"It's just like... it's just like what other people feel"

A phenomenological exploration of using a children's picture book in the context of bereavement therapy

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Acknowledgements

This study is dedicated to the memory of Eleanor and Eddie.

Abstract

The principle aim of this study was to uncover and produce a phenomenological description of the experiences involved when reading and discussing with others a book about death and dying. Although fictional literature is frequently used within bereavement services, there is a dearth of research to support evidence based practice. The methodological design was based on the work of Edmund Husserl, in particular his transcendental phenomenological approach to enquiry.

The participants for the study consisted of 11 bereaved young people, four of whom had Down's syndrome. A therapeutic bereavement session was attended by the group, during which a member of staff read Michael Rosen's SAD BOOK (Rosen, 2004). Afterwards a series of questions guided and stimulated discussion, gradually leading onto an exploration of their unique experiences. The participants listened, discussed, debated and shared stories, not only about reading the book but of their own grief.

The main therapeutic session was video recorded and provided data that included verbal and non-verbal language, together with details of the context in which the interactions took place. The analysis uncovered findings that included:

- a connection to other bereaved people
- discussion of crying and sadness
- a focus on prose and illustrations, especially one page which read:

This is me being sad
Maybe you think I'm being happy in this picture
Really I'm being sad but pretending to be happy
I'm doing that because I think people won't
like me if I look sad

The findings were transformed to produce a phenomenological description of the experience when reading and discussing with others a book about death and dying. It is anticipated that this research will be of benefit to a wide range of multi-professional staff working with bereaved young people, some of whom may have a learning disability.

Definitions

Child:

A child is used to describe children, young people and young adults between the ages of 0 and 18 years of age (Department of Health, 1999).

Young adult:

This term describes individuals who are between the ages of 18 and 28 (Wallbank, 1996).

Learning disability:

Approximately 1.5 million people in the United Kingdom have a learning disability. This is characterised by:

- a significant impairment of intelligence
- a significant impairment of adaptive functioning
- age of onset is before adulthood

(British Psychological Society, 2000)

Disseminated findings

Oral Presentations

1. Dudley, H. (2007) <u>The experience of undertaking a PhD study, alongside the role of hospice tutor</u>. Yorkshire Association of Palliative Care Educators (quarterly meeting). Kirkwood Hospice, Huddersfield.

2. Dudley, H. (2008) <u>Chocolates with Rudolf & Family.</u> The Needs of People with Learning Disabilities who are Dying or Bereaved, The National Association of Palliative Care for People with Learning Disabilities, 10th Anniversary Conference. Dove House Hospice, Hull.

3. Dudley, H. (2008) Chocolates with Rudolf & Family. Aspects of Grief, Diploma in Palliative Care module (The University of Huddersfield). Kirkwood Hospice, Huddersfield.

4. Dudley, H. (2008) A phenomenological exploration of a children's picture book on the subject of death and dying. Child Bereavement study day. Kirkwood Hospice, Huddersfield.

5. Dudley, H. (2009) <u>Undertaking Research with Bereaved Young Adults who have a Learning Disability</u>. Improving Patient Care Provision in Palliative Care for People with Learning Disabilities: National Association for the Palliative Care for People with Learning Disabilities Conference. The Hudawi Centre, Huddersfield.

Poster Presentations

1. Dudley, H. (2006) <u>Chocolates with Rudolf & Family: a phenomenological exploration of a children's fictional book on the subject of death and dying</u>. Trans-Pennine Palliative Care Research Network Conference. The University of Sheffield, Trent Palliative Care Centre. (Awarded 1st prize)

2. Dudley, H. (2008) <u>Chocolates with Rudolf & Family: a phenomenological exploration of a children's fictional book on the subject of death and dying</u>. Research Open Day. The University of Huddersfield.

3. Dudley, H. (2008) <u>Embracing Imaginative Free Variation</u>. Qualitative methods in psychology section inaugural conference (The British Psychological Society). The University of Leeds.

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Contents

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CHAPTER ONE

INTRODUCTORY CHAPTER

"He was there. Then he wasn't. Though in between he was blue and still and landed with a thud when 999 told me to pull him to the floor"
(Rosen, 2002, p. 48)

Within the pages of this thesis a story is woven. It is the true account of an experience so indescribably sad, yet bravely shared with others. The above words describe the moment a father discovered his teenage son had died. Michael Rosen, Children's Laureate (2007-2009), later explained his rationale for sharing this experience with others, "…if you make things very private and secret, the chances are it will hurt more" (Hattenstone, 2007). These insightful and poignant words followed the publication of his work for children, Michael Rosen's SAD BOOK (2004). Quite how Rosen's story became an intrinsic part of my thesis will be revealed in this very first chapter.

The following study developed over time and sought to investigate the experience of 11 bereaved young people, four of whom had Down's syndrome, as they read and discussed Michael Rosen's SAD BOOK (Appendix 1). The principle aim was to produce a phenomenological description of the experience when reading and discussing with others a book about death and dying. With such a unique group, techniques were merged from working with bereaved children, young adults and individuals who have a learning disability.

This introductory chapter will commence with an outline of the rationale for undertaking the study, from both a personal perspective and in relation to my work within palliative care. The development process, which began with an interest in the therapeutic use of literature to support bereaved young people, will follow. The paucity of evidence to substantiate this practice was surprising and prompted me to consider the subject for my doctoral studies, in order to explore this anomaly further.

As I had chosen to undertake an empirical study, it was evident that with such a potentially vulnerable group, the need for creative and sensitive research approaches

would become a high priority. Several precautionary measures were built into the methodological design so as to navigate some of the issues that arose. My rationale for choosing a qualitative and phenomenological focus will be introduced within this chapter and followed by a résumé of Rosen's book.

Child bereavement services and the support of bereaved young people with a learning disability, both central features of this study, are often placed within the remit of Palliative Care. Therefore, this may be an appropriate point at which to define the term. Palliative care describes the 'total (holistic) care' of both patients and their carers. Furthermore, it aims to improve '…the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems' (World Health Organisation, 2006).

1.1   Background to the study

This study emerged from my work in a local hospice, together with an on-going interest in how the media and literature influence young children. When commencing my doctoral studies, I was employed as a hospice tutor and had on a number of occasions assisted the in-house counsellors with both child bereavement and bereavement support for young people with learning disabilities.

Within the United Kingdom there are approximately 4 to 7 percent of the population who lose a parent before the age of 16 (Ribbens McCarthy, 2006). When one considers young people who are fostered, adopted or being cared for by public services, the figures are much higher. With this latter group, it is thought that the incidence of bereavement is increased, both as a contributory reason for entry into care and/or the fact that their parent(s) have died of alcohol or drug related causes (National Children's Bureau, 2007). A growing number of bereaved children and young people are offered support through services very similar to the one I had worked alongside.

The National Service Framework for Children (Department of Health, 2003) highlights a need for robust services, thus enabling children to lead healthy lives, especially when challenges such as bereavement arise. Julie Stokes, Founder and Chief Executive of Winston's Wish (a national child bereavement organisation), states that evidence based

practice must become integral to service delivery, ensuring the support provided is both relevant and appropriate (Stokes, 2004).

However, whilst The End of Life Care Strategy (Department of Health, 2008) also draws attention to the importance of research activity within hospices, this key aspect of service delivery is limited (Turner et al, 2009). Subsequently, there is a relatively poor amount of evidence for services to base their practice (Rolls, 2007).

Much of the literature on child bereavement has been adapted from theories and models which apply, in the first instance, to adults (Rolls, 2008). Interestingly, Blackman (2003) suggests that to understand how people with learning disabilities grieve, one must first of all examine how the capacity to mourn develops within childhood. If these two statements are true, the theoretical knowledge I had previously assumed was grounded in empirical evidence may actually have been adapted from adult bereavement data.

When I tentatively undertook a preliminary search of the literature, there appeared to be a limited amount of evidence in relation to the way young people read books on the subject of death and dying. This activity is frequently used as a therapeutic medium when supporting bereaved individuals and one I was particularly interested in. Bibliotherapy, the more precise term used to identify the planned use of fictional or non-fictional literature, aims to facilitate and enhance a person's coping skills (Jones, 2001). Within child bereavement work, it is utilised to stimulate discussion and promote understanding about a number of issues relating to loss. However, there appeared to be a dearth of empirical evidence with regard to how young people experienced reading these books. I had expected to uncover a wide assortment of comments about what they understood from the stories or their personal experiences of reading the publications.

Despite the growing popularity of utilising bibliotherapy as a tool to support bereaved children, I concluded that there was very little empirical evidence to both inform and support practice. Furthermore, whilst there is a good range of recommended booklists from all child bereavement organisations (Appendix 7), the reviews appeared to be written by a professional rather than a child. The significance of both these points will be explored further in Chapter 3 (Section 3.2).

