc., reduced quality of life and significant negative effects on family and extended family and friends (Hannah’s Foundation 2009).

The symptoms and behaviours of unresolved grief reported by Lindeman, Freeman and Worden were similar to those identified by Hannah’s Foundation (Lindemann 1944; Freeman 2005; Worden 2005). While many of the symptoms identified can be considered ordinary during the acute early phase of grief, they were considered major signs of unresolved/complicated grief if they remained for unusually prolonged periods of time. Similarly, Buckley et al. reported increased levels of heart rate in early bereavement and altered autonomic functioning which, if left untreated or unrecognised, had the potential to trigger greater levels of psychological symptoms such as depression and anger. Buckley’s study also concluded that if the person had an existing heart condition, this increased heart rate significantly increases the risk of a new coronary event (Buckley et al. 2012).

Freeman further explored the impact of grief-related symptoms and reported that the more symptoms an individual exhibits, the more likely they are to experience unresolved grief (Freeman 2005; Worden 2005). Some of these symptoms are listed below.

<table>
<thead>
<tr>
<th>Over-activity without a sense of purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquisition of symptoms belonging to the last illness of the deceased</td>
</tr>
<tr>
<td>Alteration in relationships with friends and relatives</td>
</tr>
<tr>
<td>Somatic symptoms representing identification with the deceased, often</td>
</tr>
</tbody>
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4Hannah’s Foundation is a national charity, born from the tragic drowning death of the families’ little girl in their backyard pool. Hannah’s Foundation supports and advocates for families who have experienced a water tragedy, and promotes water safety education to reduce drowning tragedies across Australia.
<table>
<thead>
<tr>
<th>Symptoms of the Terminal Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agitated depression with tension, insomnia, feelings of worthlessness, self-accusation, obvious need for punishment and even suicidal tendencies</td>
</tr>
<tr>
<td>Furious hostility towards someone connected to the death</td>
</tr>
<tr>
<td>Acts detrimental to one’s social and economic existence (e.g. giving away belongings or making unsound economic decisions)</td>
</tr>
<tr>
<td>Unaccountable sadness during various times of the year</td>
</tr>
<tr>
<td>Self-destructive themes</td>
</tr>
<tr>
<td>Phobias about illness or death</td>
</tr>
<tr>
<td>Over-identification with the deceased leading to compulsion to imitate the dead person</td>
</tr>
<tr>
<td>A depressive syndrome to varying degrees of severity</td>
</tr>
<tr>
<td>Symptoms of guilt and self-reproach, panic attacks and somatic symptoms</td>
</tr>
<tr>
<td>Lasting loss of patterns of social interaction</td>
</tr>
<tr>
<td>A feeling that the death has occurred yesterday even though the loss took place a long while back</td>
</tr>
<tr>
<td>Inability to discuss the deceased without crying</td>
</tr>
<tr>
<td>Inability to speak of the deceased without experiencing intense grief emotions</td>
</tr>
<tr>
<td>Unwillingness to move the possessions of the deceased even after a reasonable amount of time has passed</td>
</tr>
<tr>
<td>A history of delayed or prolonged grief</td>
</tr>
<tr>
<td>Changes in current relationships following death</td>
</tr>
<tr>
<td>Radical changes in lifestyle</td>
</tr>
<tr>
<td>A relatively minor event triggering a major grief reaction.</td>
</tr>
<tr>
<td>Exclusion of friends, family members or activities associated with the deceased.</td>
</tr>
</tbody>
</table>

Whilst a grieving person may experience some or all of these grief symptoms to varying degrees, the potential for them to become prolonged and lead toward complicated or unresolved grief is linked to their internal view of the world and the perceived or actual reactions of others. Therefore, in order to attempt to understand an individual’s ability to cope with their grief, an appreciation of the bereaves’ personal construction of the world around them, often constructed by their internal sense of self as well as the reactions from their immediate and broader society, is pivotal to offering appropriate support.
2.9 Predictors for coping with grief

There is recognition that individuals cope differently with loss and grief (Bonanno, Kaltman 2001; Miller 2003; Dyregov, Dyregov 2008). Some people grieve openly and deeply for years and only slowly return to a semblance of their normal functioning; some appear to suffer intensely but within a shorter time period whilst others appear to get over their losses almost immediately (Bonanno, Kaltman 2001). Those in the latter group often cause concern amongst their friends and relatives as to whether they may be hiding something or running away from their pain (Bonanno, Kaltman 2001).

Social support has been examined as a predictor of coping with grief, particularly in relation to partner support. Thomas and Striegel identified marital cohesion, adaptability, communication satisfaction and partner support as useful predictors for coping with infant death (Thomas, Striegel 1994–1995; Benkel, Wijk, Molander 2009). Other researchers identified the relevance of support outside of the family as significant to coping ability (Nordanger, Dyregov, Dyregov 2000; Ogrodniczuk, Joyce, Piper 2003; Dyregov 2005/2006; Steiner 2006). A systematic review of predictors of complicated grief concluded that the incomplete knowledge in this area results in interventions by health professionals and service providers that are based on anecdotal experiences and trial-and-error approach (Lobb et al. 2010). As yet, there do not appear to be studies that look at the reverse; i.e. identify the overt lack of support and perceived stigmatisation on the coping ability of the bereaved.

2.10 Coping with paediatric drowning death; a paucity of literature

The death of a child is recognised as one of the most devastating tragedies (Murphy et al. 2003; Hynson et al. 2006). It has been suggested that recovery may never be possible for the grieving parents and that the child’s death causes a significant challenge to the parents’ identity, sense of self and sense of purpose (Davis et al. 2000; Song et al. 2010). Studies on the personal impact and grief of other causes of sudden death may offer some insight into the impact of a drowning death (Bonanno, Kaltman 2006; Hensley 2006, Walsh 2007). However, there is a paucity of literature in relation to the impact of a fatal drowning on parents and other family members. The potential stigma attached to this type of death can further complicate the grief process. Whilst researchers have not directly compared fatal drowning with SIDS, a study of eight families in which the sudden death of an infant occurred concluded that families experienced significant stress including fear for their other children’s safety, marital conflict and parenting challenges (Woodward et al. 1985).
Parents of children who committed suicide often feel ostracised by friends, family and the community, blaming themselves for not recognising their child’s pain and intent to suicide (Feigelman 2009). There are similarities between SIDS, suicide and fatal immersion. These include the death being sudden, unexpected and often leaving the parent asking why, with feelings of guilt and bewilderment and often hostility from neighbours and family and community members who may question the parents’ activities or parenting skills at the time of the child’s death (Feigelman, Gorman, Jordan 2009). This experience often translates into both felt and enacted stigma (Goffman 1963), the parent feeling stigmatised both within themselves (felt) and by others (enacted).

The death of a child impacts beyond the nuclear family, affecting the grandparents, other family members as well as friends, workplaces and community members (Riches 2000, Davies 2004). For example, Maple illustrated how as many as six people in a workplace are adversely affected by the death of a co-worker’s child (Maple et al. 2007). This extensive effect throughout the community may make it difficult to talk to those close to the bereaved parents, particularly as everyone grieves differently and there is a lack of community and workplace awareness of the impact of complicated grief (Hensley 2006; Rogers 2008).

**Conclusion**

This chapter highlights the epidemiology of drowning, prevention strategies and the catastrophic effect such an event has on the family. The unintentional death of a child can cause complicated or unresolved grief in that the bereaved becomes stuck and cannot move forward. This complicated or disenfranchised grief dominates the life of the bereaved and confuses the natural grieving process. Various physical, emotional and physical symptoms can occur and require appropriate support in order to help the bereaved navigate this difficult time. Professional support varies according to the training received by the health professional and there can be a propensity toward viewing grief as a linear function, isolated within a pathology rather than viewing it as a psycho-social phenomena, affected by both pathological responses and social interactions. It is not surprising; therefore, that support for persons stuck in complicated grief is often compromised due to lack of understanding of the nature of grief itself, the resultant stigmatisation and the tendency to pathologies rather than view the complicated grief as a holistic phenomenon, requiring psychological as well as social support.
The second chapter in this literature review examines some of the challenges bereaved families face following their child’s fatal drowning and identifies some of the issues in providing and receiving support.
Chapter Three – The effects of grief on relationships and the availability and use of community and professional support: literature review (Part B)

Introduction
The previous chapter offered an overview of grief as a concept, how the understanding of grief has progressed and examined the various concepts of grief as a natural, pathological and social phenomena and how society affects an individual’s ability to manage their grief. It also addressed the circumstances in which a person could become stuck in their grief and how this could lead to complicated or prolonged grief without adequate support.

This chapter builds on the previous chapter, and examines some of the literature which contributes to these different grieving patterns such as the experiences people have with professional services, experiences and interactions within their social circles and inherent gender differences in coping with grief. All these experiences form a unique pattern for each individual, which in turn, affects their continued relationships with themselves as well as the people in their world. The way in which a person experiences their own reality and is affected by internal and external influences helps shape their journey through grief and their ability to adapt to their new reality. In addition to other reasons for differing grief journeys, gender appears to be significant. Men and women experience the death of their child differently and, as a consequence, their expressions of grief also differ (Lang, Gottlieb 1993; Wijngaards-de Meij 2005; Dyregov, Dyregov 2008, Doka 2011). These differing expressions can have a significant impact on significant partner relationships and therefore in order to provide appropriate support for bereaved parents, it is necessary to appreciate some critical differences in the way in which men and women may approach their grief. Health professionals need to be aware of these differences in supporting the bereaved. Whilst it is important not to focus on generalisations, some common themes are evident.

3.1 Gender differences in seeking support after the death of a child.
There are acknowledged gender differences in experiences of grief (Littlewood et al. 1991). Men tend to become immersed in outside activities, converse less and often use alcohol or drugs as a way of managing their grief. Women on the other hand, find greater solace in talking and having social and professionally supportive networks to share and express their grief (Littlewood et al. 1991). The significant difference are due to communication styles; as men pull away and often become more immersed in ‘the doing’,
women need more closeness and conversation, often resulting in greater confusion and distance between couples (Wijngaards-de Meij 2005).

Song et al (2010) researched marital quality following bereavement, and suggested that variables other than genetics may contribute to gender differences toward grief. They proposed that as the mother tends to be more actively involved in parenting than the father, a mother may appear to grieve more intensely and have more negative response to the death. To complicate this further, gender differences may also contribute, with the father withdrawing and appearing to be unsupportive to his spouse and a third factor links to the type of child death. A violent or sudden death causes greater complications and is likely to result in prolonged, complicated grief (Song et al 2010).

Doka and Martin (2010) support this more multi-faceted approach to gender differences, They proffer a modern framework) which suggests that grieving differences may be more influenced by factors such as personality, culture and socialisation experiences than the more traditional view of predominantly gender (Doka, Martin 2010, Niemeier 2011). They describe two primary grieving patterns; intuitive which has a more female orientation, and instrumental, which is more representative of the male approach to grief. Whilst these two patterns are mirrored by other researchers in that women tend to express their grief through emotion and men through strategic and focussed activity, they suggest that the affective, more feminine style is often perceived as more acceptable and that instrumental grievers may be seen as unfeeling and uncaring. These factors are then combined with other moderators such as personality and culture. In this way, men and women’s grief can be better understood and not viewed in a judgemental fashion; rather the health professional and support people need to understand that the combination of these three factors, i.e. gender, personality and culture will influence the individual’s ability to show their grief.

Studies have attempted to identify the support sought by mothers and fathers following the death of their infant child. These studies identified that women tend to lean toward an emotional support model, using friends, family and other networks to support their grief management (Nordanger, Dyregov, Dyregov 2000; Anderson et al. 2005; Doka & Martin 2011). Men, on the other hand, seek emotional, decision making and concrete support, often sourced from health professionals or a renewed social network (Aho et al. 2009). Issues which can affect men’s ability to cope with their grief include their tendency to
become busier and absorbed in outside activities and/or work and not discuss their grief as readily as their female counterparts (Fish 1986; Smith, Borgers 1988–1989; Bohannon 1990–1991; Lang, Gottlieb 1993; Schwab 1996; Murray, Terry 1999; Song et al 2010) Communication may be a key variable, with men placing a lower value on communication than women (Kamm, Vandenberg 2001). This may result in the woman believing that the man does not care as much because he will not share his grief. Men also have a tendency to take substances such as alcohol, drugs and cigarettes as a means of managing their grief. However, it appeared that these avoidance factors were reduced in relation to the perceived relationship that the man had with his partner. Low levels of marital quality appeared to be directly associated with male avoidance behaviour (Wijngaards-de Meij 2005). In the case of sudden child death, where spousal support appears to be critical, this discordance can prolong the complicated grief journey (Song et al 2010).

Doka and Martin (2011) present an interesting paradigm which has been utilised in contemporary understandings of grief and illustrate how society and one’s role in society can affect how one grieves. They suggest that there are two primary patterns of grieving, the intuitive style which suggests that a grieving person may be able to express their grief emotionally but that in turn, inhibits their daily functioning; and the instrumental griever who grieves through activity and strategies, often neglecting their affective needs (Niemeier 2011). The intuitive style reflects a more feminine approach, the intuitive, a more masculine approach. Doka & Martin go on to suggest that men and women can exhibit either or both of these mourning styles, in particular as women have higher level jobs, they may be more intuitive in their mourning style. Appreciating the variables that influence an individual’s mourning style is central to being able to provide appropriate, non judgemental support. It is the response of others that can influence how one navigates through this dark tunnel of grief.

Whatever the grieving style, grief is a personal journey and that it exists within a continuum. Grief patterns are different for each individual and must be seen as permitted, and not deficient. This permission is intrinsically linked within the individual’s social framework and how they and those around them choose to construct and react to the situation (Doka and Martin 2011).
3.2 Grief and partner relationships

Whilst it is acknowledged that there are various approaches to grief support, and that individuals have different coping methods for their loss based on a range of variables, the end result is still a significant effect (positive or negative) on the individual and families as they experience the grief of their loved one (Nixon, Pearn 1977; Martinson 1994; Schwab 1998).

Song (2010) reviewed the literature and found that marital and individual functioning is affected by the circumstances surrounding the child's death. The impact appears to be greater if the child died suddenly or violently, (Dyregrov et al. 2003; Keesee, Currier, and Neimeyer 2008).

Limited research has examined the long-term marital relationship in the wake of a child's death and to understand the lived experience of effect on married couples (Dewees 2005). One longitudinal study covering a 20 month period after the child died found three 'levels of grief intensity. Those whose child had died that parents whose children died by traumatic death (accidents and suicide) reported the most complicated grief, parents whose children died as a result of illness experienced less intense grief, and bereaved parents whose children died in infancy had the lowest degree of grief (Wijngaards-de Meij et al 2005). The management of this complicated grief can have a significant effect on marital relationships.

Dewees conducted a qualitative phenomenological investigation of married couples that experienced the death of a child under 18 years of age and examined coping strategies of bereaved parents and the effects a child's death has on the marital relationship (Dewees 2005). Her study comprised in-depth interviews with seven married couples who had lost children within the past three years. Eleven major themes emerged that were common to the study participants: (1) commitment to the marriage, (2) respect for individual grieving patterns, (3) faith in God or a higher power, (4) creating a memorial, (5) mutual/community impact of the child's life/death, (6) need to parent surviving children, having subsequent children, and effects on other children within the family, (7) outside support, (8) paradoxical disconnections and expectations from others, (9) questioning, (10) guilt and blame, and (11) acceptance. This research sought to understand the needs and complications of bereaved parents, and in recognising these potential experiences it was hoped that counsellors better assist bereaved couples.
Two limitations in the Dewees (2005) study suggest an opportunity for further research. Dewees did not investigate the relevance of the circumstances surrounding the child’s death; hence the question of guilt and potential stigma was not considered in the context similar to a young child’s fatal drowning in which a degree of parental supervision is expected. There is still a paucity of literature regarding the range of relevant support available to meet the complications of this stigmatised grief. The other key factor is the time frame: the impact of child death is so great that the time to 'heal' is longer than any other type of grief (Bugen 1977; Nixon, Pearn 1977; Lehman, Ellard, Williams 1987). As such, it would be interesting to see if these 11 categories changed over time in both presence and impact.

Nixon and Pearn (Nixon, Pearn 1977) identified the incidence of marital strain and separation in their study of 111 childhood immersions or near immersions but there was no long-term follow up. The authors recognised that the potential guilt as a result of a child’s death from a home unintentional injury can add additional layers of burden and blame which may cause greater difficulty within the relationship than a non-injury-related death. This was the first (and possibly the only study) to acknowledge the different intensity and length of grief following a child drowning compared to other types of child death. Further research is required to ascertain the impact of a fatal child drowning and extent of grief and support needs for families, whilst acknowledging that support needs differ based on circumstances of a range of variables.

The experience of marital strain following a sudden child death has been examined by a number of authors, offering various insights into the effect of child death and partner relationships (Murray-Parkes 1980; Martinson1994; Schwab 1998; Kamm 2001); Schwab et al. (1998) conducted a literature review to investigate the effects of a child’s death on marriage and concluded that there is no evidence that bereaved parents are likely to divorce as a result of a child’s death and found that the majority of marital relationships survived the strain brought about by a child’s death and may even be strengthened in the long run. A number of factors may impact on the relationship outcome such as the combination of circumstances surrounding the unintentional death and/or problems, which may have been existent prior to the child’s death. Martinson reported that where divorce or separation did occur, less than half the bereaved couples felt that the child’s death
contributed to the divorce (Martinson 1994). However, this result needs to be considered with caution as the ability to determine contributing factors can be masked over time as well as emotional/mental wellbeing at the time of reporting. Another cautionary note is linking the ‘marital strain’ with divorce. Marital strain is common following a child death, especially as men and women grieve differently. This does not suggest, however, that the strain results in divorce; rather it may indicate the communication challenges experienced between couples and that time may be a natural healer in this situation.

Schwab recognised that grief often intensified in the second and third year after the death of the child and therefore the varying ways in which individuals handle their grief could have a profound effect on their relationship (Schwab 1998). He raised the relevance of timing of professional interventions and identified that parents who had experienced a sudden child death reported mental distress and trauma two to three times higher than the normal population some five years after the death. This suggests that for research on the impact of child death and relationships to be of value, perhaps a longitudinal study of at least five years would be useful. This is supported by a study in the USA which examined parents’ mental distress, the presence of PTSD, acceptance of the child’s death, marital strain and the time it took to accommodate to the death of their child (Murphy 2003). Results indicated that for every parent, change over time was significant, with improvement in accommodation of their child’s death happening, but not until three years after the death. Pervasive symptoms of negative aetiology were present in all parents. Marriages were stable; however, a limitation of the study was that parents had an average of 18 years marriage duration and therefore may have had a strong basis to their relationship before their tragedy. There is a need to further explore the impact on sudden child death in relationships of shorter duration prior to the child’s death, as well as the impact of various supports at different time stages of their grief. A longitudinal study comparing the divorce/separation rates of parents who have experienced their child’s sudden unintentional death compared to a child who had been in palliative care and their required and received supports would inform and enhance the current literature.

In identifying the confusion between marital distress, separation and divorce, Schwab emphasised the importance for professionals to not assume the path of divorce as ‘the norm’ and to exclude any preconceived notions of how the relationships ‘should’ or are
likely to result (Schwab 1998). The likelihood of the relationship becoming stronger or weaker appeared to be more determined by the status of the relationship prior to the death than the death itself. That is, strong relationships became stronger and weaker relationships were unable to withstand the pressure of the bereavement. Further research is needed to identify if this varies according to the circumstances of the death.

3.3 Grief intervention for parents of deceased children

Doka (2002) defines disenfranchised grief as grief that is not openly acknowledged, socially accepted or validated or publicly mourned. Provision of support is an essential element of the bereaved person’s healing journey, yet there is confusion amongst health professionals and the community about providing appropriate grief support. Different opinions regarding the concept of grief itself, the different predictors and factors that may influence grief management are complex and unique to the individual, creating challenges for those providing support. Grief may become more complicated depending upon the circumstances surrounding the death, including the child’s age, the place where the drowning occurred, who was responsible for the child at the time of the event and the support responses from family, friends and the community (Freeman 2005).

Researchers have suggested that medical social workers, hospital paediatricians, general practitioners and parents’ self-help groups are in key positions to help the bereaved (Schwab 1998). Schwab identified a critical factor being the training and confidence that the supporter had regarding understanding the processes of bereavement, the stages of loss and grief and the uniqueness of each bereaved individual to manage their grief. Schwab concluded that support should be offered to all parents who have experienced a sudden infant/child death. The work of a support person is stressful, so it is also important that the person facilitating the task has the appropriate training and personality type to handle the challenge as well as ensuring supervision is available to the support worker (Watson 1981).

Appropriate bereavement intervention and timely support may help minimise/mitigate the development of the physical and emotional conditions linked to the sudden death of a child (Walsh, Curry 2008; Wender 2012). Colville and Pearce (2012) conducted a longitudinal study with parents whose children had been in paediatric intensive care. Whilst these
children did not die, over half the families experienced post-traumatic stress 12 months after returning home, and families whose children were admitted due to sudden illness or unintentional injury had higher levels of anxiety and post-traumatic stress (Balluffi 2004; Colville, Pierce 2012). The authors suggested these results had implications for long-term follow up and support for these families. This research did not include fatalities or drowning events. Repeating this study for fatal drowning would offer guidance to the impact of a child’s drowning death and the need for timely and appropriate follow-up to minimise delay in emotional and mental adjustment.

One of the challenges facing interventionists is identifying what combination of supports are appropriate and creating opportunities for access to support at times when parents can best benefit from the interventions. Given that there is confusion over three key issues – understanding of grief as a phenomena, the impact of a sudden child death and predictors of complicated grief – providing timely and appropriate support and interventions is a challenge for the professional and lay community.

Support provided for bereaved parents may include hospital support; social worker support for counselling as well as referral pathways; GP (medical and counselling); psychotherapy, psychiatric intervention, psychology and counselling; support groups; online support; and non-professional support of community including schools, religious associations, family and friends. Whatever combination of supports are accessed by bereaved parents, main elements of support need to include the provision of hope, reassurance, strategies to adapt to the changed reality and ongoing support over time (Diamond et al. 2012).

3.4 Emergency services and hospital staff
3.4.1 Support needs
Support from the hospital and other medical and bereavement services has been discussed in the literature (Davies 2004; Contro, Sourkes 2012; Wender 2012) but suggests little regarding optimum support and effective timing of support. There is also little information regarding what support parents actually have experienced after their child’s unexpected death and what parents say they needed.

One retrospective study in Vancouver aimed to evaluate parents’ perceptions of support received after the death of a child up to five years old (Segal, Fletcher, Meekison 1986). Families were contacted with the help of health care professionals and the news media. A
standardised questionnaire was used in a personal interview or occasionally by mail. The contact with health care professionals after the child’s death was frequently considered by the 61 families not to have been helpful: Eighty percent of the families judged the information or counselling they had received to be inadequate, and over 50% had received none; many listed comments and behaviour that they considered harmful. The families desired both full medical information and grief support, which they reported not having adequately received.

3.4.2. Support from medical staff

In the past decade it has been recognised that paediatricians are in the best position to provide timely and affective bereavement support but this service is often not given (Cook, White, Ross-Russell 2002; Meert et al. 2011). Bereaved parents whose children died either from a chronic condition or as a result of a sudden unexpected death were interviewed in a number of studies (Cook, White, Ross-Russell 2002; Meert et al. 2007; Van der Klink et al. 2010). They reported wanting to meet with the physician who treated their child in order to gain emotional support and clarity of medical information about the death. In a study from the Netherlands (Van der Klink 2010), 35% of the 52 bereaved family members interviewed who had experienced the death of an adult relative in the intensive care unit reported a need for a follow-up service after they had left the hospital to discuss their emotional needs and medical understandings of the death. In some cases, the opportunity to thank the relevant staff was considered to be important. These meetings were considered important to both ameliorate the physical and emotional reactions to unresolved grief and to provide adequate information to help the family cope with their loss (Van der Klink et al. 2010). However, Meert et al. reported that these meetings were rare with 33% (23) of physicians in their study reporting never having had a scheduled meeting with parents. More experienced physicians were more likely to schedule parent meetings either at the hospital or within three months of the child’s death (Meert et al. 2007). Similar findings were found in a British study of families of 51 children who died suddenly or unexpectedly in a paediatric intensive care unit (Cook, White, Ross-Russell 2002). The authors reported that post-death meetings happened in an adhoc way, dependent on a number of issues such as paediatricians training in communication and ability to talk to the families following the death. Meert reported barriers to physicians implementing meetings in clinical practice such as scheduling, willingness of the physician and family, language and cultural issues, parent anger, lack of paediatricians’ training in dealing with such meetings, and transportation. Cook et al. suggested changes to medical training to better
equip doctors with these bereavement conversations as well as gaining a better understanding of grief and its management (Cook, White, Ross-Russell 2002). They also suggested five key elements to be included in follow-up meetings with the parents. Meert suggested that nurses were also pivotal to parents post-support and would be beneficial to include in the meetings. She reported a large variation in physicians’ attendance at such meetings and that 18% had never participated in follow-up meetings.

These studies were not conducted in Australia, and apart from Cook, White, Ross-Russell (2002) (who acknowledged the limitations of this study, with the youngest deceased child of the participants being three years of age), they did not interview parents who had experienced a sudden or unintentional injury-related infant death. There would be benefit in replicating the research within the Australian context, exploring a range of causes of death.

3.4.3 Support from other hospital staff

Acts of kindness and bereavement support both in the hospital and during the bereavement period were considered helpful to the parents’ adjustment to life after their child’s death (Macdonald et al. 2005). Macdonald undertook a qualitative research study with 12 parents whose children had died in the intensive care of a tertiary care paediatric hospital. She concluded that receiving sensitive acts of kindness from all the hospital community including parking attendants, cleaning staff and medical staff, as well as follow-up support such as sending cards and attending memorial services, were well received by the parents. Parents reported experiencing a lack of support as disappointing. One recommendation from the study included allocating a specific contact person at the hospital to coordinate these tasks and reported that parents were better able to revisit the hospital after their child’s death if they had received this positive support. In a study by Gordon (2013), social workers were seen as significant coordinators following palliative care and subsequent death of a loved one (Gordon 2013). Whilst this study did not relate to sudden paediatric death, further research into the critical contact person for grieving parents whose child died in the ED may help identify the appropriate staff position to coordinate these processes.

Limitations of Macdonald’s study in relation to this research were threefold. Firstly, parents were recruited from the paediatric intensive care unit (PICU) so were already linked into the hospital community and support. It would be useful to conduct similar research for
parents who had only been through the Emergency Department and whose child had died from an unintentional injury. Secondly, the authors did not state what length of ‘bereavement period’ was considered as part of the follow-up. Thirdly, the study was based in the USA and therefore may not be applicable in an Australian setting.

Woodward et al. support the importance of hospital staff bereavement support for parents experiencing a SIDS death (Woodward et al. 1985). They identified that hospital staff provided help at various stages of the families’ grief, including social workers to help with the initial arrangements such as the funeral, conversations with the paediatrician, home visit from a health worker and some longer term counselling. The authors concluded that positive support should be offered to all families with babies who have died suddenly, coordinated by the health or social worker. They commented that the success of this support is largely dependent on the relationship established with the health worker.

One Swedish study investigated whether or not parents can ever come to terms with the loss of a child and whether professional or social support facilitates the long-term grief process (Kreicbergs et al. 2007). Anonymous, mail-in questionnaires were sent to parents who had lost a child to a malignancy four to nine years earlier. Overall, most parents (74%) stated that they had worked through their grief “a lot” or “completely” at the time of the follow-up. Parents who had shared their problems with others during the child’s illness and who had access to psychological support during the last month of their child’s life were more likely to have worked through their grief than parents who had not shared their problems. In cases where health care staff in the hospital offered parents counselling during the child’s last month, the parents were more likely to have worked through their grief. The researchers concluded that most parents eventually work through the grief associated with losing a child to cancer. In the long term, sharing the emotional burden with others facilitates the grieving process.

The challenge of generalising from this study is that it reflects experiences of parents with an expected death that may be quite different to an unexpected death. Further research into parents’ experiences following an unexpected death will help inform health professionals and offer guidance in how best to support the bereaved parent. Health professionals may have an expectation that grieving a sudden child death is similar to an expected death where palliative care has been available. This reflects the need for improved training in specific types of death and potential grieving patterns.
The attitude and shared information from the hospital doctor has a critical role to play in the grief experience. “A sympathetic, informed doctor is an important step for many parents to come to terms with their loss” (Woodward et al. 1985:365). Specialised bereavement training in bereavement for all hospital staff involved in the child’s death would increase the opportunity to provide optimum support to the grieving family.

Providing support is linked with building trusting relationships. Building trust between the family and the medical and hospital staff involves open and honest communication. This may create the potential for emotional risk for the clinician as this communication may include them engaging in personal disclosure, yet appears to offer significant support and connection for the family (Truog et al. 2006). Truog’s USA study recommended guidelines for responding to families with life-threatening injury which included follow-up phone calls to assess the parent’s grief status provide information about the grief process and recommend community support resources. No such study has been reported in Australia.

3.4.4 Outreach hospital programs

While the specifics of the suggestions above have not been emulated in Australian research, two Australian studies have investigated the establishment of a bereavement program in the Emergency Departments of two major teaching hospitals in Melbourne (LeBrocq et al. 2003) and an audit of bereavement programs in adult intensive care units (Valks et al. 2005). The bereavement program was developed as a direct result of concerns by staff in dealing effectively with bereaved families and in recognition of the effect of their interaction on the grieving process for families. The program was intended to support both staff and families. Whilst the program identified some key concerns and improvements for staff including the need for further grief and bereavement support education, it demonstrated results in increased awareness of client needs, increased coping ideas, and improved staff support and job satisfaction. However, the response rate from families was only 11% and may not have represented families as a whole. It is possible that those who did respond had been searching for an outlet to express their appreciation of the support they received, a statement often made by bereaved families. The comments reflected the value of care and attention and the appreciation of a condolence letter. There is no suggestion in the study report regarding expansion into other hospitals or specific needs of certain types of death.
The second study involved a mailed survey to senior intensive care nurses and results identified the majority of units surveyed had adopted some elements of bereavement programs, albeit only minor components (Valks et al. 2005). These included a follow-up phone call, a sympathy card, attendance at funerals and referrals to counselling and community support services although these were offered by less than one-third of the participants. Little evaluation of bereavement services had been undertaken. Current literature clearly indicates the importance of bereavement support by the hospitals and further studies are required to establish what is needed and how these programs can be delivered. A limitation of this study is that it was conducted amongst adult units. It is reasonable to assume that similar needs would be experienced for children’s hospitals, and possibly more extensive support given the complexities of grief following a sudden child death.

In contrast to the limited published research on support following a fatal child drowning, ‘end of life’ care has been well documented although most studies are from the United States and address death in the PICU rather than the Emergency Department (Copnell 2005). Knazik et al. did report on the ideal processes and follow-up procedures in America following the death of a child in the Emergency Department and included reference to pathological grief as a significant factor in a sudden child death. He, like researchers before and since, acknowledged that post-death bereavement pathways need to be developed and implemented in order to support families (Knazik et al. 2003). A Belgium study exploring the perceptions and needs of families confronted with sudden unexpected death recommended that hospitals provide the opportunity for a bereaved relative to have ‘conversations at home’, particularly in the case of a sudden death which often manifests increased psychological problems (Merlevede et al. 2004). Participants reported great value in having their questions answered by the medical and nursing staff but were often too shocked to ask the questions at the time of the event.

Along similar lines, one study in an Irish hospital suggested a model for bereavement support (the Beaumont model), which included an outreach/follow-up support service either in person or via various forms of communication if the family is unable to geographically access the service (Walsh, Foreman, Curry 2008). The main implication of this study is the finding that twice as many parents were likely to access the service if their child’s death had been unexpected and sudden.
After leaving the hospital, the GP is often the first person bereaved people go to for advice and support. If they are experiencing negative physical or emotional symptoms, there is an expectation that the GP would either be able to offer the support needed directly or have access to various referral pathways (DeCinque et al. 2004).

3.4.5 The role of the GP

Adverse emotional and physical reactions are typical following a sudden child death. As a result, people often go to their GP as the initial contact (Wiles et al. 2002; O’Connor, Breen 2014). The death of a child is associated with increased mortality in mothers and affects fathers similarly if the death was from unnatural causes (Jiong et al. 2003). Short-term reactions are more prevalent for those having experienced an unnatural death of a relation, and long-term pathophysiological changes could increase susceptibility to diseases such as cancer and heart disease. Studies indicate that women are more prone to these increased health problems than fathers, and, again, that an unnatural death increases these risk factors (Jionget al. 2003).

Whilst most GP’s recognise that bereavement support is an integral part of their role both to support the bereaved and to refer them for additional support (O’Connor, Breen 2014), “bereavement care is a vital area which is often neglected in both health promotion and medical education” (Woodward, et al. 1985;Charlton, Dolman 1995: 429). Whilst the GP is the logical choice for health and emotional support, there is evidence to suggest that GPs may not have the skills to support people during their bereavement (Saunderson, Risdale 1999; O’Connor and Breen 2014). Carlton suggests a standardised bereavement protocol, which includes informing the bereaved person’s GP of their loss. GPs need to be aware of a person’s bereavement so they can raise the subject as part of a routine consultation, hence offering the opportunity for the patient to discuss their concerns (Main 2000). Main (2000) suggested that GPs should offer a message of sympathy at the very least and be available to explain any outstanding questions that may present concerns or lack of closure for the bereaved. However, she identified studies in the UK which indicated many GPs do not have the skills to support their bereaved patients and often refer out to services such as counsellors, psychologists, psychiatrists or support groups (if known) (Main 2000; O’Connor and Breen 2014).

O’Connor and Breen (2014) conducted a qualitative, social constructionist study in Western Australia with 19 GP’s to explore GP’s understanding of bereavement support
and their professional development needs. They concluded that there were four key issues, which caused tension in understanding and offering support needs. These were the differing views regarding grief as a standardised, linear process compared to a unique individualised process; the confusion between intervening versus promoting resilience and the tools to cope within a social construct rather than professional support; tension between offering bereavement support themselves or acting as a ‘broker’ to refer patients to specialised services; and fourthly, the lack of formal training available to GP’s and the different views in regard to the need for professional training as opposed to ‘on the job’ training’. O’Connor and Breen concluded that there was a distinct lack of knowledge regarding current theories on grief and bereavement and therefore, patient support needs, including referral processes. They advocate for “urgent need for education both at undergraduate and post-graduate degree levels and in continuing professional development” (O’Connor, Breen 2014:9).

Consistent with these findings, there is little research to identify how GPs make referral decisions. In Australia referrals are facilitated by the Better Access to Mental Health Care initiative (Pirkis, Harris, Hall & Ftanou 2011), but a challenge is knowing when to refer and the balance between pathologising grief and seeing it within a social paradigm.

Therefore, whilst some may take into account issues such as the nature of the death, the social support available and the patient’s reaction to the bereavement, without adequate training in grief and its confounding factors it is unlikely that GPs will be able to accurately ascertain the best referral pathway. Wiles’ study concluded that GPs need to be more aware of problems associated with bereavement and that social support needs to be explored and be a positive benefit to the patient (Wiles et al. 2002). They raised the issue of the expense of counselling and that some people would be unable to afford this service. In addition the researchers concluded that further training for GPs in psychological theories of bereavement and identification of those most at risk is needed.

It is important to acknowledge the relevance of different types of death and age of person’s death in making treatment and referral recommendations as well as the difficulty in sourcing appropriately trained health professionals and support groups. Further research into Australian GPs’ referral processes and available referral databases would benefit this process.
The link with GPs may also influence a parent’s reactions following an autopsy and coroner’s report. Biddle (2002) demonstrated the positive and negative effects of autopsy events and coroner’s reports and suggests that, for a positive outcome, clear communication protocols are required in order to prepare the parent for the processes and communicate the outcomes in an appropriate manner (Biddle 2002). The GP may have known the family prior to the child’s death and may be sought out by family to provide emotional or medicinal support through their intense grief. The GP’s ability to communicate with the family regarding medical procedures may be the only opportunity parents seek in order to understand the autopsy process. A study by Oppewal, Meyboom-De Jong (2001) supported the importance of the GP’s role in explaining the autopsy process and results to the parents in order for the parents to feel supported in both an informational and emotional context. Several parents were concerned about the appearance of their family member and some wanted clarity regarding the cause of death and acquittal of any sense of blame. The authors discussed the important role of the GP in helping families with their grief by creating opportunities to discuss these issues with an open attitude and provision of information. It is unclear if in Australia there is any protocol to encourage GPs to take on this role, or indeed if GPs feel confident enough to perform the task.

The research on GP support for bereaved families identifies critical factors in optimum care such as early contact and continued support, identification of complicated grief, effective training in bereavement support and up to date and informed referral pathways. There are a number of reasons why GPs’ referral processes may be compromised. Lack of access to a database listing specialised bereavement services may result in GPs referring to a generalised list of psychologists or counsellors without being aware of their specific expertise (Hannah’s Foundation 2009). In addition, GP confusion over the difference between ‘normal grief’ and depression may result in an inappropriate referral, particularly as, inappropriately, a depression scale is often used to measure grief, reflecting the lack of understanding amongst many health professionals about the difference between depression, grief and complicated grief (Neimeyer, Prigerson, Davies 2002). It has since been recognised that these are quite different states and require different measurement tools. In addition, the optimum support through the normal stages of grief, compared to clinical depression, may be distinctly different.

This could create confusion regarding appropriate support services for people bereaved by a sudden unexpected death such as a drowning or traffic crash and who may experience
complicated grief, compared to death following an illness which is less likely to be of a complicated nature. The length of time between the death and some form of professional intervention is also an important consideration. Epstein et al. (1976) investigated the relevance of appropriately timed intervention for the bereaved. They asked health professionals to rate the appropriateness of various community intervention strategies. Results indicated that there was a need for such assistance programs, but no clear consensus as to the specific type of program that was appropriate/optimum. This may reflect the uniqueness of the grieving process based on a range of variables, so there is no ‘one size fits all’ approach. They also concluded the most beneficial time to intervene and support the grieving process was within six months of the death. Another key finding was that the more experienced grief support workers were the strongest advocates for family support work. This reflects the importance of well-trained intervention therapists who have the confidence to manage the complexities that such grief and loss bring to the individual and the family dynamics.

3.4.6 The role of the psychologist and counsellor

Whilst there do not appear to be any studies in relation to the efficacy of counselling parents specifically bereaved through their child’s drowning death, there are studies which have debated the efficacy of generalised grief counselling (Larson, Hoyt 2009; Neimeyer 2010). However, research does suggest that the more formalised professional therapeutic interventions for those experiencing complicated grief reactions can be effective. This may not apply to people who have lost a loved one and are experiencing a natural healing process rather than complicated grief (Schut 2010). Schut suggests that until early interventionists such as hospital staff and the GP can accurately pinpoint risk factors and target interventions, counselling will remain somewhat hit and miss in its success.

It has been suggested that psychotherapy can relieve aspects of grief. However, a number of studies (Borins 1995; Schwartz 2005; Linenfield 2007) have suggested potential harmful effects of psychotherapy. Schwartz reviewed published articles examining the effects of psychotherapy linked to social support and social connections (Schwartz 2005). He noted that contrary to the opinions of professional psychotherapists, psychotherapy can actually harm the process and opportunity for enhanced social connectedness, bringing into question the role of such professional support. Other researchers (Borins 1995; Lilenfield 2007) have also identified harmful effects of psychotherapy but acknowledged the limited research in relation to potential harm of
psychotherapy and whether it is based on inappropriately timed interventions, mismatch of type of intervention related to the incident, inappropriately trained therapists/professionals or a general misunderstanding of the stage of grief that the individual is experiencing.

In addition to psychotherapy and bereavement counselling, other styles of counselling such as art therapy or ‘conversations’ have been suggested as appropriate supports, especially for children. In particular, children who have witnessed a traumatic event (such as sibling drowning) may not benefit from ordinary counselling techniques or even play therapy (Black, Tufnell 2006). Black identifies the importance of involving the child’s school and other voluntary organisations to provide support as well as attendance at family therapy sessions with specialised bereavement counsellors. Art therapy offers an opportunity for the traumatised parent or child to effectively express the particular emotions they feel at the time (Lister, Pushkar, Connolly 2008).

Opportunities for professional support can be compromised in rural and remote areas. Breen and O’Connor (2013) studied cancer patients in rural Australia and identified key factors, which may inhibit bereavement support. These included; inequity in regional versus metropolitan services, often due to the geography and tyranny of distance, which in turn required the providers to be a ‘jack of all trades’ and not being able to remain current with research and practice in any one area. Resources in rural areas are more limited, resulting in the inability to provide post-bereavement services. The authors also identified the difficulties in accessing professional development (although they also recognised this as a national issue (Breen and O’Connor 2014). Costs of travel and time to travel when based in a rural area limited professional development, to which they suggested maximising the use of technology would help bridge some of these challenges. Finally, Breen and O’Connor (2013) recognised the need for a state-wide directory to improve referral pathways.