1.2 Researching children's experiences

I contemplated possible reasons as to why there appeared to be so little evidence of how young people experience grief in general. According to Engel (2005), in 'Researching Children's Experiences: approaches and methods', it appears 'unfashionable' to expect children to share their thoughts and experiences. Furthermore, the author points to the possibility that this idea may never have been fashionable in the first place. In another publication 'Reflections on Death', the author "regretfully" only interviewed adults, as "…it is not feasible… to interview a child, so a description of a child's bereavement is included here instead" (Dinnage, 1992, p.1).

Fortunately, in the last few years there appears to have been an expansion of research within the area of child health, challenging the above assumptions and culminating in several projects, conferences and study days. Whilst I still found a dearth of new material with regard to the 'experience' of bibliotherapy, testimonies of young people and their experience of loss have started to emerge. One recent study was carried out by The National Children's Bureau (Penny, 2007). The accompanying report presents a deeply moving and eidetic description of the participants' grief. A poem, composed by several young people in care, all of whom had experienced a variety of separations and losses in their lives, describes their grief thus:

A thousand daggers twist in my guts
the hurt like spiders crawling up my throat
worry wriggles under my skin

My legs are stiff as steel
My arms are stiff as trees
My eyes puff up like bags of crisps ready to be popped

Stomach erupting volcano
Numb body full of ice
Mouth is clamped shut

My head holds an electric storm
Body frozen, everything stops
and my eyes just stare.
(Penny, 2007, p.11)

With such powerful research starting to acknowledge and uncover young people's experience of loss, it is a privilege to contribute to this new, albeit growing, body of knowledge.

In 2006, I attended two study days related to my area of interest that merit specific mention. The first was entitled 'Consulting with Children and Young People: the where, the why and the wherefore', organised by the Royal College of Nursing 'Research in Child Health' (RiCH) group. The presentations incorporated evidence from many practitioners undertaking investigations with children and young people. The second day was 'Narratives and Story Telling in Palliative Care Research and Creative Practice' organised by St Christopher's Hospice. Whilst the subjects covered were not directly related to the 'experience of reading books about loss', it was excellent to hear how creative methods had been used to support patients or bereaved individuals and, furthermore, that research regarding these approaches was being instigated. Issues from both study days will be explored within later chapters.

1.3   Research challenges for child bereavement services

The National Council of Palliative Care (formerly National Council for Hospice and Specialist Palliative Care Services) recognises that '…involvement in research is one of the elements defining a specialist palliative care service and the implementation of evidence-based practice is a key aspect of service quality' (NCHSPC, 1999, p.11).

However, when Blanche and Smith (2000) undertook an overview of child bereavement groups within the UK, they found a paucity of research. Contributing factors included finite resources and the recognition that evaluation takes a significant amount of time, a luxury few services could spare. Consequently, the challenge of finding ethical and appropriate ways to evaluate practice, along with the above mentioned issues, had resulted in a limited amount of empirical studies.

Findings from a survey seven years later found the situation had not been resolved (Rolls, 2007), with child bereavement services having little evidence on which to draw or situate their own practice. Rolls progressed to stipulate that one of the main reasons was in relation to an increase in referrals, not only the number of individuals, but the complexity of cases. The author found that where research had been undertaken, the main methodological approach was 'user satisfaction surveys', rather than more

sophisticated approaches. Developing links with academic institutions was one of the possible solutions proposed and interestingly (due to my doctoral studies) a strategy utilised for this particular project.

As with all areas of nursing and social care, despite the above challenges, a need for research within palliative care is of crucial importance. Without this, it is unlikely that practitioners will progress beyond what they already know and stagnant practice, rather than progressive evidence-based practice, will take place (Holmes, 2007). Furthermore, irrespective of securing funding streams to boost research activity, studies in this area are strewn with complexity. Reasons for this situation are often due to the ethical dilemmas of working alongside patients and their families, many of whom are experiencing acute distress.

Cicely Saunders, a physician often credited with founding the modern hospice movement (Clark et al, 2005), emphasised a need for palliative care practitioners to consider the holistic nature of bereavement. Following the death of a close friend, Saunders surmised that although painful, the experience of grief is something that can be studied endlessly and will allow practitioners to move from a purely clinical approach to one which considers philosophical and theological insights.

Saunders encouragement to uncover new philosophical insights about the experience of bereavement became one of the key considerations within this study. Nevertheless, I was very aware that due to the potential vulnerability of bereaved children and young people, the ethical dilemmas within my study would be significant. In 1995 the National Council for Palliative Care (NCHSPC, 1995) highlighted the importance of balancing a conflict between the duty to improve future service delivery and protecting those included within any research activity, thereby ensuring they still receive the best possible care. Although this seems very straight forward, even by having preliminary discussions with patients and family members about their possible involvement adds another decision and possible dilemma onto their already difficult journey.

When evaluating services, Johnston (2008) addressed the issue of involving family members and suggested that investigators should consider creative ways of designing studies, to lessen the potential impact and disruption on their lives. Within his research, the author merged individual interviews with focus groups and stated that contrary to

many people's concerns, innovative ways can be all-inclusive and offer participants a sense of empowerment. Furthermore, this allows them to feel valued and know their involvement will contribute to improving future practice. This emerging view, of clinical engagement and systematic research being beneficial for both parties, was noted in a study involving 157 bereaved children (Christ, 2000). According to the author, the participants received an improvement in their care.

After considering all the issues discussed so far, especially the paucity of empirical evidence in relation to the experience of reading books about death and dying, I decided to continue with this line of enquiry. It seems to me that despite the myriad of dilemmas involved within any investigation, authentic clinical research can only improve our understanding and ability to support individuals within our care. Chapter 5 will explore how I addressed and acknowledged the issues raised when undertaking an empirical study with a young and vulnerable group of bereaved individuals. I will describe in detail how the issues were navigated and closely monitored, both by my supervision team and the Hospice Research Monitoring Group.

1.4   Permission to work with a bereaved family

Prior to commencing my doctoral studies, I worked alongside colleagues from the hospice in supporting a large and close extended family, who had experienced the sudden death of a young family member. Eleanor (pseudonym) had died suddenly, survived by her husband and two children. Within her extended family were adopted siblings, some of whom had a learning disability. Several young members spent a day at the hospice in order to explore their memories, feelings, worries and concerns about the deceased and their subsequent bereavement.

Several months later I contacted the parents to tentatively discuss my doctoral study. This was a mutually beneficial telephone call, as they had considered asking for support, due to the approaching anniversary of Eleanor's death. The parents felt that a further day would not only help their young family members but also offer them some reassurance. Similar to many bereaved parents, they wanted to know everything possible had been done to ensure the children would gradually adapt to the loss of their sister or mother. I explained my proposed study and asked the parents if they would consent to this becoming part of the support offered. Subsequent meetings with all the

family members clarified their consent, details of which are in Chapter 5. Thereby, the participants within the session included 11 of Eleanor's close family members.

1.5   Rationale for choice of book

There are several therapeutic approaches utilised with bereaved children and bibliotherapy was the specific tool I had planned for the data collection period. Identifying an appropriate story to use proved to be a complex task, as some of the participants were not living with their birth parents. I found many books used traditional family units to explain death and the impact of grief. For example, in Grandma Come Back (Limb, 1993) the author describes how Bessie (the central character) experienced the death of her grandmother and the subsequent support she received from her mother and father. When Bessie grew up and had a child of her own, she recognised mannerisms and features of the baby which were reminiscent of her late grandmother. This was something that a number of participants in the study may never experience, especially if they do not know or have contact with their maternal or paternal grandmother.

After much searching (further details of which are in Chapter 3, Section 3.2), the book I finally chose was Michael Rosen's SAD BOOK (Rosen, 2004). There were several reasons for my choice, in particular the story-line and illustrations that I thought may appeal to a wider age group. This was an important point, as ages within the group ranged from six to twenty-eight years of age. Furthermore, whilst Rosen referred to both his son and deceased mother, he also spoke of sharing his feelings with friends. The omission of any description in respect to a traditional family unit, ensured there was enough flexibility within the story-line for all the participants to identify with at least some of the characters.

1.6   Principle aim of the study

The principle aim of this study was to investigate the experience of 11 bereaved children and young people, including four individuals who had a learning disability, when they read and subsequently discussed Michael Rosen's SAD BOOK. This broad aim was refined during the course of the study and is explained in more detail, together with a description of the design, in Chapter 5.

1.7 Influence of the chosen theoretical framework

When considering various theoretical frameworks, it was important for me to choose one which would counter the lack of empirical evidence, with regard to how bereaved young people experience reading books about death and dying. I looked for a clear framework that would provide a strategy in which the participants' experience could be presented, without overt interpretation. After reviewing a number of theoretical approaches, I chose Transcendental Phenomenology, based on the work of Edmund Husserl from 1913 to 1938.