In recognition of the dilemma between various modalities of support, a recent study explored therapists’ perceptions of the relative benefits and pitfalls of group work and individual counselling for bereaved clients (Vlasto 2010). Results indicated the benefit of individual counselling in the initial stages of grief combined with a more long-term benefit offered by group work. Individual counselling was seen as a safe place to express one’s grief and one’s story. The groups provided a more social setting to share one’s grief, to see how others grieve and to feel less isolated (Vlasto 2010).
The groups in this study were run by professionals and were time limited. It was unclear in the study if the bereaved participants had experienced similar deaths regarding age of and relationship to the deceased. Further research comparing a mixed bereaved support group with a specific age or circumstance of death cohort would add value to the research.

3.4.7 The value of support groups

Support groups were first established toward the end of the 19th century as a result of European migration into the USA to help people adjust to their new lives (Fobair 2009). Early into the 20th century, support groups were established through hospital social work departments, beginning with support for patients with tuberculosis and developing into the current model of care for a range of medical and non-medical conditions (Fobair 2009).

Over the past two decades, support groups have further developed to support a wider spectrum of needs and specifically those, which impact on quality of life. The choice to attend or participate in a group is a very personal decision. Some people find it helpful listening to others who have experienced a similar journey to theirs (Stebbins, Batrouney 2007). The group can provide emotional connection and support, understanding and shared experiences, practical coping skills, useful resources, emotional release and the opportunity for the parent to feel they are contributing to others by sharing their experiences. For parents who have experienced a child death, this contribution may be the only positive, motivating association for the parent since the death of their child.

Schwab examined people’s motivations for attending support groups. Results indicated that the majority of bereaved parents who were more likely to seek out a support group had experienced sudden and traumatic loss and particularly a loss of a unique kind where they had not been able to find others who had experienced a similar grief within their other support networks (Schwab 1995–96). Parents of children who had died from unintentional injury, suicide or homicide appeared to be the most prevalent members and often these participants sought help from more than one group. Schwab also identified that the sudden unexpected death of a child creates such a depth of grief that even with a supportive social network and professional support, parents needed to express their grief with others who had similar experiences because no one else really knew the depth of their grief.
The importance of identifying with others and being heard instead of judged is an essential component of a support group (Murphy 1990; Stebbins, Batrouney 2007). Murphy also acknowledged the relevance of time, with more than 50% of parents in one matched control study (n=41) demonstrating self-blame, painful memories, lack of meaning in the death and reporting unhelpful, insensitive and ill-timed comments from others two to seven years after their child’s death (Lehman, Ellard, Williams 1987).

Researchers examined the usefulness of self-help groups and professional therapy in recovery from the loss (Bouckaert 2000). From a convenience sample of 72 mothers, using a self-report survey questionnaire, they concluded that mothers who sought support from self-help and grief-oriented groups were more likely to have managed their loss in an integrated fashion and been able to move on with their lives than those who did not use such groups. They also recommended that mothers utilise self-help groups prior to individual counselling or intensive grief work in order to normalise their grief (Bouckaert 2000). This suggestion differs to Vlasto’s study in which he suggests individual counselling before group counselling in order to deal with issues of shame and anger in an individualised and safe setting (Vlasto 2010). These opposing suggestions reflect the uniqueness of grief and the limitations every study has in generalising recommendations.

Research regarding fathers’ experiences of self-help groups is more limited. This may reflect the fact that it is women who tend to attend this form of support as their need to talk and share experiences is a more ‘typical’ gender specific coping mechanism than their male counterparts. Men tend to become more distanced from the situation and deal with their grief in a more isolated, detached and indirect manner such as becoming busier or more absent. However, a few studies have illustrated that men may seek long-term support from self-help groups or groups of people who have experienced similar bereavement (Aho et al. 2011). Fathers reported receiving less support than their female counterparts after their child’s death and that the peer support that was available to them was more beneficial than the professional support. Support, for both practical issues as well as emotional needs were considered important. As other studies have shown, the timing of support was crucial. The provision of an early support contact could provide the opportunity for fathers to access support at a time they considered appropriate.

Support groups can be peer led or professionally facilitated, each of which have benefits and potential barriers. Peer led groups can provide a lower cost intervention than
professionally led groups, with the potential for consistency and less reliant on changing funding priorities (Pallaveshi, Balachandra, Subramanian & Rudnick 2014). In their study of participants with co-occurring disorders, Pallaveshi et al also found both groups provided a positive environment and personal growth, but in the peer led group, participants reported feeling more comfortable, and in the professionally led group, participants reported greater knowledge gain. Hence the authors suggest that a providing a combination of peer and professionally led bereavement groups may provide optimum results.

Support for families participating in organ donation requires specialised training and it has been suggested that specialised support services should be available to families making organ donation decisions (Vajentic, Calovini 2001). This support needs to extend beyond the hospital setting, as other social supports may not understand the facts of the process or the impact or the decision. Suggestions for support included assisting the bereaved in the four components of mourning identified by Worden, i.e. accepting the loss, working through the pain and grief, adjusting to an environment without the deceased and moving on with life. Vajentic et al. 2001 studied a group whose purpose was to provide bereavement education and emotional and social support. The groups lasted for three years and were evaluated on a regular basis by the participants. Family groups were also conducted and had a positive outcome of families being able to grieve together in a supportive setting. Specialised groups for children were held at the same time as the parent groups so childcare was not required. Whilst this model was developed for organ and tissue donation families, its application would appear to be appropriate as a general bereavement support program. Further research into the viability and facilitation of such programs within a broader bereavement context is required.

3.4.8 Social supports and stigma.
Social support is described as the perception and/or experience of support that assists the recipient in acknowledging that they are valued and cared for in a timely, sufficient and available manner (Breen, O'Connor 2011). The ability to adapt psychologically following a sudden death can be dependent on the bereaved relationships with those expected to offer support and the support which is actually made available (Burke, Neimeyer, McDevitt-Murphy 2010). The mental health of a bereaved person may be influenced by how they regulate their emotions, thoughts, and actions through conversations and shared activities with the people in their lives, rather than through conversations about how to
cope with the stress of the death itself (Lakey, Brian; Orehek, Edward 2011). Directly associated with this support therefore, is the concept of stigma. Goffman et al (1963) described stigma as a negative social interaction in which an individual becomes dehumanised as a result of negative social interactions and hence the individuals sense of social identity is challenged (Kulesza, Ramsey, Brown and Larimer 2014). Researchers have since extended this theory to include public, perceived and enacted stigma, all of which refer to negative experiences with the potential to have an adverse effect on the individuals’ mental health (Corrigan, Watson 2002; Kulesza, Ramsey, Brown and Larimer 2014). Public stigma has been described as negative attitudes toward the person or persons that results in discriminatory behaviours toward that person or persons (Corrigan, Watson 2002). Enacted stigma is the direct action resulting from this discrimination and self-stigma can be described as negative thoughts, feelings and sense of identity as a result of the discrimination. Perceived stigma may not be a result of any of the above behaviours, yet the individual perceives that people hold a common negative opinion of them (Kulesza, Ramsey, Brown and Larimer 2014).

It is not surprising, therefore, that studies have shown that social support has a significant impact on the grieving process (Benkel, Wijk, Molander 2009). Making meaning is a significant aspect of grief work and reconstruction of meaning following a devastating loss is affected by our social world, which in turn affects our emotional and spiritual well being (Neimeyer, 2011). The opportunity to hold some form of narrative in regard to their child’s death may offer some support toward making meaning and developing a sense of resilience to cope with the grief (Hooghe &Neimeyer, 2012). Research suggests that in some circumstances, those with a strong spiritual connection are more able to make sense of their loss (Lichtenthal, Currier, Neimeyer, Keesee 2010).

Social support is recognised as having an important influence on managing grief, in particular, complicated grief where there is a delicate balance between mental health and the ability to heal (Schwab 1995–96; Bath 2009; Breen, O’Connor2011;Kulesza, Ramsey, Brown and Larimer 2014). Positive social support influences one’s sense of self, creating the opportunity for a positive self-image if the recipient perceives that they have the opportunity to remain connected, be able to continue to contribute to society and receive favourable feedback (Wilkinson 2006). Negative social support occurs when a relationship discourages a person’s positive sense of self or reinforces unhealthy behaviours (Stansfeld 2006; Pettus-Davis et al. 2009). In particular, if the interaction is negative, stigmatised and non-supportive, the recipient of these negative behaviours can experience
significant stress (Shinn 1984; Finch et al. 1989). For this reason, social support and stigma are discussed together in this section.

Positive social support can serve as a “protective” factor to people’s vulnerability on the effects of stress on health (Cassel 1976; Wanderwerker, Prigerson 2004). In a study of 293 bereaved individuals (mean age 61.5 years), social support was consistently protective against complicated grief and some of the negative outcomes, which can be associated with complicated grief (Wanderwerker, Prigerson 2004).

Stress and health are often linked with social networks and influence how people cope with stressful events. House (1981) identified four types of social support: emotional, instrumental, informational and appraisal. Emotional support includes sharing life experiences in an empathetic and caring manner which in turn develops trusting relationships and bonds; instrumental support includes active behaviour such as providing meals, assisting with organising daily and necessary events and documentations etc. Informational support includes giving advice, usually linked to professionals; and appraisal support is used as a reflective process, often including social comparisons and meant to be of a constructive nature (House 1981). Breen and O’Connor (2011) described social support as the perception and/or experience of support that indicates one is valued and cared for which reflects both the intrinsic purpose of support and encapsulates the majority of players in the bereavement journey. They identified three main elements, similar to House’s four elements though excluding the affirmation component: the doing part of support, referred to as instrumental support which includes assistance with goods, services and money; emotional support; and informational support, the latter being accessed via a range of avenues including peer support; and professional guidance and intervention.

Mickelson (2001) conducted a longitudinal study to examine the effects of perceived stigma and perceived support available, including personal interactions and evidence of depression. She identifies the cultural influence of stigma labelling and hypothesises that this is a two way process, creating a cause and effect outcome. In this study of parents with children with special needs, Mickelson found that perceived stigma contributed to the erosion of social support as well as an increase in depression. However, she also emphasised that this is an individual experience, with some individuals experiencing
different levels of stigmatisation even though the social stressor was constant. She identified a difference within and between families; participants experiencing greater perceived stigma and lack of social support from grandparents as opposed to their spouse. However, the study did not extend beyond family members and further research would value add to the degree of perceived stigma by other members of the bereaved' social network.

The experience of being stigmatised not only affects relationships but also contributes to chronic disease and health problems and as a consequence has been recognised from its initial position in the social science arena to the public health field (Weiss, Ramakrishna, Somma 2006). Goffman described two specific types of stigma: felt and enacted (Goffman 1963), the former representing an internalisation of belief, emotion and blame, the latter representing the response of others toward the individual, such as ostracising the person. However, Goffman still did not capture the health-related aspects so specific to stigmatised persons. Weiss extended Goffman’s formulations to address the context of social structure, which in turn, affect the social interactions (Weiss Ramakrishna, Somma 2006). In acknowledging the emotional impact of stigma which may inhibit people’s conversations or willingness to seek help for fear of the reaction, and the subsequent health consequences of inhibited expression, Weiss, Ramakrishna, Somma (2006) and Link and Phelan (2006) included stigma as a social process, experienced or anticipated, which included aspects of exclusion, rejection, blame or judgements about a person or a group. These researchers recognised the relevance of this within the formulation of health policies. In the last decade, this understanding has helped address coping mechanisms for those having experienced the suicide of loved ones, though the application to fatal drowning appears absent in the literature even though the essence of the formulation, in particular the concept of rejection and blame, are marked experiences of participant parents.

Link and Phelan (2006) also identified significant health issues related to stigma, which can affect social relationships, help-seeking behaviours and coping mechanisms. They identified three major forms of discrimination: direct, structural and insidious. These involve overt behaviour (direct), behaviour embedded within society that results in a form of exclusion (structural) and insidious stigma related to people making judgements on others, often resulting in breakdown in social networks and compromised quality of life. Goffman (1963) identified the term ‘courtesy stigma’ which reflects the negative experiences of a
person who encounters others with a judgemental attitude toward their situation (Corrigan, Miller 2004).

Support from a range of networks is clearly important to bereaved families. Accessing social support within known networks is often the primary contact that can be a supportive or detrimental experience. The social support and the social context in which the parent survives within that support structure is directly linked to their ability to live in the post-death world (Berrera et al. 2009). In Barrera’s study of parental adjustment following the death of their child to cancer, four meaningful ‘relationships’ emerged. These involved the importance of the relationship with their partner and appreciating the different grieving styles of each; the link between the parents and their surviving children; the role of social networks, including family and friends; and self-identity. All these factors were mentioned by the participants, and illustrated varied experiences and impacts of these relational experiences on their grief support/management (Berrera et al. 2009).

Support from family, friends and colleagues influence a person’s ability to cope after they have lost a loved one (Breen 2011). Social isolation following a sudden death was a significant predictor of psychosocial health, further complicated if the death was a child, if there was perceived preventability of the death and a lack of social support (McKissock and McKissock 1991). Studies have shown that adequate social support equates with a reduction in psychological stress (Vanderwerker, Prigerson 2003; Joseph et al. 2011).

Murray (1999) examined the importance of social support to enable parents to express their grief and found it to be of great assistance to mothers dealing with the death of their child although the benefit was only apparent in the long term (15 months post-loss) (Murray, Terry 1999). This benefit seemed to be more related to the mother than the father and related in particular to the support of extended family. However, whilst this study did refer to stillbirth and neonatal death, the potential stigma and blame attached may look different to that of a drowning death. Seeking family or extended social support following a stigmatised death such as toddler drowning may result in quite different support.

White et al 2008 examined support with intergenerational family members and provided useful insight into the social support between grandparents and their adult children following an infant death, although again there was no reference to unintentional death (White, Walker, Richards 2008). Using semi-structured, open-ended interviews with 21
parents and 19 grandparents’ from ten families, six categories of support were identified: being present, acknowledgement, performing immediate tasks, information, unskilled support and no support. The study reported the importance of the support given by grandparents and the potential harm caused by ambivalent relationships that actually complicated the grief process. Ambivalence was not reported as intentional, rather the inability of one of the family members to know what to say or do under the circumstances.

Youngblut et al (2010), examined the impact of the death of a grandchild on grandparents and also identified challenges in communicating with the parent of the deceased child. They identified a wide range of activities shared between grandparents and grandchildren which created a sense of being valued, adding purpose to their lives, providing social and emotional reward and, in some cases, continuation of the family line and name as well as being able to do things ‘differently or better’ with the grandchildren than they were able to do with their own children. After their grandchild’s death, a grandparent’s grief was often forgotten or unsupported. Like the parents, they too experienced numbness, disbelief, bitterness, exhaustion, helplessness, blame and survivors guilt. The latter is particularly relevant to grandparents, feeling they should have died in their grandchild’s place as the child’s life was just beginning and they had already had their lives. Grandparents may experience physical as well as emotional symptoms such as sleep disturbances, panic attacks, flashbacks and increased use of alcohol. Support for grandparents was limited and whilst many (48%) turned to their spouse for support, this had the potential to be difficult if gender coping differences occurred.

Youngblut et al. (2010) also identified a significant number of grandparents who turned to the deceased child’s mother for support, though a similar number reported refraining from talking to the child’s parents for fear of causing them more pain. Relationships between mother and grandmother often changed following the child’s death, with over half of the parents and grandparents in the study reporting some sort of change in their relationships (though this change was not explored). Many grandparents turned to their daughter for support, though others were reluctant to talk to the deceased child’s mother for fear of increasing the parent’s pain. This confusion was consistent with other studies having identified difficulties in discussing the deceased and parent’s disappointment with how family members managed or avoided conversations about the deceased child. Support for and from grandparents requires further research to gain a better understanding of
grandparents’ need for and access to support; and how to optimise the communication and new relationship dynamic with the grieving parents.

Support is often compromised when people are uncertain of how to treat parents who are grieving. As Murphy suggests: “even though members of the social networks of bereaved persons want to be supportive, they frequently do and say the wrong things” (Murphy 1990:175). Long-term support is needed following a sudden child injury death. Murphy (1990) identified that family and social networks soon tire of the rumination and grief that is a central part of loss and Bugen concurred, adding that this is further complicated when the grief is more intense and prolonged and linked to perceptions of stigma (Bugen 1977). There is a lack of more recent published research on stigma and complicated grief in relation to child drowning.

Bath studied 160 university students in Australia to ascertain their intention to support a bereaved person (Bath 2009). Whilst the study had limitations due to the size of the cohort, the results are worthy of further investigation with a bigger sample. Bath identified that people will or will not offer support based on their perception of the consequences and outcomes of that support for both themselves and the bereaved, coupled with their confidence in the effect of their interaction. This suggests that education can influence beliefs on issues of efficacy and could encourage people to offer more support. Whilst this is a community issue, education could begin in places like the workforce and schools as points of relatively easy access to community members, and also provides a reasonably controlled opportunity for evaluation. Schwab (1995–1996) recognised that a highly stressful event such as the loss of a child may require additional support to that which a social network can provide, such as mental health interventions and support groups. There is limited literature regarding what actually comprises the totality of social support and the experiences of these supports by bereaved families.

Brabant et al. studied parents who had lost their child and were members of the Compassionate Friends USA® (Brabant, Forsyth, McFarlan 1995). Although this sample may have biased the study cohort as the parents were obviously seeking additional support not evidenced within their social structure, Brabant examined parents’ experiences within four social contexts: clergy, family, friends and co-workers. Support from family was reported as insufficient and in most cases far too short in terms of time. The lack of

5The Compassionate Friends is a worldwide organisation offering bereavement support.
support mainly related to the families’ inability to talk about the deceased child and parents reported on the painful repercussions of that behaviour. Inappropriate comments from family members created rifts in family relationships. Friends were reported as shying away, making inappropriate comments and acting as if nothing had happened. This appeared to generate anger with the parents. The main comment was that friends expected parents to ‘get over it’ within some preconceived time frame and that friendships collapsed because of this lack of understanding of the depth of their grief and time it takes to manage their lives in the absence of their child. Whilst some parents mentioned supportive clergy, most expressed disappointment either with no acknowledgement of their demise, or short-term support of just a few days with no ongoing support. Some of the parents, who were trying to come to terms with their sense of self, and also their ability/difficulty in linking their tragedy with some broader worldview and life perspective, felt they needed more support from their religious leaders (Brabant, Forsyth, McFarlan 1995).

3.4.9 The role of the workplace in supporting bereaved employees

Grief costs the workplace millions of dollars each year in lost productivity (Bento 1994, Attridge, VandePol 2010; Johnson 2012). In the United States, it is estimated that 25% of employees are grieving at any one time and the annual cost to business in terms of lost productivity, lost business and poor performance is more than $75 billion with $46.9 billion attributed to the death of a family member, colleague, friend, or animal companion alone (Johnson 2012). In an Australian study of 103 bereaved parents, lost income due to their child’s death was estimated between $2,500 and $600,000 (Stebbins 2007). Cost benefit studies relating to Critical Incident Response workers have indicated an overall positive return to investment when providing psychological support in the workplace, with some studies showing a reduction of 73% frequency of lost times claims and a 77% decrease of number of days paid per claim (Attridge, VandePol 2010).

Grief in the workplace can be divided into two categories: open and hidden (Tehan, Thompson 2012). Open grief is clearly apparent with the bereaved person showing their distress; hidden grief is more discreet, often indicated by loss of concentration, changing moods, reduced quality of work and general irritability. Behaviours exhibited in both categories can have a marked effect on all employees (Tehan, Thompson 2012). Recognising these behaviours and providing a supportive environment is seen as critical from both an emotional and a safety perspective. Those responsible for providing support
included line managers, colleagues, and, where they exist, trade union or other staff representatives (Charles-Edwards 2009).

Support at work was seen as critical to a person’s ability to adapt to their loss, and responses from people at work impacted on how bereaved or terminally ill colleagues managed their grief (Charles-Edwards 2009; O’Connor et al. 2010; Tehan, Thompson 2012). However, experiences of support in the workplace were mixed. Some parents in Brabant’s study reported colleagues completely avoided the conversation which caused them significant discomfort and anger. They expressed the desire to talk about their child, yet no one at work was prepared to broach the subject. Others mentioned supportive bosses, some being very flexible regarding time needed away from work, others offering supportive conversations. This study was limited in that those reporting positive work experiences worked with other family members and it is unclear if the same level of support would be offered in non-familial workplaces.

In order for workplaces to support their employees, Charles-Edwards (2009) suggested a minimum process for workplaces to adopt. These included:

- an understanding of the nature of the bereavement process including the emotional switchback that may be taking place; what support, if any, is appropriate with funeral and short-term practical issues, while the bereaved person is off work; managing the return to work; immediate support and reactions of colleagues and the impact on work groups; longer term awareness, monitoring and support; work and personal issues faced by a terminally ill or bereaved member of staff; and what level of contact and communication is appropriate with next of kin and family, with special sensitivity in the case of terminally ill and gay staff. (Charles-Edwards 2009: 435)

Minimal research has been done specifically on loss and grief in the workplace, though there is a small development in the Australian literature in recent years (O’Connor et al. 2010), including a study conducted on behalf of the Compassionate Friends Victoria (Stebbins, Batrouney 2007). This study highlighted some of the challenges parents face in returning to work after their child’s death, and the authors proposed recommendations to address the shortfalls in support.

Recent attention to workplace wellbeing in Australia has acknowledged the human component of the workplace, recognising that protecting the most relevant resource,
people, will enhance the health and wellbeing of the workplace and the individuals affected (Tehan, Thompson 2012). The Commonwealth Rehabilitation Service Australia (CRS Australia) was formed in 1997 and has developed eight ‘Networks of Excellence’ to promote best practice in providing rehabilitation services, some of which link to bereavement. Tehan suggests a ninth network, focusing on flexible return to work policies for the bereaved. What is missing in her suggestion is a tenth network, which applies to supportive, non-judgemental communication skills training for all employees.

3.4.10 The importance of the school in the bereavement journey

Beyond the family relationships, schools are considered an integral part of community life and as a consequence they play a significant role in the support, or otherwise, of families’ grief. Educators have a key role in identifying and supporting childhood traumatic grief (Cohen, Mannarino 2011). Teachers need to be aware of the behaviours, which may occur with a grieving child and refer the student to a school counsellor or psychologist for a mental health evaluation. Teachers will be less likely to incorrectly treat the bereaved student as if they have a behavioural or learning problem and, equally as important, if appropriately referred in a timely manner, the student is at lower risk of developing further trauma-related issues such as PTSD. However, if the school had a policy whereby teachers were informed of a child’s bereavement they may be able to be more attentive and reduce the grief-related behaviour with a caring and trained approach. Also, singling a child out for ‘mental health assessment’ in the school environment may encourage isolation and stigmatised behaviour rather than a whole of community approach.

Johnson and Rowling support a whole of community approach and stress the importance of young people in crisis needing supportive, normalising, and affirming contact (Johnson 1989). Schools can help young people understand the patterns of loss experiences, identify feelings associated with their loss, and encourage them to seek support or be supportive to others. In this context, grief is viewed as a normal life event; young people need preparation and support, individually and in groups from their school community (Rowling, Holland 2000; Rowling 2008). Rather than addressing individual events as they arise, they suggest it is important to integrate grief and suicide as part of the curriculum so it is viewed as an integral ingredient in young people’s educational experience (Kraus 2005; Rowling, Holland 2000). Rowling and Kraus expressed the importance for loss and grief to be seen as part of a social interaction with peers and teachers supporting this by helping the bereaved define their loss, express their loss, provide support and interaction.
and integrate their loss into their lives. They suggested it should be seen as a part of the health-promoting school framework rather than an independent activity (Kraus 2005). Open and optimal dialogue with parents, teachers, school-based mental health professionals and possibly community mental health professionals whilst being aware of the confidentiality parameters was considered an integral component of support (Cohen, Mannarino 2011).

In New South Wales, Australia, schools have a mandatory requirement to develop a management plan and develop procedures for coping with traumatic incidents and to educate both staff and students about grief (Rowling, Holland 2000; Rowling 2010). There is also a requirement to offer support for the bereaved. Rowling’s study identified that Australian teachers were aware of a range of training opportunities around grief, though it did not identify the take up of these opportunities or the content, accessibility or cost of the training. Every NSW school participating in Rowlings’ study reported offering individual counselling to students who were grieving and 75% reported offering group counselling following a suicide. Seventy-five percent of the participant schools reported providing support for their staff following a critical incident, although, again, that support was not clarified, nor was it clear if a critical incident referred to a sibling death.

Queensland does not appear to have a similar mandatory requirement. According to the Brisbane Regional School Community Liaison Officer (personal communication 2014), there is a policy to support students health and well being (The State of Queensland (Department of Education, Training and Employment 2012) but this does not specifically apply to bereavement. It was suggested that each school principal should address the support needs for the family on an individual basis.

Rowling and Holland (2008) examined the importance of a public health approach to supporting students and teachers affected by grief. They suggest that communal caring, time out to express grief through various avenues and a multi-strategic approach is needed to support the whole school community. Seeing the school as an integral part of the community, there is a need for a “comprehensive framework for taking action in response to loss and grief, a whole school community needs an ethos that enfranchises, validates, and restores the quality of life among its membership that includes students, teachers and school leaders (i.e. principals, head teachers)” (Rowling, Holland 2008: 245). What Rowling do not discuss in this paper is the impact of parental grief, its influence
on continued parenting of surviving siblings and how parents can best link with the school in order to gain support for their children and their own changed family dynamic. Further research into the existence and efficacy of this public health approach in relation to bereavement support is required.

There have been a number of studies identifying what educators can do to assist the grieving child in the school environment (Goldman 1998; Rowling, Holland 2000; Lowton, Higginson 2003; Cohen, Mannarino 2011; Heath, Cole 2012; Jenkins, Dunhan, Contreras-Bloomdahl 2011). Having a plan in place for when students experience grief is recommended as well as more specialised training for health professionals (Jenkins, Dunhan, Contreras-Bloomdahl 2011). Improving the opportunity for social adjustment, strengthening social support and taking opportunities for adaptive teacher involvement to assist the bereaved child with coping strategies and reducing isolation are seen as key to a grieving child’s management and adaptation to their grief (Heath, Cole 2012). Grief support groups for children experiencing loss, facilitated by school counsellors can be an effective means of supporting bereaved children, providing a safe place for children to express their fears and to begin the process of letting go. Providing this in the school environment provides familiarity and safety for the child as well as reducing the potential for isolation (Samide 2002). School-based music therapy has been shown to be effective in helping children come to terms with their loss. In a small study of 26 participants, Hilliard demonstrated a significant improvement in the behaviours and grief symptoms of bereaved children who participated in music therapy. He also noted that a more comprehensive impact was experienced when combined with social work support and that music therapy alone resulted in better adjustment outcomes than social work support alone (Hilliard 2007). What is unknown from the Australian literature is what schools actually do to support grieving families and what the barriers to effective implementation may be.

Whilst teachers are usually the main contact point for the students and can observe behaviour changes, in most cases teachers have received no training to handle these situations (Jenkins, Dunhan, Contreras-Bloomdahl 2011). Jenkins’s USA study confirmed the lack of training and confidence that teachers felt when placed in a situation of student bereavement. It also confirmed that in the schools where a bereavement plan was in place, staff were unaware of its existence. This is mirrored by a study conducted in the UK, which identified “many school staff reported being apprehensive of talking to students
about death and bereavement, despite children initiating the discussion of these issues. However little attention has been paid to the way that teachers manage bereavement in the class (Lowton, Higginson 2003: 731). This experience is consistent with Jenkins’s et al. study in which they conclude “the results of this study were surprising and disappointing. It translates into the need for administrators, school counsellors, school psychologists and teachers to become better equipped through formal education and additional training or personal studies regarding grieving students” (Jenkins, Dunhan, Contreras-Bloomdahl 2011:8). Australian studies into schools’ management of bereavement are not evident in the literature. However, Rowling et al. identified a mandate for schools in NSW to have a management plan to respond to critical incidents and to protect the schools from legal claims related to responding to people’s bereavement needs and supposedly to educate the community regarding supportive practices (Rowling, Holland 2000; Rowling 2010).

Further research in the Australian context into the effectiveness and uptake of similar policies and the referral process to support services will help clarify the benefits, implementation and barriers for Australian schools to adopt this approach. There appears to be confusion over an integrated curriculum approach and the specialised services of trained professionals as well as the implementation of policies, which only provide for minimal legislative protection of the institution rather than the desired benefit for the bereaved families. There is a significant gap in the literature to identify what bereavement supports are available in Australian schools, consistencies or otherwise in the delivery of these supports and an analysis of resources and training opportunities to provide optimum and timely support. Further studies into policies, training and resourcing for bereavement support in Australian schools combined with interviews with bereaved parents regarding support they received from schools would provide a realistic perspective linking theory and practice.

3.4.11 Online support – beyond time, financial and geographical constraints
Online support offers an additional dimension to face-to-face support. Use of the internet eliminates geographical boundaries, connects people who may be in a minority with their suffering and allows for a 24 hour global reach to contact people experiencing similar trauma. This style of support is low cost and easily accessible (Van der Houwenet al. 2010). The limited research available on the use of the internet by the bereaved indicates that main users are younger than the average population, have lost a child and are less
likely to be associated with a religious community (Van der Houwen et al. 2010). Use of online support has been categorised into two groups: ‘synchronous’ groups describe people who use the internet in real time, such as emailing and chat rooms, whereas ‘asynchronous’ groups such as internet forums and email lists may not involve real time exchanges (Van der Houwen et al. 2010). In their study of 156 bereaved internet users in the USA, Van der Houwen et al. identified an almost equal use of synchronous and asynchronous access and participants spent an average of 7.4 hours per week on the internet. It is unclear if the amount of time on the internet changed with time since their child’s death. Interestingly, when comparing rural and urban living with internet use, there was no significant difference, possibly suggesting that distance from services may not be a significant reason for internet support. Further research is required.

Mourning and loss groups make up 10% of all electronic support groups in the health and wellness section of Yahoo, “making bereavement the third most popular subject after diseases and conditions (43%) and weight issues (13%)” (Van der Houwen et al. 2010). Within this category, groups that have a focus on child death comprise 23% of all mourning and loss groups, suggesting that parents who have lost a child may need support for longer than other bereavement situations and that other support networks may tire of giving their support over a lengthy period. This is consistent with other research which suggests family and community tend to place a judgment on how long a person should mourn for their child before they start to ‘get on with life’ (Murphy 1990; Brabant, Forsyth, McFarlan 1995; Breen, O’Connor 2011). Online support offers additional support for bereaved people and is not a substitute for other forms of support Van der Heuwen et al. 2010. However, it is possible that dissatisfaction with other supports encourages people to gravitate to online support. Few studies have examined the efficacy of online support or its protective factor for developing mental health issues. Van der Heuwen et al. did not identify a link between mental health and online support over a three month period; however, a longitudinal study would offer further relevant information considering the duration of grief following a child death.

In contrast, Vanderwerker and Prigerson did identify a potential protective factor associated with internet use amongst older adults with a mean age of 61.5 years who displayed enhanced quality of life which they attributed to internet use (Vanderwerker, Prigerson 2003). Results also suggested potential protection against psychiatric disorders following a bereavement, which differs from Van der Heuwen et al findings. Given that the
loss of a child is one of the highest risk factors for complicated grief and hence potential psychiatric disorders, further research examining internet use by bereaved parents will offer further insight.

Social networking such as the use of Facebook and other internet-based forums have been prominent in the last decade as a means of communication and is often used by those who may not have accessed other more traditional and one-on-one support. In particular this is relevant to teenagers. Ninety-three percent of teenagers in the USA use the internet and more than half of those use online social networking as a means of regular communication (Williams, Merton 2009). No Australian publications were available although it is reasonable to consider that these figures are likely to be comparable with Australia, with adolescents using Facebook and other chat rooms to explore and express their grief in relation to either the death of a family member or close friend.

Social networking differs from memorial websites that are often established by families or funeral homes after the child’s death, in that the social networking sites can represent communications both before and after the person's death, creating an ongoing dialogue and an essential frame of reference in regard to a continuity of the relationship. Maintaining this relationship with the deceased is seen as therapeutic and online social networking sites have been found to be useful in sharing personal experiences, thoughts and feelings, which may assist the grieving process when a peer dies (Williams, Merton 2009).

Interactive memorial pages provide the opportunity for a range of grieving activities such as leaving a message for the deceased or posting a photo, to prompts to light candles, remember birthdays and significant events as well as possibly coordinating fundraising or other charitable events. They facilitate the opportunity to continue the bond with the deceased as well as continue bonds with the extended family and friends, hence keeping not only the parent–child relationship alive but also the social dynamic. This type of site allows others to respond in a similar fashion and hence the grief can be expressed and shared without a face-to-face encounter (Maddrell 2012). However, Maddrell also identified a potential negative side to this exchange: the possible substituting of these memorial site exchanges for actual attendance at funerals or other gatherings where people come together to mourn or even talk about the deceased. This has the potential to
create isolation and impact on the bereaved person’s ability to adapt and live with their grief.

### 3.5 Conclusion

Whilst there is considerable literature on grief and the different approaches to support, there is discord between the modality, content and length of support required for different types of death. There is abundant research into support following palliative care, as well as information on support following a sudden infant death (SIDS), suicide and HIV. However, there was limited literature on support available for families following a stigmatised child death and a notable absence for fatal child drowning, with only a handful of papers regarding the experiences of a death in the hospital Emergency Department. Families of children who die in the Emergency Department are not usually linked to hospital support networks as they would have been if the child had been admitted. There was a minimal number of studies reporting the experiences and needs of parents from the time of their child’s death through their bereavement; limited Australian research on the role of schools and the workplace; a scarcity of studies investigating support challenges faced by service providers when working with a family who had experienced a fatal child drowning; and a lack of information regarding training programs for support workers.

With the exception of a handful of papers, most publications were from the USA and UK. Further research is required to investigate the psychosocial support requirements for families experiencing a sudden child death, in the context of the unique Australian social, geographical, cultural and political environment, which dictates policy and funding for services and research.

Given that there is considerable research on broader areas of grief as well as a growing literature on the relationship between stigma, mental health and grief, there still appears to be a gap in the application of this research to the experiences of parents whose child died from drowning. Further understanding of the responses by professionals, the community and family members will help to identify some of the gaps in professional and social support and perhaps offer some direction for further research. To appreciate these experiences, this research will focus on the impact of the fatal drowning; the actual support available as well as the perceived support from bereaved parents. The research will also attempt to identify some of the factors that lead to positive and negative experiences of support, which in turn, influence the mental and emotional well being of the bereaved.
Chapter Four—Methodology

Introduction
The previous chapter highlighted the limited literature identifying parents’ psychosocial and support experiences following an unintentional child death, and even fewer publications regarding a fatal child drowning death. As a result, there is limited understanding regarding parents’ experience and support needs following their child’s fatal drowning.

This chapter outlines the qualitative methodology used in this thesis to examine the psychosocial impact on parents bereaved by their child’s fatal drowning and their subsequent experiences with support. A social constructionist approach has been adopted, consistent with the intention of this study to appreciate that each person forms their own reality based on the interpretation of the interplay between various discourses within their world.

The aims of this research were to establish a greater understanding of experiences of parents bereaved by a fatal child drowning, and the various supports available to them. This enquiry is not evident in current literature. Therefore, to facilitate this body of knowledge, the following areas were explored:

- The impact of a child drowning death on parents
- The support available to parents bereaved by a fatal drowning
- Parents’ experience of social, organisational and professional support
- Factors that influence the delivery of support

These aims were investigated in a qualitative study of parents bereaved by a child drowning and agencies/organisations that may provide support to these parents (service providers).

4:1 Methods

Qualitative approach

“Qualitative research enables us to make sense of reality, to describe and explain the social world, and to develop explanatory models and theories. Doing qualitative research requires the researcher to be methodologically versatile, to have extensive knowledge of
social science theory, to interact skilfully with others and to be persistent, focused and
single-mindedly committed to research. It requires the researcher to constantly distinguish
between another's world and one's own, yet become close enough to the life of another so
it can be both experienced and analysed. It requires the researcher to be able to
conceptualise, write and communicate. Doing qualitative experience is an intense
experience. It enriches one's life; it captures one's soul and intellect.” (Morse 1995:1)

Qualitative research has been utilised in bereavement research as well as research for
which there is little existing literature (Liamputtong 2007). Qualitative research provides
participants a voice that is both heard and relayed with sensitivity (Finlay 2011). This voice
allows participants to share their world, not just the event itself, but how they experienced
that event and what impact it had on them (Finlay 2011). Qualitative research assists in
recognising that each individual has their own unique set of experiences of an event and
life following the event. This style of research provides in-depth understandings in order to
ask more specific and focused questions for future research. It also provides a more in-
depth appreciation of the experiences of study participants and creates the opportunity for
rich insight into complex, sensitive issues. It does not aim to find a right or wrong, more or
less, better or worse approach; rather it acknowledges that the experience of each
participant is unique and comprises their own story (Berg 2001).

The sensitive nature of this study lent itself to a qualitative approach. Whilst there did not
appear to be any qualitative studies exploring the impact of interviewing parents who had
experienced a fatal child immersion, there have been qualitative studies which have
explored parents’ experiences of being involved in research following their child’s death
(Dyregov 2004; Hynson et al. 2006; Taneja at al 2007; Dyregov et al. 2011). These studies
have suggested that the participants found the experience positive overall and suggested
that, whilst the interviews were emotionally draining for many participants, they also had a
beneficial effect, allowing the opportunity for the participant to vent their feelings and to
help others by sharing their experiences and providing further insight into their situation.
In many cases, this opportunity to relay personal experiences has a cathartic effect on the
participant, offering validity to their experience which may previously have been

Qualitative approaches can provide the opportunity to document difficulties and obstacles
and therefore provide insights into ‘why’ certain interventions are not successful (Rosser
In addition, qualitative research can help uncover unintended consequences of service development and delivery and highlight experiential differences between intent and actual experience (Griffiths, Hughes 1998). This is directly relevant to this author’s study.

A qualitative approach was therefore appropriate for this study for a range of reasons: the rarity and potential stigmatisation of child drowning, the lack of published literature on which to build an understanding of parents’ bereavement experiences, the exploratory nature of the research objectives and the sensitivity of the issue. Qualitative research allows for a richness of information, which can then be used to develop future qualitative and quantitative studies on a topic that is new to the literature.
Theoretical approach

In the last 50 years, research into medical sociology has utilised a social constructionist approach, acknowledging the social dimensions of illness and the influence that various broader social and cultural discourses have on one’s ability to adapt to their current situation (Conrad, Barker 2010). The basis of this approach was developed from the recognition of the distinction between disease, i.e. a pathology, and illness which may be embedded in social implications. As such, a social constructivist approach is relevant to the state of grief, which is understood as both pathological and social contextual.

Social constructionism originated from the recognition that deviant behaviours are considered within a social context, further emphasised by statements and judgements within a social group, often resulting in a form of social control (Conrad Barker 2010). Behaviours and illness are labelled within a subjective framework and need to be deconstructed to fully understand the relationship between the illness and the behaviour.

Similar to grief, certain illnesses and expressions of illness are embodied within cultural norms and attributed certain meanings. Some illnesses such as leprosy, mental illness HIV/AIDS have become stigmatised, resulting in limited access to treatment and support and effecting relationships and a sense of identity. Social constructivists suggest that it is not the condition itself that causes stigmatisation but how people and society respond to the condition and how the condition manifests itself as well as responding to the type of individuals who suffer from the condition that make it stigmatised (Conrad and Barker 2010). Priya (2012) suggests that biomedicine excludes the impact of social and community influence and sees the sufferer as a patient, rather than a person, hence focusing on disease. This exclusion can lead to the perception of blame onto the sufferer, rather than examining the system in which the sufferer is positioned. Savvidou (2003) suggests that a person adapts to the context of their environment creating an active interchange and often conflict between the social environment and the individual’s narrative. The concept of ‘social erosion’ in which diagnostic categories and medical terminology can help to isolate, rather than support those who are suffering contributes to this dissonance (Gergen 1994).

Social constructionism, is the perception one has of ‘self’, and this perception becomes a reality based on a combination of discourses which form meanings and interpretations through language, statements, representations and images in a certain way to create an individual reality (Savvidou et al 2003). The construction of these discourses is what
creates meaning in people’s lives and affects all relationships. When discourses conflict, often due to differences between scientific observations and common sense, confusion, stigma, and ill health can result.

Suffering and healing are not necessarily disjointed experiences; rather a combination of these emotions help to restore a person's sense of self, influenced by culture and society, roles, history, relationships and the perceived future (Priya 2012). Suffering is culturally constructed, associated with physical illness but may not be associated with a disease or disorder (Priya 2012). Suffering occurs when a person is not able to meet the socio-moral demands within their own local space or world. On the other hand, healing involves the process of making some form of sense out of the suffering, giving meaning and value to the experience. This is only possible through cultural processes such as symbols and rituals, empathic witnessing by another person. If the culture within which the sufferer resides rejects the socio-moral situation, healing could be severely impeded (Cassell 2004; Priya 2012).

The implications of this cultural perspective on illness (or grief) suggest that people are less likely to seek help and may also result in a lack of acknowledgement of their condition and perhaps suspicion regarding the validity of their situation. This interplay also supports the social constructionist approach that reality is a combination of an action both within and toward the person's world. This is an active, dynamic process, which gives credence to understanding that a particular state of illness (or grief) differs from person to person; that the experience of the illness is different to the experience that the patient has with that illness. Charmaz (1991) builds on this further, suggesting that people construct and manage their own illness, and in the case of chronic illness, they may isolate themselves from the outside world and have a pessimistic view of their future. They may struggle to make sense of their situation, trying to make meaning of their lives within key elements of their lives such as social situations, personal and professional relationships, general health, financial, spiritual and cultural beliefs.

Priya (2012) identified four main elements that form to explain the social constructionism phenomena. The first element questions the contextualisation of reality and how reality is perceived through the process of induction. This element acknowledges that each individual will perceive their situation based upon a range of discourses such as gender, personality, role, grief religion etc. The second element acknowledges that reality is
developed through social interchange, hence when this differs from previous experience, for example in the case of feeling stigmatised whereby others within one’s social context do not validate or acknowledge a person’s grief, a specific reality is formed. Thirdly, social interaction tends to defer toward some form of regulated social interaction, so if one’s circumstances does not fit with the acknowledged interaction, reality is redefined. Finally, Priva (2012) recognises the importance of, the dialogue between the researcher and the participant as non-hierarchical so that each world view is seen as legitimate.

Constructivism can be succinctly described as the enquiry into how ‘we construct worlds we know in a world we do not’ (Onuf 1989:38). Specific meanings are given to objects or perceptions and then defined, discussed and acted upon within that preconceived framework (Durrheim2012). These meanings are often based on stereotypes, developed using a cognitive paradigm, devoid of the influence of social, spiritual or emotional influence and later, the impact of language as a persuasive tool was recognised (Bargh 1996). Meaning was allocated based on the person’s use of language within a socially constructed world, which held its own set of accountabilities. This created a more complex situation in which meanings could be interpreted through a range of means; words, concepts and utterances, all of which could vary according to the emphasis placed on these units of communication by the speaker and the recipient (Edwards 1997). Actions are judged against social norms and these norms are used as a guide for how people behave under certain conditions. Language, both verbal and non verbal became a significant contributor to this interplay (Durrheim 2012). The outcome of this communication between the communicator and the recipient is what creates the environment, positive or negative to which the recipient responds.

Social constructionism offers guidance to understanding an individual’s suffering within their socio-historical context (Priya 2012). It takes into account the role of culture; of human responses to healing; of the impact and development of chronic illness due to suffering and the inappropriateness of dealing with the medical expected outcomes as a means of managing a person’s healing journey. Heidegger (1927) refers to the temporal sense of ‘being’ and that both fear and anxiety about the unknown aspects of the future contribute to ones sense of self. This sense of uncertainty, mixed with one’s social and cultural environment form an individual’s present state of being. This new state of fear and anxiety, formed by a combination of the interplay between personality, gender, role, culture and communication reflects the situation bereaved families find themselves whilst attempting to
readjust to a life without their child. A constructivist approach, while acknowledging the importance of past experiences and social and personal history, also tries to make sense of the future in relation to creating identity (Berenskoetter 2011). Making the future meaningful in the face of uncertainty is critical to this study and is consistent with the constructivist philosophy that the future is both a ‘source of anxiety and that it renders being incomplete’ (Berenskoetter 2011:652).

A social constructionist approach assists with the identification of support, and discrepancies within that support in the participants’ unique social, cultural and spiritual framework. Grief work is also affected by the ‘realignment of relationships with the deceased’ (framework (Neimeyer, Klass, Dennis 2014:492), hence the experiences the participants reported could have been significantly influenced by the social construct of their world. In addition, the association between resilience, making meaning and adapting life without their child is integral to the social constructionist model, impacting on the individual’s emotional and physical health (Neimeyer, Klass, Dennis 2014).

Validating each person’s grief experience and healing journey is a critical factor toward developing an empathic understanding of each person’s current sense of place (Priya 2012). The purpose of this research was to focus on the subjective experience of each participant by using in depth interviews to create an ‘insider’s view’ of both the parents’ and service providers experiences with regard to sudden child dearth. Using a social constructionist approach to observe the context and relationship between the event, the individual and their environment facilitated this understanding (Gergen 2001). The context of the interviews was therefore a critical factor in the research: “What something means depends on the cultural context in which it was originally created as well as the cultural context within which it is subsequently interpreted” (Patton 2002:112–113; Allen 2011). This approach was ideal for researching an individual’s experiences following a child death because it assists the researcher to understand the nature of an individual’s reaction between self and their environment, embracing new questions and therefore potential for new understandings. Linked with the participants’ context, the fact that the researcher was experienced in both drowning issues and counselling skills created a safe context for the participants to open up and trust that their personal stories would be treated with respect. Counselling skills are recognised as useful in qualitative research (Finlay 2011), utilising
reflective enquiry techniques by listening, checking back and identifying both the spoken
meaning and underlying meanings which may be evident to a trained counsellor through
tone, gesture, posture or creative language. The researcher can be flexible in that the
participant and researcher help add focus, direction and content to the information
gathered, based on the unique culture and context of their shared experiences. As
qualitative research does not presuppose outcomes, it is important for the researcher to be
reflexive and be guided by the participant, hence validating the participant’s contribution.

This research therefore offers a picture of the participants’ experiences regarding sudden
child death with the intent to gain a greater understanding of the impact and needs of
these participants in order to navigate through the situation.

4:2 Ethics
Ethical consideration is particularly relevant when interviewing bereaved individuals or
people working within bereavement support services. Concern regarding the emotional
wellbeing of bereaved participants has been a concern amongst ethics committees; yet
research indicates that when a study is conducted with sensitivity and appropriate rigour,
the bereaved participants experience a positive benefit from their participation (Beck,
Konnert 2007; Roberts, McGilloway 2011). Risk management protocols in accordance
with UQ protocol were addressed, with participants being offered a list of support
networks in the event of adverse reactions following from the interview experience.

Studies have shown that interviewing parents bereaved by the death of their young child
can actually have a cathartic effect, with parents perceiving that they are contributing to
significant information that will help others understand their grief and potentially facilitate
change (Dyregov 2004; Beck 2007; Dyregov et al. 2011). Whilst previous research has
suggested a minimum of one year between the death and interview, parents appear to
have mixed responses to this question, offering no clear indication of an acceptable time
frame (Dyregov 2004). However, what is clear are criteria for the researcher regarding
conduct. These include attention to the initial contact process; clear written information
regarding the study; flexibility regarding venue for the interview; sufficient time to conduct
the interview; and appropriately trained interviewer who is reflexive, attentive and
respectful, creating the opportunity for participant reflection (Dyregov 2004). Dyregov also
identified the importance of follow-up, self-care for both participant and researcher and the
opportunity to discuss and provide feedback on the results.
Initial approval was received from the Behavioural and Social Sciences Ethics Review Committee at the University of Queensland (Appendix 7). A separate ethics application was required and approved to interview staff at the Royal Children’s Hospital, HREC Reference number: HREC/12/QRCH/21(Appendix 8). This study upheld the four values regarding human research: research merit and integrity, beneficence, justice and respect for autonomy (NHMRC 2007).

4:3 Participants

Two sets of participants were sought from two groups:

- Parents of children who had experienced a fatal drowning
- Participants from organisations or private providers who offered support services following a child drowning death.

The study included only Queensland families and service providers for four main reasons: 1) support networks and government regulations vary state to state; 2) Queensland is a diverse state with a combination of rural, remote and urban living; 3) the cost of a national study was inhibitive; 4) this study could act as a pilot for a national study if the research suggests significant areas for further investigation.

4:3:1 Inclusion and exclusion criteria

Parents were eligible for inclusion in the study if at least 12 months had passed since their child’s death, the death occurred less than ten years ago, and the incident occurred in Queensland. Participants were also required to be English speaking. The time frame was selected because the different stages of grief may affect the parents’ readiness to seek help, in particular the importance of experiencing first ‘anniversaries’ such as birthdays and Christmas’s without their deceased child. However, awareness of the research initiated interest from two families outside of these parameters (one just ten months since her child’s drowning and the other 11 years since). Fourteen parents were included in the data collection, in which four were couples.

Service providers were included on the basis that they offered some form of support, professional or otherwise, to families who have suffered a child drowning death. The service provider list changed significantly as the study progressed, informed by snowball sampling, and finding new sources of support not considered prior to the parent and
service provider interviews. Some organisations contacted did not respond to any correspondence or the three follow-up emails and calls. Seventeen providers finally contributed to the research.

4:3:2 Sampling
This study involved a combination of purposive sampling (criterion) and snowball sampling for both the parent group and the service provider group. It was necessary to employ both these approaches as parent participants needed to have experienced the death of their child through drowning and providers needed to be providing, or thought to be providing support for these families. Families also needed to meet a criteria regarding time since their child’s death. Snowball sampling acted as insurance in that the researcher did not exclude a service provider mentioned by a parent or suggested by a participant provider. In addition, it was considered appropriate that if a parent had heard of the study and wished to be involved (on the basis they met the time criteria), this involvement would be welcomed. This sampling approach is consistent with qualitative inquiry in that it allows for in-depth enquiry with relatively small specifically selected samples (Patton 1990). Criterion sampling, an aspect of purposive sampling, was used as it involves identifying a specific set of participants who meet predetermined criteria, hence ensuring the research focuses on those who can contribute most appropriately" (Liamputtong 2009: 14). Sampling was also chosen on the basis that specific concepts were being explored. These concepts underpinned the questions asked. By comparing and integrating statements based on these concepts, the numbers of participants interviewed reached saturation, i.e. when a point was reached whereby little new information was being presented to value add to the understanding. Once narratives started to repeat such concepts or themes, the researcher had no need to continue the sampling process (Allen 2011).

This style of purposive sampling is appropriate as the research focuses specifically on individuals who had experience in each of the two groups, i.e. as a service provider or as a parent of a deceased child. It is only these specific people that can supply the information required for this research. Therefore, purposive sampling strategies for both sets of participants were used to allow for the selection of “information rich cases for study in depth” (Patton 1990:230).

Snowball sampling allows participants the opportunity to suggest other people they think will be interested in participating and is often used in research involving participants who
may be difficult to access or are only willing to participate if referred from known networks. Participants in both groups accessed in the current study had the opportunity to suggest other families who they thought may wish to be involved in the research. This style of sampling is particularly useful when a study involves the use of gatekeepers to access participants. Snowball sampling was more evident with the service provider group than the parent group. In this instance, gatekeepers provided all the referrals in the parent group with one exception, though this was not the case with the service providers. Consistent with Walter’s suggestions, gatekeepers themselves recommended other potential participants that had not previously been considered or accessible to the study (Walter 2010).

The sample size for parent interviews (male: n=4; female: n=10) was based on participant availability as well as the recognition that the richness of the study is in taking time to gather a thorough understanding of the range and depth of issues rather than quantity. This is consistent with qualitative research in that the concentration is on flexibility and depth, focusing on the key questions, rather than quantity of responses (Padgett 2008). Although it was hoped that parents suggest other parents in line with the snowball sampling approach, only one parent suggested another parent to contact for the study. However, three parents suggested a service provider that had not previously been contacted for the study.

Purposive and snowball sampling was used to identify and contact service providers. Appendix 4 lists the service providers included in the study. Half of the interviews occurred as a result of recommendations from other service providers, and, suggestions from parents. Seventeen service providers were interviewed between July and October 2011.

4:3:3 Contacting the parents
Parents were selected via gatekeepers who had professional or personal contacts with bereaved families. Families were initially contacted, through direct contact from the gatekeepers by phone, by letters or postings by organisations on their websites and/or Facebook pages and asked if they would consider being part of this study. In addition to this purposive approach, with the intention of finding families who had not used an organised support network, an article was placed in a Sunshine Coast parent magazine. This occurred due to the author’s personal contact with the magazine editor and was
therefore an opportunistic approach to capture some families not identified through the other avenues; however, there was no response.

When a potential participant indicated their interest to participate in the study to the gatekeeper, permission was sought by the gatekeeper to provide the researcher with contact details. Once received, families were contacted within 48 hours and the researcher introduced herself and explained the research. Families were then sent an information sheet (Appendix 1) and consent form (Appendix 2) on UQ letterhead describing the purpose of the study and citing the ethics approval. The letter included a return slip which families were required to complete to indicate their willingness to participate in the study. Due to the sensitivity of the issue, the letter included an explicit statement that no questions would be asked if families did not wish to participate.

Following written acceptance into the study, participants were sent a consent form which described the aims of the research, the full scope of the study, the questions to be considered during the interviews, the commitment to the process, the opportunity to exclude themselves at any stage and the process regarding the interviews and the written/published outcome. Participants were asked to sign these forms and return them prior to interviews being scheduled. In reality, most parents and service providers did not return the forms prior to the interview. When contacted by the author 24 hours before the interview to reconfirm, the form was mentioned and if it had not already been sent, it was agreed that this would be handled at the time of the interview. This checking process to confirm understanding and expectations from both parties during the interview and the procedures following the interview was critical. The grief journey is non-linear and certain triggers, either just a bad day or a key anniversary date, could have (and did for some) prevent the participant involvement at that time. Under such circumstances, we were able to reorganise the interview.

Every family that was sent the letter did either return the slip or contacted the researcher via phone to indicate their willingness to participate.

Meetings with those who had agreed to participate were arranged over the phone and email confirmation was sent with a copy of the draft questions. This helped the parent to prepare for the interview and was also intended to minimise any fear or concern about the focus of the interview. However, it was also made clear that this was a draft and the
researcher was keen for the parent to include other issues which may have been omitted. Whilst there were only a few changes, the final questions used in the semi-structured interviews were given to the participant at the commencement of the interview. Families who agreed to participate were also asked if they would like to suggest other families who may be interested in participating (This question was also asked at the conclusion of most interviews).

Seventeen Queensland parents initially indicated interest in the study, and 14 participated. One potential participant was ineligible as she was not the parent of the deceased child. The other two sets of parents were not interviewed, as they were unable to organise an interview due to other commitments, even though opportunities were offered over a seven-month period.

Parents were telephoned to confirm arrangements 24 hours prior to the scheduled meeting. Of these interviews, six (6) of the fourteen (14) interviews had to be rescheduled. Arranging the parent interviews provided some insight into the challenges these families faced, potentially developing an unspoken bias regarding the researcher’s perception of the impact of the traumatic event. The venue required a place with minimum interruption and ambient noise. Participants were given the choice of meeting places. In the end, six interviews were held at the author’s office, eight in participants’ private homes, and one in a pre-arranged private McDonald’s room near Sydney airport (the Sydney interview occurred interstate because the drowning occurred in Queensland but the mother had recently relocated to Sydney). Whilst it was possible to manage the noise factor in the office, it was more challenging in participants’ homes. Nevertheless, only one interview was of concern; the house was on a flight path and airplane noise interrupted on a regular basis. The high quality digital recorder helped ameliorate the interferences and therefore ultimately did not affect accuracy in transcribing.

4:3:4 Contacting service providers

In most cases, initial contact involved a phone call to the service provider, introducing the research and requesting the most appropriate contact to discuss the study. In some cases, this was a simple task. In others, over six months of calls, emails and assurances to meet ended up without an interview due to staff changes, system changes and inability to identify key personnel. In one case, additional ethics approval was required and finally approved.
Of the 17 service provider interviews conducted, 13 were face-to-face interviews, one was a brief telephone interview and three responded via email. In contrast to the face-to-face interviews, the emailed and telephone interviews lacked depth.

Having established the best point of contact, a letter was sent to the service provider, explaining the study and requesting permission to pursue contact. If service providers responded to this letter, a second letter with the questions for the in-depth, semi-structured interview and possible focus groups (if applicable) was sent and the venue and date for the meeting was established. The meeting was further confirmed 24 hours prior to the agreed time and date. Appendix 5 lists the Service Provider questions.

Similar to the parents, it was important to build the trust of the service providers. Although they had received a letter explaining the study (Appendix 6), it was important that they felt confident that the information they would be sharing would be treated with appropriate sensitivity, especially if there was occasion to criticise their own service. It was made clear that these questions were only a guide and that participants were encouraged to expand and include further areas of relevance and significance. It was also clarified that these questions were based on a limited understanding and that the purpose of this research was to achieve a more in-depth appreciation of the issues based on their personal and, in some cases, professional experience. Participants were open and constructive in their responses and all had a desire to offer improved and expanded services. In contrast to the face-to-face interviews, the emailed and telephone interviews lacked this depth.

4:3:5 The interviews – parents / service providers
Parents
Using in-depth, semi-structured interviews, the focus is on participants’ subjective meanings and interpretations they give to their experience (Denzin 1989). In-depth interviews allowed the author to gain an understanding of the social interactions and renegotiated pathways that the participant developed since their loss. Parent participants were asked if they would prefer to be interviewed individually or with their partners. Participants were assured that either was acceptable. Suggestions regarding a possible benefit of speaking individually were discussed, including the opportunity to discuss sensitive issues that they may not have been able to discuss with their partner, perhaps due to different coping styles. Alternatively, they may have preferred the support of their
partner present. All participants chose to be interviewed individually. Rice concurred with this, suggesting that by interviewing partners together, they may have difficulty discussing sexual issues as well as the ‘expected role’ that they had performed prior to their child’s death (Rice 1999). This was seen as an opportunity for families to ‘have a voice’, an essential ingredient in qualitative research where participants may be marginalised through stigma, finance, social isolation or ill health.

Parents were sent a list of questions prior to the interview, which suggested various themes and were intended merely as a guide (Appendix 3). These questions were developed over a few months based on the literature and in negotiation with colleagues, Hannah’s Foundation and the author’s professional experiences in drowning prevention, clinical counselling and knowledge of some legal aspects in relation to a fatal drowning. The question on home ownership was based on suggestions that a number of domestic pool drownings occur in new or rented homes, when families are unfamiliar with the surroundings, and/or with limited ability to make changes to the environment.

Questions pertaining to support were developed on the basis of discussions with injury prevention colleagues and support services, counselling colleagues and knowledge as a clinical counsellor of challenges people face when confronted with grief, and the added complexity of disenfranchised or stigmatised grief.

Providing the questions prior to the interview helped to give some focus to the research and also to minimise any potential fear or element of surprise in the interview process. It was made clear to participants that these questions were only a guide and participants were encouraged to expand and include further areas of relevance and significance. Participants were advised that these questions were based on the author’s limited understanding and that the purpose of this research was to achieve a more in-depth appreciation of their personal experience.

This semi-structured interview approach allowed participants to contribute their own experience rather than be confined to a rigid questionnaire that may not reflect their issues, or may only offer limited opportunity for explanation/response (Walter 2010). The questions were used as a tool to maintain focus on the research objectives, rather than a prescriptive menu. In relation to this study, this approach was intended to help the participant relay the events and the meaning of those events in their own words and in
relation to their own social structure (Walter 2010). As Plummer pointed out, the impact is more about the relevance and importance of the event rather than the actual ‘truth’ of the event itself (Plummer 2001). It was originally considered that part of the reason for people being involved in this research was their opportunity to be heard, and the possibility that, through the outcomes of the research, they were able to help others. This is consistent with the research that suggests participation in research has an altruistic element offering a further coping strategy amongst the tool kit of strategies that the parents had already adopted in order to survive their grief (Neimeyer, Prigerson, Davies 2010).

It was important for the researcher to be flexible and receptive to the information received, whilst maintaining a clear focus on the aims of the study. This created a healthy and rich partnership between researcher and participant and respect for all contributions.

Adopting an iterative approach to the interviews reduced the possibility of becoming limited by preconceived ideas. It was therefore important to engage sophisticated open listening techniques and be aware of the participant’s positioning, rather than my own view of the world. This approach embraced the introduction of new questions, rather than having preconceived questions and concepts. In this way, the research was flexible in that the participant was able to add focus, direction and content to the information gathered, yet still keep in mind the key areas that the study intended to explore. This created a rich partnership between researcher and the participant and a respect for all contributions. Strict guidelines were followed to ensure reliability and validity whilst being flexible enough to embrace new and unexpected information.

Participants were able to share a range of their experiences in a safe, secure, non-judgmental setting. Parents were referred to the study by people that they knew and trusted and had built relationships with since the death of their child. Referring persons also explained that the researcher had 20 years’ experience working in drowning prevention, a psychology and clinical counselling background and was passionate about facilitating parents to have a voice in their experience and contributing to the knowledge regarding support needs.

Eliciting each individual’s story and unique experience was built on developing a positive, trusting and supportive relationship with the participant. Given that the process only called for one interview per participant, attempts to become temporarily immersed into ‘their
world’ was dependant on quickly developing rapport and trust with the parent. For the parent to be sharing such personal and emotional insights was a humbling experience and it was essential that this process was approached with respect and sensitivity.

All interviews maintained a healthy conversation flow and were often highly emotional, reflecting the unique and rich experience of the participant. In all the parent interviews, this was their first opportunity to discuss such a diverse range of issues, resulting in a potentially therapeutic impact. Conversely, if handled insensitively, the impact could have become negative and potentially harmful.

Recorded interviews averaged 80 minutes, though there were two interviews that were considerably longer and recorded in two parts. In addition, the researcher spoke with parents for approximately 30 minutes prior to the official interview in order to re-establish a supportive and trusting rapport and following all the interviews informal conversation occurred ranging between 30 minutes and three to four hours depending on the parent’s need to informally debrief.

Interviews were only a single event and as a consequence, particularly with the parent interviews, exploring the experiences without the opportunity to revisit meant efficient management of the emotions and potential exhaustion of the participant. Open-ended questions based on draft questions were essential to ensure the research questions were addressed but the key difference to facilitation skills appeared to be creating the opportunity for the answer to lead wherever the participant wished it to go, rather than have some set agendas and time restraints.

Upon completion of the interviews, participants were offered the opportunity to review their transcript and make any further comments that they believed relevant. This reflected not only the two-way trust process and open communication, but also the opportunity for parents to feel more relaxed, knowing that if they thought of something after the event, they had the opportunity to include it without the additional tension of time restrictions. Because the subject matter was so emotional, it was reasonable to consider the need for further information when they were not sitting in the emotion of the storytelling. However, only three parents requested the transcript to review and two parents made some additions to the transcripts. These additions included information on the name of a referral organisation and a request for more support in the ‘wish list’ section of the interview. In
addition, two other parents sent in further information, i.e. references and resources and one suggested a potential participant for the study. This reflected an altruistic experience from the study, recognising that further input would benefit the study content and ultimately help others who experience a child drowning death.

It was interesting to note that all the parents showed photographs of their child and, for the interviews conducted both in the parents’ homes and at alternate venues, parents shared various memorabilia and precious items in memory of their child.

As previously mentioned, each person’s experience is unique. Open ended, iterative style of interviewing allowed for the development of concepts from each participant that could be considered in terms of a range of variables such as gender, presence at time of event etc. (Walter 2010:33). This suggested that husbands and wives might have had different experiences, although sharing the same tragedy. As a consequence, four parents were interviewed separately, gaining insight into the husband and the wife’s perspective of their journey since their child’s death. This was consistent with Rubin’s thinking that it is highly possible that parents will report different versions of the same event, based on their perspective and, again, experiences that may have influenced their perspective (Rubin, Rubin 1995).

**Service providers**

Group interviews offer the opportunity for exploration and more robust exchange of ideas. This was only relevant for one provider which enabled individual experiences as a support person/organisation for bereaved parents to be balanced against the organisation’s mission statement and practice procedures, while exploring the potential for consistency, variance and/or rethinking of certain policies and procedures. This provided rich knowledge for the researcher in regard to the real practice of the service providers and the intent of the organisation, identifying a gap in delivery (Hansen 2006). In addition, in-depth discussions with individual service providers provided rich information regarding what the service provider believed they are offering and the actual experiences of the bereaved families.
Sensitivity to bereaved participants

Sensitivity toward the parent group and the service providers was a critical element of the study. For the service providers, it was important to be aware of their organisational affiliations and loyalties as well as the emotional impact of working in bereavement support. For the parents, there was potential for the interviews to evoke painful memories or probe feelings and thoughts about the deceased that had been hidden, and, as a result, there was a risk that participants could find the interview emotionally difficult. This is consistent with research on interviews regarding child death although research suggests that participants may experience a therapeutic component to the interview process (Cook, White, Ross-Russell 1995; Taneja et al. 2007; Dyregov et al. 2011). This is particularly relevant when the death may cause emotions such as guilt, shame, confusion and stigma, emotions, which are directly relevant to a child drowning death, suicide and other unintentional deaths. In order to attempt to mitigate this potential distress, a number of strategies were put in place.

Participation was voluntary, and participants were contacted via gatekeepers and not directly from the researcher. Their willingness to participate, rather than feeling coerced or obliged, suggested that participants appreciated the opportunity for their stories to be heard. This was consistent with the researcher’s background knowledge, anecdotal evidence that parents often do not get the opportunity to talk about their deceased child, and literature which suggests that some parents may want to share their story in order to support others through their tragedies (Dyregov et al. 2011). Sensitive, qualitative interviews can also have a therapeutic impact on the participants (Newman, Walker, Gefland 1999). For example, reported benefits from studies with parents who experienced suicide include increased self-awareness, gaining insight into the death, feelings of empowerment, feelings of a sense of purpose and the feeling that their participation will help others in the future (Dyregov et al. 2011).

Leaving an appropriate length of time between the child death and the interview was a consideration. However, whilst there is some debate about the timing, there is some consensus that allowing the one-year anniversary to pass is appropriate (Hynson et al. 2006). This study followed that protocol, with the exception of two participants. These participants were one month and one year respectively outside of the original parameters. For these, variations to the original UQ ethics committee application was sought as these parents heard about the study and requested the opportunity to contribute their
experiences. Rationale for seeking the variations was based on the unethical stance that for parents to be denied the opportunity to participate may prevent the cathartic effect of being able to share their story. Both applications were approved.

In addition, it was important to be aware that irrespective of the calendar dates, bereaved parents have good days and bad days. If the interview happened to be scheduled on a day when the parent woke up feeling bad, it was necessary to be flexible and reschedule. This occurred with three parent interviews.

The approach to the interview as well as the interview venue may have a significant impact on the bereaved parents’ participation experience (Hynson et al. 2006). Research suggests that “the home environment was the most conducive to the interview process for reasons of emotional comfort, as well as convenience” (Hynson et al. 2006:807). For this reason, participants were offered the choice of venue (their home, my office or some alternative) for the interviews, resulting in the researcher taking one interstate and one intrastate flight to meet these requirements. Participants also reported the value of having received information prior to the interview to allow for any questions about the research and to “think and reflect on the merits of the invitation’ (Hynson et al 2006 :807).

Whilst there was an expectation that some of the participants (in particular, the parent participants) would find the interviews highly emotional and become tearful, it was important to be sensitive to the value of this emotional reaction and to acknowledge the pain without minimising the emotion or trying to ‘move on’ too quickly. This has been identified as important by other researchers, resulting in a positive experience for both participant and researcher (Dyregov et al. 2011).

4:3:7 Confidentiality
Due to the sensitivity of the subject, care was taken with regard to protecting each participant's privacy. Whilst names were not used in the reporting, due to the small numbers of people being interviewed and the relative rarity of child drowning, confidentiality was challenging. Although each participant had signed a form stating that the information would be de-identified, the possibility of potential identification was discussed. All parents acknowledged this difficulty and were still happy to proceed with the interviews.
Tapes and transcripts were stored securely in a locked safe. Information on the recorder was password protected. Only the researcher and principal supervisor (if requested) had access to the original identified data. All identifying data will be destroyed following UQ procedures for shredding sensitive data and by using verifiable procedures for wiping recorded interviews.

**4:3:8 Debriefing**

Due to the sensitive nature of these interviews and the possibility that for some participants this may be their first opportunity to address certain issues, a risk management protocol was developed. This included the opportunity to request a referral to a support service if deemed necessary. As previously mentioned, on completion of the interviews, participants were offered the opportunity to debrief. Further opportunities for contact and ‘checking in’ occurred with participants who forwarded further information after their interview, or who requested to view the transcripts. As far as I am aware, no participant accessed further support. However, one male participant did comment that as a result of the interview and being able to reflect on his situation, he planned to seek further counselling to address some of the latent grief issues affecting his life.

Participants were informed that the outcome of the combined interviews will be a published document and that they would be notified once this document became available.

The original intent was to send a thank you card to each participant, but this was changed to an email exchange for two reasons. With regard to the parent participants, there was consideration of the potentially harmful impact of a card as parents’ expended significant emotional energy during the interviews and all interviews closed on a positive, supportive note. Further contact so close to the interview may have triggered emotions, which were difficult to handle without support in their often precariously balanced lives. With regard to the service providers, upon reflection, an email was more appropriate and professional.

My personal debriefing occurred with my clinical supervisor and UQ supervisors.

**4:4 Analysis**

*The thematic approach*

A thematic analysis was utilised in this study. This qualitative, style of research, using words and expression to elucidate experiences, lends itself to thematic analysis,
sometimes referred to as interpretive thematic analysis (Braun; Clarke 2006). This method involved identifying, analysing and reporting patterns (themes) within the data.

**Five stages of analysis**

Pope’s stages of thematic analysis have been utilised in qualitative health research.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Familiarisation</strong></td>
<td>Listening to the taped interviews in order to list key ideas and themes</td>
</tr>
<tr>
<td><strong>Identifying a thematic framework</strong></td>
<td>Using the key ideas to index the data into manageable chunks based on the aims and objectives of the study</td>
</tr>
<tr>
<td><strong>Indexing</strong></td>
<td>Coding the data into themes</td>
</tr>
<tr>
<td><strong>Charting</strong></td>
<td>Rearranging the data into key themes, each likely to be the main chapter topics</td>
</tr>
<tr>
<td><strong>Mapping and interpreting the data</strong></td>
<td>Finding meaning and explanations from the data</td>
</tr>
</tbody>
</table>

In this study Pope’s five stages of thematic analysis was utilised to methodically understand, analyse and interpret the data (Pope, Mays 2000). Pope outlines how thematic analysis also uses the four key learning styles: visual, auditory, kinaesthetic and tactile. By listening and observing the participant during the interview, then listening again in order to type, and then reading the transcript back many times, this allowed for a deeper understanding of the information on a range of levels. The first stage suggested by Pope, listening to recorded interviews in order to list key ideas and themes, involved intense concentration and resulted in a heightened emotional effect whilst transcribing. It was at this stage that repeated patterns of meaning became apparent which is intrinsic to developing key themes (Braun, Clarke 2006).

Themes became apparent from listening and reading back the transcripts. Whilst typing, a separate log was maintained as ideas and concepts formed. After they were transcribed, the documents were re-read and themes were noted.

The next stages (Pope, Mays 2000), identifying a thematic framework (using the key ideas to index the data into manageable chunks based on the aims and objectives of the study), using a storytelling approach to gain context, indexing (coding the data into themes),
charting (rearranging the data into key themes, each likely to be the main chapter topics) and mapping and interpreting the data (finding meaning and explanations from the data) were systematic processes in order to make sense of the data. Finding meaning and explanation in ideas is the purpose of thematic analysis: “A theme is more than a category. The generation of themes required moving beyond a description of a range of categories; to an explanation, or even better, an interpretation of the issue under investigation” (Green et al. 2007:549).

Using this combined approach helped identify patterns and themes within the participants’ responses. The inclusion of observational experiences and other documentation provided by the participant provided rich information and added context to the meaning of the spoken word. Nonverbal cues alongside the verbal cues were noted during the interview, as well as recording gaps, tears or sighs identified on the digital tape (Kellehear 1993, Emerson, Fretz, Shaw 1995; Vaitkus 1995). This added richness to the translation, providing insight into emotion that often speaks louder than actual words, or, at times, suggests the absence of language to express the emotion. Interviews were transcribed verbatim; another essential element of qualitative research, ensuring every word was captured so as not to miss a significant piece of insight into that person’s story (Baum 1991). Themes were sorted into chronological order (Gibbs 2007). Again, observational techniques were employed in the form of descriptive or reflective notes taken both during and after the interviews. These combined approaches helped enrich the quality of information which in turn contributed to the understanding and meaning of the participants’ experience (Lemon, Taylor 1998; Berg 2001).

Transcripts were numerically organised in that each paragraph was numbered in order to reference the coding process. This coding process occurred in a number of stages. First, questions were highlighted, numerically coded and assigned a number in accordance to the draft questions that guided the semi-structured interviews. Then the transcripts were analysed according to these questions, resulting in each transcript showing various colour and number articulations. In the service provider questions, question 7, ‘The cost of service’, ended up being coded a little more broadly to include funding for the service itself and not just focusing on the cost to the consumer. In addition, service providers and parents were asked what they would like to see improved and these responses were coded as their ‘wish list’.
This style of research and analysis offered the opportunity to document difficulties and obstacles and therefore provide insights into ‘why’ certain support interventions were not successful (Rosser 2003; Pini 2005). This was applicable to both the service providers and the parents of the deceased child. In particular, recognising that each person’s experience is unique, the use of generic labels did not offer sufficient insight into the experience. In some cases, parents discussed the impact of guilt and blame, yet the context of this label may have been quite different for the parent who was present at the time of the child’s death compared to the parent who was absent. This approach also had the benefit of being able to determine the activities and services of the service providers and how these may have been similar to or diversify from the parents’ experience. In addition, qualitative research can help uncover unintended consequences of service development and delivery (Griffiths, Hughes 1998), another critical factor in this study.

In utilising this inductive, theoretical approach to explore both the participants’ unique sets of experiences following their child’s fatal drowning and their use of a range of supports, a level of insight was achieved regarding the concordance between individuals’ experiences, use of social or health service supports and the support/delivery intentions of the services themselves. This information lent itself to triangulation, attempting to gain a better understanding of the actual experiences of the parents, the services available and the actual service usage.

To analyse the data, word processing was used using split screens in order to constantly reference back to the original transcripts, and later the themed groups, in order to ensure accurate representation. Benefits of constantly handling, re-reading, re-organising and categorising the data allowed for a more intimate knowledge of the data and, consequently, further richness and depth of information. Using the ‘search’ function split screens and colour blocking were the main processes used to organise the data.

4:5 Reflexivity
The reason for conducting the study in the first instance was based on my combined experiences in drowning prevention, including legislation, advocacy and prevention, and my role as a clinical counsellor. I became acutely aware of the lack of literature regarding the impact of fatal drowning on these families and the challenges with finding support through their grief. This helped create the positive dynamic relationship and also an
awareness of my subjectivity. However, it was important to engage active listening skills and openness in the interviews to ensure I captured the participants’ world-view, rather than that based on my initial reasons for conducting the research.

My background in behavioural science and clinical counselling played an important role. My ability to be sensitive to the participants’ emotional wellbeing was an asset, creating an atmosphere of safety while supporting the individuals’ choice in managing their emotions and need to continue or break during the interviews. This compassion as a witness to participant’s stories can be an integral part of participants feeling comfortable sharing their stories, creating an experiential space where the participant feels valued and heard (Priya 2012). This compassionate understanding also endorses the participants suffering, or difficulties, hence validating their emotions and creating an open environment for exploration of their experiences. Trust was paramount and developing this trusting relationship in a short period of time was critical to the richness of the research. Husserl proposed that the investigator should reject their natural attitude and suspend all pre-conceived and theoretical notions (Husserl 1970). This is supported by Cerbonne who stressed that it is the natural attitude based on our own experiences, which we as individuals bring to a situation, which can pre-suppose an outcome (Cerbonne 2006). Moran, suggested that the investigator has to ‘bracket’ their attitude in order to present the phenomenon as it appears to those who experienced it, rather than the bias of the researcher (Moran 2002). However, a balance is important, engaging a combination of trust and sensitivity with the researcher using a professional lens in which to facilitate a relatively unstructured interview in order to create an atmosphere of equality between the researcher and the participant (Allen 2011). There are significant benefits to the researcher having some background into the issues faced by the participants and that, rather than rejecting their own experience, they need to bracket it within a subjective context (Finlay, 2011). Allen (2011) also acknowledges this interplay, stressing the importance of the researcher being aware of their own insights and blindness in order to hear the experience of the participant from the participants’ perspective. This adds richness and depth to the interview process, creating a dynamic and purposeful relationship between the researcher and participant (Finlay 2011).

Adopting a reflexive approach, paying attention to the stories as they presented themselves rather than to filter through my own experiences, was important for the reliability of the enquiry (Hammersley, Atkinson 1990; Vaitkus 1991, Altheide, Johnson
Participants’ knowledge of the researcher’s experience and passion in drowning prevention and role as a clinical counsellor proved a positive aspect to families being able to relate to and trust the researcher.

It is important for researchers to be honest and straightforward about their research and to respond honestly and openly to any questions. This was particularly relevant with all participants, as some families may have already developed mistrust and frustration with the process that followed their traumatic event. In terms of the service providers, it was important to explain that the intent was to identify the services that are available and seek their advice on benefits and potential improvements to their services and not to cast aspersions on their existing service. In this way, they were active, contributing participants, aware that their input was based on their passion and commitment to their job/role and the opportunity to offer constructive suggestions based on their experience.

In developing that trust, participants were offered the opportunity to review their transcript and make any further comments they believed relevant. This reflected not only the two-way trust process and open communication, but also the opportunity for people to feel more relaxed, knowing that if they thought of something after the event, they had the opportunity to include it without the additional tension of time restrictions. Because the subject matter for families was so emotional, it was reasonable to consider the need for further information when they were not sitting in the emotion of the storytelling. Allen (2011) recognised that this participatory action from the participants provided an extra layer of ‘voice’ and that ‘by giving the participants the final word on the accuracy of the final analysis, the methodology incorporated a participatory action research approach’ (Allen 2011:39) this is consistent with the social constructivist paradigm as it adds insight into the quest to ‘understand what people do, how they interact with their world, their value, what it is they mean, and what are the discourses by which they interpret their world’ (Allen 2011:39).

Semi-structured interviews allow participants to contribute their own experience rather than be confined to a questionnaire, which may not reflect their issues or may only offer limited opportunity for explanation/response (Walter 2010:171). It allows for the participant to describe how ‘their actions and interpretations co-exist with broader social structures and patterns (Walter 2010:24). The participant had the opportunity to relay both the event itself and the meaning of those events, present and future, in their own words, The importance
of reflexivity within the social constructivist paradigm recognises that the researcher is hearing experiences that relate to a world that is unknown, a future that has no guidelines, yet one in which there is no choice but to enter (Berenskoetter 2011). It was therefore important to be aware of potential bias in looking for certain responses that may not be applicable to the participants’ experience.

4:6 Rigour and validity
The effective use of quality research requires attention to both reliability and validity (Charmaz 2006). To address the validity of a qualitative study, Charmaz suggests it needs to provide assistance to a defined population, contribute to the thoughts of further substantive research and contribute to a body of knowledge to improve the quality of our world.

Planning and careful execution of the prescheduled collection and analysis of data assisted the rigour and reliability in minimising any data contamination based on information outside of the interview process. Interpretative rigour and inter-rater reliability was achieved through independent readings of interview transcripts by supervisors, in-depth discussions and refinement of themes. Service providers and parent interviews were undertaken to provide a complex and interwoven perspective of participants’ experiences.

This potential intrusion of researcher attitude and the importance of reliability were addressed by establishing good interviewing techniques, field notes, recording the interview and using an open approach to analysing the data. Open-ended, exploratory questions, setting aside any pre-judgements prior to the interviews, enhanced the reliability of the research as well as the effective use of written notes and active listening techniques (Creswell 2005; Bryant 2009).

At the commencement of this study, I thought I was an accomplished interviewer, having interviewed prospective staff for positions within my professional team, and using counselling and facilitation skills as part of my professional life. After a few interviews I realised that interviewing skills for a qualitative, social constructivist study involved a combination of counselling and facilitation skills with the addition of a more open, non-time-constrained process, encouraging the development of ideas and retelling of experiences, to respect and acknowledge each person’s journey and vision for the future as their own unique pathway within their social world. I learned that interviewing skills for
this type of qualitative research had elements of facilitation whilst being less rigorous regarding achieving a preconceived outcome; rather to try to understand some common themes. Counselling skills were certainly valuable, and the absence of a time constraint imposed by a ‘session’ allowed for greater exploration.

4:7 Conclusion
This chapter described the qualitative, social constructionist approach used in the study to investigate the lived experiences of families and support providers following a fatal child drowning. It described and justified the methodology chosen, the theoretical approach and the process used to contact the participants, conduct the interviews and analyse the data. It also addressed the approach to ethics, reliability and validity within the study and raised some limitations with the recruitment process.

The importance of a reflexive approach was valuable to this style of research. It was important to look for not just the previously expected themes but to be open to new themes and concepts within the themes. It was important not to justify preconceived beliefs and knowledge but to hear and validate the experiences of all participants, which is conducive to excellence in qualitative enquiry.