Husserl's epistemological work informed all aspects of how I assessed, planned, implemented and evaluated the session, in addition to presenting the data. Initial contact with the participants had raised my awareness that several members of the group may have a limited vocabulary with which to describe their experience, a concern when contemplating the premise of my study. However, even at such a preparatory stage, I knew that by applying a great deal of thought to the matter, Husserl's phenomenological approach would allow me to uncover a rich and detailed account of their experience.

Therefore, to increase the quality of the participants' description, I decided to supplement the data with my personal reflection of the session. Material for the formal reflection document had been compiled throughout the data collection period and over the subsequent two years. I approached this task by considering a structure originally devised by Edward de Bono (1999) and named my own modified version the 'Seven Hat Framework', full details of which are in Chapter 6 (Section 6.4) and Appendix 10.

Todres (2002) echoed my own ambitions for this study, when he described a phenomenological approach as providing 'a language that cares for the human order'. He states, it is a methodology which:

"…demonstrates a concern to care for our informants' voices, to care for the human phenomena that are being expressed, to care for how our own voices as writers and researchers reveal, conceal and co-create, and to care for our readers as part of the ongoing conversations of understanding" (Todres, 2002, p.2).

1.8 Analysis method to complement theoretical underpinnings

Whilst I would never propose the data collection session was an example of a faultless therapeutic encounter, it was one with a healthy balance of emotions and behaviour.

What the data captured was a detailed portrayal of a 'moment in time', when a group of bereaved individuals were invited to comment on their experience of reading Michael Rosen's SAD BOOK. Similar to when I visited the participants within their home, a warm, lively, often chaotic, yet respectful encounter took place. They opened up and shared their personal reflections, whilst the younger ones jumped about, sat on our knees and gently tugged my hair for attention. The whole group (including staff members) listened to the story, ate chocolate and shared their experiences.

When considering various ways to analyse the above session, I searched for a method that would not only do this effectively, but one to complement Husserl's theoretical underpinnings. As previously mentioned, this needed to focus on the participants' description of their experience in as much detail as possible. After a good deal of deliberation, I chose Amedeo Giorgi's phenomenological method of analysis (1985). Rather than claim to provide objectivity to the analysis, his methodology prompted me to acknowledge my involvement and perception of the session. It provided a sound, clear and detailed protocol, thus enabling me to carefully consider the data from a variety of perspectives and 'transform' it further. This process led to what is referred to as 'eidetic intuition', the point whereby essential features of the participants' experience were uncovered (Sokolowski, 1999). More details of these terms and the analysis are provided in Chapters 4 and 7.

As the data were unusual for a phenomenological study, especially with regard to the group interview, I needed to be flexible in how I utilised the analysis method, without compromising my adherence to Husserl's transcendental theory. Further details of this task are in Chapter 7, closely followed by a detailed presentation of the findings within the subsequent chapter.

When taking into account the small size of the group, I have at times encountered scepticism from colleagues regarding to the potential value of my study. I welcome such enquiry and view it as an opportunity to discuss the principle on which phenomenological studies are based, a point discussed further in the concluding chapter. Giorgi (2008) states that within these investigations, rather than focusing on the number of participants, a crucial element is the quality of the research. He points out that the amount of time invested, when methodically analysing each person's pre-reflections, is more important than recruiting large cohorts of participants. Even if resources are

increased and 30 people recruited, there may be diminishing returns as the 30th description is uncovered. Furthermore, it does very much depend on the context and diversity of the phenomenon investigated, in relation to how many cases are required before arriving at a point whereby 'what is essential to the experience' has been revealed.

My aim for this study is to produce an insightful piece of work, where the findings contribute to what has already been written, rather than produce material that simply fits in with current theories. More importantly, it will offer bereaved young people an opportunity to say how they experienced the use of bibliotherapy. I hope readers are moved to think and act differently, considering the impact of their own 'taken for granted assumptions' when recommending or reading picture-books with bereaved young people.

The final part of this chapter will offer a résumé of the chosen publication, Michael Rosen's SAD BOOK.

1.9   Résumé of Michael Rosen's SAD BOOK

Michael Rosen presents a story in which he describes his sadness after the sudden death of his much loved son Eddie. He was a vibrant, athletic, 6'4" tall, 18 year old who complained of feeling ill one evening. The following morning Rosen went to wake him and found he had died in his sleep from meningitis. The author decided to write about Eddie's death and discovered that he began to put the experience in perspective.

During an interview with Hattenstone (2007), Rosen discussed the rationale for sharing his story:
"Part of me thinks... deep and difficult feelings of any kind... we shouldn't really share but I suppose when I wrote it, it's about sharing the fact that I've had these feelings and also saying you can have those feelings too, let's share it. If you make things very private and secret, the chances are it will hurt more" (Hattenstone, 2007).

Before publishing his work for children, Rosen wrote a book of poetry for adults, entitled Carrying the Elephant: a memoir of Love and Loss (Rosen, 2002). Although the wording is very different in the children's book, several similarities are evident in both publications, particularly in relation to his emotional turmoil. Below Rosen depicts the powerful and at times overwhelming impact of his son's death:

In Paris where we went to find out what we thought about him not being with us any more I bought a card. It's from an engraving by Jean Baptiste Oudry (1755-1759) 'Les deux aventuriers et le talisman', an illustration of one of La Fontaine's Fables. A man is carrying an elephant – bending under the weight of it. He bends at the knees as well, head down, face to the ground. What's more, the man is trying to walk. He's struggling to take a step forward up a mountain. Above him is a rocky shoulder and across from him is an even bigger crag, overlooking him. But he hasn't fallen over and he's got that elephant gripped round its front legs. He's carrying the elephant. Jean Baptiste Oudry has made sure that he'll go on and on carrying it. At least as long as I've got it on my notice board. He's carrying the elephant.
(Rosen, 2002, p.53)

Whilst there wasn't a recommended age cited for reading Michael Rosen's SAD BOOK, it is 32 pages long with less than 1,000 words and therefore considered a large format picture-book (Jordan, 2007). Walker Books (the publishers) promote the publication on their website as suitable for children from the age of five. Quentin Blake illustrated the book and was also responsible for adding to the story-line. In an interview with Radio 4 (Harwood, 2008), Rosen states that he had no input into the last two pages, illustrations of him looking at a photograph of Eddie, lit by a candle. Rosen expected the book to finish earlier, then turned over the page and found an additional picture, of which he commented "… it just took my breath away again… you know, I just thought, you know… wow… where did that come from… I was quite overwhelmed".

Several years later, Quentin Blake discussed his role as illustrator for Rosen's book during an interview for the Guardian newspaper (Jeffries, 2007). Jeffries asked Blake what had been his most difficult drawing in over six decades of work (including over 300 book illustrations). Blake replied that it had been the illustration of Rosen grinning, even though, as the text explains, he was really feeling very sad. "I did it 15 times, but I just couldn't get it right… It wasn't so much that he was sad, it was that he was sad, but

trying to look happy. I did it once and he looked too cheerful, another in which he looked too sad. It was a matter of trying to dose the happiness".

Rosen's book starts with the aforementioned illustration, accompanied by the narrative:
This is me being sad.
Maybe you think I'm being happy in this picture.
Really I'm being sad but pretending I'm being happy.
I'm doing that because I think people won't
like me if I look sad.

Often bereavement work with young people seeks to stimulate discussion of similar feelings to those described above, with the intention of uncovering any worries or concerns they may have. Gilbert (2004) notes that bereaved children sometimes feel they are the only ones to experience these emotions and therefore it is important to help 'normalise their grief'.

Blake also reveals, through his illustrations, the darkness of grief as it enveloped Rosen with the accompanying words:
Sometimes sad is very big.
It's everywhere. All over me…

What makes me most sad is when I think about my son Eddie.
He died. I loved him very, very much but he died anyway.

There are several brightly coloured and comical illustrations, in particular one with a cat which reads:
Sometimes because I'm sad I do bad things.
I can't tell you what they are.
They are too bad. And it's not fair on the cat.

On other pages the text is not only powerful but also very rhythmical, making it fascinating to listen to, with prose such as… 'making my cheeks go whooph, boooph, whooph'. Alongside this, the confusion and turmoil of emotions which surround grief are presented, as the following depicts:

Sometimes I'm sad and I don't know why.
It's just a cloud that comes along and covers me up.
It's not because Eddie's gone.
It's not because my mum's gone.
It's just because

In the second half of the book, Rosen acknowledges the fluidity of his emotions and his search for coping strategies, in order to manage his sadness:
I've been trying to figure out ways of being sad that don't hurt so much.
Here are some of them:

I tell myself that everyone has sad stuff.
I'm not the only one. Maybe you have some too.

Every day I try to do one thing I can be proud of.
Then, when I go to bed, I think very, very, very hard about this one thing.

Every day I try to do one thing that means I have a good time.
It can be anything so long as it doesn't make anyone else unhappy.

In contrast to other publications which offer a linear progression through grief, often finishing the story-line with understanding and calm (Limb, 1993), Rosen presents a more realistic picture of the fluctuation between good days and the more difficult ones:
I write:
Sad is a place
that is deep and dark
like the space
under the bed

Sad is a place
that is high and light
like the sky
above my head

When it's deep and dark
I don't dare go there

When it's high and light
I want to be thin air.