Transcribing the interviews created the opportunity to both see and hear the interviews over and over again. Taking diary notations whilst transcribing, then using those notations to create some form of thematic sense and then going back to the transcript to cross-reference and expand on concepts and emotions, wove a rich tapestry way beyond what can be captured by the spoken or written word alone.

The use of a social constructionist, qualitative approach created the opportunity to explore the experiences of both parents and service providers in relation to the drowning death of their child and the range of supports available and needed in such circumstances. In using in-depth, semi-structured interviews, participants were guided in the general direction of the research aims while creating opportunity for new insights into participants' experiences.

The following chapters describe the results from the interviews, highlighting key aspects with direct quotations from the participants.
Chapter Five – The grief journey

“It was horrible; it was just so horrible to have to tell him what happened. You never expect in your wildest dreams that your life could turn around so quickly.”

Introduction
This chapter examines the grief journey experienced by parents and offers insight into the wide range of influences that affect how these experiences are interpreted. As a significant number of areas were identified, the theme map below offers a brief overview of the key themes identified from parent interviews.

Table 2. Themes Derived from Parent Interviews

| An altered state – the impact of their child drowning | • Emotional and physical well-being  
| | • Gender differences  
| | • Religious/spiritual well-being  
| Relationships | • Spouse  
| | • Family  
| | • Friends  
| Parent as Protector | • One less child – a parent’s dilemma  
| Honouring their Child | • Keeping their child alive through conversation  
| Returning to work | • Financial challenges  
| Parents perceptions of support through service providers |  
| Hospital and Emergency Services staff |  
| Autopsies and coronial investigations |  
| Funeral Homes |  
| Role of the GP |  
| Referral processes; counsellors, psychologists and psychiatrists |  
| Support organisations | • Peer support organisations  
| Suggestions for improvement to support |  
| Community support | • Perceived public attitude to parent’s |
This chapter comprises three sections. The first section addresses the first study objective; the impact of a child drowning death on parents. It highlights fundamental changes to parents’ lives after the death of their child. These include impact on physical and emotional health; relationships with spouse, surviving children, extended family and friends; the importance of continuing to honour their deceased child; and changes to work and financial situations. Section two reflects the second and third objective; the support available to parents bereaved by a fatal drowning and parents’ experience of social, organisational and professional support. Parents’ experiences with professional, organisational and community support are explored. The professionals mentioned by participants include emergency services and hospital staff, autopsy/coronial staff, funeral homes, general practitioners (GPs), counsellors, psychiatrists, psychologists and support organisations. This section also includes suggestions from parents on how to improve services for a grieving parent. In the final section of this chapter, the motivation by some parents to ‘pay it forward’ and use their experience to support the prevention of further fatal immersions and offer help to others in similar circumstances is discussed.

In examining the data, a range of themes and sub themes became apparent which formed the structure to present the data. These themes ultimately linked to the study objectives. Whilst the experiences of parents in this research differ, there are some common threads in the process of events relating to their child’s death, from the time of the actual drowning event to leaving the hospital without their child. The flow chart below was developed from the experiences reported by the parents in this study and offers insight into the journey of a grieving parent following their child’s fatal drowning. Experiences along each stage of this journey form the framework for the parents’ subsequent healing process toward re-assimilating into some form of productive life after their child’s death.
**Table 3. Parent participant information**

The following table illustrates a snapshot of the participants’ marital status, home ownership, age of child who drowned, location of drowning event, whether they had other children and if they had knowledge of first aid. These questions were asked at the commencement of the interviews.

<table>
<thead>
<tr>
<th>Parent</th>
<th>Home rented or owned</th>
<th>Marital status then</th>
<th>Marital status at interview</th>
<th>Where child drowned</th>
<th>Age of child who drowned</th>
<th>Other siblings</th>
<th>First-aid knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Rented</td>
<td>Single</td>
<td>Single</td>
<td>Public pool</td>
<td>5yrs 1month</td>
<td>Yes</td>
<td>Yes – pool staff</td>
</tr>
<tr>
<td>#2</td>
<td>Owned</td>
<td>Married</td>
<td>Married</td>
<td>Family member’s pool</td>
<td>2yrs 2 months</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>#3</td>
<td>Owned</td>
<td>Married</td>
<td>Married</td>
<td>Causeway/river</td>
<td>14yrs 22days</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>#4 and #9</td>
<td>Rented</td>
<td>Married</td>
<td>Married</td>
<td>Neighbour’s pool (unintended access)</td>
<td>5yrs 1month</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>#5 and #13</td>
<td>Owned</td>
<td>Married</td>
<td>Married</td>
<td>Neighbour’s pool under construction (unintended access)</td>
<td>3yrs 3 months</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>#6</td>
<td>Owned</td>
<td>Married</td>
<td>Married</td>
<td>Home pool</td>
<td>6yrs</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>#7 and #8</td>
<td>Rented</td>
<td>Married</td>
<td>Married</td>
<td>Visiting party – home pool</td>
<td>3yrs 11months</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>#10 and #12</td>
<td>Owned</td>
<td>Married</td>
<td>Married</td>
<td>Home pool</td>
<td>2yrs 10months</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>#11</td>
<td>Rented</td>
<td>Separated</td>
<td>Divorced – but new relationship</td>
<td>Public waterway</td>
<td>3yrs 10months</td>
<td>Yes</td>
<td>?</td>
</tr>
<tr>
<td>#14</td>
<td>Rented</td>
<td>Separated</td>
<td>Separated</td>
<td>Visiting family – home pool</td>
<td>2yrs 1 month</td>
<td>Yes</td>
<td>No – sibling used CPR sign</td>
</tr>
</tbody>
</table>
5.1 Impact of fatal drowning – an altered state

“We had a beautiful life before: it’s not beautiful now, it’s just life.”

Participants highlighted how life changed forever the day their child drowned. Parents’ emotional, physical and spiritual states were compromised, which for some impacted negatively on their financial situation. Recurrent fundamental themes were expressed by participants in relation to their overall sense of wellbeing. These themes included their physical and/or emotional health; their sense of identity and the impact on their identity of their perceived failure as protector for their child, surviving children and spouse; the nature and importance of ongoing relationships with immediate and extended family, friends and colleagues; the importance of continuing to honour their child; and the impact of their child’s death on work and finances. This section will explore these reactions.

5.1.1 Emotional and physical wellbeing
Participants commented on their physical response to their grief since their death of their child, and spoke of a variety of symptoms including chest pain, headaches, general bodily aches and even changes to their menstrual cycle.

“I ended up in hospital thinking I was having a heart attack. It was just stress.” #6F

“I thought I was having heart attacks but found out I had pneumonia. My health hasn’t been good since.” #9F

“There was a medical doctor and a counsellor supposedly who was doing this talk and it was, the thing that they promoted was the physical symptoms of grief. And I was really interested in that because I didn’t know how your body does react to grief, even breathing can become difficult. And this pain, this pain I was carrying in my chest for a long time. And after your arms would ache because there was nothing in them. Before I could almost tell you to the day (of my period). 28 cycle, seven days, five days dadada. And then later on further down the track, I actually, I was having all sorts of period related issues and they put me on some stuff to try and regulate them in some way. I actually
thought I had cancer in 2001 but it wasn’t till, um, 2002 I was diagnosed with cancer, the same week that (son) died.” #2F

Participants described connections between their emotional state and their physical health. A number of parents expressed disturbing dreams, sleep disturbances, overwhelming sadness and panic, depression and some had contemplated suicide. Sleep was a recurrent issue with experiences ranging from difficulties in getting to sleep or staying asleep to nightmares and the deceased child visiting in dreams. Peaceful refreshing sleep appeared to be lacking for most participants even many years after their child’s death.

“I am not sleeping. And when I do sleep I have all these dreams and stuff. It’s nice that he comes into my dreams but I am just so exhausted. I am on the highest dose of antidepressants already.” #14F

“My husband cried every night in his sleep. He screams every night in his sleep. We are all very depressed but we all pretend we are OK because that’s what other people want us to be.” #6F

“I was basically quite withdrawn, quite depressed. I contemplated suicide quite a bit. Which is really weird for me because I am not that sort of person. I sort of got my own way out of it – took about a year. Then I stopped thinking about things like that, sort of started to get on with my life. I think it was just the way I handled my grief.” #13M

One participant described the intensity of her pain profoundly, such that she experienced it as real physical pain, or “heart hurt”:

“I just have days when I miss her so much, it breaks my heart. I can actually feel my heart, it’s in pain. My actual heart hurts.” #1F

Participants spoke of ongoing emotional challenges since the death of their child, including an emotional short fuse, constantly reliving the experience and memories of their child, and the difficulties in facing the reality of the situation.
“People see you and think, gee, you are doing well. It’s a brave face. They don’t know what’s going on in my head. I still go to bed every night and cry myself to sleep. I wake up every morning and look at his photo and wish you were still there and I kiss (sibling) goodnight every night and it’s like looking at him in his cot. She is like the spit out of his mouth. People say the wrong thing to me; I snap at them, I get cranky. I was having these flashbacks. I could be driving, I could be sitting on the lounge, I could be in bed. Things like it wouldn’t necessarily be right from the beginning. It could be a flashback from when I found him in the pool; or it could be when I said goodbye to him or it could be the funeral or it could be the ambulance arriving. Any part, it could be anywhere and just flash. It was like a movie. People think, you see these movie sequences but that’s how it was. Right in front of my eyes. I couldn’t get it out of my head. I still get it.” #14F

“You are numb for quite a long period of your life. For three years I was just on auto. I find it really difficult because you live out some of those visions and thoughts and they are so hard to cope with, you don’t want to think too much anymore about them. You try and shove it back in there and keep it away because otherwise it eats you up. You never move on. You just cope, or try and cope.” #5F

A number of participants commented on how their personalities changed following their child’s death. Many recognised that they had become more socially isolated, and one participant described how she and her family had become more active in an effort to distract themselves. After a period of time she realised this was not an effective coping strategy and that their busy-ness was masking the grief in herself and remaining family members, and that they had to learn different ways of living in the altered family dynamic.

“I would say I am lost within myself. I don’t know what I need and what I don’t need. I am an ever-changing animal.” #8M

“I became very much a recluse and was quite happy just to sit at home in my pyjamas all weekend and read books.” #11F
“It was very scary to be just the three of us. Very scary. We did three things in a weekend just to keep us busy – that’s how we would cope. After about eight months we needed to reconnect as three, scary as it is. So we made a conscious decision to slow down. And since then it’s been great.” #3F

Gender differences in grief
There were differences in the ways that male and female participants described the emotional and physical impacts of their child’s death from drowning. Participants in relationships also recognised that their spouse experienced and expressed pain differently to themselves. One male participant described the effect on his self-image, and consequently on his weight.

“I have put so much weight on. I actually start Jenny Craig on Monday. I got fat, just didn’t care, didn’t care less. It’s been ten years. It’s like come on, time to do something about it.” #13M

Male and female participants acknowledged that men tended to become more introverted and actively absorb themselves in some kind of distracting activity such as work or alcohol use.

“He drunk for a while, a long while. He would always listen to me. But I did get to a point because I said you need to stop, or we can’t stay together because you keep drinking. You are not doing what you are supposed to do and (son) is missing you”. #7F

“I would say I am lost within myself, I don’t know what I need and what I don’t need. (Wife) does need the support from, reassurance, and that she is doing the right thing, that she is being a good mum and that her choices are correct and 10 out of 10 they are.” #8M

One participant spoke of his awareness of the harm alcohol and drugs could have caused him when in such a vulnerable state and consciously chose to avoid alcohol, especially after his wife had overdosed in an attempt to ameliorate her pain.
“Like I was cranky at her for the overdose but I forgave her very quickly because I knew why she did it – because she wanted to take the pain away, she couldn’t cope with the pain and, like, I fully get where she’s coming from with that. I made a very conscious decision early on to steer away from alcohol.” #13

Two of the male participants spoke of their silent private grieving, and that they felt it was important to hide their emotion from their family.

“When it first happened it got to (wife). It got to me too, but I didn’t show it until I was on my own. I’m not one for showing my emotions in front of people. (Wife) would sit there and she just started crying.” #4M

“I don’t show my emotions the way she does – it’s a bloke thing. And I thought, well, you don’t see me when I’m on my own.” #4M

In contrast, female participants acknowledged that they needed to communicate about their pain with others.

“You know, I couldn’t shut up. I’m a talker, talk talk – LAUGH–he went, you know, quiet and more introspective, um, you know, I found things that he had written like poetry and songs and that type of thing. So, yeah, it was kind of different. We all had our separate spaces. We found as we went along, that when, when I was OK, he was down.” #2F

**Religious/spiritual wellbeing**

Spiritual and/or or religious changes following their child’s death were raised by participants. Most described some kind of struggle with their belief in God, and some discussed their attempts to reconstruct thought patterns and faith. This involved significant inward contemplation, and, for some, discussions with extended family and religious members of their community to offer guidance with their struggle to realign their faith.
“We actively hold to it. I did a TV thing one time, not that they put to air but afterwards the person that did the interview from the ABC said to me how has faith helped, or hindered what’s gone on. I said well, um, I said I would be a liar if I said to you I didn’t question why this had to happen and why it did and why things didn’t turn out a different way, but there’s nothing wrong with taking your faith apart and then either reconstructing it or realising that the foundation of what your belief system is true and solid. And while we have to live with the sorrow and the pain this side, your faith helps you hang on to what will come, being reunited.” #2F

“But my personal comfort is that heaven is not going to be a physical place but I am going to have a child in heaven to hold because he is already there. And that gives me comfort, the thought.” #2F

Some parents acknowledged that they had had lost faith in God since their child’s death and expressed anger and a loss of trust in God. One parent commented that if there truly was a God, their child’s death would not have happened and another parent expressed confusion regarding God ‘taking’ their child rather than providing them with another child to care for who ultimately, in a timely manner, would return to God as an angel.

“Trust in God has gone out the window – if God wanted another angel, my, my feeling is why wouldn’t he give (husband) and I another one rather than take one? I’m really angry with God.” #11F

“There is no reason, there is no God, there is no reason. If there is a God and he’s done that, he’s an asshole.” #11F

Some participants described feeling the physical presence of their deceased child in the house, as well as the car or more public spaces. Participants also spoke of their experiences with clairvoyants and unexplained events. Some parents described what they perceived as a supernatural experience, such as keys being moved and temperature changes to the body. Most of the parents who commented on these kinds of experiences had previously been
sceptical about clairvoyance yet were convinced and comforted by these events after their child had died.

“I know if (son) is around me because my feet go ice cold and I can’t get warm. And I was laying on the bed. And I said to my daughter, come, we’ll watch a movie and I said Mummy’s feet are really cold. And she said, mummy (brother) is lying on your feet. And as I said, well, tell (brother) to come and lay on the pillow beside us – as soon as she said Philip and tapped the pillow, my feet went warm. So now every time I am in bed and my feet are cold, I know he is there.” #9F

“At lunch break I was laying back in the seat of the truck with my feet on the dash my hands folded on my chest and my work bag was on the passenger seat. And I heard this noise and I thought that seems like my workbag. And I sort of just rolled my head on the side and my workbag was on the floor and I seen P sitting on the seat. Well, I had, the truck door was open to let breeze in and I fell out of the truck. It scared me that much. I hurt my head. I was a blubbering mess. Mmm, but I haven’t seen him since, although things happening around the house that you can’t explain. We had our car keys on the table. Daughter hasn’t touched them. They’ve gone missing. We asked her, where are the car keys? I haven’t touched them, I haven’t touched them. But they moved.” #4M

5.1.2 Relationships

Spouse

“My husband and I became the patients”

These changing personal situations experienced by participants had a profound effect on their relationships. Changes in participants’ physical, emotional, spiritual and financial wellbeing impacted their relationships. Participants spoke of changing relationships with their spouses, immediate and extended families as well as friends. Some commented that they no longer felt that they were the same person as before their child died. It appeared that for most parents, the spousal relationship after the death was intensified in whatever the direction it was
heading in prior to their tragedy. Strong relationships appeared to become stronger while differences appeared to be magnified in less stable relationships.

Some parents reported positive impacts on their relationships. They spoke of balancing each other out, and the importance of recognising when their partners needed support and “sharing the load”. For these parents, it seemed that understanding each other’s styles of communication was a significant factor; recognising when their partners needed to talk, needed to be alone, needed supportive and not judgemental words as well as physical support with managing daily tasks such as shopping, cooking, getting children to school etc.

“He supported me, whatever works for you. We both changed as people and I always say we are both lucky that we liked who we changed into. I’ve got no qualms about us separating or anything like that. It’s just too strong. We’ve been through too much. Not that I did before. But now I know, if that makes sense.” #3F

“I think it’s strengthened our relationship. There have been times over the past eight years where it’s been a big strain.” #4M

Some relationships did not survive. One set of parents stated that while they were still married, their relationship had changed irrevocably.

"We tended to; when it first happened we talked a lot about songs we wanted at the funeral. We had one purpose, something we were doing together to organise the funeral. Afterwards we just didn’t talk anymore about it. It was just too painful for both of us. We just turned into hermits, just didn’t discuss. And even to this day we don’t, because it’s just too hard, it’s too hard. We sort of grew apart. We just became very introverted I guess. We sort of did our own thing. When (daughter) was born it was a turning point for us. If that wouldn’t have happened, I just don’t feel like, if we hadn’t had another child together I don’t think we would still be together.” #5

Parents spoke about the destructive force of self-blame and perceived blame by their partner for their child’s death on their relationships.
“We always have verbal fights; one of us yells at the other one and we somehow get over it. Yes, I think I spent a lot of time trying to destroy our relationship because I didn’t understand how (husband) could not blame me for (daughter’s) death – a lot of, oh my god, this is so fucking hard it would be easier apart, kind of thing. Then the realisation of having to do it on your own, we realised, no, it’s not easier on our own. Every day he says ‘I love you’ and I go mm, yeah OK because I don’t fully understand how he doesn’t blame me and he does love me.” #7F

“Probably for the first 12, 18 months after (wife) wanted me to tell her that I blamed her for it all, so we fought about everything and she was egging me on to blame her.” #8M

Difficulties in communicating with each other about their child’s death were mentioned by parents. These tensions resulted in an extremely challenging and lengthy period after the death of their child.

“It was pretty rough. We had a pretty rough time for about three years; it was pretty hard on our relationship. Neither of us wanted to talk about it much.” #13F

Some reported the sense of responsibility they felt in relation to the wellbeing of their partner, and how this influenced their own grief reaction.

“My husband lost it – as far as I’m concerned we know he passed. We don’t need to know how long he was in there (the pool) because if we do that, my husband and son are going to punish themselves more. They are already punishing themselves – I’ve pretty much dealt with the police. I kept (husband) out of it as much as I could. We had (husband) pretty much sedated for the first seven days. I was nowhere near as bad as (husband). I didn’t have a choice. I was being; I really had to be strong. There was no time for me to break down, no time. I had to get my baby sorted out. My baby had to have the best.” #6F
Family
Relationships within the immediate family network were also changed. There was marked variation in experiences with extended families. Some parents openly praised their families and talked about them being a lifeline in their time of need.

“My sister stayed. She actually lives in (town). My niece flew down from (town). She arrived at the hospital the night when (daughter) actually went in. so she was there that night, caught the next plane down. My sister helped and she did everything. She organised which funeral parlour we were going to use, she worked out all of (daughter’s) funeral details and stuff. I still had an input. If I said no, it was no. She ran everything by me. She didn’t just take over.” #1F

“All the people, with everything they could have done, my mum was the best; the stuff she did for me. Because she said, you know, you are my child and I can’t do anything to stop the hurting, I can’t change any of this. And it was so hard on her. After she got me through the initial stuff she really went downhill. She’s, um, she stood behind me and if she wouldn’t have been around, I don’t know what would have happened. She’s a good old stick, my mum.” #11F

Other parents perceived that their families blamed them. Different expectations of grieving intensity and management caused tension and conflict. A number of grandparents and one uncle caused friction amongst their families. Some parents felt that their relatives expected support from them. There was a suggestion that some relatives felt more entitled to grieve than the parent themselves because of this blame. In one case, an uncle became so distraught that he became violent and eventually estranged from the family.

“Mother (grandma) told me ‘it’s all your fault that (son) drowned because you weren’t watching him’ – so it was really hard – my stepsister is another one who has said that, but she has denied it. She said, ‘I have always blamed you. If you had got off your fat arse and watched (son) he would be alive today’. And that was the biggest kick in the gut, in the stomach that I have had.” #9F
“My brother who was (son’s) godfather became very violent – he trashed the house, smashed windows, broke photos and he said that the day (son) died my life ended. We had to get a restraining order out and have him taken by the police; he threatened to kill us – and my brother was my best mate. He was dead set my best mate and he went and did that. I haven’t spoken to him since. Everyone else got by and did the best for their mental health that they could by speaking to people, going to doctors and whatever we needed to get through that situation, we did, so I was angry with him that he didn’t. So it’s another loss, someone you completely and utterly trusted. You know, the day before the funeral he went to Spotlight and bought ribbons for the bloody order of service. A bloke going to Spotlight. Freaky. Someone who was so there for him, and just lost the plot and is not there.” #11F

The impact of grief on extended families appeared to strongly influence the emotional journey for parents. Blame and anger became destructive behaviours in some families whilst physical and emotional support from family members was gratefully received and positively impacted on future relationships.

**Friends**

“It was contagious to go near her. Your children may die as well”

Friendship experiences following the death of participants’ children also varied. For some, existing or past friend relationships were consolidated. Most parents commented on changes in at least some friendships. There were experiences of frustration and disappointment, as well as appreciation. Almost all parents spoke of the challenges with people getting on with their own lives and having some judgement or expectation of the grieving parent to be coping in a certain way by a certain time. Being able to talk about the deceased child appeared to be an important factor in consolidating relationships, as well as ‘being there’ both in the early stages and later on to just support the parent.

”Just be there. You don’t have to talk to them. If they want to go and lie down on the bed, if they don’t want to eat for three days, let them not eat for three days. But just be there in case they need to talk to you.” #1F
Parents who reported positive experiences with friends following the death of their child described varying emotional and physical characteristics of these friendships. Positive experiences included friends checking up on them all the time; physically being with them; talking about their deceased child; remembering birthdays and special events and offering to include them in various activities. It was clear that parents needed a consistency of support and for friends to persist with staying in contact and helping with organising various life needs, not taking ‘no’ for an answer.

“It’s just that they would ring up and check on you. If they hadn’t heard from you yesterday they’d just check up or drop past or something like that. The amount of times that they would, they wouldn’t call; they would just rock up at my place. Sometimes I was just sitting outside bawling. They didn’t have to say anything. They didn’t judge. They would just be there, giving me a hug and tuck me in bed and just, that type of friendship.” #11F

“I have friends at work, she always remembers, she always acknowledges his birthday; it’s really special to me. And she’ll be sitting there crying at work, sending me an email, saying she’s thinking of me. And it means so much to me. It’s so important that someone can do that.” #5F

“I got a mixed bag of everything – (my wife) got the opposite side. Some of the people at school wouldn’t talk to her. It was like it was contagious to go near her; your children may die as well. So you truly found out who your friends were and who they weren’t. Quite a few people stuck by her and others disowned her.” #8M

As observed in relation to family relationships, other parents experienced lack of support and felt that they were being judged by friends. These perceived judgements ranged from the circumstances surrounding the drowning event, expectations of where the parent should be in relation to ‘getting over’ their grief and judgements on to personal issues such as parent’s desire to have more children.
“Friends would say, ‘Oh, you had two. Shouldn’t you just be happy?’ and things like that really. Well, we always wanted more children – always wanted a big family.” #8M

Parents often commented on how others (friends and families) appeared to have some kind of inbuilt time frame for when grieving families should ‘get on with their lives’. Participants displayed frustration and anger and commented that that people did not grasp the depth and longevity of their grief. Some participants suggested a way forward.

“It’s been 22 months now and friend support isn’t always there now, you know what I mean? People now look at you and think OK, they’re OK and they’re getting on with everything. But it’s quite the opposite, quite the opposite.” #6F

“Just to keep the contact and just, tell them what they are feeling is normal. Don’t judge what they are feeling.” #7F

“Remove your judgements and remove your own personal opinions and beliefs.” #12M

Empty promises and the disappointment experienced when friends didn’t follow through with their commitments (e.g. a visit) were recognised by parents as influencing personal relationships. During such vulnerable times, this appeared to have a great impact.

“I had some friends that made empty promises early in the piece. We’ll come round and help you do the grocery shopping tonight or something like that. They wouldn’t show up or call. I felt very disappointed by that. Not that I, I don’t expect anyone to do anything for me, but when you put an offer out there to someone that is vulnerable and you don’t make good on that promise, it’s disappointing and I learnt pretty quickly to cull a lot of those people.” #11F

“After the day of the funeral they said ‘Ah, you know, we will come in the school holidays, we will come and visit, come and visit’. So every morning (son) and I would get up and I would make muffins in case somebody came. But they never came. Waited and waited but they never came.” #2F
“The kids’ grief was probably the hardest.”

Parents’ sense of identity as ‘protectors’ for their child, surviving children, and spouses, was altered following the death of their child. Most participants described their inability to function in their expected or perceived role. They discussed feeling self-blame and guilt associated with their inability to perform the ‘natural’ parent role to protect one’s own child. Participants reported feeling that they had betrayed their deceased child, as well as surviving family members.

“I still blame myself. I know, if you were to come to me and said I lost my son in whatever circumstances because you had taken your eyes off him for only a minute, we can’t watch them 24/7, seven days a week. It’s just not possible—I would say it’s not your fault, but when you are in a position, you can’t, you can’t tell yourself that because—I would always say to him, I will always look after you and I will always be there for you because you are the one man who is never going to break my heart. And I feel like I betrayed him because I didn’t look after him. And nothing anyone will say or do will change the way I feel. I am his mum. I am supposed to protect him and look after him.” #14F

“I mean, mums are supposed to fix everything in the family – you know, you put band aids and cuts and hug kids when they cry and I couldn’t fix this because, um, I believed that I caused it. The kids’ grief was probably the hardest as well and looking at (husband) every day, waking up and seeing his heartache and thinking, my God, this is what I have done to my family.” #10F

“I am the parent; I didn’t look after my child.” #6F
Others described how partners contributed to their ongoing sense of pain and guilt in their perceived failure to protect their child.

“So I rang him and told him and his exact words to me, they will stick in my mind forever; he said to me, how the fuck did you let that happen? If anything happens to him I will kill myself.” #14F

Parents spoke of their responsibilities and sense of concern for surviving siblings. This included protecting them from the scene at the time of the event, being overprotective at times such as no longer allowing sleepovers, buying excessively as compensation, taking them to places they had promised to take their deceased child, and trying to control their grief in the presence of siblings so as not to be emotionally dependant on their children.

“If I’m driving my daughter to school, it’s not appropriate for me to burst into tears. It’s not safe and I have to get my daughter to school.” #3F

“We won’t forget him. We are concentrating on (sister) now. I promised I’d take him to SeaWorld and I didn’t get him there. So I intend to take (sister).” #4M

Focusing energy on parenting surviving sibling(s) was acknowledged as a coping mechanism for some participants:

“I made a choice that for (sibling) I was going to keep going and as hard as that was some days getting out of bed. I can’t remember having a good sleep for years after that happened.” #11F

Regardless of the difficulties faced in personal relationships among parents, there appeared to be a synergy in their concerns for the emotional and behavioural changes for their surviving children. Parents spoke of their concerns for the welfare of their surviving children and the challenges faced since the drowning death. Trying to keep life going as normally as possible was very difficult for most parents. Many siblings had significant emotional reactions and diminished effort in schoolwork was also common. Mood swings in surviving children
appeared to create a lot of tension in the families and often parents were uncertain about how to manage these changed behaviours while they too were grieving.

“She started going through a bit of obsessive-compulsive habits she hadn’t done before. Counting things, doing her hair X amount of times before she was happy with it. Shoelaces, clothes had to be a certain way. It was frustrating to me because I didn’t realise what it was. She tried to tiptoe around it, what had happened. She would get very angry, very cranky. One day – I didn’t know what to do. She was kicking and screaming.” #14F

“Her schoolwork is a lot of crap. She wags school now where she never ever did before. She was getting As and Bs and now she’s getting Ds and Es in her schoolwork. Everything about her has changed.” #1F

“(Son) basically shut down and didn’t speak and became almost autistic in his mannerisms. There was a lot of head banging, grunting etc.” #12M

One mother described the impact on her surviving children in relation to their altered motivation in all aspects of life since their sibling drowned.

“My oldest children did competitive swimming for 11 years – well, they haven’t swum since. (Oldest daughter) doesn’t want to swim anymore; she turned away from her music. You know, she put on nearly 40 kilos.” #9F

Another mother described in depth her eldest son’s experience since his brother’s death. She commented on his struggle with being an only child, his ability to form positive and continued friendships, and his tendency to sabotage any potential positive experiences that come his way. She concluded by saying that her son suffers depression that was triggered by his brother’s death.

“The shadow of everything that has happened is still very much there for (sibling). I think, everything that’s happened to (sibling) all comes back to that one thing. I think
that (surviving son) loved being a big brother. That’s something that he bitterly regrets. I think, that he doesn’t have a sibling. That shadow of (sibling’s) death is in his relationships, and I believe, amateur psychologist that I might be, is that at the heart of it, because of what happened to (son), I don’t think (surviving son) believes he deserves to have a good happy life so he will sabotage relationships if they get too close, you know. Things going really well for him, he panics and that sort of thing happens. He has been diagnosed as having depression and an anxiety disorder. #2F

Difficulties in balancing efforts to honour their deceased child and the impact on the relationship with surviving child(ren) were acknowledged by parents. In one family, the older children have moved out of home since the death of the sibling, and the youngest child is struggling with a combination of his sister’s death and the loss of his other siblings’ presence in the home.

"The kids’ grief was probably the hardest as well, because I’ve lost my relationship with my two older kids because of it – my son’s chair was the one that (daughter) used to climb the gate, and he was told to put it back two days before. It wasn’t supposed to be there. The kids can’t cope with it – they don’t come home. They have actually left home. They just can’t cope. So our (young son) comes from a family of five kids to his sister dying and him being really alone because everybody’s moving out of home – so everybody abandons (son). Including family.” #10F

“Since (daughter) drowned, (sibling) barely speaks to my wife now – he doesn’t grieve very well and he doesn’t cope with his grief. He spends a fair bit of time drinking.” #12M

Only one mother spoke positively about the social support her daughter had received since her teenage brother’s fatal drowning. The parents perceived that it was acknowledged that their teenage child had made a poor decision and the parents did not blame themselves or perceive that others blamed them.
“She is good. We are very open and she has a very good network of friends, so we’re lucky.” #3F

One less child; a parents’ dilemma
Parents described the overwhelming challenges associated with parenting surviving children. Difficulties were described in relation to previously routine issues – such as responding to a question when meeting someone new about the number of children in the family. Two participants spoke of the how their surviving children were similar in physical appearance to their deceased child. Whilst they expressed that in some ways it was wonderful, it could also be a very confronting experience for them.

“Younger child is the spitting image of (daughter). Her mannerisms and that, they are so much alike. I love it and I hate it. I love it because it would give me some insight now that she is the same age into what (daughter) may have been like. But at the same time, it’s so frigging difficult. I just look at her some days and I just want to say to her are you sure you are you and not her. Because I know you are you, but you really just seem like you are her.” #7F

Dealing with the changed sense of identity as a parent following the death of their child was also confusing for parents who did not have surviving children. Parents described a sense of bewilderment, and of being lost.

“I find myself, if I walk through a shop and see, at the moment ‘Cars2’ is out, you see all this car merchandise and I lose it when I see that because he used to love cars. Anything boyish, I think, I wish I could buy that. And a couple of times this year I found myself going to pick up things from the boy’s dept, going to check out and thinking what am I doing? I don't need this. There is no point in buying this anymore. Like if I get into that sort of situation I get very upset and I cry and I get panicky. I literally get really anxious and I panic.” #10F

“We had a beautiful life when (daughter) was in it. It’s not a beautiful life now, it’s just life. And we just live from day to day.” #10F
“I've got a man who puts me up on a pedestal and thinks the world of me and treats me like this princess. But I don't have my baby boy. I feel like I've had to trade one for the other. If I had (son) with me everything would be absolute bliss. Just perfect. He is the only thing missing. I am just not me. I can still have a laugh and a little joke around. I am getting a little bit better at it. I don’t have energy. It just seems like every day I am just going through the motions again. I just don't see an end to it.” #14F

5.1.4 Honouring their children
Participants described the importance of honouring their child immediately after the drowning death, but also in the months and years following. Parents honoured their children through beautiful eulogies at their child’s funeral, specific rituals, particularly on their child’s birthday and/or anniversary of their child’s death, and keeping and displaying memorabilia. One parent sponsored a child overseas with the same birth date as her deceased son.

“On the day of his passing we just get the balloons with ‘miss you’ on it. His favourite was vanilla coke and cheese and bacon balls. So we buy a bottle of vanilla coke. We all have a sip. It doesn’t matter if we are at his grave or here, we just tip it out and we all have cheese and bacon balls and crumble the rest for him.” #4M

“We still have birthday parties for him – and the day he died, I don’t work that day because I find the lead up to it, I’m quite vague, or I’m angry. Normally on the day, my friend comes over, mum comes over, we just sit around and chat and laugh about things he did and all that type of stuff. We have a few tears when the time on the clock goes by, that’s it, just a fairly regular day. I don’t do too much. I hide away. But his birthday, we have cake and we also sponsor a child. I always said that if we could find a sponsor child that had the same birthday as (son) I would sponsor him. And we did. So we sort of have a birthday party for both of them.” #11F
Parents described various ways of honouring their child’s memories on a daily basis. Approaches included having their ashes at home, photographs on display, photo albums, tattoos, car number plates, dedicated rooms or cabinets and for some, changing their work focus or work–life balance to pay tribute to their child’s life. Parents who kept their child’s ashes at home expressed the importance of being able to be ‘with’ their child at any time of the day or night without the limitations of distance or access to a burial site.

“(Son) is with his family, he is with us; we kept his ashes here with us. I thought, my little boy is not going to go to a place where they can shut the gate on me and I can’t go in when I want to. If I want to go up at midnight, not that I would. Or someone else control whether I leave flowers with him or not. I want him with me and if something happens to me or if something happens to (husband), then whoever goes first, (son) will probably be interned with them.”  #2F

Parents spoke of the importance of photographs of their child and other significant objects owned by their deceased child. Some parents had active interaction with the memorabilia, openly touching and showing the items. Other parents had a more passive approach, so that the significant objects were locked away or separated in order to protect them from being handled by their other children or visitors. On the occasions that interviews were conducted in the parents’ home, both the passive and active displays were evident.

“I have a cabinet that has all his special stuff in it. Like, you know, his favourite bowl he used to eat out of, his favourite pyjamas, his favourite shoes. And I got photos and locks of hair and presents the kids have given him Christmas and Easter and that.”  #14F

‘There is a section in (sister’s) room that they are not allowed to touch; none of the children are allowed to touch.”  #7F

While honouring their child in this way was important to parents, they also recognised the challenges associated with responding to questions elicited by these pictures and objects when new visitors who were unfamiliar with the family’s experience were in the home.
“It’s like you have this, like need that you have to still recognise your child so people ask me how many children do you have and they say where’s the other one and you say and then they say ‘Oh my god’ and don’t know how to deal with it and they run away.” #7F

Some parents also had more externalised reminders of their child such as number plates, specific trees or flowers planted in the gardens, or tattoos.

“That’s (daughter’s) tree, it smells nice. I actually boil it up and make lavender water.” #10F

‘We all have tattoos with his name. I have a big picture of him on my back and I’ve got tattoos on my wrist. That one is when we let the balloons go and this one says my being is gone but still I am not dead. It means that even though I have lost (son) I am not dead. I am still living for him in some way. Mums’ got a little forget me not with his name on it. My brother’s got (son’s) spirit lives on. His father’s got a picture of him as well on his chest. His uncle got his name on his heart. We’ve all taken our own way to memorialise him.” #11F

Keeping their child alive through conversation
Parents also acknowledged the importance of honouring their child through talking about them with friends and family, and the value in being able to talk freely about their child. This appeared to consolidate friendships and resulted in sustained relationships.

“My friend who lost a child, used to be like a session for me to speak to her; it helped me immensely. And I had friends who didn’t shun away from me, and they would come down whenever. And they still do.” #3F

“Friends were good actually. Used to talk about him all the time, which was good. We didn’t want them not to talk about him because it would make us feel bad if we went to their place and they had to watch what they said, you know.” #4M.
The challenges experienced by parents in keeping their child alive in this way were also described. Most parents reported that they often had to take the lead in these conversations, or help continue the conversation when people found it awkward to mention the deceased child’s name. It was important for parents that friends or family members remember and honour the deceased child through conversations or rituals and many parents expressed disappointment if their friends or families did not acknowledge this.

“I hate that people don’t talk about her. The avoidance. I hate that, I hate that.” #7

Some parents identified that it could be difficult to honour their child through conversation when others close to them were struggling with grief over the child’s death.

“Um, my dad still isn’t coping; even after all this time, my dad is not coping at all. Whenever we talk about (daughter) he cries. And that breaks my heart, seeing dad that, that sad and upset. But he doesn’t want to talk to anybody. I have told him I could get counselling. He doesn’t want to talk. He is 83. He says his heart is just so broken, he can’t talk to anybody about (grandson)– he says his heart is just so broken.” #1F

Difficulties in responding to questions about the number of children in the family were identified, but parents expressed that it was important to convey to others that the family should be acknowledged as one unit, including the deceased child.

“There was some friendships where the conversations would never go there, would never go there. (Sibling’s) friends at one time were there and they were obviously looking at the two boys together and I would come in and say those are pictures of my two boys, and I’d say something to them, you know, yes I have two children, this is my other son (name) and you sort of try and let them know that it’s OK and you just sort of know that they wouldn’t want to open up anything that would be hard to cope with. It’s like another wound. If people don’t let you even acknowledge that you had two children. Even now when people ask me how many children do you have, I always say now I have one surviving child.” #2F
5.1.5 Returning to work

The death of their child affected participants’ physical and emotional health to varying degrees. Challenges within spouse, family and friend relationships also significantly impacted on the ability for bereaved parents to manage their grief. These changes consequently influenced participants’ ability to work. The workplace is an influential environment and parents described positive and negative experiences with workplaces following the death of their child. In tandem with the other challenges faced by parents after the child's death, the level of support experienced by parents in the work environment considerably influenced their subsequent ability to re-enter the workforce and maintain their jobs, and this influenced their long-term physical and emotional health.

“Work was really wonderful to me. They said we don’t care if you don’t come back for a year. Just take your time. And (husband’s) work was fantastic too. Geez, they were fantastic. They put the wake on for us – raised money for the funeral and met the cost of the funeral. We had people in the community who nearly lost their child to drowning – they donated $5000.00 – you’ve got no idea of the supports. We didn’t have to worry about money.” #3F

One couple spoke of the counselling support available from their work to anyone affected by the drowning death, as well as the continued payment even when not at work, and the flexibility from the employer.

“All member of the family that needs support, it’s made available to them. It’s probably one thing (work) does very well – when things went horribly pear shaped there was basically nothing they couldn’t do for me. They made arrangements for me to be on leave for whatever period of time I needed, um, they did a collection through the union and through my work to assist with expenses, funeral expenses. One of the (workers) went and bought tea, coffee, cigarettes, milk and stuff; a lot of practical things that you don’t, as a grieving parent, think about.” #11M
In contrast, other participants spoke of the lack of understanding and compassion at work, often resulting in emotionally painful situations for the parent.

“They put a lot of pressure on me that didn’t need to be there. I’d say they never dealt with anything like this before. There was no compassion. It was, OK, well, you are back at work now. I’m not going to make allowances for you because I’d have to make them for others too. I got that sick and stressed I couldn’t (stay). I didn’t enjoy my job after that. I persevered. My boss wasn’t very supportive of it. He just pretended like nothing had happened – he didn’t come to the funeral or offer any words of support.” #6F

A number of participants spoke of their difficulty going back to work, having to face comments in reference to their tragedy and not being in a position with their grief to have the confidence to manage their responses in a healthy fashion.

Going back to work scares me because I don’t want to have to explain to people why I am like that all the time. And they will say, ‘I am sorry you have lost your child’, and what am I supposed to say to that? – or they will say, ‘I know how you are feeling’, and I think, you don’t know how I bloody well feel because you haven’t lost a son.” #13F

5.1.6 Financial challenges
Changes to work situations were inextricably linked with changes in financial situations. All participants spoke of changes in their financial situation since their child’s death. This included financial pressures associated with cost of the funeral, time off work, and inability to return to the same work. Financial changes and employers’ reactions to their child’s death were mentioned as significant factors by nearly all participants. Some parents struggled to meet the financial demands following the expense of the funeral and inability to return to work with the same focus or time commitments as they had done prior to their child’s death. However, not all the experiences were negative. One mother was offered support to start her own business as a result of community donations. Other participants had understanding employers, mainly from larger companies. This understanding included extended paid leave, flexibility in the hours worked, fundraising by work colleagues and an attempt to facilitate
colleague support by coordinating good wishes through a central point. Those without such support appeared to struggle more.