This last bit means that I don't want to be here.
I just want to disappear.

There are several pages full of colourful illustrations, acknowledging the author's happy memories of his son, especially one which shows the avid football supporters:
"...playing saves on and off the sofa"

Towards the end of the book, the pages portray Rosen's love of celebrating birthdays, brightly illustrated by Blake. In an on-line review for the Parents' Choice Foundation, Toni Rowden (2005) remarks on the way colour was utilised to convey emotion:
"...Quentin Blake's illustrations show us pain. Blake reveals the darkness of grief as it envelops the father with grey, slate blue and black. Whenever the man feels melancholy grey creeps in as sadness moves to overshadow Rosen. His happy memories of his son and mother appear with bright soft blue, green, red and gold pastels… as glints of hope appear in the father's vision, Blake's drawings become bright with soft yellow light…"

The final two pages, created by Quentin Blake, are indicative of a close relationship between the writer and illustrator. There are innumerable ways to describe these pages, as will be seen within this study. However, I will leave the participants' insights and descriptions for Chapter 8 and conclude this résumé of Michael Rosen's SAD BOOK with a reminder of the author's reaction when he first saw the illustration:

"…it just took my breath away again… I was quite overwhelmed".

1.10   Thesis outline

The first chapter has focused on my rationale for undertaking this particular study and will be followed in Chapters 2 and 3 with a literature review, relating to both bereavement issues and bibliotherapy.   Chapter 4 introduces the work of Edmund Husserl and his distinctive philosophy, Transcendental Phenomenology.   The methodological design, informed by Husserl's theoretical underpinnings, is outlined within Chapter 5.   This will highlight how I provided a setting to uncover both informative and insightful data, with regard to the participants' experience.   Integral to the design were strategies which ensured the environment was safe and the session therapeutic, with scope for disclosures of a sensitive and emotive nature to take place.

The compilation of data was complex due to the limited language that was present when transcribing the initial verbal pre-reflections.   How this was navigated and enhanced will be discussed in detail within Chapter 6.   The following chapter will progress to outline the search for an appropriate method of analysis, one which provided a clear, coherent and robust structure.   This allowed me to consider all the details and thus effectively analyse the data.   Chapter 8 will utilise the Seven Hat Framework as a way of organising and presenting the findings, by describing rather than interpreting the data.   This process enabled me to consider the session from a clear, theoretical-free position and a variety of perspectives.   The subsequent chapter (nine) considers relationships amongst the findings and will discuss these in dialogue with theoretical literature.

The final chapter will highlight issues relating to the involvement of children and young people in research.   I will also reflect on the utilisation of Transcendental Phenomenology and the innovative Seven Hat Framework.   The significance and relevance of the findings, alongside several implications for practice, will provide an appropriate point at which to conclude my thesis.

1.11   Summary

Within this first chapter I have explained the rationale for my study and it's relevance to practitioners who support bereaved children, young adults and people who have a learning disability.   My initial ethical concerns, with regard to the participants' involvement have been discussed, in addition to the theoretical approach utilised to study their experience.   Steering the development of such a sensitive and complex piece

of research has resulted in a fascinating journey of exploration. The remainder of my thesis will guide readers through the research process, including how I discovered a unique way to structure and facilitate the session, collate and analyse the data, describe and ultimately uncover the phenomenon of reading and discussing Michael Rosen's SAD BOOK.

CHAPTER TWO

LITERATURE REVIEW: Grief and Bereavement

"Death teaches us a great deal. Perhaps its greatest lesson is the fact that nothing lasts forever. Not even sadness and grief. Experience of loss can make us aware of the preciousness of life and our need to make the very most of the time we have on this earth".
Susan Wallbank (1991, p.31)

This chapter is designed to review literature in relation to the particular areas of interest within this study and highlight key issues. A wide variety of sources were used to access both classic and current texts, especially the information generated from discussing this project with a diverse range of professionals working within nursing, psychology, palliative care and child bereavement services.

The general topic area of grief and bereavement will be presented first, before progressing to look at how this transpires at earlier points in life. A proliferation of child bereavement groups over the last twenty years will then be discussed, along with the model of best practice (Stokes, 2004), as utilised for this study. Issues that require consideration when supporting young adults with a learning disability will also be addressed. The second part of this literature review is situated within Chapter 3. This will focus on fictional and non-fictional literature used to support young people and adults with learning disabilities to increase their understanding of grief.

As with other phenomenological studies, the literature uncovered will be explored further once the findings and structure of the phenomenon have been presented. Chapter 9 will highlight areas where the findings either confirmed or cast doubt on details within the literature and also where they added something significant to what is currently available.

In contradiction to many other research approaches, transcendental phenomenology suggests a limited review of literature before any study is carried out and analysed (Bloomberg and Volpe, 2008). With regard to my own investigation, the purpose of undertaking such an approach was to limit my awareness of theoretical literature that might have influenced how I analysed and described the data. Consequently, a

significant amount of information within this chapter was collated after the data collection period. Nevertheless, it was also essential that I acknowledged and addressed my 21 years experience of working as a nurse, during which I had amassed a substantial amount of knowledge and experience in many areas covered in the literature review. Chapter 4, particularly Subsection 4.3.6, will explain the process undertaken to 'suspend' any prior knowledge until after the analysis period.

2.1   Grief and bereavement

The exploration of grief and bereavement has evolved significantly in the last century, with more consideration given to the wider context of an event which, at some point, touches all our lives (Machin, 2009). Grief can be applied to many forms of loss, such as losing a partner, divorce or even mislaying a treasured object. Therefore, whilst it is not only bereaved individuals who experience the emotion of grief, in the context of this study I am referring to the loss of a family member.   Both literature and experience informs us that the death of a significant person in our lives is a ubiquitous event (Cobb, 2008), yet one of the most challenging occurrences to manage. As such, the language we use to describe the impact of grief reflects this.

2.1.1   Defining grief and bereavement

The common root of the word bereavement is 'reave', to forcibly deprive of, to take by force and carry off (Allen, 1990, p.1000). Gersie (1991) states that this powerful description still echoes for us today, when the death of someone significant in our lives often leaves us feeling vulnerable or naked. Whereas bereavement is often described as a state, a consequence of loss, grief refers to the process, our affective reaction to the loss (King, 2003). One definition of grief is 'deep or intense sorrow or mourning' (Allen, 1990, p.519), although as this study will illustrate, it is unique to each individual and involves a complex web of reactions which may not always be visible or understandable to others.

Walters (2004) addresses the individuality of grief and introduces the point that grief also affects individuals who know they are dying, an issue addressed further in Section 2.1.3: "…dying in one's own way, in one's own style [that] may well include the elements of protest, complaint and awkwardness, perhaps with humour, perhaps with curses, without

all the problems necessarily being resolved or relationships restored – but with integrity and honesty" (p. 408)

Throughout history there are accounts of bereaved relatives and communities having what was termed a 'period of mourning', in order to signify the depth of their grief (Clark, 1993). Mourning is identified as an expressive act of grief and usually a reflection of the customs within the cultural setting in which a person resides (Durston, 1998; Payne, 2008). As an illustration, amongst Native Americans one tradition is for bereaved individuals to have their hair cut (Haberecht and Prior, 2006). This is intended to symbolise how when a person habitually reaches to comb their long hair and it is no longer there, they are reminded of the loss. It also allows other community members to see at a glance that they are grieving, thus requiring special care and consideration. As the hair starts to grow back a little more each day, finally reaching its original length, this symbolises the bereaved person's passage through the healing process of grief.

Holland (1997) describes some customs that originated in Victorian times, where 'full mourning' included the closing of curtains and wearing black clothes for a prescribed period of time. Following the death of Queen Victoria's husband, Prince Albert, she both created and utilised many rituals. Some of these can still be seen today, for example, the use of mourning cards (Clarke, 1993).

In the earlier part of the twentieth century it was common practice for a deceased person to be 'laid out' in the family home and remain there until the time of their funeral. Todd (2006) explains the origins of this practice which evolved from 'waking', a ritual that is still honoured by some cultures today. Historically, on the eve of a funeral 'waking' took place to confirm a death had taken place and ward off evil spirits that may 'mislead the soul' (when it eventually departed the body). Friends and relatives visited to pay their respects and food or drink was often taken in the presence of the corpse, as a means of removing sins from the deceased. In my own relatively recent experience of this ritual, children and young adults often help with incidental tasks such as greeting visitors and have an opportunity to view the deceased in the coffin, whilst listening to the conversation of adults when discussing death and dying.

2.1.2   Professionalisation of death

In the early 1900's, not only were people 'laid out' in their family home, it was the most common place to die. Today the number of people who die at home has fallen to 18% with 58% of deaths occurring in NHS hospitals; 17% in care homes; 4% in hospices and 3% elsewhere, such as in prisons or through accidents (Department of Health, 2008). Consequently, it is often a nurse or ancillary member of staff who manages the care of a person in the last few moments of their life, with the deceased swiftly taken to a mortuary (in the case of a hospital or hospice) and then a funeral home.

Due to the above change in circumstances surrounding death, it is suggested that a de-skilling of the local community has ensued. This is sometimes referred to as the 'professionalisation of death' and has resulted in a professional role for almost every aspect of when a person dies. Subsequently, a shift of control has taken place away from dying people and their families, towards professionals whose actions are shaped by their own specific needs, values, perspectives and interests (Komaromy, 2004). According to Thompson (1993), by enlisting the help of a professional, an individual concedes that he lacks the relevant knowledge and skills, with only professionals able to carry out this role.

However, it is not only adults who have gradually become de-skilled at managing death but young people and, in particular, individuals who have a learning disability. Holland (2001) notes that children are often excluded from activities towards the end of a person's life, resulting from a lack of encouragement (or even permission) to visit the hospital and later to see the deceased or attend their funeral. Consequently, crucial aspects of a young person's life experience may be missed (Durston, 1998). Furthermore, research has shown that people with a learning disability are not only unlikely to attend funerals, their involvement in many aspects of bereavement is either limited or non-existent (Read, 2006), a point followed up in a later section of this chapter. Whilst both Holland and Read suggest that attending funerals is a positive and healthy activity, it is also important to acknowledge how different cultures may have contrasting opinions. For example, Muslim young girls and women are not usually present at funerals, due to specific beliefs within their religion (Gatrad and Sheikh, 2007).

2.1.3   Theories of grief

The impact of grief has been considered within social sciences for almost a century (Neimeyer, 2001), starting with Freud's Mourning and Melancholia in 1917 (Payne, 2008). Freud's earlier work focused on the tremendous loss of life during the First World War, in which he highlighted the similarities and differences between grief and depression. This was the first description of normal and pathological grief, prompting further enquiry that has subsequently evolved into a rich picture of how loss has such a profound impact on human beings.

A further theoretical development occurred in the United States, through the publication of 'Death and Dying' (Elizabeth Kübler-Ross, 1969).   Kübler-Ross was a hospital psychiatrist and incorporated accounts from her work with over 200 patients who were dying. The book was ground-breaking and challenged medical practices, especially with its focus on 'talking' to the dying. Whilst today this may not appear revolutionary, at the time a more paternalistic approach was frequently used, where individuals were often denied accurate information. Kübler-Ross found her patients related similar accounts of how they experienced their situation, including: denial; anger; bargaining; depression and acceptance. Subsequently, these testimonies were utilised not only to understand the needs of people who were dying but also bereaved individuals (Kübler-Ross, 1969; 1997).

The publication had a mixed reaction and Kübler-Ross found the many criticisms of her work harsh, viewing the experience as a personal test to see if she could "take negativity and hostility" (Schatzman, 2004, p.48). However, with such a radical stance on understanding grief, an alternative viewpoint could have been that the criticisms were simply 'healthy debate'. This insightful book prompted many discussions about what was, particularly within medicine and healthcare, a taboo subject.

Kübler-Ross described how she noticed her patients were frequently shocked by news of an impending death and denied their diagnosis. Other emotions noted were those of anger and blaming others for the situation, even trying to bargain with a spiritual source for more time to live. She described patients' dawning of reality, where they frequently experienced depression and sometimes acceptance. This latter experience, acceptance, was usually evident where there had been sufficient time for a person to work through

their grief. Whilst these descriptions are still used within bereavement services, some authors suggest the term acceptance is replaced by descriptors such as adaptation, denoting that individuals have become accustomed to the reality of their situation (Gilbert, 2004).

In order to provide an explanation of her findings, Kübler-Ross presented them as 'stages' of grief, a process which has largely been interpreted as linear. Certainly, in my experience of palliative care, these stages have frequently been utilised to explain the grieving process. One reason for the continued popularity of this model may be its coherent, orderly and pragmatic structure, the content of which both students and practitioners recognise and find a useful guide. However, students also need to have their awareness broadened and substantiated by more current research, in line with a holistic approach to considering grief, discussed further in Section 2.1.5.

Critics argued that the 'stages' Kübler-Ross proposed were mechanistic and individuals had a much more varied path within their experience, rather than moving through the universal five stages in a linear way (Copp, 1998). A cursory browse through her book does suggest a linear path and it seems to be this that many writers have focused on (Niven, 1994). However, it is perhaps the style of the publication which has resulted in so much criticism, rather than the content.

Occasionally, in contradiction to the above criticism, there is an acknowledgement that Kübler Ross did not suggest everyone progresses through all the five stages in the same order (Payne and Relf, 1999). On closer reading of Death and Dying, it becomes apparent that the author was flexible with her 'model of grief', as the following illustrates, "…the stages do not replace each other but can exist next to each other and overlap at times" (Kübler-Ross, 1969, p.236). Within her publication, she also refers to an unknown source and suggests the acute experience of grief is balanced by other thoughts, "...we cannot look at the sun all the time, we cannot face death all the time" (Kübler-Ross, 1969, p.35).

Further criticisms of Kübler-Ross's work are in relation to an omission of the multi-faceted elements to death and dying (Copp, 1998) and the fact that her theory was not based on any systematic research programme (Niven, 1994). However, it is important to

understand and appreciate the publication in context. For its time, 'Death and Dying' was indeed a seminal piece of work and opened debate, thus allowing others to develop their own propositions further.

John Bowlby, also a psychiatrist, considered the impact of grief in a slightly different way (1981). He focused on bonds that individuals create between themselves and the tremendous impact which transpires if they are separated. His work (initially using animal studies) demonstrated that following a separation such as loss, observed behaviours can be categorised as protest, despair and detachment. Bowlby proceeded to identify four phases a *separated* individual may experience, including: numbing; yearning; disorganisation or despair and reorganisation (Bowlby, 1981). His research suggested that from the age of six months, a child is likely to become overtly distressed during separation, with similar reactions to loss evident in later life. Current literature confirms this finding, stating attachment to significant others generally happens after the age of five to seven months (Deacon, 2007).

Bowlby's theory of loss proposed that an individual's response to bereavement is a result of early development experiences (primary attachment). As with Kübler-Ross's work, much debate followed Bowlby's propositions, specifically the way his empirical evidence focused on single primary attachment figures which were maternal in nature. However, Bowlby later acknowledged this flaw and subsequently amended his position. He noted that studies with foster children had illuminated the influence of family conditions, "…nothing has impressed me more deeply than the evidence showing the pervasive influence at all stages of the pattern of a human being's family life on the way he responds to loss" (Bowlby, 1981, p.439). This consideration of the familial landscape, together with the social context in which loss and grief occurs within contemporary society has been developed further (Machin, 2009) and will be discussed in Section 2.1.5.

Colin Murray Parkes was a protégé of Bowlby's and developed his 'phase' theory by considering the wider aspects of an individual's social world. In 1973 he became involved in the 'Harvard Bereavement Study' and later identified the significance of a bereaved individual's 'assumptive world' (Parkes and Weiss, 1983 and Parkes, 1988). When considering the psychosocial transition an individual goes through when a loved

one dies, he stated that a pragmatic and real challenge is for the person to revise assumptions which are habitual, often developed over the course of a lifetime. In my working practice I have seen this many times. Bereaved individuals have discussed feeling 'foolish' and then 'forlorn' when a table has been set for two rather than one, if too much milk has been purchased or simply rolling over in bed to touch their spouse. At each of these points they have momentarily 'assumed' the person was still alive, an experience often said to accentuate grief.

Brown and Farley (2004) offer another way to consider the above issue for bereaved people, linking their response to the neuromatrix theory. This term is more commonly used to explain an amputee's belief that the limb is still attached to their body. In a similar manner, the authors' postulate that when faced with an acute emotional loss bereaved individuals may experience a sensation of the dead person's physical proximity or believe they have heard, smelt, touched or even seen them. This focus suggests that at a neurophysiological level there is an assumptive world, where individuals assume a person is still alive when in actual fact they have died.

However, the neuromatrix theory does need to be cautiously considered. A phenomenological approach would suggest the experience of grief needs to be viewed from as many perspectives as possible (horizontalisation). This would avoid biological reductionism, such as assuming grief can be understood just in terms of a neurophysiological explanation.

Returning to the earlier theories of grief, Parkes (1988) proposed the phases a person goes through not only occur in sequential patterning but that overlapping phases can last for approximately two years. This was the start of a more fluid approach, in which a person's individuality became the focus. However few studies, including the one mentioned here, have followed participants for longer than two years (Payne et al., 1999). Furthermore, the majority of research or published papers appear to be written by professionals with clinical experience or interest in supporting people who experience complex grief, therefore focusing on an atypical population. Interestingly, Kübler-Ross, Bowlby and Parkes were all psychiatrists who worked predominantly with people who were having difficulty in coming to terms with their life threatening illness or

bereavement. Ultimately these studies omitted a large number of bereaved individuals who were possibly more resilient in their grief, an unrepresented population.