“I only started my business up after (daughter) died because the Hannah’s Foundation did an appeal to help raise funds because at the time when (daughter) passed away, I was at the stage of being kicked out of my unit because my rent was so behind and because the money that was donated I was able to start my own business – so it’s good because if I need to go and cry, I can go and cry an still do my job at the same time.” #1F

A number of participants changed jobs because of their altered emotional states or were unable to return to work at all. Two families were unable to purchase antidepressant medication as the cost was prohibitive. Financial challenges were also incurred by excessive spending as a way of coping with grief.

“I’d love to be able to go down and get medications for husband, but we just can’t afford them. I get very angry, very angry with the whole situation – son going out the back. If he hadn’t this wouldn’t have happened. We used to have savings and we are financially fuccked.” #6F

“Financially I do things now that I wouldn’t have done beforehand. Like if I have a really bad day, my therapy is to go shopping while I’m crying all the time. And I spend money I shouldn’t be spending.” #1F

“My biggest current challenge is outlook. I live day-by-day, week-by-week; and we have got ourselves into a lot of debt.” #8M

Expectations of friends, family and the community are borne out of culture and experience. Whilst support from these sources is pivotal to parents’ progress through their grief, other links also impact on their ability to move forward. A number of other influences can affect a parent’s ability to cope with their child’s unexpected death, including the media, professional organisations, schools and religious organisations. Parent vulnerability following a fatal child drowning requires support beyond the normal social supports and at times health
professionals and other organisations offer an opportunity to help parents through their grief journey. The following section identifies some of the experiences participants had with these services.

5.2 Parents’ perceptions of support through service providers

In this section, participants’ experiences with professional service providers, organisations and community providers following the death of their child are explored. Parents identified a number of sources. These include: emergency services and hospital staff; autopsy/coronial staff; funeral celebrants; general practitioners (GPs); counsellors, psychiatrists and psychologists; support organisations; and peer support. These categories were identified by parents and were not prompted during the interviews.

5.2.1 Hospital and emergency services staff

“I remember the nurse that I met. She was absolutely lovely.”

“The head ICU doctor had the bedside manner of an animal; he was unapproachable.”

Emergency staff and hospital staff created a lasting impression on the parent participants. Parents experienced a mixture of positive and negative responses, ranging from sensitive, professional, caring support and information exchange to what were perceived as insensitive and cold behaviours from staff members.

Most parents had strong opinions regarding the hospital support and that of the emergency service staff that were with them from the scene of the drowning through to the hospital. Positive experiences regarding the emotional sensitivity of the emergency staff and the emotional and medical interactions with the hospital staff were related.

“The best thing that happened that night as far as comfort and help was, there was a policeman there, I looked at his card just this morning, his name was xxx, and, um, when we left the hospital he, he came up to me and said ‘I will stay with your little boy; I’ll look after him’. He told me that they were going to take him to the John Tonge
Centre, so he said he would take care of him. That night he couldn’t have said anything better, just that he was going to look after him, make sure he stayed with him.” #2F

“He (policeman) sat there and he tried to keep me talking. He had been crying – I could see his eyes were red, like I could see he was upset. But he still tried talking, asked me where I came from, what my other two kids were like, how old they were, did I need to make a phone call, were they OK, where were they? Like, he didn’t just sit there. He tried to keep me from falling to bits. #14F

One participant reported a less favourable experience with police regarding insensitive language and behaviour on the night of his child’s death.

“For the statement – they took me in the back of the police car and I remember the two cops were laughing and joking in the car and I was sitting in the back and I thought it was pretty insensitive.” # 13M

Some participants spoke of their desire to thank the paramedics who attended the scene of their child’s drowning incident, but either had no way of contacting them or when they did request contact, this was not acknowledged or facilitated by the hospital. The need to offer their appreciation to these staff stemmed from the parents’ gratitude for the additional time they had with their child, or the opportunity that had been provided to them by paramedic staff to say goodbye and have time to gather the support of family and friends.

“There are a couple of people from that day I’d like to see again. You know, it’s just to, it’s just to say thanks. Although the outcome wasn’t perfect and we couldn’t save him, nobody could have saved him, if all that wasn’t done we wouldn’t have got the extra two days to say goodbye. You know, we had him on life support for two days. I got to sit with him we got to take photos of him, the girls got to see him, my family got to see him, my friends got to come and be with us.” #14F

“I have not heard from the hospital. I even wanted to contact the ambulance service people that helped us but nobody has got back to me how to do it. I have rung them
and said I need to; I want to thank these guys personally for what they did. Because they tried and it must have been very hard on them as well because it was only a young child. And I wanted them to know that I appreciated all they did. But nobody has contacted. We left messages after messages.” #6F

Positive experiences included the opportunity to have a lock of their child’s hair or foot and handprints, as well as support from a specialised counsellor regarding organ donation. Respect from nursing staff while children were still in their care was considered important. Parents appreciated efforts to ensure that their child was treated with dignity and as if they were still alive whilst in the presence of the parent. Parents also commented on the importance of being kept informed during their ordeal and having support regarding maintaining a positive attitude until the very end.

“And then the doctor said, um, he said, time of death – a.m. (date). That was it. He was gone. Then the doctor said to me straight away, right, organ donation. I asked him about organ donation and he didn’t go into it. He said you either do or you don’t. However, the social worker organised for someone from the organ donation team to come and explain; she said, ‘Look, I can get somebody from the organ team to come and talk to you’. And she did. I can’t remember the lady’s name from the organ donation place but she was so good. She worked with the social worker and they explained everything. And the nurses were really good too.” #14F

“I said, ‘You know, I want to take some of his hair’, um, I cut his finger nails and I kept his finger nails and she said, ‘OK, we can do some little hand and foot prints’, and she had this special stuff. It was like carbon paper. And she said how many do you want and she had these beautiful little folders. And B and I got to sit there and did his hand and little foot print and she said how many do you want, for ourselves, and one for each member of the family that was close to us and that and his godparents and all that. And then she cut a lock of hair and put it into a little bag, a little pinky colour bag that went with the pink folder that was with it. And, um, we took photos, we did videos, we just, all this last stuff that we would never get to do with him again. That time waiting on the bed there was worse than what I had been through all day because I
was waiting for them to actually come and take my baby away and the only way I could describe that is like, we were sitting there waiting to be executed. That’s what it felt like. And the, nobody wrote him off in that time in the hospital. They still kept coming in and checking him and turning him so he didn’t get sores. Because he had the tubes up his nose and his throat. He had yucky coming out of his nose and there was a male nurse who kept coming and wiping his nose for him and checking his wound and stuff. They still treated him like he was alive.” #14F

“The nurses, the ambulance lady and the doctor; they kept coming in and letting me know what they were doing and that they were trying and don’t give up hope.” #6F

Other parents perceived that hospital staff were insensitive. Harshness of tone, comments regarding ‘replacing’ the deceased child with another child and gender confusion were some of the experiences parents relayed. It was clear during the interview that the impact of these experiences had not diminished over time.

“One doctor at the hospital turned around and said,’ Oh well, you and your husband need to try for another child because that would make this all better’, yet I’m infertile! I could have slapped him. It was so insensitive and they just don’t realise it.” #10F

“He looked at me while I was standing there at the water fountain, and this is what he said. He said,’I’ll see you in there with the rest of them’ and walked off into the room! And I just stood there stunned, thinking, who are you, you know? And um, it gets worse. And, um, so I walked then after them, they walked into the room and we’re just standing there when I walked in and then when I came into the room, the doctor said, um (PAUSE) that (PAUSE)‘She died’. And for a minute I thought it was somebody else’s little girl that had died and not my (son). I said, ‘My little boy(TEARS), my darling little boy’. And the doctor said to me, turned around and said, ‘Well, he’s dead, your son’s dead’. That’s how he told us that our boy had died. It was so upsetting. My aunty was in the room cuddling (sibling) on the couch. She said it was the most callous thing she had ever heard in her life.” #2F
Some parents received social work support from the hospital whilst others did not have that opportunity. Receiving support resulted in a more positive hospital experience. Parents that did not receive support reported feeling angry and lost. One mother explained that due to the suddenness of her child’s death out of the hospital environment, her family did not feel that they were part of the hospital infrastructure, and that they did not have the opportunity to establish any relationships with medical or support staff within the hospital. Thus, they felt that they were not entitled to the services and benefits as a family whose child had been an inpatient. This was reported by more than one participant, and resulted in parents feeling lost and confused, lacking information and professional support to help guide them through the dying process and the immediate few days following their child’s death.

“The hospital was good. They offered me the social worker. I had a social worker there. One night shift and one day shift. I had lots of paperwork given me too with this number and that number Sids and Kids also called me, NSW organ donors called me to just check up to see how I was, and also rang me to tell me where (daughter’s) organs had gone.” #14F

“I don’t know if on the night having a social worker may have helped. Nine-to-five a social worker would have been assigned to the family, but because it was outside hours that this unfolded. I think it would have been really good to have been able to call someone who could have come.” #2F

“All I got told was the undertaker would be here to take (son) away, so the cops are coming here to stay till he goes. They could have sat us down and said, OK, this is what’s going to happen – if you need help here are some phone numbers to get you through the night. Here are some phone numbers to get you through the week. Here is this and this. But there was nothing. They didn’t even, we left and they didn’t even say goodbye.” #6F

Two parents whose child had gone through the Emergency Department of a Children’s hospital spoke positively of support post-death via the annual memorial ceremony hosted by the hospital. They also recalled receiving referral information for bereavement support,
although neither of these families made use of that information, possibly due to the time at which it was given. It seemed that the specialised children’s hospitals were more equipped to offer support under these circumstances than a general hospital.

“Every year they send you an invitation, you go and make a candle and like do a memory page that’s kept in a book that’s kept in the chapel.” #7F

“I think the hospital gave quite a large paraphernalia to (wife) at the time. Being a children’s hospital they specialised in that area anyway. The hospital foundation was there as well, I think also gave us some documentation in regards to support.” #8M

5.2.2. Autopsies and coronial investigations
Due to the nature of a fatal child drowning, these deaths require an autopsy and in some cases, a coronial investigation. Some parents expressed negative experiences including inappropriate language and tone used by health professionals, the autopsy being performed without the parents receiving information about the process, and difficulties in accessing information about their child following the autopsy.

“They just went ahead and did it. They didn’t ask permission or anything like that – so that was really tough, seeing him after he had the autopsy done without too much warning – I looked at him and his eyes were half open and when they’d done the autopsy they didn’t put his skull cap back on in alignment and he had, you know, the full autopsy with all the stitches and that. I wanted to pick him up and hug him, but I thought am I allowed to do that. I wasn’t sure. And I regret I didn’t, just, he is my son, I could have just picked him up. But I didn’t expect to see him like that.” #11F

“I had about three conversations with the coroner and he said if I wanted to he could retrieve the information. And in part of the conversation he referred to some photographs that were taken. And I said photographs? It would have been the dog door and the scene. And I said would I be able to get copies of those and he said he wasn’t sure. Next time I spoke to him about it he said he had rung the police and some police woman, it was a woman that was there, said, ‘Well, if Mrs xx wants access to
those photographs, she is going to have to apply for it under freedom of information or something like that’. I said, ‘Why would that be such a problem? It’s not like I want it for a coffee book thing’. It’s part of the story. I just sort of left it, you know. I didn’t have the strength to fight battles at that time.” #2F

However, other parents had a different experience, encountering a caring and considered approach from the autopsy team.

“I know that we asked for it to be as less invasive as possible, for an autopsy – so our wishes were done. She wasn’t sliced and diced as they usually do.” #8M

Following the autopsy, the coronial investigation can be a lengthy and complex process. Parents perceived that professional support during this time was limited, with only one dedicated coronial support officer in North Queensland. Support from this officer appeared to be of immense value to the parents. One mother spoke of a police officer’s attempt to explain the process although he himself had never experienced a coronial investigation. The experience of not knowing what to expect from the coronial process and the emotions that accompanied that situation was a common thread with nearly all participants.

“She went far beyond her job as a police – she was great, she was totally great” #9F

“X from the police has gone through a little bit with me. He has never been to one of these inquests before. He said he’s been through a criminal inquest before but not something like this. He explained to me how a courtroom works and things like that. I have never set foot in a courtroom.” #1F

A number of parents raised the issue of a timely and accurate death certificate being important to their emotional well being and affecting the management of their grief process.

“I do have a death certificate but it has ‘still under investigation’. But I did get a letter yesterday, 19 months later, saying I can now have a death certificate with cause of death, drowning. It does make a difference to me. I am glad that now I can actually
have a death certificate with the reason on it. All this time though I was still wondering, did they find something that I don’t know about? Was (daughter’s) accident really an accident? Because, I had no idea. I don’t know what’s going on. And to have that on my mind for, like, 19 months is crap.” #1F

5.2.3 Funeral homes
Experiences with funeral homes were only mentioned on a few occasions, apart from the funeral costs that were commented on by a number of parents. Two parents reported an excellent service from the funeral home whilst one mother mentioned the lack of communication between their family and the funeral home. A number of parents spoke of confusion as to who would be in contact with them, and within what time frame following their child’s death.

“We got support from the funeral director actually. At 10.30 at night I rung them up and within half an hour she was at our kitchen– sorting out (son’s) funeral. So yeah, that was really good.” #4M

“No body said if we could or couldn’t give him clothes – the whole time it wasn’t discussed. The whole time of dealing with this, I wasn’t told anything. I wasn’t told how I could go about things or if I could do this. There was no information given.” #6F

5.2.4 Role of the GP

“I think if it wasn’t for her, I think things would have turned out a lot differently for me. She was very, very good.”

Participants spoke of the relevance of their GP following their tragedy. GPs are often considered as the first place people go for assistance with their grief. This assistance can take the form of a quasi-counselling session or the opportunity to be prescribed medication to assist through the initial trauma. Some parents mentioned that because their GP knew them prior to the event, they perceived the GP to be a person of authority and comfort. A few
participants mentioned that if the family had been with the same GP for a long time, the GP may then be in a strong position to assess the parents’ coping mechanisms through their grief and be aware if the parent requires extra support from the GP, or if it was necessary to refer them to a specialised service. One parent spoke highly of their GP’s sensitivity and support, whilst a number of parents were frustrated with the lack of perceived support from their GPs and the inappropriate referrals to counselling or psychological services.

“The most important thing I think for the GP is that they have seen you when you are good – pre-tragedy, the GP’s got your zero here, they can see you right down in those deep depths, whereas a counsellor might be around here because they have only seen you at your lowest.” #12M

“My doctor was really good. At the time my GP, she was very, because I needed to see someone and I went and saw her. I hadn’t seen her before and she was just a blessing. And she would see me for an hour or so at a time. It must have been for six months, I’d see her every week. Unfortunately, her whole family moved back to Perth, so I lost her. I was really devastated because it was so nice to have someone you could put your, you know, she knew what had happened and I could trust her with everything I told her. I think if it wasn’t for her, I think things would have turned out a lot differently for me. She was very, very good.” #5F

“We went to a GP obviously and got referrals to psychologists and, um, they were absolutely useless, I mean, they didn’t know where to start with us.” #10F

5.2.5 Referral processes, counsellors psychologists and psychiatrists

“It was good to have someone say it was normal.”

“The counsellors couldn’t deal with it. They ended up in tears.”

Parents acknowledged limited referral practices from the hospitals for bereavement support as an area for improvement. In the instances that referrals were offered, some parents felt that giving the referrals so soon after their child's death was not useful, or that the referrals
were of limited value. Parents commented that peer support would have been the most helpful but most parents were unaware how to access this peer support.

“You need people that have been through similar experiences, um, would be good to talk. Like someone who has lost a child. It doesn’t matter how they come about losing a child, but someone who understands the grief of losing a child – I didn’t know of anyone” #5F

Both the timeliness of referrals and the cost or perceived cost of counselling and medications were barriers for a few participants. Cost was an inhibitor for many families regarding access to counselling, especially those that had a number of children needing support. One father who suffered severe depression following his child’s fatal drowning was not a permanent Australian resident, and was unable to afford either counselling or medications. During interviews many parents mentioned that the first few weeks they were in robotic mode, organising funerals, visitors and in a state of numbness and shock. It was not until all the arrangements had been finalised and extended family had left, that the extra support was needed.

“We can’t afford medications for anybody – there’s no financial help at all because we are not full residents. We haven’t had help because we can’t afford the help – if there was any help offered it would have been in the first couple of days. And the first couple of days I was organising funerals, family members to come, organising to try and get beds sorted out, organising doctors for my husband, I am not going to remember you sitting there saying, come on. They need to back off and give people time. Give them a week.” #6F

Parents’ experiences with counsellors and psychologists varied. Two participants reported positive results from counsellors, one of whom was a qualified GP who specialised in bereavement counselling and the other counsellor was from a specialised organ donation bereavement service. Most other participants who had either seen or attempted to see a health professional for support reported negative experiences. These included difficulties in getting appointments, lack of consistency with the same counsellor, lack of sensitivity,
concern regarding counsellor/psychologist training in dealing with child death (specifically a drowning death) and the limited rebates available through the public system.

“Because I donated (daughter’s) organs, I did get heaps and heaps of information for counsellors. (Donate life) – they are more on the medical side of things, like I can ask any medical question in relation to (daughter) when she was in hospital; they can answer that for me. I can still talk to them about whatever I want and, like, I blame myself for (daughter’s) death and if it wouldn’t have been for them, I would still be doing that.” #1F

“There was the counselling from (husband’s) work. But we didn’t get anything out of that. I saw a psychiatrist after that and I found him more useful. He kind of said, that’s not wrong to feel that way, whereas the psychologist said OK, we acknowledge you feel like that, what can we do to change it? And it’s like, you can’t change it. It’s a part of you, who you are right now. I can’t change how I feel, I can’t just walk out the door and smile and say hey, everything is perfectly OK, because it’s not OK, it will never be OK.” #7F

Some parents commented on their experiences regarding the issue of blame and judgement, and how this was dealt with by psychologists and counsellors. They described how health professionals appeared to assume emotions, suggesting that it would be natural that one parent would blame another parent who was present at the time of the drowning. Parents who had experienced this felt that this implied responsibility and blame for the child’s death. Participants also commented on stress caused by some of the health professionals' apparent academic and linear approach to stages of grief, rather than being active listeners and responsive to the grief place that the parent was trying to express. Participants perceived that counsellors made inappropriate comments such as saying they understood how the parent was feeling and that the parent should be at a certain stage in their ‘grief journey’. Parents expressed frustration that counsellors did not actually listen to them and tried to box them into what the counsellor perceived as an appropriate stage of their grief. Some parents believed that the health professionals did not ask the right questions to facilitate a constructive session and that the need to build trust with their health professional was compromised by either their
perception of the counsellors’ and psychologists’ attitude to their situation, and/or the number of times they were financially able to attend appointments.

“Counselling was offered for myself, wife and son, the in-laws and any family who were involved. At the start it was really good because we just wanted to talk without family being there, so we all had our individual sessions and wife and I had group sessions as well. Wife and I, we were going good and then we got split up into individual ones, that’s probably about tenor 12 weeks into it. It was helping the whole way up until one that was sitting there by myself and wife was in her own counselling session and the lady says to me ‘So you will be at the anger stage now’ and I said to her it’s not as simple as a kpi to meet. I don’t even believe I have got past the first stage yet because I wasn’t even there, how can I be at the anger stage. And she said ‘oh’. And then the whole conversation for that session turned around, should I be blaming wife and should I feel hatred and anger to wife and all this stuff and I was like, hang on, this is totally off. I don’t hate her, I don’t blame her. It felt like I should be doubting what my feelings were. So counselling definitely worked, we definitely needed to talk about it, so in general I think it worked as a package but it just got to a certain point when, I hadn’t advanced as far as they thought I should have at that stage!” #8M

“We started doing counselling; that was a waste of time. The first counsellor, all she did was sit down and cried more than we did. The second counsellor, all she wanted to do was tell us where we should be in our grieving period, and the third one, well, was just a textbook. ‘This is what the book says you should be doing’. The second one, as I said, all she did was tell us how we should be feeling, not asking us how we felt. The moment they started telling us that, I said, ‘no more’.” #4M

“I started counselling shortly after losing (daughter). We tried four psychologists and they were fucked, um, you’ve got to have a certain level of trust to be able to talk to someone about I guess your personal feelings and your loss. That’s not something you can pick up in like, sort of walk in, 30 seconds and spill your guts. It’s something you need to build up over at least four to five visits just to feel comfortable; and that’s really hard when you only get six goes at it (re the mental health plan).” #12M
A few participants also spoke of the counsellors’ or psychologists’ inability to cope with their own emotions during the sessions, causing more angst for the parents as the counsellors dissolved into tears.

“The counsellors couldn’t deal with it – they ended up in tears. Like I go in there and offload my sadness and I’m making the counsellors cry? I’m sitting there going, I appreciate the fact that your human and you’re touched emotionally but, fuck me, you’re supposed to be helping me and I walked out of two of them sort of really frustrated. #12M

Parents raised the issue of difficulties in getting appointments due to long waiting lists or if the death happened around a public holiday. They also discussed the importance of seeing one consistent person rather than different people each time and having to explain their circumstances again at each appointment.

“I got a referral from (peer support organisation) for somebody. The lady saw me once, then she, the next appt I had she had to reschedule it, and the next one I had, it was leading up to Xmas. I was just a mess at Xmas. First Christmas without him. And I got a phone call the morning of my appt and it was somebody else saying, um, what’s her name, JH. J can’t keep your appt today. I said OK can I reschedule and she said I wouldn’t be taking any more appointments for her until the New Year. #14F

“We went once, together. But she was leaving after that. It was like the story of our lives. You know, so why, it’s pointless them having given, assigning her to us if she was going to be out of there in a week. You don’t want to go through explaining the situation again to somebody.” #5F

“The first overriding concern was we had to find someone we could see consistently because there’s nothing worse than I spend 55 minutes telling you my story and then the next week I spend 55 minutes telling someone else my story.” #12M
Two parents spoke of the geographical and emotional challenge with attending counselling at the John Tonge Centre (the mortuary for Queensland Health Forensic and Scientific Services) because it was the same place at which they had to either identify or view their child’s body post-autopsy. One parent persevered and found the counselling useful.

“I found that really hard to try and walk those steps again. Extremely hard. Just getting, you know, you walk in and that picture of that bed with him lying and you know you were in the room next door before you went to identify him. I did struggle with housework and doing dishes and all that. I kept going to a counsellor at John Tonge and she got me through that.” #11F

While some parents sought support through health professionals, others looked for people who had experienced similar tragedies in order to gain some comfort and support. This often resulted in linking to support organisations, though finding that support approved to be a challenging experience for many parents.

5.2.6 Support organisations

“It was hard to relate to someone who hadn’t been through it themselves.”

Many parents initially assumed that GPs could refer them to support organisations but this did not appear to be the case. No parent reported that their GP had referred them to a bereavement support organisation. However, parents sourced various support organisations through their own research or from suggestions via friends or family. With one exception, organisations suggested were of a generic bereavement support nature, though some specialised in particular age groups. This created some issues for parents who felt they could not relate to other families who had not experienced the same type of death.

“I was going for a while to x, but there was no one there who had suffered a drowning and, um, lots of the people, um, their children were older as well, like three is kind of like the borderline like if they are under three they go to SIDS – but then (daughter)
was exactly three years 11 months so she was nearly four but then like, it’s not a common age to lose a child. There seems to be groups, like they’re more close to their teens– or in their early 20s, do you know what I mean?” #7F

“It was hard to relate to someone who hadn’t been through it themselves.” #13M

Similar to the experience with health professionals, a number of parents spoke of the difficulties regarding availability of support during critical times. This included times when organisations were closed for holiday periods or telephone support lines that did not have the capacity or training to manage the number of calls they received.

“It was like Christmas time when I rung (organisation) and I got an answer machine and I had to wait for someone to get back to me, those kind of things, because everyone closes down.” #7F

Onesupport group was mentioned in a positive light by several parents, especially in relation to the literature provided, and the candlelight memorial service.

“I am a member of x which did help me immensely getting the newsletters. Still get them and I read them through and it’s lovely.” #3F

“I used to say I have (sibling) and I have (son) and (son) just drowned. It would all spill out really uncomfortably. And then through x and literature, you can do things. Like when I sign cards or letters, you know (husband, me and sibling) and I’ll do a heart and that’s (son). He goes to the candlelight service. We have been to a few of those and we find those really really good. It’s a really safe place. If you cried then no one else would say, stop crying.” #2F

Two parents also spoke of the positive support they received for their surviving children from another organisation, which specialised in children’s grief.
“It was more for sibling because they were the only ones who did any sort of counselling for little ones. He only had to go a couple of times and they sorted out whatever it was.” #11F

“It was all about like dealing with change in your life and stuff – that was amazing, it was fantastic. He really enjoyed it; he found that really really helpful.” #7F

One of the fathers interviewed spoke of his challenge in talking about his child’s death, except with the friend who provided CPR at the scene. Interestingly, this father felt the need to ‘do’ something about his experience and adopted an intensive, advocacy role in promoting legislative changes and education around pool fencing and other prevention strategies.

“Probably like a lot of men, I don’t like going along to those kind of groups, ripping the scab off, because if you leave it too late, that’s how it feels when you go to counselling; they want you to start from scratch like six months after it happened. You don’t want to talk about it. You just want to put it out of your mind. I had a real issue with actually picking up the phone and ringing them.” #13M

One mother explained how grateful she was for the support of one voluntary organisation, without which she would have been in dire straits financially and emotionally. She spoke of the importance of their support at any time of the day or night, and still some years on from her daughter’s death.

“Financially, if it wouldn’t have been for them I probably would be living in the gutter because of all the help, raising funds to pay all my rent and they paid a lot of my debt. And they are there for me. They are still there; so any minute of any day I can ring them; so they are lovely people.” #1

Most participants mentioned the timing of the offer of support. Some participants could not recall if they were given information for support groups or counsellors at the hospital, some remembered being given information and others were adamant that none was offered. Those that did receive information from the hospital at the time of their child’s death had either
forgotten it was there until the interview, or had tried to follow up a few of the contact groups suggested and had no success.

“I did get a little pack I think from the hospital itself, which I still have in my drawer and I haven’t looked at. I did also get HF phone number given to me at the hospital, but I wasn’t really ready to talk to anybody. So I went home and I went to bed. And I stayed in bed. I didn’t eat, I didn’t sleep, I didn’t do anything.” #1F

“The hospital gave us a form with information if we wanted to have counselling, or like a grievance support centre that was at the Mater. But as time went by I phoned up and it no longer existed. It was nothing. There was nothing anymore.” #5F

Parents expressed a need to speak with others who had experienced similar tragedies and could therefore relate to their challenges in adapting to life without their child. Whilst generic bereavement services offered support for some, it was lacking in that connection and 24 hour availability. This research covered a ten-year span of drowning deaths and, for some of the families there were no drowning support bereavement services at the time of their child’s death. The first drowning support bereavement service in Queensland was established in 2008, and a local support network was established in North Queensland in 2010.

5.2.7 Peer support organisations

“Unless you have lost your child there is no way in hell that anyone can understand.”

Parents described how important it was to talk to someone who had experienced a similar situation to them, who could appreciate all the challenges that a sudden and often stigmatised death created. Parents in the study whose children had died more than four years prior commented on the lack of peer support at the time of their child’s death. Consequently, one family established their own local support group.

“There was no real support. So we just started. Someone said it’s really nice to have a cup of tea with someone else with two heads. Safe Hands is what we call it because
you have safe hands to fall into. So, what we decided is we got the booklets together that we like to hand out, things that have helped us. Or I put inspirational stuff in there. I’ve also got a friend’s booklet to hand out to friends. I take it around to the house and friends read it and say ‘thank you’. We meet once a month at the Irish club. I send out a text reminder and people just turn up. They don’t have to say if they are definitely coming.” #3F

“I searched for groups of people who had gone through the same thing but there just was not any.” #9F

“I didn’t really want to talk to anyone who didn’t understand me and we couldn’t find anyone who understood.” #12M

Every female participant and two of the four male participants described the importance of linking with other people who had experienced the same type of child death. Some parents were comforted by the friendship and support from a parent whose child had died in other circumstances. This comfort took various forms, from practical advice, to just ‘being there’, not giving up and most importantly, listening without judging.

“I get a lot of benefit from peer to peer support because they get me, they understand me – you only want to talk to someone that gets you or understands where you’re coming from.” #12M

“If you were put in touch with someone who had lost a child it would be a lot easier. Because a lot of people don’t want to talk about it. Your family don’t want to talk about it; people you work with don’t want to talk about it and everyone just kind of pretends it didn’t happen because it’s too uncomfortable for them.” #13M

“Just talking to (peer support) and having somebody else who had gone through exactly the same thing I had gone through, and knew how it feels and things like that – like having no conditions on you. I find family and friends, they have conditions on it. But like, there’s no conditions.” #8
It appeared important for parents to share their own grief experiences with other bereaved parents to help 'normalise' their grief. The feeling of lack of emotional control was apparent in all parents following their child's death and intermittently for various periods of time afterwards. The ability to talk about their loss and these experiences appeared to offer comfort to other parents as well as the sharing of practical advice such as issues related to funeral arrangements and general coping mechanisms on a daily basis.

“I had a lady who had just lost her son through suicide and I turned up and she just said to me, ‘Thank God you walked through the door. You were the only one that could look at me without quivering’. And I gave her practical advice like searching for a funeral song on the net. I wish someone had told me. It was good having a friend to talk to who had been through it. She would give tips about what helps. She said, ‘I knew you understood when you kept coming round. You “got it”’.” #3F

5.2.8 Suggestions for improvement to support
Whilst parents reported a mix of experiences with health professionals and other support organisations, they were also keen to offer some suggestions for improvement in the services. Suggestions for health professional included improved referrals; control of what was perceived as judgemental language; improved active listening skills; and better information and support for the autopsy process. Issues such as frustration with either the lack of available support; the timing and passive nature of professional support as well as the ability for professionals to be effective supporters through a person’s grief are reflected in the following comments.

“I am angry with the help we got. We got no help. Make it known. Give them pamphlets, give them a booklet. Ring and check. Don’t just presume OK, you’ve given this pamphlet; they will ring if they needed to. Push for it. If somebody pushed for me I think we would have got some help.” #6F

“I think a lot of counsellors need to be trained more to listen, not tell people what they are supposed to be feeling.” #4M
“I think they (counsellors and psychologists) need to be more proactive. They need to understand that if someone doesn’t turn up for an appointment or someone is reluctant to get engaged in counselling, they shouldn’t just give up. They should actually keep trying. Because that’s just the way it is – you need to be put in touch with someone who is quite motivated to help you.”  #13M

A few parents mentioned the difficulty in finding support even if it did exist. This support included financial as well as emotional support as the effect of a child death has a wide-reaching impact and is not limited to emotional instability. One suggestion was some kind of road map to help navigate this path.

“A clear road map to different places you could go to depending on the level of trauma you have suffered – support groups as well, physical, emotional and financial support for some people.”  #8 M

“You almost need, like, a project manager. You need someone who is going to give you information. You can’t take much information in when you have lost a child – so they need to help you cope with what’s going on immediately. I think they need to be more proactive.”  #13M

A suggestion regarding the autopsy process was especially significant for the parent that was not present at the time of the child’s death. Having last seen the child healthy and then seeing him or her post-autopsy was considered too great a mental leap.

“Don’t let a family see their child who has had an autopsy before they get to see them without. They need to make that transition between that child who was running around yesterday, now he’s dead, now he’s had an autopsy. It’s a big thing to see your child like that.”  #13F

Finally, whilst many parents spoke of prevention, including the importance of fencing, evaluation of the legislation and ongoing education, one parent also spoke passionately about
the importance of a first aid kit in every pool owner’s home, equating the potential risk of a home pool with owning a gun.

“Mandatory first aid kits, to own a pool you should have mandatory first aid training. It’s mandatory that in Queensland you can’t own a gun unless you have been on a gun safety course. Why would you be allowed to own a pool unless you have been on a first aid course?” #8M

“I still see in Australia that mental health is not really discussed. And it’s such an issue. I know plenty of people who have lost family and I know plenty of people who are no longer here because they have committed suicide. And I think the approach to mental health is pretty sick – it’s a kind of self-service sort of thing”

5.2.9 Community support
Bereavement support takes many forms and participants spoke of the impact of the community on their ability to cope with their grief. A community is a place or state in which certain commonalities are shared; for example, values, beliefs, geography. Since the internet, communities are often considered without the geographical boundaries but with emphasis on shared values and beliefs. Other researchers (Long 2003, have used a sense of community index (SCI) to measure community support which illustrates the higher the sense of community, the less depressive symptoms people experience. Whilst professional intervention and peer support are an integral component for some, the attitudes of the families’ micro and macro community appeared to impact on their emotional wellbeing. The term ‘community’ means different things to different people; in this context, whilst a formal measurement tool was not utilised, the roles of the school and general public were raised by the parents, as being integral aspects of ‘community’ as well as the impact of the internet and media.

5.2.10 Perceived public attitudes to parents’ grief
Parents spoke of positive and negative experiences with regard to public attitude to their loss. One participant spoke with gratitude about a large sum that had been donated to them
following their child’s death. This sum was donated by a family whose child had nearly drowned. and they were sensitive to the bereaved family’s plight, recognising how it could have easily been their situation.

“We had people in the community who nearly lost their child to drowning. The child was saved and went to school with (son) and they donated $5000 – you’ve got no idea about supports. We didn’t have to worry about money.” #3F

This same parent spoke of the strong community support from the tight-knit community in which they lived. The teenage child had drowned in a waterway well known to be a potentially dangerous attraction.

“There were people all night looking. There were hundreds of people, it was just amazing – and because we had so many people turn up, our whole backyard was just full of people. There was constant food. They organised a big food storage area at the school. It was just amazing. And later on with the food, it was wonderful because I couldn’t cook and we could still just reheat lasagnes that people had made.” #3F

Whilst this parent experienced positive community support, she also commented on people’s difficulty in broaching the subject after her son’s death. Even though she stated that she was an extrovert and that the community hadn’t shunned or blamed her for her son’s death, she still had to make the first move with regard to talking about her son.

“I’m a bit of an extrovert anyway and I like talking to people. I’d say hello, how are you, so they’d realise I was still there. So I had to make that connection, to create the first opening.” #3F

One participant spoke of the support from their church community and the kindness of people who were previously unknown to the families.

“I rang my best friend from church to get everyone, we have prayer chains and I asked for everyone to start praying for (son).” #2F
“He had a poem, he had a friend that wrote this poem and I’m going to stitch it one of these days. I stitch everything. It’s just a bit raw. I had a conversation with him. He wrote a poem that nailed it, nailed. He wrote what happened that day, it was unbelievable. That night he rang at our home and I told him about what had happened; he cried, he cried at the other end of the phone. It wasn’t faking. It was such a tender moment. Someone you didn’t know, but felt you sort of did. He was just so compassionate.” #2F

In contrast, parents who reported negative experiences believed that this was linked to the stigma of a child drowning death.

“Drowning is a very stigmatised death – my wife had people spit at her in town – the kids were told their mother is a murderer and it’s pretty cruel, some of the things that have been said.” #12M

“And it’s the most discriminating thing I find against people who have lost their kids to drowning. I got told I didn’t deserve to be a mother because I don’t look after my son and I was to blame for his death. He basically called me a murderer.” #9F

“I have had a couple of people say to me that it was my fault that (daughter) died because I turned the life support off on her.” #1F

The comments appeared to be a combination of purposefully directed slander at the grieving family and generalised gossip. The following comment was made by council employee whilst at the courthouse during the coroners’ enquiry.

“Somebody who worked for council said, ‘I thought it was very funny when I got this call to inspect the pool; the parents of the five year old brat should have taught him how to swim’.” #9F
A number of parents spoke of people’s lack of understanding regarding the time it takes to deal with their grief; people’s vocal judgements about their desire for more children; and misplaced platitudes regarding meaning behind the death.

“We went through assisted fertility. We always wanted a big family and people were saying to us, ‘Are you only doing that to replace the child you lost?’ And I thought, cor, Christ. People said ‘Shouldn’t you just be happy?’; and things like that.” #8M

“I got sick of hearing things like ‘things happen for a reason’. If I have to hear that one more frigging time I was going to kill someone. How can you justify, what sort of reasoning can you give me that my son died, why did that happen? What’s the reason for that? It made me really angry.” #13M

5.2.11 Schools
In addition to the generalised and religious community, schools are a significant aspect of community life and participants reported on their experiences with the reactions from their school community. Most participants expressed a lack of support from their school communities, although there were a few exceptions. What appeared to be lacking was any sort of school policy or understanding of how to support families in crisis, coupled with a resource challenge of schools having access to counsellors and other support staff such as chaplaincy support.

“Obviously he didn’t want to get into the water and his teacher was going berserk at him and that, not understanding that (sibling) had only died months previously and they were trying to force him into the pool and stuff.” #8M

“I had to explain to the school, this is what has happened. You need to know in case she is crying and upset one day and you have no idea why. And this could be why. She ended up wagging school. She would just walk out of school and come home. It was like they didn’t give a shit, they didn’t; I know there are thousands of kids and stuff, but you would think that if a parent makes the effort to go into the school and explain, you think that they would make an effort to help. And so when the school got really
bad, I sent her to B, and I explained to them again what had happened. ‘Oh, we’ll get her in to see the guidance officer and make sure everything’s fine.’ Well, nothing happened. None of the schools have followed up with anything that they said they were going to do. And they still don’t. Like, I spoke to the principal, gave her my email address and she was supposed to email (sibling’s) teachers so I know what work (sibling) has got. That was like two and a half, three weeks ago. And I haven’t heard from one teacher.” #1F

The exceptions appeared to be for the family whose teenage son drowned. This family were satisfied with the support from their school, including hosting a memorial day in their son’s honour and providing emotional support for the surviving sibling.

“(Son’s) school did a memorial day for him where they unveiled a plaque. L has been brilliant. She is the guidance counsellor out there. She doesn’t push the issue but if he needs to talk he can go there.” #6F

One mother spoke of the difficulties she faced in going along to school events, reflecting many of the parents’ experiences regarding people being unsure how to approach them after their child’s death. People seemed to abandon the parents, creating further feelings of isolation and stigmatisation.

“I understand now that people don’t know how to react. I went to a swimming carnival. (Sibling) was swimming at a school swimming carnival. I went there one day, I had gone to work and had taken time off and ducked in to do it. And when I came in, um, you know, it was, I saw where a lot of people were sitting and where there were spare seats to watch his race and everything else and it was like people just left me, I really, you know, I felt really ostracised in a way and I thought they are feeling uncomfortable probably.” #2F
5.2.12 Media
Parents reported mixed experiences with the media. Whilst one parent expressed their appreciation of the advocacy support from the media, most commented on the media’s insensitivity to personal grief, ranging from ill-timed articles, to invasion at the scene of the incident and insensitive questions without any consideration of the impact.

“There was a picture in the paper on the Saturday and one of me and mum I didn’t even know had been taken, with confirmation that (son) had drowned: I felt like they had taken a moment, just me and my mum sitting beside each other and they had taken a moment of our lives that they didn’t, they didn’t deserve to have. I don’t know, it just felt intrusive to me.” #1F

“The media knew there was a drowning incident and the next morning an article appeared in the paper – without my permission, gave my name, my rank, um, a very poorly written article and we had friends finding out that (daughter) had died by reading it in the newspaper and seeing it or hearing it on the radio less than six hours after (daughter) was gone.” #12M

“‘Get over it’– I hate that terminology. The media use it a lot. How do you get over it? I remember being asked by a Channel 7 cadet journalist ‘How do you get over something like this?’ and this was three months after (daughter’s) tragedy!” #10F

A number of parents were traumatised by the media’s attempt to report a sensational experience and experienced a lack of sensitivity with regard to either the timing of articles going to print, the lack of privacy in their time of mourning, or the type of questions asked during interviews. One mother suggested a way to mediate this insensitive questioning through cadet and ongoing training.

“Training for the media to ask appropriate, not damaging questions.” #10F
Two parents were actively involved in working with the media in an educational and advocacy role and one family had framed the article regarding their child’s death because they believed the media had honoured their son, as they had requested them to do.

“Fortunately some good journalists had contacted us to ask us questions.” #12M

“We’re working very close with the state government with their pool safety campaign – we were actually at the movies last week and (husband) and I were in the cinema screen again – and it’s really hard when you’re in the cinema and your five year old goes ‘Oh look, there’s mummy’ (LAUGH).” #10F

“The (paper) wanted to do an article on him and I said as long as it doesn’t debase him, so they came out and they run the article and they actually faxed me a proof copy for approval before it got in.” #9F

5.2.13 The internet community
Most families mentioned social media. Parents who had lost their child some years ago appeared to use the internet less than those whose child had died in the past five years. Facebook and memorial sites were the key avenues for parents to be able to share their emotions and receive support from people who had experienced similar tragedies – getting a sense of camaraderie through their grief and reducing the feeling of isolation because people on the site understood their emotions were significant factors.