2.1.4 Unrepresented populations

When recruiting volunteers for any bereavement study, there will inevitably be a silent population of individuals who choose not to share their experience of grief (Holland, 1997). Kissane et al. (1997) note, in their study of 670 bereaved individuals, that one third of the families invited to participate declined for a variety of reasons. Whilst it is impossible to provide a definitive reason why they chose not to take part, the authors considered a possibility that it may have been 'to avoid talking about their grief'. Consequently, this situation generated an obvious selection bias, as there may have been issues which the unrepresented group experienced and were not reflected within the findings.

Similarly, much of the literature appears to overlook a possibility that when supporting bereaved people from a rich and diverse cultural background (Durston, 1998) alternatives or adaptations to our current knowledge base may be required. According to Mystakidou et al. (2003) grief is influenced by the meanings every culture lends to death and loss. Several differences emerged when reading the literature, for example, a Buddhist belief that nothing is permanent. This particular teaching encourages individuals to face adversity with an attitude of quiet and calm acceptance (Help the Hospices, 2003; Halifax, 2006; Barham, 2003). In contrast, within Italy the indigenous Catholic population are likely to exhibit a more overt, emotional demonstration of their grief (Collins, 2003). Another illustration can be found within the Muslim faith which professes a child's death is Allah's will and prolonged grief is disrespectful (Child Bereavement Trust, 2007).

Firth (2007) continues to explore the cultural element of grief and states that Western ideas about 'normal' or 'pathological' grief may be totally inappropriate for South Asians, as in some circumstances repression of emotions and memories are adaptive. Furthermore, anger may not be recognised or acknowledged by individuals from this particular culture, as there are deep-seated taboos towards expressing this emotion in relation to a dead family member. However, in a study of 'the perceptions and experiences of palliative care among individuals of South Asian origin', Williams and

White (2005) conclude that whilst cultures may share some similar beliefs and practices, to assume they are homogenous is incorrect. The authors found several conflicting beliefs within the population studied. One particular model of grief which recognises these cultural variations will be discussed next.

2.1.5 Development and recognition of multi-faceted grief

Stroebe and Schutt (1999) are quoted in many publications on grief and bereavement at present (Neimeyer, 2001; Machin, 2009). The authors are credited with widening the focus to consider that our experiences are much more complex than first theorised. Neimeyer (1998; 2001 and Charles-Edwards, 2007) highlights a move to challenge the individualistic nature of traditional theories, which construe grief as an entirely private process and one outside the context of human relatedness. A model of grief, namely the 'Dual Process Model' (Stroebe et al., 1998; Stroebe and Schutt, 1999; 2001), builds on previous work by providing a taxonomy which describes the way individuals come to terms with their bereavement. It considers various factors, such as stressors associated with loss and cognitive strategies that individuals use to function in their day-to-day lives. Also addressed is the dynamic process of oscillating between emotive responses (loss oriented grief) and the more pragmatic strategies when coping with everyday matters (restoration oriented grief).

As should be expected in literature today, Stroebe and Schutt encourage readers to recognise that any model of coping with bereavement is not about a linear sequence of stages but ongoing flexibility over time. Shortly after a significant bereavement the loss-oriented emotions often dominate a person's experience. However, in order to maintain some balance most individuals will fluctuate between loss-orientated and increasingly restoration-oriented activities. To explain the main elements of the Dual Process Model allow me to offer a personal example. After experiencing a significant loss several years ago, the emotions I encountered were overwhelming and could have been adequately described by any of the previous models discussed, Kübler-Ross or Parkes in particular. However, whilst feeling overwhelmed with grief in private moments (loss oriented grief), I also had the resilience and capacity to manage changes which the loss had brought about. This ability to continue running a home, work full-time and ensure my family remained well, is defined by Stroebe and Schutt as 'restoration oriented grief'.

Furthermore, Neimeyer et al. (2002), describe grief as both a natural occurrence and a constructed event. Whilst it would appear that this has been so for centuries, today there is a much more dynamic social climate which potentially impacts on the way individuals manage loss. For example, families are more dispersed (Department of Health, 2008) with communities demonstrating a rich mix of cultural beliefs and practices when death occurs (Department of Health, 2009; Gatrad et al., 2007). As a result, traditional rituals for expressing grief have significantly evolved and religious explanations are no longer the dominant way in which loss is conceptualised (Payne, 2008). Whilst these changes do have some merit, they can also be confusing for the families involved who may struggle to make sense of their loss.

Many cultural rituals with regard to death and dying, such as a Catholic funeral mass, Jewish shivah or secular memorial services, provide a structure for individuals to construct the meaning of their loss and integrate this into their lives (Komaromy, 2004; Mystakidou, 2003). Whereas in the past individuals may have turned to religion for comfort and guidance, as previously noted, there is evidence today of an increasing secularisation and thus a different approach to supporting our spiritual needs (Bailey et al, 2009).

In tandem with the above development, bereavement support services have proliferated. Professionals have to consider a variety of ways in which individuals find meaning and resolution to their situation, often independent from any religious teachings (Payne, 2001). However, Payne's claim that 'religious explanations are no longer the dominant way for loss to be conceptualised' and Bailey's proposition of 'increasing secularisation' could be challenged. Certainly individual's belonging to minority ethnic groups or those who live within countries such as Italy (Collins, 2003), still appear to focus on their religious beliefs around death and dying. This was substantiated by McGee and Johnson's study (2007) which suggested individuals from ethnic minorities are more likely to say that religious identity *is* important. Acknowledgement of these conflicting opinions is crucial, not only when supporting palliative care patients (Johnson, 2009) but when providing bereavement support, especially in communities where the recipients of care may not be from the white population.

2.2   Child bereavement

We should not make light of the troubles of children.
They are far worse than ours, because we can see the end of our trouble
and they never see any end

W. B. Yeates (1955)

The tremendous impact when a significant person in a child's life dies, whether suddenly (Dyregrov, 1991) or after a long chronic illness (Mallon, 2000), is acknowledged within the literature, especially their need to effectively manage the emotional element of loss (Smith, 1999). Often children not only have to recognise and cope with their own grief but experience the impact of this on other members within their family unit (Neimeyer, 2002). Previously I discussed how children's cognitive development and experience results in a wide range of abilities in relation to understanding the concept of death, dying and bereavement. Equally, it is acknowledged that young children are vibrant beings who utilise all their senses when exploring the world (Bremner, 1994), a point which also applies to learning about the experience of grief.

In a publication for the National Children's Bureau (Penny, 2007), the author described how bereaved young people in care were frequently affected by multiple losses. Headaches, pains and difficulty sleeping were the most common reactions, whilst other symptoms included memory loss, eating problems and itchy skin. This particular group also found it more difficult to concentrate on the 'here and now', which greatly affected their performance at school or college. Considering these significant reactions to grief, it appears paramount for skilled therapeutic support to be available.

The professional support offered to a bereaved child will vary and be facilitated through a variety of mediums such as therapeutic play or bereavement counselling, in both individual and group settings (Parton, 2004). Bibliotherapy, the focus of this study, is another approach utilised to encourage a child's exploration and understanding of death and dying (Smith and Pennells, 2000; Collins, 2005).

Although, there is limited empirical data on which to consider therapeutic approaches for bereaved children, literature is available in relation to:

- the impact of development on a child's grief (Dent, 2005; Gilbert, 2004 and Holland, 2001)
- techniques to use when supporting bereaved children (Liossi, 2000; Stokes, 2004 and Worden, 1996)
- 'creating new stories' following the death of a significant person (Fredman, 1977 and Gersie, 1991)
- discussing death and dying with children (Turner, 1998 and Willis, 2005).

An early example of a booklet in relation to discussing death with children was entitled 'Someone Special Has Died', created by the Department of social work, at St. Christopher's Hospice in 1989. There appeared to be great demand for this particular form of support, as it was quickly translated into eight languages, selling over 50,000 copies in England alone within the first six years (Willis, 2005). A subsequent publication 'Someone Very Important Has Just Died' (Turner, 1998) is recommended by several child bereavement organisations and, as the title suggests, it explains how to explore a significant loss with children.

Frequently both carers and professionals are hesitant when supporting bereaved children, often because they are concerned about upsetting them and do not know what to say or how much to disclose. Furthermore, an adult's visible discomfort in discussing death with young people is often fuelled by a notion that they need to be protected from harsh realities (Stokes, 2004). However, much of the bereavement literature states it is important for children to be told the facts about what happened, using a vocabulary they will clearly understand, depending on their maturity (Holland, 1997). Therefore, a bereaved child will require as much accurate information as possible, although it must be in a dialogue which is not only clear but appropriate for the child's *cognitive level,* rather than their particular age.

In 'Grief Encounter: a workbook to encourage conversations about loss between children and adults' (Gilbert, 2004) the author guides readers through the various development stages, suggesting what capacity young people may have with regard to understanding death. Gilbert acknowledges that flexibility is required, depending on their circumstances, a point which reflects a more recent awareness of the need to consider a bereaved child's internal *and* external world.

In order to consider the connection between 'age related concepts' to death and dying, commonly found in child bereavement texts (Christ, 2000; Smith, 1999) and children's cognitive development literature, I have developed a diagram outlining the key issues (Figure 1). Most of the details are derived from the work of Piaget (Phillips, 1969) and it is widely accepted that the ages provided are purely averages. These will vary considerably depending on cognitive development, cultural background and other socio-economic factors. However, whilst the various stages are said to progress in a linear fashion (Phillips, 1969; Dyregrov, 1991), bereaved children may in fact regress to earlier stages of development for a short period of time (Gilbert, 2004). Thereby, even more flexibility is required when considering possible age-related reactions and understanding the concept of death.

Stages of development and age range	Common characteristics of cognitive development	Understanding the concept of death
Sensorimotor **0 – 2 years**	Differentiates self from objects	Will probably notice the effect on the family
	Recognises self as an agent of action and begins to act intentionally	Change is likely to produce distress
	Achieves object permanence: realises that things continue to exist even when no longer present to senses	May have little or no language but will experience a sense of loss
Preoperational **2 – 7 years**	Learns to use language and represent objects by images and words	Has a limited concept of death and will ask when the person is coming back (magical thinking)
	Thinking is egocentric	Short periods of distress only
	Classifies objects by a single feature	Literal view of the world
	Magical thinking takes place	Expresses self through play
Concrete operational **7 – 10 years**	Can think logically about objects and events	Develops a more mature concept of death
	Classifies objects according to several features and can order them in series along a single dimension, such as size	Able to compare the before and after
		Aware of other people's feelings but finds it difficult to express own

Formal operational 11 years and upwards	Can think logically about abstract propositions and test hypotheses systematically	Greater realisation of what is lost and gone forever
		Able to express self more clearly
	Concerned with the hypothetical, the future and ideological problems	Play is still important for expression of self and externalising feelings

Figure 1.   Details adapted from Piaget's Stages of Cognitive Development

(Phillips, 1969) and Age Related Concepts to Loss (Gilbert, 2004)

Professionals frequently refer to the above stages, especially with regard to how a child's progress evolves throughout their formative years (Smith, 1999; Dent, 2005). As an illustration, in the age group of approximately 3-7 years, Figure 1 shows a tendency for young children to rationalise what is happening with a series of imaginary versions of reality. If bereaved children are not supported appropriately, the stories they create tend to focus on scary, negative aspects of their situation (Lindsay and Elsegood, 1996). When upset they may develop untrue beliefs as to why the person died. Some children even think they have the power to cause a person to die by their 'bad behaviour', a belief closely linked to the magical thinking stage of development (Delvin, 1996). The anecdotal phrase "you'll be the death of me" may contribute to their misunderstanding. Although this illustration could appear extreme, within my own clinical practice I have witnessed very young individuals sharing similar worries.

However, when supporting bereaved children there is always the exception to the rule, with those who defy to be neatly placed in any one specific section of the above model. When this occurs, it is important to consider the 'stages' rather than 'ages' in relation to how they are communicating. As an illustration, I have already mentioned that a child may regress developmentally during bereavement and therefore not fit within the expectations for their age group. The reason for this is often thought to be a result of the tremendous upheaval which many children experience following the death of a parent (Penny, 2007). They may not have a secure home or school environment, are often excluded from making decisions about their future and lose important friendships (if they

move away from home). Subsequently, these factors have a significant impact on their development (Holland, 2001). Furthermore, when considering this need for a flexible approach, children also reflect their cultural and ethnic backgrounds. Ultimately, this may influence how much they understand about the concept of mortality (Help the Hospices, 2003).

Whilst I have noted a regression in some children's developmental level, Jones (2001) found in her study of bibliotherapy and bereaved young people that in some areas they were developmentally more advanced than their non-bereaved peers. One particular example was their ability to explore and discuss issues around death and dying. Packman et al. (2006) continue with this point and refer to a certain maturity, alongside an increased ability to be adaptable and flexible within their lives. The authors propose that a greater capacity for empathy, cooperation and compassion frequently transpire. Therefore, practitioners need to be cautious when considering bereavement literature relating purely to a young person's chronological age.

There are several empirical investigations relating to child bereavement, with a substantial study carried out by Fauth et al. (2009). The authors undertook a secondary analysis of the *2004 Mental Health of Children and Young People in Great Britain* data. They investigated associations between childhood bereavement and a young person's background and experience. This substantial report provides data in relation to child bereavement and the parental experience of grief. Below I will focus on some key findings which introduce several points that are expanded further within this section.

The population of the survey was 7,977 children and young people (excluding children in foster care). Across the sample, 9.5 per cent of children (n=739) were reported to have experienced the death of a parent/sibling or friend. Those who lived within the most disadvantaged backgrounds were *more likely* to have experienced the death of a parent or sibling. The authors also found that bereaved parents were more likely to experience depression, a point they felt may subsequently have an impact on bereaved children. Reasons for this included a child's exposure to financial concerns, relationship issues and physical or mental illness (an issue I will return to later in this section).

Interestingly, whilst Kennedy et al. (2008) proposed that bereaved children may utilise self-help resources to manage their grief, the bereaved parents in the investigation by Fauth et al. (2009) reported that neither they nor their children had turned to telephone help-lines, self-help groups or the internet for support. Unfortunately, there was no further data to substantiate or explain this latter finding, which does appear inconsistent with the growth of such groups and sources of support (details of which are in Section 2.3 and Chapter 3). However, as the data for the investigation by Fauth et al. was originally undertaken in 2004, this form of support had possibly grown by the time Kennedy et al. (2008) were collecting their data.

In line with many of the studies within this section, the data showed that bereaved children had experienced significant levels of stress as a direct result of their loss (Fauth et al., 2009). They were also less likely to participate in school and social activities, alongside their non-bereaved peers. Furthermore, children who had experienced the death of a parent or sibling were most likely to have been in contact with health services, with a third receiving help from a teacher, doctor or child mental health professional. The main reasons for this were in relation to the child's emotions, behaviour or concentration difficulties. Therefore, it is possible to appreciate the tremendous impact these issues would have on their lifeworld and the need for a wide range of therapeutic interventions.

Additional findings which shed light on child bereavement, relate to data that indicated those who experienced the death of a friend, reported more acute *sadness* than young people who had experienced the death of a parent or sibling. Due to this emotional reaction to loss being the key story-line within my own study, the focus on sadness interested me. Unfortunately, Fauth et al. surmised that as the data did not provide a timeframe in which the respective bereavements had occurred, it was impossible to determine reasons for this. Throughout the report there were similar issues which would have benefited from more qualitative detail, thus highlighting a limitation with using data initially collated for purposes other than investigating child bereavement.

According to the above study, a third of bereaved children had received professional help. I therefore sought out further literature regarding the support available through a school environment. An investigation into this area was carried out by Tracey and

Holland (2008) using two geographical locations, one in Hull and the other in Londonderry. Whilst both areas reported that child bereavement was a relatively high priority, only 37% of schools in Londonderry and 28% of schools within Hull had a formal support procedure in place.

Despite the two locations both residing in the United Kingdom (UK), several differences were found within the data. In Londonderry schools 17% of the help accessed for child bereavement was through the clergy, compared with only 5% in Hull, a point which may reflect cultural differences within the two areas. Although both schools incorporated loss within their curriculum, the staff requested further education in this area. It therefore appears important to provide information relating to loss, before recommending that particular therapies (such as bibliotherapy) are utilised with bereaved pupils.

When considering the education needs of both professionals and carers who support bereaved children, Dunning (2006) discusses several areas which need to be addressed. Wherever possible, the importance of a proactive role is emphasised, as delaying interventions until after a death may contribute to maladaptive communication. A framework is presented, incorporating three essential aspects of support, cognitive, affective and behavioural. It is acknowledged that all these will need to be explored in a language appropriate to young person's developmental level.

A cognitive frame will typically include essential information about the disease, its causes, treatments and prognosis. Dunning suggests that misunderstandings will only serve to compound a child's grief. An affective frame relates to supporting a child to identify and label feelings. The final behavioural frame consists of addressing behaviours a child may be observing or experiencing for the first time. This includes behaviour of the person who is dying and individuals within the child's family or support network. Frequently, when adults are under intense stress from a palliative situation their behaviour is erratic and very much out of character, an experience which can be frightening and bewildering for young people. This aspect was alluded to within Rosen's publication when he stated, "...sometimes because I'm sad I do bad things. I can't tell you what they are. They are too bad".