“Chatting on Facebook – I guess you see it with a lot of our families, it’s like, um, someone will post a comment ‘I’m having a fucked up day’; within 5 or 10 minutes there’s usually one or two other families who have been through a loss, sitting there going, ‘Yeah, I know, this happened to me, that happened to me’, so they’ll chat.” #12M

“I go on quite a few sites. I found it fantastic at the beginning. I had my, what I would call them, (son) sites and I would go to bed or sit on my back and cry and go to those grief logs. There’s memorial sites you can go on ‘gone too soon’ and then you can go
Parents also spoke of negative experiences with the internet, mainly related to stigma and blame.

“You get some negative comments on Facebook: you should have looked after your kids 24/7. And I’d had enough one night. This bloke kept gobbing off at (wife). No one can look after their kids 24/7. You’ve got to go to the toilet, have a shower; your wife’s got to cook tea. Where are your kids then?” #4M

Amidst all this tragedy, many parents spoke not only of the importance of supporting each other, but in going the step further to prevent other families experiencing the grief and devastation that they have since their child’s death. The final section in this chapter describes some of the altruistic activities that parent participants became involved with since their child’s death.

5.3 Resilience and repair

“And I call it the terrible gift. To be able to walk into someone’s house and not be uncomfortable when they’ve lost a child.”

This section illustrates how some parents used the experience of their bereavement journey to help others and includes comments on participants’ reasons for their involvement in this research. Other altruistic behaviour included activities toward preventing further fatal drowning events as well as offering a range of support for families who had experienced a fatal drowning. The concept of ‘pay it forward’ was mentioned by many parents and illustrated in a variety of ways: supporting families online; supporting families face-to-face; contributing to organ donation; talking in the media; giving permission to use inquest recommendations; developing and delivering school-based prevention programs; being an advocate for drowning prevention; and, in a few cases, completely changing employment to work that supports safer water environments.
5.3.1 General support: online, telephone or face-to-face

Providing support to others was an important aspect of parents’ bereavement journeys. Informal conversations with other bereaved parents by phone or internet as well as establishing more organised telephone and online support groups was considered a valuable contribution. Knowing the support person had experienced a fatal child drowning was meaningful to the bereaved parents and created a shared support with benefits to the giver and the recipient.

“It’s part of our grieving process that we want to do because I know the immense satisfaction out of being able to help someone, umm, I can literally be eyes hanging out of my head with exhaustion and get a phone call on the 1800 number at 2am and spend an hour or two talking to someone who has been through it; at the end of the call, to know I have been able to help someone: it gives me a massive lift, a real sense of purpose for (daughter’s) life.” #4M

“I know for me that it helps me in my grief to be able to help someone and I get an immense amount of satisfaction and for me that makes the sacrifices, the time that we’ve given up and the amount of personal resources we’ve put into the foundation, all worthwhile. Um, the movie, ‘Pay It Forward’ is a philosophy that I think really highly of.” #12M

One mother from a country town spoke of how her local priest had rallied her into supporting other families because of her experience and positive approach to managing her grief. She joined with a friend who had also suffered the loss of her child and together they formed a support group, regularly collating relevant information to share with other grieving families, visiting people in their homes and providing the opportunity for a regular ‘meet and greet’ for bereaved families.

“Father M was fantastic from the church. He was really good. He’s a realistic man. He has now rallied me into helping. He rings me when there’s been a death in the community. After (son) died, a friend who had lost her daughter came over and, um, she decided to just meet up and let’s just start a group going. Because I need
something that’s positive and they could go forward with. There was no real support there. So we just started something. Someone said, ‘It’s really nice to have a cup of tea with somebody who has two heads’. And I call it the terrible gift, to be able to walk into someone’s house and not be uncomfortable when they’ve lost a child. I’d Google and think, jeez, that helped me. And I’d print it out and started putting them into a folder and now I can sort of hand them out – so this is what we take around to families. And I encourage them if they find anything to put stuff in there as well.” #3F

5.3.2 Organ donation

Two parents who were able to donate their child’s organs saw this as an opportunity to give something back to the community and this opportunity created a sense of value around their child’s death.

“He’s lungs were completely destroyed. There was no child that needed a heart so that went to research. Two of his heart valves and two of his heart vessels are put on what they call ice so they can be used up to ten years down the track. It made me feel happy knowing that, you know, part of him is out there helping somebody else.” #14F

“The day I got married I got a letter from Donate Life to say that they had just used one of (daughter’s) heart valves to save a little baby. So that was the best wedding present. Even though it was screwed, that was the best wedding present.” #1F

5.3.3 Benefits of the media

Many parents displayed remarkable strength in telling their story to the media in the hope of raising awareness and preventing further tragedies. One parent whose child may have accessed the pool through a dog door spoke of her urgent need to get the message about the dangers of dog doors and swimming pool access into the public arena. She contacted Lawrie Lawrence, well known promoter of a pool safety public media campaign, and shared her story with him in the hope that he would relay her message in the public arena:

“(Son) died on the Saturday night and it (campaign) started on the Monday. Of course when I heard that I bawled my eyes out. And it was some weeks later that I contacted
L. I didn’t think I would ever get to speak to him of course. I heard about the campaign and wanted to tell about the dog door. Somebody’s got to do that. It can’t be me. I can’t do it but I have to tell somebody to do it. So I rang up his swimming pool, and talked to a lovely lady there. He rang me at home that night. Yes. People that were a shining light at that time. He gave me something to do so I could channel what I had to do and he asked me to do some ads. And the script for it is in one of these books. From the very, the very first weekend that it happened, I always remember thinking, what are we going to do in two years’ time when he will be gone as long as we had him? What, what, and so in some ways the second anniversary for me was worse than the first, although they are all bad, that was the thing, and what can you do, and I felt like, whoa, I did radio ads, I did TV. I see this as an opportunity to maybe put the message out. Whether people say it won’t apply to me, we are careful or whatever, at least we tried to do that.” #2F

“If I can go and spend an hour talking to a journo to get ten seconds of air, I’ve got ten seconds in which I can hopefully make a difference to people.” #12M

5.3.4 Information sharing to inform legislation
Similarly, families were willing to share the experiences and outcomes of their child’s inquest in order to help other parents, and to contribute to the pool fencing debate and changes in legislation.

“We wanted people to understand what the risks were. Look, out of the coronial inquest a lot of good things came out of that. Like fencing pools on construction sites. Look, we got a good result. Obviously it helped change fencing legislation and it helped educate people I think.” #13M

“When we were asked if it would be alright if they contacted us to get permission to use (son’s) findings at their inquest – I said yes, if it’s going to help, fine, go right ahead. I was told that it was (son’s) recommendations from his inquest that actually pushed the new pool laws through parliament. That made me feel proud.” #4M
5.3.5 Work re-focus

Some parents completely changed their work focus in order to take on advocacy roles or some form of drowning prevention/education activity. Parents spoke of developing and delivering school-based water safety programs, spending time advocating for changes to legislation, and training as pool safety inspectors in order to actively be involved with improving water safety for children on a daily basis. One mother gave up her work to be a full-time volunteer in a charity organisation. All these parents were proud of the decisions they had made regarding their fight toward creating a safer place for children and to prevent other families experiencing such sadness.

“Doing pool safety inspectors course so I can make sure that pools are compliant. If it saves another kid’s life, it’s good. We are trying to organise to do some talks at the schools plus I’m trying to organise some fund raising events.” #4M

“We try to lecture high schools now with our Positive Choices program.” #10F

“My involvement in the safe communities program was because I wanted to make a difference; you feel quite hopeless, there’s not much you can do because, you know, government is so full of inertia and politics. There are not many ways you can influence an outcome with government unless you have loads of money or you are in a group that can lobby them.” #13M

One father spoke of motivating colleagues at his workplace to help support families who experience trauma.

“The second year I organised for everyone at work to donate a present and we had 14 bags of presents – it’s one of those things that until it actually happens to you, you don’t realise how many children actually get injured on Xmas day, or disabled, or dead, and how it affects the parents – so we donated all the presents. And that first year, everyone donated money, about $4 or $5000 we donated to the hospital as well. Because they were great, the support and everything they gave us.” #8M
In essence, the overriding feeling for parents with such altruistic intentions was summed up in the following statement:

“I want to stop other mums from feeling like me; and having my life. Why should a mum have my life when we can prevent it in the first place?” #10F

In this chapter, insight into bereaved parents’ grief journey following the drowning death of their child has been explored. Positive and negative aspects of parent experiences have been identified. Parents described how their emotional, physical and spiritual states were compromised following the death of the child, in relation to their sense of identity, the impact on their perceived role as protector for their child, surviving children and spouse; the nature and importance of ongoing relationships with immediate and extended family, friends and colleagues; and the impact of all of these factors on their work and financial situation. Sources of support and areas for improvement within these professional, organisational and community support sources were discussed. The importance for some parents of focusing energy on raising awareness about child drowning and, in some cases, advocating for change or establishing support for other grieving families, were identified. The following chapter will describe the participant service providers’ experiences of supporting bereaved families.
Chapter Six – Results from service providers

6.1 Introduction
This chapter explores the fourth objective; factors that influence the delivery of support. The experiences and insights from 17 service providers interviewed regarding their role in supporting Queensland families bereaved by a fatal child drowning are reported. It describes their specific roles, the professional challenges within those roles and the personal impact of providing this service.

Table 4. Themes Resulting from Service Provider Interviews.

| The unique geography of Queensland | • Impact on service provision  
| • Challenges to service provision |
| The impact of bereavement work on service providers | • Emotional  
| • Effect on families  
| • Personal motivation |
| Benefits and challenges of support groups and support organisations | • Role of the support service  
| • Limitations of support organisations |
| Service providers’ comments regarding support for bereaved families | • Challenges  
| • Different grieving styles  
| • Community support  
| • Coronial support  
| • Writing about grief |
| Suggestions to improve support services | • Professional training  
| • Referrals  
| • Education  
| • Resources |

The chapter addresses the above themes, concluding with a ‘wish list’ from some providers on how their services might be improved.
The table below illustrates a brief summary of the services provided to participants following the death of their child. It offers an overview of the function and accessibility of the service and provides a snapshot of the range of services offered to parents.
Table 5. Summary of key roles and services of organisations which may provide bereavement support for parents after a fatal drowning. These providers were not necessarily accessed by the parents in this study.

<table>
<thead>
<tr>
<th>Name of organisation</th>
<th>Key role of service</th>
<th>Type of service</th>
<th>Who can access service</th>
<th>How long can service be accessed?</th>
<th>How does a family contact the service?</th>
<th>Cost</th>
<th>Geographic reach</th>
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<tbody>
<tr>
<td>Major Brisbane children’s hospital (#17)</td>
<td>Social work support</td>
<td>Supporting family during hospital attendance. Debriefing family. Liaising between medical team and family. Helping with the 'best possible death' for the child</td>
<td>Immediate family members</td>
<td>Whilst at hospital</td>
<td>In hospital referral</td>
<td>Nil to family</td>
<td>Brisbane</td>
</tr>
<tr>
<td>Other major Brisbane children’s hospital</td>
<td>Referrals</td>
<td>Footprints and hair for under 12months Information about the coroner and coroners counselling service.</td>
<td>Immediate family</td>
<td>In hospital</td>
<td>Hospital referral</td>
<td>Nil to family</td>
<td>Brisbane</td>
</tr>
<tr>
<td>Donate Life</td>
<td>Grief Counselling for families who have donated their child’s organs</td>
<td>Support and referral to other relevant bereavement services Any person affected by the child’s death</td>
<td>Indefinite</td>
<td>Hospital referral</td>
<td>Nil to family</td>
<td>Brisbane-based</td>
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<td>Name of organisation</td>
<td>Key role of service</td>
<td>Type of service</td>
<td>Who can access service</td>
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<tr>
<td>Sids and Kids (#16)</td>
<td>Bereavement support for family with any child death less than 6 years of age</td>
<td>Counselling service face-to-face, email or 24 hour volunteer staffed telephone line. Annual memorial service. Weekly support group</td>
<td>Anyone affected by the death</td>
<td>Nil to family</td>
<td>Referral from coroners' office, possible emergency services and occasionally self-referral or word of mouth. Advertising for Red Nose Day</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td>National office and member organisations in each state</td>
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<tr>
<td>Hilda’s House</td>
<td>Palliative care hospice and counselling and bereavement support</td>
<td>One-on-one counselling for children and parents and group work</td>
<td></td>
<td>Free</td>
<td>Referrals from organisations such as schools, paediatricians, community mental health, palliative care network and Supportlink and local knowledge</td>
<td></td>
<td>Services in a few centres across Queensland</td>
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<tr>
<td>Name of organisation</td>
<td>Key role of service</td>
<td>Type of service</td>
<td>Who can access service</td>
<td>How long can service be accessed?</td>
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<tr>
<td>Compassionate Friends (#5)</td>
<td>Self-help support group for bereaved parents</td>
<td>Candlelight service. 24 hour telephone support</td>
<td>Only immediate family members</td>
<td>As long as required by family</td>
<td>Other organisations and word of mouth</td>
<td>First 6 mths free. Then $25 per family if affordable</td>
<td>Brisbane only drop-in centre</td>
</tr>
<tr>
<td>Paradise Kids (#4)</td>
<td>Bereavement support</td>
<td>Workshops and one-on-one counselling</td>
<td>Children, teenagers and adults affected by the bereavement</td>
<td>As long as required</td>
<td>Community, other organisations, word of mouth</td>
<td>$50 t</td>
<td>Brisbane and Gold Coast</td>
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<tr>
<td>Hannah’s Foundation (#10)</td>
<td>Peer and coronial support for families affected by drowning,</td>
<td>One-on-one support, coronial support, 24 hour phone support, advocate for legislative change and increase awareness of water safety</td>
<td>Anyone affected by drowning</td>
<td>As long as required</td>
<td>Referrals, word of mouth, emergency services, various organisations</td>
<td>International (via internet)</td>
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<tr>
<td>Name of organisation</td>
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<tr>
<td>GP/grief counsellor</td>
<td>Counsel parents who have experienced a bereavement</td>
<td>Bereavement counselling; explanation of technical issues to better understand the autopsy process</td>
<td>Any bereaved person</td>
<td>As long as required</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Lifeline (#11)</td>
<td>To provide support for people who are in crisis</td>
<td>Telephone counselling line, counselling service, suicide bereavement program (Qld) (Standby),</td>
<td>Any member of the public</td>
<td>As long as required</td>
<td>History, charity shops, phone book, book fairs, organisations, word of mouth</td>
<td>Nil to client</td>
<td>Twenty centres in Queensland</td>
</tr>
<tr>
<td>Past Coronial Advisor (#15)</td>
<td>Keeping families informed during coronial process</td>
<td>Explain process, negotiate with lawyers, help interpret legislation, organise viewings and general family psychological support.</td>
<td>Parent dealing with coroner inquest</td>
<td>From death through to finalisation of coronial process</td>
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<tr>
<td>Name of organisation</td>
<td>Key role of service</td>
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<tr>
<td>Grief coach/author/funeral celebrant/website (#6)</td>
<td>“To help people find a place of inner peace and inspiration”</td>
<td>Grief coaching, funeral celebrant and inspirational author – biography of journey since child’s death</td>
<td>Located on Gold Coast – internet access to grief support via <a href="http://www.motherswhohavelostachild">www.motherswhohavelostachild</a>.</td>
<td>As long as required. Grief coaching is a 12 week block</td>
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<tr>
<td>Art Therapist (#3)</td>
<td>Help client make sense of their experience</td>
<td>Talking therapy as a client witness to their journey</td>
<td>Anyone – if can travel to Redlands City</td>
<td>As long as required</td>
<td></td>
<td></td>
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<tr>
<td>Monter College</td>
<td>Registered training authority</td>
<td>Training for counselling supervisors</td>
<td>Web-based</td>
<td>Self-paced course</td>
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<tr>
<td>Name of organisation</td>
<td>Key role of service</td>
<td>Type of service</td>
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<td>How does a family contact the service?</td>
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<tr>
<td>Australian Counselling Association</td>
<td>Registration of counsellors and psychotherapists</td>
<td>Professional accountability and public access to counsellors</td>
<td>Anyone</td>
<td>As long as needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private grief counsellor (#1)</td>
<td>Bereavement counselling</td>
<td>Counselling, teaching and education</td>
<td>Counselling – Brisbane-based</td>
<td>As long as required</td>
<td></td>
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<tr>
<td>Swim Australia</td>
<td>With swim schools to deliver a positive learn to swim experience</td>
<td>Secondary role – drowning prevention and annual conference</td>
<td>Swim school members</td>
<td>Whilst member of a swim school or public attending conferences</td>
<td></td>
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</table>


6.2 The unique geography of Queensland

Many of the service providers described how the geography of Queensland (size and uneven population distribution between metropolitan, rural and remote areas) impacted on their service provision. Queensland has a population of approximately 4.6 million (20% of the national population), with a growth rate of about 1.9% per year. Approximately 50% are based in Brisbane and 20% in the Moreton region, the rest being scattered in other cities, townships and rural remote areas in the state. Queensland's size is 1.7 million square kilometres (ABS 2012).

Queensland has the most decentralised population in Australia. Queensland Council of Social Services (QCOSS) recognises that Queenslanders in regional, rural and remote communities face additional and unique challenges in accessing quality services and participating in community life, such as transport and distance to services, opportunities and conditions for professionals and spread out populations (QCOSS 2009).

6.2.1 Impact on support provision

Service provider participants described the effect of this population diversity, in particular how this diversity created a challenge to providing services for bereaved Queenslanders outside the South East corner. These challenges included providing basic social work and counselling support as well as required specialist services. One participant who provided organ donation counselling commented that they could only offer home visits in the Brisbane area and had to refer families to community organisations in other parts of the state. These referrals were of a general nature and in most cases staff lacked the specific knowledge and skills available to Brisbane-based families, thus providing a service that may not have the capacity to meet the bereaved family’s needs. Similarly, the major hospitals mentioned by participants were Brisbane-based and offered social work support for those who accessed those hospitals’ services; however, the service was limited to the actual time the family spent in the hospital with an occasional follow-up phone call once the family had gone home. Home visits and continued phone follow-up was outside the resource capacity of most hospital social workers. Participants reported that smaller regional hospitals were not equipped to resource even the basic social work support. Two of the support organisation services had their main drop-in centres in Brisbane, but had chapters throughout the state, which offered varying voluntary...
peer support groups, one-on-one peer support and phone support depending on the volunteers available in that area. One combined bereavement and hospice centre operated primarily as a hospice in the SE corner but had similar centres with linked bereavement services in three other city-based locations. Another service offered family support in Brisbane and on the Gold Coast and offered professional training at a national level with plans to expand to international training.

Services such as community groups and counselling and psychology services offered broader, non-specialised bereavement support. They were geographically limited in that the main centres were SE Queensland-based with no or little support in the rest of Queensland. Specific knowledge or support regarding drowning death was limited.

In order to provide services to meet client needs, a number of issues and challenges were raised. The following section identifies some of these challenges.

6.3 Challenges to service provision

6.3.1 Training and referrals
Service providers described a range of challenges affecting their abilities to meet their client’s needs, including sourcing appropriately trained support for their clients and having a relevant and current referral database.

One common theme identified by the service providers was lack of specific bereavement training. A number of participants commented on the fact that bereavement training (if offered at all) formed only part of counselling or psychology training and it was possible to graduate as a counsellor, psychologist or social worker without any form of bereavement training. Where there was training, some participants considered it to be lacking in specific bereavement information and potentially inappropriate. For example, one participant referred to training and restricted application of the linear stages model of grief as “the dog’s breakfast” model of grief and was committed to challenging that approach.

“It’s the first myth I am committed to bust. One can actually go through a whole degree in psychology or counselling and not touch on anything in loss and grief, and yet
counsel someone in loss and grief. Where it does exist in academia, it tends to be mostly process or theoretically based, with emphasis on grief as an illness rather than a natural process, and a linear approach to the grief response, rather than facilitating a natural process from a strength-based framework.” #1

There was concern that inexperienced counsellors, psychologists and general practitioners may only know this diagnostic and linear framework and therefore may be untrained to facilitate a natural grief journey.

“If someone wanted to train specifically in loss and grief, they would have to do their own research apart from that. I guess my frustration is, for a GP, what they have in their mind is someone who has a psychological issue. They are upset. Upset equals psychological issue. I will send them to a psychologist.” #2

Reflecting a similar difficulty regarding GP’s lack of knowledge in grief and loss support was one participant who commented on the role of the GP in bereavement counselling.

“There is a lot of pressure, a lot of suggestion that grief interventions are the answer and sometimes they are: but sometimes they just take their time.” #2

The same participant reported that GPs were not exposed to grief and loss training as part of their medical training unless they had chosen to research loss and grief independently. He reflected on the fact that even where training is conducted, there is no right or wrong answer and went on to discuss the limited availability of specific training; this was mirrored by another participant who had recently given a lecture to social workers in a hospital:

“Bereavement work is not an intervention; it’s facilitation, walking with someone while they are going through something, not necessarily to change them. I always remember that psychology and social work students would often say this is the first time we had any sort of training in grief and loss. So many people came up to me and said,' I never knew any of that stuff'. I was gobsmacked.” #2
A few participants commented that they were unaware of any course that addressed the impact of drowning or other sudden unintentional deaths linked to disenfranchised grief.

One of the service providers interviewed had recently started providing specialised training for professionals working in the bereavement sector although not specifically related to unintentional death. This training evolved as a response to the limited training available and intended to create networking opportunities and provide an income stream for the service.

“We have noticed in Brisbane that Brisbane is really starved for want of a better word, of grief and loss training for counsellors and professionals. (We) offer staff to go down to a seven week training on grief and loss. We (also) provide a lot of training here – training in narrative or art therapy or sand tray therapy or conversations about grief and loss. So we do a lot of variety training for professionals in the sector. Professionals all come here for training. We also have a strong work gathering where every six weeks, all the workers in the sector that are working with families that are affected by loss, come here. We have 10–20 people coming along every six weeks and we all just sit around and talk about what our services do.” #4

Hospital staff commented on their challenges in providing appropriate referrals. Specifically, they commented that they had limited referral lists, that these lists were not updated, and that they did not know of any specific drowning support service.

Social workers from a major hospital indicated that where there are different grief responses as with a disenfranchised death, they usually attempt to link with local services.

“We try and link with local support services, but there is not much around. We need more resources and services specifically for child drowning and driveway run-overs.” #17

One organisation offered a bereavement service (though with no drowning speciality) in their local community, but it was confined to one locality and whilst there were other centres and
services across the state, they were mainly known through local knowledge. Referrals to three of the participating organisations came from other organisations and occasionally word of mouth. One well-established organisation was well known in the community via the phone book, book fairs, clothes shops, TV advertising and word of mouth. However, limitations with their service included their 24 hour crisis line experiencing a poor response rate and counsellors untrained to deal specifically with drowning deaths. Another limitation was that a caller would be unlikely to get the same counsellor twice, resulting in having to tell the story over again and not being able to build up a trusting rapport with the phone counsellor. The counsellors on the crisis line often suggest other services, but these are still of a generic nature.

“One of the features of the crisis line is that it’s a one-off call. They won’t necessarily get the same person again. We encourage people to contact their GPs and/or their local counselling centre.” #11

Service providers interviewed acknowledged the unique challenges of a fatal drowning and that there was no specific training available to support families following a drowning death, and only limited training for generalised bereavement. It was also clear that sourcing a specialised support following a fatal drowning was a challenge.

6.3.2 Communities challenged to finding qualified support
Two of the interviewees specifically referred to the need to have a more holistic approach to training; that a whole of community approach was needed to support families, which included the general public, schools, clergy and workplace, basically all of society.

“The thing that is underrated and therefore quite critical is the services being able to develop the community’s own capacity to support people who are bereaved, so that it doesn’t just become the clinician, but it’s the friends, the families, the neighbours not choking on what to do or say.” #11

It appeared there was limited knowledge regarding how to offer this support. Most participants acknowledged that referring families to relevant services once they had experienced a fatal child drowning was fraught with complications.
“It’s random. For example, I remember someone saying to me that they looked up grief counsellor in the yellow pages and I, you know, I don’t want to be rude or anything, but they, um, the qualifications! I don’t know who they went to see but the story to me from the family was that it was an elderly nun who wanted to have prayers and so forth. So that was, you know, grief counselling.” #1

“You would have a terrible time. You would hope that, you know, in situations like this they will go to their GP and the GP may or may not know someone. Most likely not know. So I have had mothers, I am sure lots of therapists have heard the most horrific stories of parents being sent to different practitioners who are supposedly able to deal with grief and traumatic loss in that acute phase, and I am horrified at the sort of experiences they have had.” #1

She also spoke of the challenge of a traumatised individual looking for bereavement support and her frustration of not being able to guide them adequately because of a lack of coordinated information.

“I feel frustrated, you know, how in an absolute state you are expected to go trawling through bloody counselling registers.” #1

6.3.3 Resource challenges
Service providers were concerned about limited resources. Whether the service was self-funded, utilised a fund raising system or was partially or totally supported by benefactors or government, each service commented on resource limitations in terms of dollars and human capacity. Limitations affecting services included insufficient time to develop and deliver services; financial restrictions; limited education opportunities and therefore a lack of skill base within the support sector. One participant from a community organisation indicated that their organisation could only support immediate family in their bereavement due to limited capacity, and their reliance on volunteers.
“The extended family can be so large – we don’t have the resources to support them. We rely heavily on volunteers to do so much because funding is basic.” #5

Organisations that relied on part or full self-funding were also affected by external influences such as other high profile charity organisations capturing the public and private sector dollar, and the 2011 Queensland floods which resulted in three quarters of Queensland being declared a disaster zone.6 One manager of an established organisation commented:

“Funding is a huge ongoing challenge in a variety of ways – and this particular year because the floods hit Ipswich so hard and people gave so generously to the floods, we knew it was going to make it harder in terms of fund raising.” #10

Lack of time and expertise to fundraise, apply for grants or develop a strategic plan were identified as challenges. One organisation’s approach to identifying capacity for fund raising developed a training scheme for psychologists and counsellors within their facility and engaged some of those students to apply for grants. For a number of the participants, funds were needed for the most basic requirements in order to maintain the service. One service managed on half government funding, half fund raising, but expressed concern that with government funding, priorities can change and hence affect the services.

"We are actually in the process of applying for a funding grant for computer assistance here in the office. Our computer system is very old and we just don’t have the server capacity for the database.” #16

“We created a training arm where we can bring in extra money and lots of referrals, and to bring in students and support the students.” #4

“We get some funding from state and federal government but that’s less than half our costs each year. We would raise about $1 million from the community. There’s a little bit of nervousness about how tenuous this is. Is someone going to say, well, actually

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you no longer fit the guidelines, so we are not going to give you the funds anymore? And that would close down the bereavement support service.” #10

6.3.4 Referrals
In addition to the above issues, limited funding also limited the opportunity for a robust referral infrastructure. Many participants mentioned that without reliable funding, effective referral processes were compromised. The hospital social workers acknowledged that if they had more time (hence funded positions) they would be able to maintain a better referral list.

“We do have a list of places we might refer. The issue is maintaining it and updating it. Often, because of the circumstances, they leave here and there is not a lot of support for them; so we need better referrals. I think there is a lack of support services specifically for child drowning.” #17

These same participants also acknowledged the importance of appropriate timing for follow-up support and would have liked to offer more follow-up with families at critical grieving periods. However, resources were so limited that they were unable to meet the basic follow-up, let alone ongoing follow-up at critical periods.

“I mean, we try, we do the best we can in doing that, but we are stretched and there’s a limit to how much we can give.” #17

Service provider participants commented that while private support services such as counselling, art therapy and psychology are available, they are mainly fee for service, and might not be financially accessible to families. One participant commented on the importance of bulk billing because bereaved families were often incapable of thinking clearly enough about paying bills and were often financially crippled as a result of their child’s death. Another participant reiterated the families’ often confused state and spoke of families feeling that they were on another planet with their grief, which she described as feeling as if they had been ‘transported from Earth to Mars’ #1.
“I predominately bulk bill because at that stage in the game, people often do not have spare cash and are often in no fit state to even remember about paying bills” #2

Service providers observed that the grief experienced by parents can be so intense that the parent may not be able to return to the workforce, hence experiencing new financial limitations and less ability to pay for services. Consequently, they access fewer (if any) bereavement services, and these families may miss out on bereavement support.

There were also a number of comments from service provider participants regarding the difficulty of providing resources such as information booklets. Whilst one commented on the difficulty and potential confusion for families by giving them resources that may not suit their emotional or educational capacity, another participant spoke of the challenges of keeping up to date with resources. She spoke of their extensive library, which needed a significant upgrade.

“We are in the process of changing all our VHS tapes to CD. But everything is such a huge job. It’s the time to phone around and find people who can help.” #5

6.3.5 Volunteers
The difficulties associated with trying to find a balance between lack of time and the need to provide volunteers ongoing support were recognised. Those struggling were either in their infancy, or had been unable to update their policies and procedures due to various staffing difficulties. Developing a skill base with volunteers was recognised as both time consuming and challenging due to availability of appropriate training. Services that were able to provide some training, internally or otherwise, tended to access more general bereavement training because there was no specific training for professionals or volunteers in regard to drowning deaths.

A few participants summarised the challenges of insufficient time and the need to provide volunteers ongoing support, training and to emphasise a work–life balance to minimise burnout:
“It takes quite a toll to be actually working with, and supporting other people” #17

"For us that's a huge problem. That’s another area. You’ve got me working 20 hours a week and there’s so much to do, get into the newspaper, get onto the radio. You know there’s just so much to do for one person so you rely heavily on your volunteers to do a lot for us”. #5

Another well-established organisation was creative with their approach by utilising students from various disciplines in their training scheme (e.g. marketing).

“So the next step which is happening in October is to get the benefactor and some of the students together to look at what our image is going to be.” #16

Whilst resource challenges affected most services, another aspect that arose from the interviews was the personal impact on the service providers of working with bereaved families. Participants commented on both the effect on the families receiving the service as well as the effect on the service providers themselves.

6.4 Human impacts: service providers’ perspective on the impact of bereavement work on staff and volunteers

6.4.1 Emotional impact
A common theme amongst many of the service providers was the impact of the intense environment of bereavement support work on their personal lives:

“You feel like you have been run over by a truck. Some things just get to you; I put my tongue on the roof of my mouth and push as hard as I can”. #17

Service providers described the difficulties in debriefing outside of work, recognising the importance of an internal support structure to minimise the personal risk to the service provider.
“People outside the workplace don’t understand, and we don’t need to traumatis e them more. I was suffering from PTSD. Probably a combination of both deaths pushed me over the edge. The second little boy that passed away actually had the same birth date as my son: I had colleagues say, ‘toughen up’. I ended up on medication with a psychologist. I was on the point of suicide.” #15

Recovering a child who bore some similarities to the participants’ own family situation had a significant impact:

“To this day I can’t use orange blankets. That was the colour of the blanket they used in the mortuary. Can’t use orange blankets to the point that I actually went home and threw away my son’s orange blanket.” #15

Some support groups and organisations were conscious of protecting their staff and their participants’ emotional health and therefore had a policy that volunteers or staff must be at least two years into their bereavement in order to offer best support. One of the support group managers stated:

“We wouldn’t bring someone in as a volunteer if they have experienced a significant loss in the past two years, because it’s too raw and makes it difficult to step outside of your own stuff to work with someone else’s stuff.” #5

6.4.2 Impact on the families of volunteer bereavement support workers
Service provider participants who relied heavily on volunteers commented on the extensive commitment required from the volunteers and the importance of appropriate support to sustain their involvement. Whilst this support was evident in a number of services, it was lacking in others. At times, volunteers committed to a roster system had to put family commitments second to their volunteer role. Whilst similar impacts may affect paid workers, none of the paid worker participants raised the impact of their work on their families.

One manager from a volunteer supported organisation stated:
“I couldn’t keep talking to my family and stay happy, so it does affect.” #16

The less established organisations reported the considerable commitment and compromises they had made, and commented on the impact on their immediate family relationships.

“(There’s an) enormous amount of me invested in the (service). (Wife) doesn’t work at all. She has given up her job and devoted all her time to the (service). It takes an enormous toll on our personal life; there are a lot of sleepless days and nights and taken a lot of, I guess, our own money. I think I have probably put close to $50,000 of my own money. I won’t even ramble on as to the lack of relationship time we have and how long it’s been! When will people realise that this is killing us personally? When will the government realise that our service is important and crucial to families surviving? When will our message be heard so that drownings won’t happen and then we can close for good? I can only dream!” #14

One therapist, who had experienced her own loss prior to establishing her art therapy practice, spoke of the importance of expressing oneself through creative therapy. She established her art therapy business as a result of the benefit she derived from artistic expression of her grief, when words were unable to express her emotional status. She also identified the value of art therapy in that such creativity can also occur outside of a therapy session, hence offering a grief management tool, which is not constrained by time, geography or finance.

“When I draw what my grief and pain looks like, it lifted. Using the creative side of the brain, the right side, which is not with language – because sometimes, there are no words? It’s about self-care and finding comfort when there’s nobody else to comfort you.” #3
6.4.3 Personal motivation behind some of the service provision

Some support organisations began because of a traumatic incident experienced by the founder. Services were often developed by bereaved parents as a way of honouring the life of their deceased child, coping with the intense resultant grief and often had a cathartic impact.

“I am living K’s life. I am doing hopefully what she would want me to do – I am doing something positive out of her loss. And that helps me with my grief. It gives me motivation to get up in the morning.” #14

Some of the service providers described the lack of support services available to meet people’s specific grief needs rather than generic grief support. One organisation was founded approximately 12 years ago by a reverend who realised there was no parent support group for those who had suffered the death of a child and one participant spoke of the establishment of a support service due to a more personal experience.

“In recognition for the lack of support for young people who suffer the death of a loved one, and then in 2009, the hospice and bereavement support program was opened in recognition of the lack of a similar group in the Brisbane area.” #4

“Dr H had a daughter who died and she was concerned about the kind of services and supports that were available to her.” #10

One participant offered another reason for establishing a support service – the opportunity to honour his deceased child and to give him a reason for getting up in the morning and continuing to function.

“If I can start getting changes made by using my position, both policing, the (service) and as K’s dad as advocate, to get those changes made; I struggle with explaining this, it gives meaning to K’s loss. Something positive can come from it I am exceptionally proud of who and what I have become since losing K. K has given me so many great gifts, and the expression, live my life, not my death, and I am now living K’s life. I am doing hopefully what she would want me to do. I am still bitter but I am doing something positive out of her loss and that helps me with my grief. Look, it drives me. It
“Talking about K’s death and explaining where I am coming from, that helps me. There is a trust issue with our families; we share our stories, our pain, our suffering, which helps us and them”. #14

Of all support services involved in interviews, only one offered a service dedicated to water-related deaths. Founded by parents whose child died as a result of drowning in their home pool, the male participant reported that his first-hand experience of being unable to find support for his family’s grief was the initial stimulus to provide the service. In addition, the strong need to ensure such a tragedy did not befall other families resulted in an advocacy and education component to the service. This service included coronial support and financial assistance with funerals:

“We decided to start the (service) to provide peer-to-peer support, but also to advocate for change with things we noticed were wrong with the loss of K. We provide financial assistance for funerals – that’s the first sort of hurdle for the families to get over because nobody has money lying around waiting for somebody to die. So that just helps the families cross that particular burden at that time. The fact that I have been involved in the coronial process for so many years through the police; I have the advantage of being a policeman. I know how the coronial process works, but we have also lived that journey. And speaking from my own personal experience, to have a
coroner come back and say there is no negligence or contributing factors towards the death can actually be quite a healing experience for the families.” #14

This same organisation also provides the option of a gatekeeper role between emergency service workers and the families. The participant explained that a member from the service could approach both parties and if signed consent was given, they could then facilitate that contact on behalf of the family and emergency service worker. He raised the value of this for some service providers.

“Emergency service workers don’t get any feedback on how the family is coping three, six, nine, 12months down the track and there’s a lot of emotional investment in those emergency service workers.” #14

Two service provider participants had children who died in their infancy and both reported negative experiences with counsellors and support groups. They wanted to create environments for people to move positively through their grief rather than “staying stuck”. One participant commented that there had been no-one to help their family with the specific support needed following their child’s fatal immersion. They recalled that there was no service which could relate to their specific needs resulting from the type of tragedy they had experienced. He, like many other participants, used the phrase ‘They didn’t get it’.” #14

This concept of understanding where the families were coming from in their grief was a common thread discussed amongst participants who had experienced a similar tragedy. These participants acknowledged that building rapport with the bereaved families was important:

“I usually mention at some stage that I have lost a child myself to build up the rapport with the family. The one big thing that certainly helped me, and I guess I try and teach, or let them discover, how I sort of moved myself through my grief. Meditation and writing certainly helped me and use that to help them move through it. And just finding that inner peace; that’s really important”. #2
“It’s important as the coordinator to have a connection, so we do know where they are coming from. Parents often want to do something to help them with their grief. I thought when my son died, three months later I was ready to save the world. We have a two year rule here; there is no official capacity until two years into your grief.” #5

Participants who had created a service because of their own grief experience believed that, by providing services for others in a similar situation, they were able to honour their child. The next section reports on how some of the services were developed in order to facilitate this process, and raises some additional benefits and challenges for support organisations.

6.5 Benefits and challenges of support groups and support organisations

Service providers commented on the value and challenges of their services to themselves. For service provider participants who had lost a child of their own, the key benefits included honouring the deceased child, providing an opportunity to give something back to families in similar circumstances to their own, and helping with their own healing process. Counselling and bereavement support organisations staffed by health professionals who may not have experienced bereavement themselves also recognised the importance of making a connection with the family. One participant described bereavement support as:

“The raw, critical hard end that challenges every single emotional fibre of our being”. #17

6.5.1 The role of the support service

Support groups and organisations help bereaved parents cope with the challenges of life in ‘the new normal’. Support groups where bereaved parents supported newly bereaved parents were reported as providing significant help to managing life. This same coordinator who herself had been twice bereaved stated:

“I started planning my life around my meetings because I got so much out of coming, listening to other parents, how they survived or how they dealt with a situation. Sometimes I came home feeling that I was a lot better off than some people”. #5
Another significant connection with support groups was that attending parents or family members often enquired about the organisation or individuals’ connection or experience with child death. Participants commented on this connection.

“They often ask, well, most of them ask, have you lost a child? Because they want that connection.” #2

“We work here because we actually have the experience. I am actually a registered midwife and have the experience at the other end of the bed, stillborn deliveries and babies that die.” #4

One participant expanded this concept to the benefits of support from people who had experienced the same type of child death, in particular the uniqueness of a drowning death.

“The biggest problem is lack of understanding amongst mental health professionals of drowning. It is a different type of death. We have had families told that drowning is a terrifying experience, yet we have had other families who have had near drowning experiences say, that’s not how drowning is. And these mental health professionals are telling people the wrong thing, which is further adding to their trauma. In many cases, when in crisis or you are having a shit day, you want to talk to someone now, and you want to talk to someone who knows.” #14

However, there was still acknowledgement of the role of other health professionals to support the bereaved:

“I am not saying a psychologist or psychiatrists don't have their role, but we have our little role as well in understanding exactly, well, not exactly because everyone grieves differently, but we do know where they are coming from. Often a parent or friend will give them some kind of platitude. And they will ring here and say, ‘They just don’t get it, they just don’t!’” #5
Building rapport and trust was identified as a key factor by a number of service providers. For some services that was difficult to achieve due to lack of understanding of drowning death and for some it was changing rosters and unavailability of the same support person. For the dedicated drowning prevention service, building trust was seen as a priority.

“We have the ability to share and, like, it’s not a one way street, um, we don’t just take. We invest a lot of ourselves in our families and they become family. And there is a trust issue. We share our stories, our pain, our suffering, which helps us and also helps them to understand that we know where they are coming from”. “The expression you get a lot from families is ‘they get you’ or ‘we get them’, or ‘they get us’.” #14

The need for support at critical times for the bereaved (often early hours of the morning) reflects the importance of 24-hour support lines. However, whilst the immediacy of contact was important, one service provider reported a limitation of this service;

“One of the challenges is being able to find the same, well trained, consistent person. It’s the consistency that’s the big issue; you’ve got to build that particular level of trust up.” #14

The importance of a personal approach from the support group rather than a more formal business/clinical environment was another reason for using support groups. Even in the counselling support groups, rather than the non-counselling peer support organisations, the ability to connect with the family was paramount. Participants also acknowledged the stigma and different type of grief for parents who experience a child death such as SIDS or drowning

“It’s a very personal experience that people are sharing. That’s something we try and really bring into this office. That is, as much as this is a business, this is also a place where people come to grieve. The people that work here work here because we want to make a difference.” #16

“It carries a certain stigma, and they get different types of grief. They get different types of sympathy from people as well. SIDS mums suffer stigma, they tend to blame
themselves more; they were responsible for the baby. It can take up to five times as long as whatever the normal grief process is. So if you would expect that after a couple of years, if you lost your spouse, you might be able to function reasonably well; with a child, it might take ten.” #16

Whilst acknowledging the benefits of support groups, limitations were also recognised. Benefits include offering a range of services from one-on-one counselling, specific gender group work, children’s support groups, professional counselling, peer support from bereaved to bereaved parents, advocacy, coronial support and education and media exposure. Participants commented on challenges including available training in terms of cost and content, being time poor, pressure on volunteers, and resource and funding limitations.

6.5.2 Limitations of support organisations

Service provider participants also offered insights based on their experiences into the potential limitations of support groups. Building rapport in an organisation which depends on volunteers can create challenges. Most participants discussed the significant time commitment for volunteers and, depending on the organisation, could be ad hoc, or as part of a scheduled roster. One participant spoke of the challenge this could create due to the importance for bereaved parents to have a consistency of support and not having to relate their story to a different person each time:

“It’s the consistency that is the biggest issue, when you are getting a different person each time you speak. You’ve got to build a particular level of trust.” #14

Another participant from a well-established organisation reported on the low (60%) crisis line response rate, largely due to volunteers not showing up for the evening shift. From September 2011, they attempted to counter this by shifting from a volunteer approach to paid positions for the night shift telephone counsellors. When volunteers were on roster they had to be available 24/7 for the two week allocated period. Paying for the night service is intended to increase response rates in the higher volume timeframes. And while there may not be a high usage, he reported that it’s the unknown that causes resource challenges.
Service provider participants reported that training for peer support and counselling services was a costly exercise and not all organisations were able to afford or access training for their volunteers. Organisations did refer parents to other organisations, but there was the complication of a limited referral database and, within that referral base, limited training in the specific issues relating to fatal child drowning.

“It’s very hard to find (professional people who actually really understand). And trust is a big issue, especially with judgement. And the biggest problem is the lack of understanding among mental health professionals of drowning. It is a different type of death.” #14

“We do an initial orientation type of training as the way we understand loss and grief here. We encourage them, we try and get them some funding to attend conferences – and we continue to do updates and training along the way.” #10

One bereavement counsellor was concerned about support groups keeping families stuck in their grief rather than moving forward. She commented that it was possible that, in some groups, members could dwell on the sadness and not be able to support each other to learn to manage their grief. Another participant mirrored the same concern from his experience following the death of his child. Attending a support group where families experienced different causes of death had the potential to create more conflict than benefit.

“I will give you an example of what happens sometimes in the support group involving disenfranchised loss or some kind of stigmatised experience. I do a lot of family court and child protection work and I see experiences where there are terrible, terrible things happen to children because of neglect, so it’s not just a random ‘I took my eyes off them for two minutes and the next thing he was floating in the pool and oh my god’. But what happens in a support group is you get one person kind of going, ‘How dare you. I have come to a place where I know it wasn’t my fault, and you were taking drugs and you let your child – you know’. So that comparison of better off and worse off than me”. #1
Having identified a range of benefits and challenges with service provision and community support, participants were also able to comment on how families can be better supported. This is the focus of the next section.

6.6 Service provider participants’ comments on support for bereaved families

During the interviews, service providers acknowledged a range of support needs for bereaved families, both within and outside the scope of their service delivery. Common themes included:

- The challenges of supporting families who had experienced a disenfranchised child death and the compromised role of parent as protector
- The role of the GP in terms of expectation and ability to deliver appropriate support
- The different styles of grieving from a gender aspect as well as different family members such as parents and grandparents
- The role of the community in supporting families through their grief and the opportunity to express grief in a variety of ways
- The role of coronial support and the impact of coronial reports
- Writing about one’s grief.

6.6.1 Challenges to providing support for a drowning death

During the interviews, many service provider participants acknowledged the uniqueness of the experience following a fatal child drowning as well as the absence of consistent support and relevant training for service providers. Almost all of the counselling, peer group and bereavement support participants interviewed recognised that one of the most important aspects of support following a child drowning was the opportunity to be heard, not to be judged and for someone to ‘get it’. This expression ‘get it’ was mentioned by parents and service providers and refers to an understanding regarding exactly where the grieving person is coming from. However, in the absence of specific training in this type of bereavement, providing this service appeared to be problematic. It became clear that specific bereavement type support groups or organisations that were managed and or staffed by people who had suffered a similar tragedy appeared to be helpful. As long as the support group did not
encourage people to stay stuck in their grief, participants commented that validating emotions offered significant benefit to the person grieving. Participants reported that this appeared to be particularly important with people suffering disenfranchised grief as opposed to the bereavement of a child who had experienced long-term illness. In the former, because of the stigma related to drowning deaths, perceived societal judgement and allocation of blame, service provider participants reported that families appear to miss out on societal support, unlike with illness-related deaths.

“There is an extra burden that happens with a drowning death and because of that, guilt. It is my experience that with a drowning death, there is extra guilt. If a child dies of cancer or in a road traffic accident it’s almost like society says, ‘My God, what a tragedy, it’s such a tragedy’. So families get kind of free access to support.” #2

Another complication in providing support was parents’ self-blame when lack of supervision was part of the picture, as is the case in a fatal child drowning.

“Disenfranchised grief just adds to the complexity of their integration of the loss experience and somehow the parent has to keep breathing and keep doing that while you are a train wreck. People who have lost a child to drowning or other traumatic circumstances, is that the pain of grief goes on far longer than they would have ever imagined; and there is the extra burden of guilt that happens with a drowning death” #1

One participant spoke of her frustrations with the limitations of the bereavement system and reported that the system was not very supportive; so while trying to adapt to their loss, families also have to cope with the community and professionals’ naive and often ignorant attitudes.

“They enter this system of, oh my God, I can’t even think how to describe it, the system surrounding traumatic loss with kids. To do with the John Tonge Centre, the police, funeral parlours and people questioning you and people not questioning you and people ignoring you – and trying to get through it and parents are like ‘Can I go to the
A significant part of the support system involves a range of health professionals and in particular the GP who is often the first health professional a family turns to for support following their child’s death. Many grief symptoms present in a physical manifestation and often the GP would have known the family prior to the tragic event. A number of participants commented that although people may have an expectation that GPs could help parents/families work through their grief, their actual ability to do so was compromised due to lack of information and training. One participant commented that training in this area was limited, doctors were often unsure how to support families in this acute grief stage and, if they did, there was this notion of a linear approach to grief, a symptomology that interventions are the answer:

“I think the majority of GPs find it difficult to manage bereavement that isn't just a simple bereavement so to speak. And they have got limited time to make an assessment and some of the assessments are fairly complicated to do. There is a lot of pressure, there’s a lot of suggestion that grief interventions are the answer, and for some things they are. But I think there are some things that just take their time.” #2

“I guess my frustration is for a GP, what they have in their mind is someone who has a psychological issue. They are upset; upset equals psychological issue. I will send them to a psychologist.” #1

6.6.2 Different grieving styles
Knowledge of the different styles of grief and gender stereotypes can be important for a family in order to understand some of the challenges that may occur in their relationships following their child’s death. Participants recognised that this information needed to be relayed to the families, but were unclear from whom the families would receive that information. Most service providers acknowledged that the stereotype of men often feeling that they need to ‘hold the family together’ was evident in grief, but were not confident that other health professionals, GPs or even the general public were aware of the extent of these differences and hence in a position to adequately support the families. Men often appear to be coping
well, yet may show an affect some years later, often triggered by a seemingly unrelated matter. In the meantime, relationships may need support to get through this challenging grief communication between couples. Importantly, the fact that there is no right or wrong way to grieve is information that is necessary to share with families.

“The grief process for men and women kind of goes along the same lines as that whole difference in emotional intelligence and emotional expression in our culture between men and women. So the sort of stereotype of men ‘doing’ and women managing their grief by emoting and talking. And there is very little understanding that it’s just different. Unless someone tells them.” #1

“Three years later he came for work-related stress. No. It turned out it’s actually, that’s when he started the integration of his grief. The problem here is because that’s not well known amongst Mr and Mrs public, you have that risk, that terrible risk and likelihood of then that being a source of conflict in the relationship.” #1

6.6.3 Community support
Another key aspect of required support was the role of the community. Participants, counsellors and educators commented that most people are uninformed as to how to address bereavement and often judge, or ignore the topic of the child’s life (and death). People around the bereaved families expect them to move on:

“They have to manage that cultural/societal kind of message around well, you know, you kind of should be moving on by now. They have to manage that with what they are feeling, which is that they feel still awful, they are dying inside and they are just stressed and upset and for them it still feels raw. And then they are getting the external message, well, you know, it’s about time you picked up, and what do you mean you still can’t do the ironing.” #1

Public education on how to address this was suggested. One program called Casserole Positive encouraged support beyond the first few weeks of the death, providing a holistic approach to bereavement support and the notion that professional support does not substitute
for the community role. The term, ‘casserole negative’ suggests that people are not coming round with appropriately sustaining support

“It comes up definitely with families after the first month or six weeks or so; people go back to their own lives and business and suddenly they are casserole negative and they haven't got the community support.” #11

A number of participants commented that schools could and should play a greater role in supporting the family and siblings of a child who had drowned. However, the challenges associated with doing this were recognised – for example, the limited resources in terms of support staff and adequate training for these staff, in schools.

6.6.4 Coronal support
Immediately following a fatal child drowning there is a legal requirement for a coronial report and, in some cases, further investigation. Service provider participants stated that this investigation could be a confusing and extended process.

“Families are pretty much left in the air as to what to do, who to ring. They have no idea who to contact or what was going on.” #1

One participant who had previously worked as a coronial support advisor (informal position) was conscious of the benefits of providing emotional, advocacy and physical support by going to court either with the family or on behalf of the family. This participant described how these functions can help families with their healing process.

“I was very conscious of keeping in contact with them, keeping them in the loop with what was happening. The necessity of such a free service for families is that they can obtain answers to aid their grief, understand the death of their loved one and be able to accept the death in time. So many families either never attended the inquests of their children or were not subpoenaed to attend, they didn’t want to, or couldn’t because it was too hard. Some families are too consumed with grief to attend. And I am a firm believer that inquests must happen within a two-year time period and no sooner than
six months after the death. I’ve witnessed two cases of inquests where they were too close to the deaths and the family were not ready to deal with it.” #15

Conversely, if the investigations continue for an extended period, families do not receive a final death certificate until the case is closed, which can impede the grieving process, particularly in relation to a disenfranchised death where blame, feelings of guilt and stigma are often major contributors to complicated grief:

“Families have just walked away from the whole process because they felt their child’s death was dependant on money being spent for a lawyer to tell them what they already knew/felt. Their child died because it was their fault in the public’s eyes. It’s been hard for those families because they have been blamed for many years.” #14

6.6.5 Writing about grief
Service providers acknowledged that some parents may find it cathartic to write about their grief and share their journey with others. This honours the deceased child, and also provides the opportunity to give back to others and support them in their grief journey. One service provider who was also a bereaved parent (though not because their child drowned) produced a range of resources, books, short stories, conference presentations, websites, memorial sites etc., with the key benefit of maintaining the relationship with the child and to honour their life.

“I started writing the book because I realised I had to get these feelings out of my body. Meditation and writing certainly helped me, and I use that to help others move through it (the grief).” #6

Toward the end of the interviews, service providers were asked if they would like to suggest any improvements to support services for families who have suffered a fatal child drowning. Below is the ‘wish list’.
6.7 Suggestions to improve the support services

Service providers made a number of suggestions to improve support for families bereaved from a child drowning. These fall under four main categories: professional training, referrals, education and resources.

6.7.1 Professional training

There was a clear message from most service providers that health professional training in disenfranchised loss and grief was minimal. Whilst some organisations had internal training schemes, they were not specifically focused on disenfranchised grief and they did not include any specific training for drowning bereavement.

A module addressing disenfranchised grief is currently being developed but it is in early stages and as yet unclear how it will be marketed into core subjects for health professionals. One participant suggested a specific drowning module to be incorporated in professional social work, psychology and counselling training.

The manager of an established organisation spoke of his wish to see improved practitioner training in grief:

“So, I guess, improving the way in which practitioners can conceptualise loss and, in particular, traumatic loss, is one thing I would like to change.” #11

Some service providers commented that training in communication skills specific to sudden death in a child should be provided to emergency service workers. The perceived lack of training often resulted in families overhearing hurtful remarks about their circumstances and at times experiencing insensitive behaviours. Therefore, communication training, as well as support services for emergency service workers who attend sudden death situations, was suggested.

It was also suggested that a Coronal Support officer not affiliated with the police service should be available to work with the police and families and that the Cairns support unit model be applied state-wide. This officer, perhaps referred to as a ‘child death investigation
coordinator’ was recommended to support families and help them understand the coronial process:

“So every person who has experienced a child death has the opportunity to have that liaison coordinating person.”  #15

One medically trained participant acknowledged that GPs are in a prime position to support bereaved families but that they were often at a loss regarding how to talk to a bereaved person. Further, the Medicare scheme did not support the extended time required to facilitate discussions with a grieving person. Grief and loss training for GPs was suggested as well as an extension of the GP practice facility to include a nurse practitioner and possibly a counsellor on the same premises as the GP. It was suggested that she/he should have some counselling experience and training. The same participant was frustrated by the lack of time and human resources to facilitate a grief awareness education program for the public. He said:

"We would like to make the training more available. I mean, you could have columns in papers; you could have question/answer type of columns or something like that. The problem is getting to it and doing it.”  #2

One participant from a training organisation spoke of the importance of how improved standards and requirements for professional supervision amongst health professionals could help identify challenges practitioners faced in facilitating families through their grief. This went hand in hand with improved training for disenfranchised grief.

6.7.2 Referrals
Referral challenges included knowing who to ask for a referral, who to refer people to and working within an optimum time frame to maximise referral and service benefits for the bereaved. One participant suggested an ‘opt out’ service where identified referral services, perhaps funeral directors, social workers, emergency service personnel or linked referral programs could offer to contact the identified family member at a relevant time after the child’s
death. From there, they could help ascertain the family's needs and refer them to the appropriate services.

“The other way of doing it is to have an ‘opt out’ kind of thing. That you say, most people find it helpful, we will touch base with you in one, three and six months. If you don't want to do it, tell us. Otherwise we will.” #2

A number of participants commented on the ad hoc basis of referral knowledge. It was suggested that this could be minimised by having a central database in conjunction with an umbrella organisation for bereavement, with some specialised groups within that umbrella organisation. This would allow families to identify services and support organisations relevant to their specific situation.

“It may be as simple as a position in state health or one of the social workers roles, just to have this database of referrals. It doesn’t have to be a social worker. You could do it by having volunteers from one of these organisations so that you have a bereaved parent ringing you up.” #17

Another participant extended this thinking a little further, including the importance of getting this information to the relevant people.

“Maybe there needs to be some kind of register, and association, a group where there are counsellors who are known to be suitably qualified, suitably experienced and decent practitioners. GPs need to have that information – we need to collate the information. We need to get it to the prime gatekeepers who are perhaps the funeral places, the GPs, perhaps the emergency services etc.” #1

However, she also mentioned the challenge of the system with GPs utilising the current Medicare rebate scheme to guide their referrals, rather than being able to identify the most relevant service for their patient. (The Medicare scheme does not offer a rebate for counsellors).
“And again, the difficulty is they go, OK, let’s send them to x, she’s good. Now we can write out the Medicare health rebate. Oh no, she’s only a counsellor. She is more experienced than any of the psychologists on my list, ah well, bugger, go and see an inexperienced one I guess. You know, it gives me a stroke, its sick.” #1.

The dangers of mixed support groups potentially creating the situation whereby people compared each other’s deaths in terms of ‘better’ or ‘worse’ were also acknowledged. A specific drowning support group was recommended. This concept was further reinforced by the manager of an established support organisation who spoke of providing a generic service with links to a number of targeted services.

“I think there’s always going to be a case for a generic service but I think it should be enhanced and complemented by a number of targeted ones as well.” #11

6.7.3 Education

Many of the organisations expressed a desire to have the time and resources to improve education for professionals and the public on child death. One participant stated:

“The only way these people get educated is if someone like us shows up – our wish list is to continue that education.” #16

Similarly, another participant discussed the importance of continued drowning prevention messages in the media to inform both public and policy makers, as well as media sensitivity.

“My wish list would be uniform legislation across Australia. A consistent media advertising campaign for drowning prevention and awareness and that is right across the whole year.” #14

A number of service provider participants talked about increasing the opportunity for training support for bereaved parents wishing to support other bereaved parents, so their volunteer pool could be increased. In addition, there was mention of developing a stand-alone drowning module for volunteers and members of peer support organisations. This training would
increase confidence in offering support and minimise the risk of volunteer burnout and concern regarding inability to effectively support those in need. It would also standardise the information, which would offer opportunity for feedback and further development. Subsidising this training was recommended due to limited resources in these sectors.

“I guess to have some older families trained in counselling and support so we could literally divert the phone to them; we have had families who have indicated they would like to do that.” #14

Linked to this training requirement were comments from most of the participants about the professional and public perception of child death. One counsellor expressed a wish for further professional and community understanding of the impact of a child death the need for people to better understand relationship challenges and different grieving styles following such a death:

“People who have lost a child to drowning and those who have lost a child to other traumatic circumstances, is that the pain and grief go on for longer than they would ever have imagined. And they have to manage that cultural/societal kind of message around, well, you know, you kind of should be moving on. And they are dying inside. And they are getting the external message around, about time you picked up. And there is very little understanding of this; unless someone tells them, someone has to tell them. It should be on some sort of government website so that sort of stuff is obvious: I don’t think information is readily available and accessible.” #1

The availability of training, a sound referral base and community capacity are also affected by funding and resource availability. This was often stated in the context of information availability and sharing to provide improved support.

6.7.4 Resources
Social workers mirrored many of the comments made by other participants that they would like to feel less rushed so they can spend more time developing the services. They, like some
of the other organisations represented in this research, also commented on the fact that any forward planning was compromised due to over stretched resources and the reality of being reactive rather than proactive.

“Our model of care does need to be looked at as well. We have a model of care that I think is 30 years old or something” #17

These social workers acknowledged this resulted in limited training and resources for particular types of child death:

“I do think there needs to be some more resources and services specifically for families that have had a child drown. I know that for the family I worked with, it was such a disenfranchised grief that possibly other services wouldn’t understand; there’s definitely a gap.” #17

There was also comment on extending existing services to meet the needs of families experiencing different child deaths. All the social workers recognised the benefits of developing a support program for sudden child death based on their existing palliative care program.

“The other thing that would be great is with the bereavement support program, that one day it does grow and include bereavement support for all families that have a child die, not specific to palliative children who die.” #17

This wish for an extended service also reflects the lack of information for families following a child death:

“I think the information they need is to actually walk through what’s going to happen. What are you going to go through? Understanding what the processes are from the autopsy, what the police need to do, and all those things.” #15
One of the participants mentioned that perhaps the state coroner has since produced such a booklet, but was unaware of its circulation. This reflected the lack of coordination of existing resources.\(^7\)

One participant was the director of a peer support organisation which is severely limited by lack of resources. He explained the value of a shop-front office to enable improved public awareness and a safe place for people affected by sudden child death to ‘drop in’. This requires funding.

“\textit{Ideally I would like a shop front so we could access it regularly – and it could become a drop-in centre.”}\#14

This participant also expressed the wish for funding to support a staff member to help with the administration of the charity and the foundation, some payment for the coronial advisor position (currently administered on a voluntary basis with high expense outlay to attend court, visit families etc.) and the option of a professional counsellor available when needed. He also emphasised the need for the government to consider exemption of audit fees for the charity so any monies raised could go straight to the families.

\textit{6:8 Conclusion}

Service provision and support for families who have experienced a fatal child drowning appeared to be affected by a number of factors. The unique geography of Queensland and its scattered population outside of the southeast corner created challenges for a state-wide equitable service delivery. This meant that those in the city and metropolitan areas had more opportunity for professional support than those in the rural and remote parts of the state. In addition, even when support was available, it was often compromised due to limitations in training and education at all levels of health professionals. As part of this dilemma, challenges with identifying appropriate referrals often resulted in health professionals referring families to services, which may not have met the family’s needs and the subsequent frustration for the service provider in being unable to support that family. Limited funding exacerbated this problem, with many service providers aware of how their service could be improved, yet

\(^7\)A number of fact sheets and brochures are available on the coroners’ website, http://www.courts.qld.gov.au/courts/coroners-court/fact-sheets-and-publications#Brochures
lacking the capacity to achieve these improvements. Participants also recognised the human impact of providing these services, the need for professional support and the recognition of an unbalanced work–life situation in some circumstances, which impacted on the service delivery. This chapter outlined a range of benefits and gaps in service delivery, the limited understanding of the impact of child death and offered some suggestions for improvement.
Chapter Seven – Discussion

7.1 Introduction
The research highlights some of the challenges service providers face in providing optimum bereavement support, as well as the challenges parents face in finding support that met their needs. This is the only qualitative study known to the author that identifies the psychosocial impact on parents following their child’s fatal drowning, and their experiences of community and professional support, as well as the experiences of the service providers. The findings highlighted the financial impact of a sudden child death; the role of the GP in bereavement support; the lack of clear bereavement support referral pathways; the need for a coronial support officer to guide the parents through the investigation process and improved training and education for health professionals and the community in regard to supportive conversations and behaviours with families whose child has drowned.

Four overarching themes were identified from the interviews, which linked to the key study objectives. The first theme related to the extent of the grief journey for bereaved parents and the psychosocial impact of the drowning death. The second theme acknowledged the altruistic journeys taken by many parents as a way of honouring their child’s death. The third theme related to the support services and highlighted the limited understanding amongst the community and health professionals regarding the impact of the drowning death on parents. The fourth theme recognised the gaps in the support available and some of the reasons for these gaps to meet the requirements of bereaved parents.

This study identified a diverse number of support services ranging from pre- and post-hospital care through to health and allied health professionals, support groups and bereavement organisations. Whilst a few service providers offered a comprehensive service meeting their organisational goals, other service providers expressed limitations in providing support and in particular the lack of specific training and community awareness related to a fatal child drowning. Where families could identify support, it was mainly generic in nature, usually expensive or, if subsidised, available only in the short term and often difficult to access. This study identified supports which were unknown to many of the parent participants, two of which were not expensive or time limited and offered bereavement support (not specifically related
to child drowning) for the whole family but was geographically restricted to only one area. This study identified the importance of relevant training and specific support for a sudden unintentional death.

7.1.1 The psychosocial impact of grief on families whose child has drowned
The experience of losing a child is often referred to as ‘the impossible grief’, the greatest tragedy that a parent will ever have to face (Sanders 1998). Bereaved parent participants in this study described various degrees of changes over time within their behaviours, relationships and health. These changes reflected the parent’s psychosocial experiences and included changes to their health, the relationship with their deceased child, spouse and extended family and friends. They described their experience of social isolation and the pain of stigmatisation. Changes were also influenced by their experience with social support, schools and the workplace, the role of religion in their lives as well as changes in their financial situation.

There were some consistent experiences reflected in discussions with every parent participant, reflecting typical grief patterns. However, each parent participant managed or responded to their grief differently. Every parent reported somatic difficulties, changes to family relationships and friendships, and difficulty in adjusting to life without their child. However, each participant also reported unique aspects of their experience. Some parents became more introverted and isolated and unable to talk about their grief, others entered into behaviours previously outside their experience such as excessive spending, extreme mood swings and protective parenting of surviving siblings, whilst others appeared to cope well in certain circumstances but reported having to wear a mask or create a front in order to get through their day.

This is consistent with research of mothers who had lost their child at least one year prior to the study which suggested grief can result in abnormal behaviours, disturbed human relationships and in physical and mental illness (Laakso, Paunonen-Ilmonen 2002). Grief is influenced by the social and professional support experienced by the met expectations of friends, family and health professionals in providing relevant support. The type of support expected varied from family and friends just listening and providing emotional support, to
instrumental support such as helping with organising aspects of life such as funerals, food, getting siblings to school etc., and informational support which was expected from the hospital and other health professionals unmet expectations triggered complex emotions as the parents came to terms with the reality of their child’s death and the reconstructing of their identity. These emotions can manifest themselves in a range of behaviours such as confusion, anxiety, depression, and anger as well as physical reactions including headaches, chest pain, nausea, tension and insomnia (Laakso Paunonen-Ilmonen2002; Miller 2003).

While parents in the present study reported extensive grief symptoms following the death of their child, the duration of these symptoms differed for each parent. Predictors of complicated grief are multiple but, in essence, complicated grief is said to exist if grief-related symptoms appear to go on for extensive periods of time (Harper et al. 2011) and the person experiences a range of symptoms that cause them to struggle with adapting to their new situation (Lobb et al. 2010). This continued struggle causes limited or even absent interest or engagement in ongoing life, physical and emotional symptoms and resistance to accepting the pain of the reality. In their systematic review of studies on bereavement, Lobb et al. identified a number of predictors for complicated grief including having experienced a distressing childhood, self-isolation and lack of preparation for the death. However, these predictors were based on widows and suicide deaths and did not represent a sample of bereaved parents who had lost a young child, nor did they relate to a disenfranchised death such as drowning. Consequently, the comparisons need be treated with caution but offer a direction for further investigation in relation to a sudden unexpected child death. The confusion and lack of understanding with regard to the association between time and grief in these circumstances is a significant insight from this study and requires further research in order to develop appropriate professional and community support mechanisms.

Social isolation was also identified by the parents in the current study as a common experience following the death of their child, although this is not well developed in current literature. One longitudinal study with 219 bereaved couples identified a number of situational factors relating to complicated grief including the suddenness of the death, unexpectedness of the death, low social support, concurrent stressors, child’s age, cause of death, and presence of other children in the family (Wijngaards-de Meij 2005). This study highlights
similar factors to the current research but did not include the social stigma and impact of self and external blame which was apparent with the child drowning deaths and may further influence social isolation.

Parents experiencing stigmatised behaviours such as self-blame or externalised blame (perceived or direct) from other people can manifest in health-related symptoms. Health impacts of grief are well documented (Freeman 2005; Buckley et al. 2012), particularly following the loss of a child. This was confirmed in the current research. The extent of health impacts varied amongst participants but every parent participant acknowledged a change to their health status. Some participants also reported suicidal ideation and, in some cases, attempted suicide, during the first few years following their child’s death. For some of the parents interviewed, these symptoms persisted. This study was limited to parents whose child had died within ten years of the interview (with one exception of 11 years) and did not offer a longitudinal measure of change. Further research would improve the understanding of the relationship between health and the type of death, age of child, and other factors such as available social, religious and professional support. Combining all these variables would provide a more contextual understanding of grief and health-related symptoms and therefore create the opportunity for appropriate and timely support for families having experienced a sudden child death.

Support from social networks was identified by participants as important in the early stages of grief and over time. This is consistent with previous literature, in particular in relation to child death (Dyregov 2005/2006). Dyregov interviewed bereaved parents whose children had died from either suicide or SIDS. These participants identified support needs similar to those expressed by the parent participants in the current study, including: conversations about the loss, physical presence, comforting, social stimulation, practical help, childcare and financial support. Most of the participants in Dyregov’s study reported difficulty in supporting the bereaved, reporting concern about supporting ‘improperly’, awareness that they may have made untimely remarks and concerns that they felt they may have been too passive. The vast majority commented that it was difficult to sustain the support over time. These reflections reflect the experiences of parents in the present research. Social networks were often
inadequate in providing support, based on feelings of insecurity, insufficiency and ineptitude to cope with the situation (Dyregov 2005/2006).

The challenge of providing support over a long period of time is particularly relevant when a child dies, as the grief can often be more extensive and complex than that of an adult death (Weber 2001, Freeman 2005). Further research investigating the differences in support capability and willingness following a death due to a cause for which parents or carers had no perceived responsibility, compared with a death that occurred in circumstances where there was perceived parental/carer responsibility (e.g. drowning, low speed vehicle run-over), may prove useful. This investigation would need to be treated with care as this research indicated that some bereaved parents may not reach out for support due to their feelings of guilt and internal stigmatisation. While support from family and friends is important to the bereaved and may assist in reducing stress and possibly depression, this does not equate to reducing or softening the pain felt from the loss (Stroebe 2008). The participants in the current study expressed the ongoing sadness and difficulties in adjusting back into life. Whilst those that had support were appreciative, it appeared to be compartmentalised, with suggestions that the support did not minimise the grief, just helped them get through the day. This raises the question of the difference between appearing to cope and the ongoing emotions related to the absence of the child in the parents lives. Further research would inform the community and health professionals on how best to support parents including the length of time needed for support interventions, understanding that each person responds differently to their grief.

Parents who are able to make sense of their loss and find some meaning or benefit have a lower level of complicated grief (Lobb et al. 2010). The inability to make sense of a person’s death is reported as a salient predictor of intense and complicated grief. In the present study, parents indicated a clear difference between seeing a reason for the death and honouring the child’s death in order to possibly prevent other families experiencing the same type of grief, or to keep the child’s memory alive. In the current literature, these issues can be confused, such that ‘making meaning’ is combined with honouring and an altruistic approach. Again, none of the studies included in the systematic review by Lobb and colleagues involved participants whose child had died. There is need to explore differences between types of death and meaning making in relation to parents’ grief experiences.
7.1.2 Stigma
Experiencing stigmatisation was reported by a number of parent participants and this appears to be a common factor with other conditions (for example, suicide) where the community (and possibly professionals) do not understand the full impact of the bereavement or condition. A number of parent participants’ experiences appeared to reflect stigmatised behaviour. They reported feeling isolated, some reported feelings of shame, ill health, having been taunted and two parents were spat upon in the streets.

Research to date has not identified the impact of self-blame. Further research regarding the relationship between stigma and self-blame versus the relationship between stigma and blame which is perceived to come from other people (externalised blame) would shed light on the experiences of parents suffering a stigmatised loss and guide the understanding of support required in both a professional and community context.

A number of parents in the current study discussed suicidal ideations following their child’s death (Pompili, Mancinelli, Tatarelli 2003; Cvinar 2005, Worden 2005). This guilt not only creates enormous pressure on both the survivor’s ability to interact with society, but also alters the relationships within the family unit and with surrounding social structures. Worden’s research identified that where shame is associated with grief, often the guilt and isolation is so great, the bereaved may also attempt to take their own life. Cvinar (2005) and Worden (2005) identified that suicide victims’ families are more blamed and avoided than are the relatives of persons under other circumstances (Cvinar 2005, Worden 2005). Whilst both researchers acknowledged that all other stigma-related circumstances have not been compared, this finding is consistent with the experiences of many of the participant parents who shared their experiences of avoidance and blame, whether it is self-blame or from the surrounding community. Cvinar (2005) also noted that as a society we are culturally and structurally ill-prepared to offer appropriate emotional and social support for those that are suffering. It would be interesting to note if the raised awareness and education over the past decade of suicide has altered this perception. It appeared that child drowning may require significant community and professional education to lift it from the state of stigmatisation to one which is better understood and supported.
7.1.3 Ongoing relationships with their deceased child

Part of the psychosocial challenges included the importance for parents to maintain bonds with their deceased child and the difficulties that friends, family and some professionals had in comprehending their need to continue and refocus this bond with their deceased child. Maintaining bonds has been identified as a relevant predictor of complicated grief, representing a connection to self, the nuclear and extended family, and as an identification of the parental role which cannot be surrendered (Neimeyer, Prigerson, Davies 2002; Miller 2003; Lobb et al. 2010; Neimeyer, Klass, Dennis 2014). Harper indicates that the impact of the death of a child can range from 13–62 years post-death, and suggests that the impact is greater for children of younger age (Harper et al. 2011). Thus, it is reasonable to consider that information about how the parents maintain bonds with their deceased child may assist health professionals and the community in their support for a bereaved parent. However, parents in the current study expressed frustration about the lack of understanding of the need to maintain bonds with their deceased child by friends, family and health professionals. Parents’ continued connections with their deceased child often caused friction between family members as well as friends who do not understand the importance of this process. Similarly, if health professionals adopted the outlook of previously held theories that encouraged grief management through breaking bonds with parents and their deceased child, parents could experience significant stress. This stress was evident in a number of the parents who participated in the current study. This topic has received little attention in the literature (Harper et al. 2011).

Similar to the current research, Harper et al identified a diverse range of symbolic representations, such as items of clothing or special toys, a physical connection as well as symbolic representations. Although Harper et al phenomenological study of 13 parents did not include any drowning deaths, their results mirrored those of the present study in that parents connected both physically and symbolically with their deceased child. In the current research, additional challenges were identified – for example, signing the deceased child’s name on birthday or Christmas cards, leaving bedrooms untouched for extended periods of time, or the difficulty in either moving house or location which takes the parent away from the physical space in which the child lived. The current research also identified the difficulties experienced
by parents whose living children demonstrate similar characteristics to the deceased child in physical appearance, personality or mannerisms.

7.1.4 Social support
According to House (1981), social support comprises three main elements: the doing part of support, referred to as instrumental support which includes assistance with goods, services and money; emotional support; and informational support, accessed via a range of avenues including peer support and professional guidance and intervention. To varying degrees, parents in the current study experienced support in all of these areas although the instrumental support appeared to be time limited, with offers of practical help in the first few weeks in regard to funeral arrangements, provision of food and in some cases, monitoring phone calls. However, this support dwindled after a few weeks.

Social support also affects the health of bereaved persons and positive support can minimise negative biological functions such as immune deficiencies as well as alleviate separation anxiety, feelings of rejection, and depression among the suddenly bereaved (Cvinar 2005, Uchino 2006). When this social support is withdrawn or compromised, symptoms of grief become exaggerated and often more complex. McIntosh (1992, cited in Cvinar 2005: 19) suggests that there are more similarities than differences between suicide survivors and other bereaved groups, particularly survivors of other sudden deaths, such as unintentional death and that as time progresses, differences that did exist become less apparent. However, as there are no published longitudinal studies on the impact of fatal child drowning, it is unclear whether the combination of shame, parental responsibility and age of death challenge or support this suggestion. Parent participants and service providers who had worked with families whose child had drowned indicated that additional factors of parental responsibility and role of a parent further complicated the parents’ grief and added to the social isolation. Early intervention and support currently exists from professional services and the community for vulnerable groups such as those having experienced a family member suicide. Families having experienced a fatal drowning would require similar support, yet it does not appear to be available in Queensland.

Whilst the impact of intense grief is acknowledged in the literature, the combination of losing a child and the lack of understanding attached to a young fatal drowning suggest potential for
even greater avoidance and reduced social support. This was apparent with some of the parent participants who expressed disappointment with family and friends’ support. Parents in the study reported difficulties amongst family and friends in acknowledging the length of time needed to grieve, the previous existence of their child’s life and the continued presence of their deceased child in their family dynamic. Relationship dynamics between family members has a significant influence on each individual’s ability to cope with the death (Breen 2011). Lack of acknowledgement further compounded the parents’ pain, parents preferring friends and family to talk about their deceased child and acknowledge them in symbolic ways such as cards, flowers and general support and open conversations (Toller 2005). Physical rejection (including people moving away) was experienced by parent participants. This is consistent with the small amount of literature available which identifies explicit avoidance particularly experienced following the loss of a child (Breen, O’Connor 2011). This further confirms that child death is a stigmatised death with people intentionally physically avoiding the grieving parents. Based on the reported experiences of the parents in the current research, the stigmatised behaviour appears to be compounded following the death of a child due to drowning. In contrast, other participants were encouraged by support offered, although even those parents expressed some relationship casualties. However, most parent participants did comment on people’s expectation that they should start to ‘move on’ and also that they should be grateful for what they did have. This reaction, whilst possibly well intended, can be harmful (Brabant 1995), yet there is little in the literature to address how to combat these well-intentioned but hurtful conversations with the bereaved. Family and friends may not consider the need to seek advice regarding support and effective communication, as they may not believe they are causing any distress to the grieving parent. There is a need for further research to explore friends and families’ understanding of grief and how best to support the bereaved friend/family member.

### 7.1.5 Spousal relationships

Parents who experience a sudden child unintentional death often find themselves directly blaming either themselves or their spouse, resulting in damaged relationships and significantly complicating the grief process (Freeman 2005). Questions regarding the impact of a child death on parental relationships have been debated in the literature (Nixon, Pearn 1977; Murray-Parkes 1980; Martinson 1994; Murphy et al. 2003).
The only Queensland study relating to fatal child drowning was Pearn and Nixon (1977) and whilst this study identified marital strain amongst parents whose child had drowned, it was limited by the lack of long-term follow up and detail regarding various factors, which may have influenced the parents’ coping ability. Their study was important in that it was the first to recognise the potential stigma associated with a child drowning. Until this thesis, there has been no further work into this phenomenon.

A common thread in other research papers (Murray-Parkes 1980; Martinson 1994; Murphy et al. 2003, Breen 2011) is that the status of the relationship at the time of the child death is exaggerated or intensified after the death. In other words, if the relationship was strong prior to the tragedy, adversity is likely to strengthen it further; if weak, couples tend to split up after their child’s death (Schwab 1998). Breen (2011) in her study of child fatalities from a traffic crash identified that some spousal relationships were strengthened following the death of a child, whilst others collapse. However, there is debate as to whether the event itself was a catalyst to the separation, or if it just sped up the direction the relationship was already heading towards. Either way, time since the death may be a factor, hence a longitudinal study will offer a more accurate reflection of the spousal relationship.

Relationships between some parents within the current study were affected by guilt and blame, resulting in parents experiencing felt as well as enacted stigma within the relationship. Self-blame is often unexpressed and can create communication barriers and isolation with family, friends and health professionals (Corrigan, Miller 2004). This was evident in parent participants, some of whom commented that they were often unable to discuss their grief with each other due to self-blame, or fear of blame or lack of comprehension that the partner did not blame them. However, the current study also highlighted the opposite, i.e. parents constantly expressing self-blame and as a consequence, attempting to sabotage their relationship. This caused significant stress on their partners who were ill equipped to cope with this new relationship dynamic.

Combined with different ways in which men and women grieve and their different communication styles, the potential for relationship breakdown is even more significant when
a stigmatised death occurs. Miller notes that the different grieving styles and coping mechanisms between men and women are the primary reason for marital breakdown in these circumstances (Miller 2003). This information is important for health professionals in helping guide couples through their grief and knowing that a child’s death creates intense strain on relationships. However, the absence of this link between stigmatised child death and grief communication in the literature may offer some insight into the limited training available for health professionals.

7.1.6 The role of religion and spirituality
It is not uncommon for parents to report strong religious or spiritual experiences following the death of their child and while there is controversy over the link between religion, spirituality and coping with grief, there is research that suggests religion and spirituality form an important part of the grief process (Wortmann, Park 2008; Park, Halifax 2011). Parents in the present study expressed a range of spiritual and religious experiences following their child’s death, with some having sought emotional comfort from these experiences, particularly in relation to maintaining bonds with their child. Some parent participants deconstructed their faith and re-evaluated their beliefs, the result being different for each participant. Some parents reported either similar or stronger religious commitment than before their child’s death, whilst some reported a total rejection of any commitment they may have had. Interestingly, there is an absence in the literature regarding this religious examination and deconstruction over time. A longitudinal study of bereaved parents with a range of religious affiliations and practices could offer some insight into the role of religion and bereavement over time.

Participants with strong religious connections prior to the death of their child reported having received positive social support from their like-minded friends as well as drawing support from their personal belief even after major deconstruction and re-evaluation. This connectedness appeared to help with their outward coping and ability to get through the day. Whilst there is a growing body of literature on bereaved parents’ psychological coping mechanisms, there is little available regarding the role of religion and the interaction between religious beliefs and positive grieving processes (Anderson, Marwit et al. 2005). Discrepancies in the literature cause confusion regarding religious service attendance creating greater optimism toward the
new life experienced by the parent after a child’s death and the holding of religious beliefs without the regular attendance at services. Confusion also exists regarding the positive impact toward adjustment to grief offered by experiencing support from members of religious communities with contradictions in more recent literature that suggest no association between prayer, religious support and adjustment (Anderson, Marwit et al. 2005). This confusion may be due to the interrelationship between spirituality and religion without clear understandings of the differences between these two constructs. The current study implied a clear difference in the benefits and experiences of religion and spirituality, although the study did not intend to measure differences, but to elucidate the experiences of the parents. Further research would help ascertain the connection or separation between these two constructs, and help inform those supporting the bereaved about the potential roles of these beliefs and practices on the grief journey.

The challenges of coping with a child’s death are also influenced by people’s understanding of death and their religious affiliations (McIntosh, Silver, Wortman 1993). McIntosh and colleagues interviewed 124 parents who had lost a child to SIDS and identified that greater religious participation correlated with greater social support as well as a greater sense of meaning to the loss. The study identified a plethora of literature that confirmed the value of support through religious networks and lower levels of depression as well as the positive benefits of having a belief system. Increased meaning regarding the death correlated with greater religious participation. These was not reflected in the current study as none of the parents interviewed, even those with a strong religious affiliation, reported finding meaning in their child’s death. Many honoured their child’s death in various ways but that is not to be confused with finding meaning in the death itself. However, the parent in the current study with a strong religious affiliation and supportive church community reported benefit from these religious connections although this was not related to finding meaning in their child’s death.

Few studies separate the concept of religiosity and spirituality. An example of this is evident in a study which suggests that those who believe in the continuing existence of the soul may be able to apply meaning to their child’s death and have comfort in the belief that they may be reunited at some stage and hence maintain a bond with their child (Field, Gao, Paderna 2005). Parents participating in the current study expressed various connections with religion
consistent with current research (McIntosh, Silver, Wortman 1993; Anderson, Marwit et al. 2005; Field Gao, Paderna 2005); some denouncing their beliefs following their child’s death and others finding deeper solace through their faith. Field reported that those who did not have faith prior to their child’s death might develop some form of religious attachment if hallucinations occurred. This was the case with some of the study participants, reporting sensing the presence of their child and believing in a higher power that they previously had not believed in. Whilst one study suggested this might cause difficulty for some parents (Barbato et al. 1999), in this study this connection appeared to create a degree of comfort and ongoing attachment.

One longitudinal study acknowledged this gap in the research regarding religiosity and spirituality and identified that there was a difference between religious and spiritual beliefs and that this could have an impact on bereavement coping mechanisms (Van der Houwen et al. 2010). The authors of this study concluded that further research is required to separate out these concepts in order to improve early intervention strategies. This difference between religious and spiritual beliefs is consistent with the findings presented in this thesis, which identified differences experienced by the parent participants between spirituality and religion. Specifically, in this research, spiritual beliefs appeared to develop or strengthen following the child’s death, but religious beliefs which may have been previously superficial were challenged and negated. Those that had strong religious beliefs prior to their child’s death still maintained their beliefs. The strength in spiritual belief as a comforter for those bereaved is confirmed in Van der Houwen et al (2010) study as offering a platform for positive emotions through bereavement. In fact, the author’s study identified new-found spiritual beliefs following experiences parents reported after their child’s death. This aspect of spirituality is not well documented and could form the basis of new research into spiritual experiences during bereavement and the impact on maintaining bonds with the deceased resulting in a healthier outcome for the parent.

7.1.7 Financial challenges
Financial challenges included difficulties in raising money for the unexpected cost of their child’s funeral, having to repay loans from family and friends for the funeral costs and other daily costs such as rent and food that they were either financially unable to meet, or
emotionally unable to organise. Support toward funeral costs was available to some parents from charity and hospital foundations but most parents struggled with meeting the expenses themselves. Many of the participants remained in debt at the time of interview, often due to the ongoing emotional and physical impact of the death resulting in either being unable to return to work at all, returning following an extended unpaid leave period, returning part-time or changing jobs to be home more often and have less stress; all scenarios resulting in reduced income. In a study, which included social and environmental predictors of grief, financial issues were considered predictive of negative emotional states (Van der Houwen et al. 2010).

In addition, when a child dies, government benefits for that child cease, yet funeral costs and headstones were a significant, unplanned expense. In a qualitative study of 16 families bereaved by the death of their child following a long-term illness or disability, Corden et al. examined the financial impact on bereaved families and found that financial strain adversely affected their ability to manage their grief and increased levels of stress. The authors recommended government support for bereavement-related expenses such as funeral costs (Corden, Sloper, Sainsbury 2002). Little else has been reported in the literature. Further research is required to appreciate the experiences and financial challenges families face following their child’s sudden death. The findings could then help inform policy in order to help with financial encumbrances. This in turn could reduce any emotional and physical health-related aspects resulting from the stress of the tension between finances and honouring their child.

7.1.8 Workplace and schools: key components of the community
The workplace is an integral part of the community and as such requires clear policies regarding support for bereaved employees returning to work. The workplace needs to be compassionate, caring, competent and confident without complacency (Thompson 2009). Thompson suggested that Australian workplaces often do not reflect these requirements, either due to lack of knowledge and confidence in dealing with bereaved employees or too much emphasis on the company bottom line that potentially detracts from the needs of the employees. He proposed effective training so Human Resource employees can be skilled in both recognising and supporting bereaved employees and can develop relevant policies to
effectively enact the support and provide a safe, supportive and productive work environment. Families in the current study reported mixed experiences in the workplace. A common theme reported by participants was that work colleagues found it difficult to communicate with them, which often resulted in feelings of isolation, which further exacerbated the grieving person’s sense of isolation and loneliness with their grief. Dyregrov identified the importance of the workplace as offering structure and balance, fulfilling a need for social belonging and offering social support. He also pointed out that without this support, people can experience psychological difficulties and noted that mothers who returned to work were better able to cope than mothers who stayed at home (Dyregov; Dyregov 2008). Research into fathers’ return to work patterns was not mentioned.

Workers who attend workplaces with a sound and active strategy to support those having experienced a crisis fare better with regard to overall health and somatic ailments (Boscarino, Adams, Figley 2005). The authors’ study suggested that the majority of workplaces did not have any form of active policy in place to support bereaved workers. There is little Australian literature regarding workplace support (O’Connor et al. 2010) and although there is legislation that proposes minimum support, there is a need for further research into Queensland and Australian workplace protocols. The available literature tends to focus on critical incident support and it is unclear as to whether a family bereavement is considered under this umbrella. New research into existing workplace policies and required support for employees would inform the literature and create the opportunity to expand the legislation and develop relevant policies to support workers in what has the potential to be an integral part of their healing process. Policies will need to include: understanding grief including the uniqueness of grief; length of grieving period; different expressions of grief; signs and signals of a grieving person; overall support needed; effective communication between management and staff and between colleagues; flexibility regarding time at work; possible changes to work responsibilities; and appropriate paid and unpaid leave entitlements.

Whilst the workplace is a key environment for many parents with school age children, the school is a significant part of families’ sense of social connectedness. When a school student or one of their siblings die the school community is affected. Parent participants mostly expressed disappointment and anger toward the lack of support from the school attended by
the surviving sibling(s). In searching the literature, only one article emerged and this focused on bereavement education in NSW schools compared to the UK. Of the 48 schools, which participated in the research, 29% reported having some form of bereavement education as an integrated part of the curriculum (Rowling Holland 2000). Having a solid, workable plan to help students, staff and parents is seen as essential, yet none of this was apparent in the Queensland schools attended by the children in the current study. It is possible that because most of the children in the study were not of school age, the support for the sibling was not recognised, compared to if the deceased had been a student of the school. Wait lists for surviving siblings to access an appointment with the school counsellor or psychologist were lengthy and teaching staff appeared ill-equipped to cope with the changed behaviours of the siblings, possibly due to their lack of training in identifying signs from a grieving child.

Support plans and follow-up strategies are considered essential following the death of a school member, reflecting the interests of the child, the parents, extended family, pupils, teachers and any other members of the school community (Dyregov 2008). Again, this refers to the deceased being a school member, rather than a whole of community approach. Nonetheless, the teacher is a critical influence on the returning child, helping them to adjust to their situation, being understanding of their grief, offering comfort and support and trust, creating flexibility in their day and being adaptable to the emotional and physical needs of the pupil and their family (Dyregov 2008). Collaboration between the school and the home environment was considered essential and a public acknowledgement by the school of the families' loss, such as lowering a flag or having a memorial plaque, was considered appropriate. Whilst these measures appear to be common sense, only one of the parents reported receiving similar support to that described by Dyregov (2008). Further research is required into Queensland and Australian schools to ascertain the processes (if any) currently established to support grieving families. From that research, relevant policies and training can be established in order to maximise the opportunity for appropriate support at all levels of the school community.

Whilst parents clearly experienced changes within their psychological and social constructs, many managed to create positive experiences from their tragedy. These included raising the
profile of unintentional child drowning in respect of prevention activities and requirements for emotional support. The following section alludes to some of those activities.

7.2 Parents’ altruistic response to their child’s death

Parents in the current study responded altruistically to their child’s death and felt the need to honour their deceased child and inform other parents of their grief in order to prevent others experiencing similar tragedy. Lichtenthal et al. investigated the concept of making meaning, using a mixed methods study to investigate how bereaved parents ‘make meaning’ out of their child’s death (Lichtenthal et al. 2010). The study identified a common theme amongst participants, which reflected a desire to help others and show compassion for their suffering. However, the term ‘making meaning’ appears to be misplaced with regard to the current study; parents altruistic intentions were more about honouring and preventing further tragedy rather than finding meaning in their child’s death.

It was not uncommon for parents in the current study to become ambassadors for drowning prevention in some sense. Each parent who contributed to the research did so in order to share their experience in the hope that their anguish would be heard and that changes could be made to minimise this pain for others. These changes were not limited to drowning prevention, but included the type of support received following a child’s unintentional death. Research confirms that participation in studies that allow participants to share their grief can have a cathartic affect (Dyregov 2004; Kassam-Adams, Newman 2005; Dyregov et al. 2011). Consistent with Dyregov’s findings, the intense emotion of the interviews did not detract from the positive outcome for the participant, and the fact that the current study was of a qualitative nature, encouraging open discussion, may have been helpful (Dyregov 2004). Dyregov also noted the importance of a respectful and patient researcher in order to create a supportive and safe atmosphere, posing the right questions, listening empathically, not withdrawing from the pain, being flexible, confident and engaged – an environment which was created in the current study.

More than half the parents in the current study engaged in specific drowning prevention or bereavement support activities following their child’s death. These included the establishment of websites, foundations, support groups and support services, media advocacy and
education programs as well as pool fence inspectors. The challenge for these parents is the opportunity to receive support for these activities to minimise burnout or the possibility of unresolved grief that may be masked by the frenetic activity. Some volunteer organisations had a minimum two-year period before a bereaved person could participate in their programs; however, when establishing an independent support function, these boundaries cannot be enforced.

7.3 Service provider support

All families experienced contact with the emergency services at the scene of the incident, followed by medical staff in the hospital and, in some cases, social workers. Once the families left the hospital, they had contact with funeral homes and some form of communication with the coronial services. Following that, families in the author’s study accessed different styles and combinations of support, ranging from voluntary organisations, 24-hour support lines, government and non-government organisations, GPs and private health professionals.

The interactions between parents and all of these services had a marked impact on their grief management as reported by parents. This aspect of experiences by parents following a fatal child drowning has not previously been reported in the literature.

7.3.1 Linking support and families – support from the hospital

Families’ experiences in hospital varied, with some families feeling very supported to others feeling uninformed and as if they were treated with insensitivity. Access to social workers was only available to parents whose child was admitted or was participating in the organ donation program. Given that support from hospital staff is proven to be of immense importance to supporting families in coping with their loss (Cook, White, Ross-Russell 2002; Kreicbergs et al. 2007), this appears to be a gap in the Queensland health system. Medical and social work staff interviewed indicated the limitations of the support available when a child dies in a Queensland Emergency Department. Parents require two levels of support from the hospital; the first being the immediate in-hospital/ED care and bereavement support; the second being a connection beyond the time at hospital once the parents return home (Laakso, Paunonen-Illonen 2002; Wender 2012). Whilst some parents expressed gratitude for the caring
responses from the hospital staff, some also reported a range of concerns from lack of support in the ED and the absence of follow-up once they had left the hospital.

Provision of information is seen as a critical factor in support yet it cannot be assumed that information given will either be given or shared with other family members (Breen, O'Connor 2011). However, as the Day of Difference program highlights (Wakefield 2012), support is required in every aspect of life for the parent, and more information on how to offer psychosocial as well as informational support is required.

Hospital staff reported an adhoc approach to accessing a social worker, dependent on staff availability, after hour’s access, a medical staff member thinking to request the support services, and in smaller hospitals the lack of the support available irrespective of the time of day or night. Although no research appears to have been conducted in fatal drowning, research into palliative care (Kreicbergs et al. 2007; Contro, Sourkes 2012) may share some aspects of required support relevant to any child death. An Australian family-centred program (still in proposal stage), developed for palliative care and adopted by all seven of the children’s hospitals currently treating critically injured children across the country, has national support via hospital policy and the Australian Charter of Healthcare Rights as well as the UN Convention on the Rights of the Child (Wakefield 2012). This program recognises the pressures on a family following the death of their child and proposes Family Support Coordinator roles for families of critically injured children. Whilst this program is directly linked to palliative care, with the contacts initiated whilst the child is an inpatient and released to home care prior to being deceased, it is reasonable to assume that at the very least the same challenges of practical, emotional and professional support needs face parents having experienced a death in the Emergency Department; and, as research suggests, it could be argued that these parents require more support because they have not had time to prepare for the death of their child.

The Royal Children’s Hospital and Health Services District in Brisbane, Queensland, produced an informative booklet for anyone who works with families experiencing bereavement (Crowe 2006), although, again, this is mainly in the context of palliative care and not sudden death. Given the proven positive outcome of psychological and social work
support in palliative care (Knazik et al. 2003; Copnell 2005), further investigation into creating the opportunity for this level of support in the Emergency Departments would inform hospitals about supportive policies and procedures for parents once they return home (Truog et al. 2006; Walsh, Foreman Curry 2008).

Most parents mentioned the attitude of medical staff as a significant part of their ‘story’. Again, positive experiences including compassion, patience, professionalism and clear communication were seen as important supportive factors (Macdonald et al. 2005). Medical training does not address the required sensitive communication requirements in dealing with death and dying, health professionals are often uncomfortable with broaching these issues (Breen, O’Connor 2011). Parents who experienced poor communication from the medical staff, harshness of tone and apparent indifference to their grief carried these experiences throughout their grief. Contro and Sourkes interviewed 60 staff members from a children’s hospital and identified similar reasons for less optimum care to those expressed by the author’s participants: geographical constraints, logistics of time and space; staff communication and care coordination; staff training in bereavement care; mentoring and support for staff; and the importance of aftercare family follow-up (Contro and Sourkes 2012).

Effective models of care for child death in the ED, based on the palliative care model, would offer clearer guidance and support for the hospital administration and social workers to deliver a fair and equitable support service.

### 7.3.2 Linking support and families – after-hospital support

Service provider participants expressed frustration that they were unable to follow-up parents once they had left the hospital due to resource limitations. Families whose child had been admitted to the hospital and then died usually received one phone call within the month of returning home, but this was inconsistent, depending on workload. Social work staff recognised the importance of this follow-up and ongoing connection with the hospital in order for parents to ask any unanswered questions and to feel supported by those who shared the experience of their child’s death. Research clearly identifies the importance of this follow-up (Cook, White, Ross-Russell 2002; Laakso, Paunonen-Ilmonen 2002; Milberg, Olsson, Jakobson, Olsson & Friedrichsen 2008; Wender 2012), yet none of the parents in the author’s
study received this follow-up. Studies show that the majority of families express a desire for follow up, particularly from a staff member who had the most contact with their child. Follow up helped the bereaved to feel that their needs were being heard and recognised and thus helped toward addressing any guilt and meaning based coping (Milberg et al 2008). The Beaumont model of care developed in the UK (Walsh 2008) combined with the Australian palliative care models offer a template from which an Australian model for bereavement support after a death in the ED could be developed.

After leaving the hospital, all the families in this thesis study needed to organise the release of the body from the coroner and coordinate the funeral arrangements. Some families expressed confusion and lack of direction with this process. Little research is available on the needs of families within the first week of their child’s sudden death and it appeared that families with limited social support struggled to arrange these events. One service provider spoke of the opportunities for funeral homes to offer ongoing support to families, particularly as they play such a pivotal role in the bereavement process. Further research into the current and potentially extended role of funeral homes would help inform potential for a smoother transition of information and support.

7.3.3 Linking support and families – the role of coronial support
Help in understanding the legal requirements, time constraints and information gathering, delivered by a sensitive communicator was considered pivotal in a family’s ability to navigate through their grief. Whilst the coronial service in Queensland does offer counselling support (Queensland Health 2013), limitations expressed by parents in the study included both lack of awareness of this service by some, and challenges with the location and times available. Counselling services were offered in the same building where the parents had to view their child’s body; a challenge too great for some to revisit. In addition, this service is only in the one location, making it inaccessible to those outside of the Brisbane region.

Further research into the benefits of regional coronial support officers following a sudden unintentional child death would contribute to understanding the links within the bereavement pathways and the key elements of support to help minimise the risk of complicated grief symptoms.
7.3.4 Linking support and families – the role of general practitioner

The GP is often the first professional support sought after a child's death, yet only a few parents in this study reported any conversations initiated by their GP about their grief, any discussions regarding how the family was affected or offer of bereavement supports available. Those that did receive consistent and compassionate support reported it as invaluable and an anchor to their ability to manage their grief. Lack of conversation initiated by the GP is consistent with the limited research, which indicates GPs’ general discomfort with talking about death (Main 2000).

Where some families did receive referrals to counsellors or psychologists from their GPs, these referrals were often unsatisfactory. Long waiting lists often result in exacerbating the feeling of isolation. Another challenge which is possibly linked to the Australian Medicare rebate process is that there was limited ongoing availability of that therapist, resulting in having to tell their story over again and being unable to develop the necessary trusting relationship required between grief therapist and client. In order to extend the visits, or if a person was not placed by their GP on a mental health plan to access a number of free psychologist appointments, cost was often prohibitive.

In Australia, the government mental health plan has steered GPs to refer patients to psychologists or social workers who can offer a reduced rate for their services, although there does not appear to be a comprehensive list of bereavement specialists. The combination of the rebate and lack of specialisation database resulted in referrals to professionals who may not have any training in bereavement support. In researching the literature, there appeared to be no information on either GP bereavement referral pathways or GPs’ level of comfort or expertise in discussing bereavement. Steiner, acknowledging this deficiency, identified a range of opportunities to improve bereavement support that included the provision of education around grief support resources for GPs and health professionals whilst still acknowledging their loss (Steiner 2006). GPs need to be trained in recognising physical symptoms which reflect stress-related symptoms linked to unresolved grief, understand the pathways of grief and the natural phenomena versus the complicated grief symptoms. The GP would then be in a strong position to affect an appropriate referral. An integrated
approach within the surgery would offer the patient the opportunity to meet with an allied health worker trained in bereavement counselling who could then act as a conduit for either further specialised referrals or offer in-house support. In this way, the patient is familiar with the surroundings that can reduce the patient’s stress in an already overloaded stress situation and the patient is likely to trust the staff working in alignment with their GP.

The federal government already recognises the benefits of an integrated approach through the Primary Care Infrastructure Grants Program (Australian Government 2012), which aims to develop a model of patient-centred care across the country. Further research into this model and its application to support parents bereaved by a sudden child death could offer important insight and pathways to appropriately support grieving parents and hence reduce either incorrect diagnosis or referrals and/or optimise effective early intervention which in turn will improve the emotional and physical health of the bereaved. Development of a referral database would also support this practice.

7.3.5 Linking support and families – education and training for service providers

Bereavement counselling training was conducted in a few of the service provider organisations, with one organisation offering a program to a range of allied health service providers and undergraduates. However, overall, service providers spoke of the lack of available specialised bereavement training and, where it did exist, it was difficult to access, offered by only a handful of educators and not available through the standard training for medical practitioners, psychologists, counsellors or social workers. With the exception of a few stand-alone programs and only one post-graduate program in Australia based in Victoria (Australian Centre for Grief and Bereavement 2012), grief education usually followed the medical, pathological linear model which has been further compromised by the new DSM-V which suggests grief becomes depression if symptoms exist for more than two weeks, further highlighting the lack of awareness of the natural grief pathway and benefits of non-medical interventions. For those with a special interest in bereavement, there is generic bereavement training available, bereavement support in relation to palliative care and some specialised areas such as suicide support. However, it is unclear what training exists for sudden child death and particularly a disenfranchised, stigmatised death such as drowning. Further research into compulsory and voluntary bereavement training available for health
professionals would inform educators and grief specialists about the gaps and identify opportunities to improve this essential, primary understanding of grief support in order to minimise unnecessary suffering by the bereaved.

Bereaved families often gravitate toward support groups for which professional development opportunities may be limited. Benefits of support groups included meeting with people who had experienced similar grief and could understand the vast range of challenges experienced by those attending, as well as not being constrained by the limitations of a consult time schedule. However, the downside of parents’ experiences in support groups included people making judgements on other members and, at times, inappropriate guest speakers who were not in tune with the language or emotional requirements of the bereaved. Consistent with the literature, ongoing newsletters, memorial and ritual events were all perceived as important aspects of these groups as well as the opportunity for specialist groups to perhaps branch out of the more general bereavement support groups (Steiner 2006). This sentiment was echoed by both service providers and some of the parents in the study. However, many parents were not given information about support groups and had to find out for themselves, therefore often delaying the support of such groups due to the initial grief stages of being unable to focus or seek help.

Access to financial and human resources for support groups is minimal, and with continuous funding requirements to provide the service – including basic needs such as computers, transport to visit families who are unable to come to meetings, 24-hour support lines, photocopying as well as trained facilitators – these services are often compromised. Linking organisations to enhance the range of bereavement support groups and offer a central point to refer people to the more specialised groups to suit their bereavement needs would help toward ameliorating this problem.

Organisations that are based on volunteer support battle constantly with resources, training, volunteer burnout and increasing their profile. Registered charities and organisations have to provide a degree of reporting requirements including tax returns, which take time, money and expertise. Whilst there is research into some of the benefits and challenges for people attending support groups, there appears to be a lack of research into the needs of support
groups, the challenges of volunteering within the bereavement support sector and the relationships between volunteer organisations. Further research could highlight some of the needs and gaps within these services and could propose a more cohesive and hence resource inclusive structure to provide optimum support to both the organisation and those using the service.

7.5 Summary
Whilst there is an abundance of grief literature, there is limited literature mapping the experiences of the parent’s pathway from the time of the event, to the child’s death through the following years as they adjust to life. Participants clearly illustrated the impact of every stage of their grief journey, which affected their ability to cope with their adjustment; this is therefore an area requiring further attention in the literature. Part of what informs this trajectory includes: service providers’ knowledge of grief and communication style; the training available to meet the needs of the wide range of service providers; and attention to policies both within the medical and non-medical infrastructures such as GP surgeries, hospitals, schools, workplaces and funeral homes. In addition, research into improved referral processes, coordinated services and a centralised database would considerably improve access to information for those involved in bereavement recovery, from medical intervention to social support. Support from family, friends and colleague is also crucial. Research into how people react when confronted by a situation in which someone’s child is deceased would help inform this critical support arm, addressing the ‘elephant in the room’ attitude and offer insight into the day-to-day social support which is such an intrinsic component of grief recovery.

The following and final chapter recognises some of the strengths and limitations of the research and pays tribute to the participants’ voice by offering a call to action in regard to future research and recommendations.
Chapter Eight–Strengths, limitations, key findings and recommendations

This study identified some of the experiences of bereaved parents’ following their child’s fatal drowning and the also identified some of the supports available to help these parents through their grief. The research included interviews with bereaved parents and service providers, the latter of whom offered a form of organisational or professional support to the families.

This research focused on the emotional and the practical aspects of the participants’ experiences, Research more commonly focuses on a single aspect of interest, e.g. the impact on parents or the role of service providers, but rarely in combination and, as a consequence, often misses the critical context in which the experiences occur. This study captured a broad perspective of parents and service provider experiences with bereavement and offered insights into the experiences of both sets of participants.

Continuation of life after their child’s death involves a combination of roles and responsibilities. These include coping with previously unplanned financial demands; keeping house; relationship management both with partners and extended family members; changing relationships with friends; continuing employment; parenting roles if they have other children; and managing their own spiritual, emotional and physical health. Past research has examined the challenges of some of these aspects of bereavement but until this study, the opportunity to appreciate both parent and service provider experiences has been absent from the literature.

This study identified a number of new issues in relation to the experiences that surround a fatal child drowning. Using a qualitative social constructionist approach, suitable to this style of enquiry, the research displayed both strengths and weaknesses in regard to gaining a better understanding of these experiences.

8.1 Strengths
This study provides the first published insight into experiences of parents whose child fatally drowned as well as the experiences of service providers in a position to offer support. It builds
on the literature regarding the challenges of supporting complicated grief and some of the barriers bereaved parents experience on this journey.

All participants suggested ways to improve support and service providers offered insight into what they required in order to deliver this support in an appropriate and timely manner. Using a social constructionist model assisted with understanding the complex dynamics of complicated grief, providing insight into the medical and psycho-social interplay between a range of discourses. The study highlighted the need for further research into areas such as professional and community education, developing and disseminating appropriate referral pathways between health professionals and improving resource and funding allocation for both the bereaved and the support providers. By taking into account the influence of society as a whole, the study expanded the field of enquiry into areas previously unattended with regard to fatal drowning and support. By creating the opportunity for participants to offer their subjective experiences, new information regarding support needs arose. These included; the role and benefits of a coronial support officer; an evaluation of existing Australian school and workplace policies regarding support for bereaved families and an evaluation of the training opportunities for health professionals with regard to complicated grief. This study also highlights the ongoing financial challenges facing parents bereaved by a sudden child death and indicates the need for further research into the community, government and non-government organisations to identify mechanisms of support for bereaved families.

8.2 Limitations
The study was based on voluntary participation and may have created a natural bias to those having a personal agenda to participate in the study. Of particular relevance is that the parents who participated in this study were motivated toward positive action such as establishing a foundation in memory of their child, or to raise awareness about drowning. This suggests that the parents interviewed may have dealt with the death of their child in a more constructive manner than other parents may have. It is also possible that the parents who were interviewed have adjusted less well than parents who did not participate. Thus, it is important to keep in mind that this study was based on a social constructivist model, identifying individual experiences each of which were influenced by the dynamic relationship between themselves as individuals, the roles they represent and the social structure in which
they live. A longitudinal study of parents recruited shortly after the death of their child is recommended in order to obtain a more comprehensive and representative understanding of the depth and breadth of needs and experiences of parents following the death of their child due to drowning.

Due to the small sample size, the unique journeys of the parents and the experiences of the service providers cannot be generalised. To improve the understanding of the range and content of supports available, further research is required. Investigating each of the specific support services and community and relational structures would achieve a more thorough knowledge of the benefits and limitations of each, particularly in relation to paediatrician’s role in bereavement support. Identifying and accessing service providers proved challenging. Whilst the study offers a reasonable representation of types of services available, there are many more therapeutic supports available that were not represented in this study due to access difficulties and lack of initial knowledge regarding what existed. More detailed research within sets of service providers, such as GPs, counsellors and training groups, would have offered further insights into their role in bereavement support. Interviewing service providers from across the continuum of care would provide a more comprehensive overview of services available to parents, and the experiences of service providers in providing support to parents following a fatal child drowning.

Similarly, a national study with parents bereaved due to a child’s fatal drowning would offer further insight and the possibilities of identifying key areas of support that require development to provide optimum support. Financial limitations prevented this approach.

Using a gatekeeper, whilst essential for this sensitive qualitative research, may have unintentionally created a limited selection reach, although efforts were made to announce the research via a range of avenues. Advertisements in parent magazines, and contact with professional and voluntary organisations resulted in minimal response. A potential additional source of recruitment for participants in future studies could be coronial counsellors.

Taking into account the strengths and limitations of this study, a number of key findings emerged, which reflects the divergent nature of complicated grief.
8.3 Key findings

Six key issues emerged from the parents:

1. The extent of the grief journey and the psychosocial impact of losing a child to drowning; implications in relationships, health, financial and career aspects of family life,
2. A lack of perceived understanding amongst the community and health professionals regarding the impact of the drowning death on parents, in particular the length of time to grieve and the potential stigmatisation of this type of death
3. The role of schools and the workplace in supporting bereaved families
4. The importance of GP support for grieving families
5. Gaps in the support available to meet the requirements of bereaved parents
6. The altruistic approach adopted by many parent participants as a way of honouring their child’s death.

Key findings from the service providers included:

1. Geographical limitations in Queensland resulting in inequity in service provision
2. Lack of training available for health professionals in bereavement management, particularly child drowning deaths
3. Lack of coordinated database to identify key resources and relevant referrals
4. Identified need for a specialised coronial support officer
5. Requirement for follow-up after the family has left the hospital
6. Insufficient human and financial resources to meet client needs
7. Challenges with supporting volunteers to minimise burnout and provide relevant education
8. Limited support for professionals to assist them to cope with the emotional impact of their daily work
9. Limited public understanding on how to support bereaved families places unbalanced workload on support organisations.
8:4 Recommendations for further action and research

**Review**

- Current Australian Emergency Department policies and practice following unintentional child death in Emergency Departments.
- Hospital follow-up procedures for bereaved families whose child died before or in the Emergency Department.
- GP support protocols and referring processes including progress with the Primary Care Infrastructure Grants (Australian Government 2010) regarding improved patient-centred care linking their practices with allied health providers within the same building.
- Training programs for counsellors and psychologists and develop education components in collaboration with parents to address sudden child death.
- Australian school and workplace policies regarding bereavement support (not disaster support).
- Australian media’s policies in regard to reporting bereavement related incidences.
- Opportunities to model and extend existing programs such as the Australian Government Department of Health and Ageing ATAPS Suicide Prevention Service

**Research:**

- GP knowledge, training and confidence in the provision of sudden child death bereavement support.
- The opportunity for coronial support officer training.
- The impact of financial challenges following a sudden child death and potential support opportunities.
- The implications of religion and spirituality on grief and how these constructs relate to a bereaved person’s ability to make meaning
- The relationship between stigma and self blame and stigma and externalised blame.
- Type of death, social and professional support and health outcomes,
Public opinion regarding how people approach bereavement and develop skills-based training and education programs in collaboration with bereaved parents

The viability of a coordinated database of bereavement specialists.

8.5 Conclusion

Despite continued education and prevention strategies, unintentional child deaths will occur. This study has identified that a sudden unintended death may result in complicated grief and that support to help a person navigate through this grief requires a complex mix of social and medical commitment. Complicated grief requires ongoing support from all facets of society. This thesis identified important areas for further research to enhance the opportunity of providing the support needed and suggests a call to action to the community, academics and policy makers to create a more supportive environment.
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Appendices

Appendix 1 – Information sheet

PARENT/CARER PARTICIPANT INFORMATION SHEET

Principal Investigator:
Dawn Spinks
PhD Student
School of Population Health
The University of Queensland
288 Herston Road
Herston Qld 4006
Phone: 0417 633 977 Email: dawn@nothingchangesifnothingchanges.com.au

Principal Supervisor
Dr Lisa Fitzgerald.
Phone: 33655541 Email: l.fitzgerald@sph.uq.edu.au

The Study:

I am currently enrolled as a PhD research student at the University of Queensland, School of Population Health, undertaking a qualitative research project to better understand the impact of fatal child drowning and the use of support services. The findings of this study will help inform service providers, policy makers and academics of the experiences and challenges facing families following a child drowning death.

This research is being conducted in Queensland and will involve interviewing parents of children who drowned between the ages of 0-18 years, and interviewing a range of service providers who may offer support to families experiencing such loss and grief.

I am asking if you will participate in an interview regarding the role of your service to families/individuals that have experienced a child drowning death. The interviews will be semi-structured but mainly guided by your input and experiences with supporting these individuals or families. It is anticipated that the interviews will take between 1 and 2 hours at a location that suits you. I would also appreciate the opportunity to view any relevant documentation that guides your organisation and/or work practices as part of a document analysis component to the research.

Statement of Privacy:

Consent forms (see enclosed) will be stored securely at the School of Population Health, the University of Queensland, Brisbane, and will be accessible only by the Principal Investigator, Dawn Spinks.
Any reports published from this study will only include de-identified data and no personal information will be disclosed.

**Ethics Committee Clearance:**

This study has been cleared by one of the human ethics committees of the University of Queensland in accordance with the National Health and Medical Research Council guidelines. You are, of course, free to discuss your participation in this study with project staff, contactable on 3365 5541 (Dr Lisa Fitzgerald) or 0417 633 977 (Dawn Spinks). If you would like to speak to an officer of the university not involved in the study, you may contact the ethics officer on 3365 3924.

Your participation in this study will provide valuable information into the support requirements for parents who experience the tragedy of their child’s death. Whilst the study may not benefit you directly, research doers indicate that the opportunity to explain your experiences and have them validated can be cathartic.

If you are interested in participating, and/or you know of any other family who may wish to share their story, please complete the attached consent form, or contact me via email or telephone (0417 633 977) so we can discuss any matters which need clarification and arrange a convenient interview time and venue.

Thank you

Dawn Spinks – Principal Investigator.
Appendix 2 – Consent forms

Consent by Participant for Participation In Research Project

Title: The Psychosocial Impact of Fatal Drowning in Children and Adolescents in Queensland, and the Availability of Appropriate Support Services.

Principal Investigator: Dawn Spinks
School of Population Health
University of Queensland

I am being asked to participate in the following project. I understand my participation in this study is entirely voluntary, and I may refuse to participate without and fear of retribution or pressure to change my position. I am also aware that if I agree to participate, I can withdraw at any time, also without fear of retribution or pressure to change my position. I am being asked to read the consent form and encouraged to ask any questions that may arise from this form. If I fully understand and agree to the content of the form I will be asked to sign it, and will be given a copy for my records as well as the researcher keeping to comply with ethics approval.

It has been explained to me that the purpose of the research is to gain insight into the affects of fatal child drowning on families, and to better understand the support needs and challenges following our child’s death. I was informed that there were a number of procedures and protocols which the researcher will follow. These include; following written consent, an interview will be set up in a location and time that suits the participant. These interviews will be recorded and then transcribed onto a text document. The researcher will then thoroughly examine the document and use a computer based software program to identify themes which emerge from the interviews. These themes will be documented and form a significant component of the research thesis which will inform the principal researchers PhD. All names will be removed and replaced with a code to protect the identity of the participants. The list, paring participant names and numbers will be kept separate from the data in a locked file. I have also been informed that the principal researcher will also be interviewing service providers and that the final thesis will illustrate some similarities and differences between the expectations of the families and the services available. I understand I will be able to view the thesis once it has been finalised.

I understand that I will have the opportunity to suggest other families who may wish to participate in the study, as well as other service providers that the principal researcher may not have approached. It is expected that the interviews will last between 90 and 200 minutes, or more should I/we wish to continue the interview. I have been advised that whilst there is no physical risk to me or other participants in the study, I may experience some emotional discomfort in reviewing my personal experiences. Upon request, I will be offered a list of counselling referrals should I need to seek support in managing these emotions.
I have also been informed that the principal researcher is a professional clinical counsellor with a current counselling practice and that she also has a 20 year background and association with drowning prevention. I am aware that the principal researcher will not attempt to counsel me or my family as a direct result of this research.

I have been advised that I will receive no direct financial benefit from my participation in this research. However, due to the style of research, ie semi-structured interviews, I am aware that there may be a cathartic outcome in being able to relay my/our experiences and contribute to the outcome of this research.

I have been told that the principal investigator has the right to withdraw me from this study at any time. The investigator has offered to answer all my questions to the best of her ability. If I have additional questions in relation to the study I can contact the investigators supervisor, Dr Lisa Fitzgerald at the School of Population Health, UQ on 3365 5541.

My signature below acknowledges my voluntary participation in this study. It also acknowledges that the investigators and institutions involved in the study will uphold all relevant ethical procedures.

I HAVE READ THE INFORMATION PROVIDED AND HAD MY QUESTIONS ANSWERED TO MY SATISFACTION. I VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY. AFTER THIS IS SIGNED, I WILL RECEIVE A COPY OF THIS CONSENT FORM FOR MY RECORDS.

Name:__________________________________________________________________________________________

Signature of research participant. __________________________ date.________

Name of witness (please print).

Signature of witness date

Signature of principal investigator date
Appendix 3 – Parent questions

Parent Interview – date

1. Parent name
2. Parent d.o.b.
3. Suburb
4. Most recent education?
5. Current employment
6. Home rented/owned?
7. How long been in home?
8. Name and age of child who drowned
9. Other children? Names and ages
10. Marital status at time of drowning
11. Marital status now
12. Circumstances around child’s drowning
13. Risk perception of water safety
14. Response/support that day/week
15. Challenges since then
16. Financial, relationship, work, self
17. How have other family members coped?
18. Rituals?
19. Who/what was most useful support – and when. For you and partner
20. Did you get all support needed?
21. Were you informed about what support was out there?
22. Benefits of the support
23. Barriers to support
24. Anything you needed and didn’t/couldn’t get?
25. Why?
26. Current challenges
27. Open discussion
Appendix 4 – Service provider participants

1. Swim Australia
2. Hannah’s Foundation
3. Montere College (professional supervision training)
4. Australian Counselling Association
5. Sids and Kids
6. Lifeline
7. Compassionate Friends
8. Mater Children’s Hospital ED
9. Social Work and ED staff at Royal Children’s Hospital
10. Paradise Kids
11. Art Therapist
12. Hilda’s House
13. Past Coronial investigator
14. Donate for Life
15. Grief counsellor/GP
16. Grief coach, funeral celebrant and grief website founder
17. Private grief counsellor and university lecturer
Appendix 5 – Service provider questions

1. The key role of your service/organisation?
2. What type of service do you provide to parents/families that have experienced a child death?
3. How does the parent contact you in the first instance?
4. What are the costs of the service?
5. How long can families access your service?
6. Is the service available only for the immediate family or extended family?
7. Is the service accessible Queensland wide (including rural/remote)?
8. What is your referral procedure?
9. What is your service evaluation procedure?
10. How, if at all, would you like to see the service extended/improved?
11. Can you suggest other service providers?
Appendix 6 – Service provider letter explaining study

Statement of Agreement to be contacted by Principal Researcher

I ____________________________ of ____________________________

organisation agree for Dawn Spinks (Principal Researcher) to contact me in order to discuss the possibility of an interview or focus group regarding my organisation’s role in supporting families who have experienced a fatal child drowning.

I understand this agreement is in relation to permission to contact and does not at this stage, confirm, or refute my/our involvement in the research.

Signed: ____________________________

Position in organisation: ____________________________

Contact ph: ____________________________ email: ____________________________

Date: ____________________________
Agreement to be contacted for interviews or focus groups.
Official approval form

Principal Investigator:
Dawn Spinks
PhD Student
School of Population Health
The University of Queensland
288 Herston Road
Herston Qld 4006
Phone: 0417 633 977. Email: dawn@nothingchangesifnothingchanges.com.au

Principal Supervisor
Dr Lisa Fitzgerald.
Phone: 33655541 Email: l.fitzgerald@sph.uq.edu.au

The Study:
I am currently enrolled as a PhD research student at the University of Queensland, School of Population Health, undertaking a qualitative research project to better understand the impact of fatal child drowning and the use of support services. The findings of this study will help inform service providers, policy makers and academics of the experiences and challenges facing families following a child drowning death.

This research is being conducted in Queensland and will involve interviewing parents of children (0-18 years) who have drowned between 1999 and 2009, and interviewing a range of service providers who may offer support to families experiencing such loss and grief.

I am asking if, as a possible service provider, you agree for me to contact you in order to participate in the research. This will involve either an interview with one or two representatives or a focus group if more than 5 of your colleagues wish to contribute to the research. The interviews will be semi-structured but mainly guided by your input and experiences with supporting these individuals or families. It is anticipated that the interviews will take between 1 and 2 hours at a mutually convenient location. I would also appreciate the opportunity to receive copies or view any relevant documentation that guides your organisation and/or work practices as part of the document analysis component to the research.
THE UNIVERSITY OF QUEENSLAND
Institutional Approval Form For Experiments On Humans
Including Behavioural Research

Chief Investigator: Ms Dawn Spinks

Project Title: The Psychosocial Impact Of Fatal Drowning In Children And Adolescents In Queensland, And The Availability Of Appropriate Support Services - 28/04/2011 - AMENDMENT

Supervisor: Dr Andrew Page, Dr Lisa Fitzgerald, Dr Jon Adams, Dr Kerri-Anne Watt

Co-Investigator(s): None

Department(s): School of Population Health

Project Number: 2010001528

Granting Agency/Degree: Queensland Injury Prevention Council (QIPC) - Queensland Health

Duration: 31st December 2015

Comments:

Name of responsible Committee:-
Behavioural & Social Sciences Ethical Review Committee
This project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:-
Associate Professor John McLean
Chairperson
Behavioural & Social Sciences Ethical Review Committee

Date 29/4/2011 Signature JPMC
CHILDREN’S HEALTH SERVICES

Executive Administration

15th March 2012

Mrs Dawn Spinks
18 Christina Street
WELLINGTON POINT QLD 4160

Dear Mrs Spinks

Re: Research Project: The psychosocial impact of fatal drowning in children and adolescents in Queensland and the availability of appropriate support services.
HREC Reference Number: HREC/12/QRCH/21
SSA Reference Number: SSA/12/QRCH/42

Please be advised the above mentioned research project has successfully received Institutional approval following Executive review in March 2012.

The following conditions apply to this research proposal. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval.

1. Proposed AMENDMENTS to the research protocol or conduct of the research which may affect the ethical acceptability of the project are to be submitted to the HREC for review. A copy of the HREC approval/rejection letter must be submitted to the Research Governance Officer;
2. Proposed AMENDMENTS to the research protocol or conduct of the research which only affects the ongoing site acceptability of the project, are to be submitted to the Research Governance Officer;
3. Proposed AMENDMENTS to the research protocol or conduct of the research which may affect both the going ethical acceptability of the project and the site acceptability of the project are to be submitted firstly to the HREC for review and then to the Research Governance Officer after a HREC decision is made.

Cont’d:
May I take this opportunity to wish you every success with your research project and the contribution it will make to Children’s Health Services and the broader research community.

Yours Sincerely

Sue McKee
A/Chief Operating Officer
Royal Children’s Hospital
Children’s Health Services