Several emotional responses that children may experience or perceive in others do appear to straddle all age groups. One of these, as identified in the adult literature, is 'bargaining' (Kübler-Ross, 1969). Within child bereavement literature Gilbert (2004) offers an example of how this may transpire for younger individuals '…if I don't step on cracks in the paving stones Daddy will come back again'. As noted earlier, a further response included in both adult and child literature is 'sadness', the emotion explored by Rosen. In many respects, whilst the author reflected on this intangible concept through his work, he also recognised that each individual experiences it in their own unique way. Not only does Rosen describe this emotion in his book for children, it is integral to 'Carrying the Elephant: a memoir of love and loss' (Rosen, 2002), his poetry book written with an adult audience in mind.

When exploring the emotion of sadness, although many young people realise their feelings are in some way related to grief, they do not necessarily feel this emotional reaction consecutively for long periods of time. As an illustration, Way and Bremmer (2005) note that in their experience individuals are frequently referred to specialist services because they do not cry about their loss. However, adolescents may have moments of acute grief, followed by long periods of not experiencing such a tumult of emotions. In turn, it is not only their parents but the young people who believe they are not grieving in the right way and worry that they are uncaring (Wallbank, 1996). Equally, individuals may appear unemotional and avoid discussing the deceased for various reasons, including a need to blend in with their peers or a fear of being unable to control powerful emotions (Packman et al., 2006).

On a similar note, very often bereaved children are seen to fluctuate between talking about highly emotive issues and then suddenly asking if they can go out and play (Couldrick, 2001). Winston's Wish (2007), a national bereavement organisation, refers to this aspect of grief as 'puddle jumping'. On their website for young people they explain:

'…Grief is like a puddle that can be jumped into and out from. You may feel as though you are jumping in and out of puddles of grieving – or moving from sunshine to shadows several times a day – or several times an hour'.

Once more, it is clear that this psychological reaction to grief is not exclusive to children. Kübler-Ross (1969) reflected in her publication, based on adult reactions to death and dying, 'we cannot look at the sun all the time, we cannot face death all the time'. In recognition of this issue, allowing both the children and young adults an opportunity to 'puddle jump' was considered within the design for this study, further details of which are in Chapter 5.

Holland (2001) undertook a doctoral project with adults who had been bereaved of a parent when they were school age or under. The emergent findings suggested their patterns of grief were complex and did not correlate with the stage model, as noted in Section 2.1.3 (Kübler Ross, 1969). The data indicated that the experience of grief as a child was very different to the evidence in relation to adult loss. This point is crucial if we are to consider that a significant amount of child bereavement literature is based on adult grief (Rolls, 2008). As an illustration, adults tend to have more control and power over their circumstances, whereas the participants in Holland's study provided accounts of a much different experience. They described having a sense of powerlessness, with most decisions made on their behalf. These included whether they would attend the funeral or, due to their change in circumstances, where they would live and go to school. This point correlates with more recent findings in the study by Fauth et al (2009).

As discussed earlier, whilst it is important to provide information for children and young people at a level they will understand, Holland's study showed that adults have a greater ability to grasp concepts such as cancer or what happened at the time of death. They are also more likely to have an accurate understanding, as they know how to gain further information if a point requires clarification, such as through medical staff or the police. Often for children these routes of communication are closed, because details are only provided at the discretion of adults and even then might be censored. Furthermore, young people may not know what information is available to them or the right questions to ask (Holland, 2001).

One limitation which Holland acknowledged was that the participants in his investigation were recruited either as a result of personal contact or their response to adverts. As noted in Section 2.1.4 there is the possibility of a silent population who experience childhood grief in a very different way, yet do not wish to talk about their loss. For

example, his findings indicated that one-fifth of the participants thought their relationship problems as adults related directly to the impact of parental death. This very important statistic could be misleading if readers assume the data correlates to all bereaved individuals. It is possible that this finding would be very different if testimonies from those who declined to take part, the unrepresented population, were included.

In Holland's study, the most striking psychological difference between child and adult grief was in relation to how adults often experience all the different facets of loss within a short space of time. Initially, children may not have this experience, gradually accumulating the impact of their loss over a much longer period. The author proposed that this could explain why such a large proportion of his group said they felt 'normal' relatively soon after the death of their parent and only later experienced difficulties, over a protracted period and well into their adult life. Holland's finding has been noted by other authors (Katz, 2004) and is clearly important. Child bereavement studies with a shorter duration, such as two years (Christ, 2000), may miss this crucial element to studying childhood grief. Similar to adult research, few investigations extend beyond this shorter period, thus leading to an apparent gap within the evidence base (Blackman, 2003).

One study to follow bereaved individuals for longer than two years was undertaken in America (Worden, 1996). However, due to the methodological design it is difficult to transfer the findings to this country. Within the investigation there was a distinct cultural bias as the participants were largely Roman Catholic (70%) with the remainder Protestant (23%), Jewish (6%) and only 1% from other cultures or belief systems. With such a restricted group, unlike the population in the UK, the study contains limited data of cultural perspectives with regards to grief. These may include differences in traditions, rituals and expressions of loss (Cowles, 1996).

As several participants within my study had experienced a variety of complex home environments prior to adoption, I was interested in finding out more about bereaved children from a more disadvantaged background. Van Epps et al. (1997) undertook an investigation which provided a fascinating insight into the lifeworld of the participants involved. Their convenience sample included eight individuals (12-15 years of age) and was evenly divided between African-American and Caucasian young people from low

income families. All had experienced a close family member dying within two years prior to the investigation. Eight (45 minute) group sessions were undertaken at their inner-city school and audio recorded. The transcripts were accompanied by field notes written immediately after each session and incorporated details such as non-verbal behaviour and disruptions which may have affected the students' participation.

The findings showed how these youngsters had experienced acute chaos and stress within their lives. A couple of weeks prior to the investigation, all within the group had experienced the death of a familiar school counsellor and one of their peers. Two of the participants also sustained the loss of a family member during the data collection period. The investigators referred to the disorganisation and confusion in their lifeworld and also noted that the young people frequently discussed complex living arrangements, with an ever changing family composition.

Within the data collection sessions, the above group stated that they had not talked to anyone about their grief. When questioned further on this matter only one person was able to identify a person with whom he could discuss his experience. This was all the more surprising when the authors revealed that five participants had experienced the death of family members through violence (for example, an accident, murder or suicide). An interesting point to emerge from the investigation was how they underestimated the amount of time since the deaths had happened. This time distortion was thought to be related to trauma and their close association with the death.

When considering the above investigation, several similarities were evident in relation to other bereavement literature (Jones, 2001; Packman et al., 2006). One illustration of this is the participants' belief that they could help other bereaved adolescents, due to their knowledge of what it was like to lose someone, "If I had a friend [who] needed someone to talk, I'd be there". To conclude my review of this deeply moving study, I will reiterate the words used by the students when describing their feelings of loss, "hurting... an empty space... emptiness... darkness... black... lost".

The previous study highlighted the stark reality that some bereaved children experience and whilst most will gradually adjust well to their bereavement, I became aware that a small percentage may need more specialised support. Black (1998) notes that this will

typically include children who have: not responded to initial preventative interventions; been partly instrumental in causing a death; experienced multiple bereavements or expressed suicidal ideation.

Returning to the more generic child bereavement literature, Raveis et al. (1998) undertook a child bereavement investigation with participants who resided in a very different lifeworld to the one just discussed. This study of 83 families, considered the psychological distress experienced by children following the death of a parent. Prior to their loss both parents had lived together and were of white and middle or upper class status. This data supported previous research, indicating that most children had a high level of resilience following the loss of a parent with cancer.

A number of issues are of interest when comparing the study by Raveis et al. (1998), to the investigation with children from a deprived inner-city background (Van Epps et al., 1997). In the latter investigation, participants were more likely to have experienced a traumatic bereavement due to their chaotic lifeworld, where they had little, if any, support from their surviving parent or family. Within the first study (Raveis et al., 1998), the authors found a high correlation between the surviving parent's ability to discuss (in a supportive manner) the loss with their child and the level of distress experienced by a bereaved young person. It therefore seems evident that the inner-city children were at a distinct disadvantage with regard to parental care. It will be interesting to see if this aspect of support is mentioned within my own data collection session, particularly considering the complex backgrounds many of the participants have experienced to date.

With reference to a point made earlier, Raveis et al. (1998) proposed that undertaking more longitudinal studies of bereaved children may strengthen theoretical knowledge about the on-going impact of lifestyle changes relating to loss. This frequently includes situations in which the surviving parents re-marry or significant milestones, such as graduation or their own marriage. The authors conclude their investigation by highlighting a difficulty in separating psychological distress (relating to parental death) from the social impact of life transitions set in motion by the experience of loss.

A more recent study of bereaved young people, undertaken by The Joseph Rowntree Foundation (Ribbens McCarthy and Jessop, 2005; Ribbens McCarthy, 2006), addresses the above issue and asserts that to expect an individual will 'get over' their loss, within a defined period of time, may be quite inappropriate. Furthermore, the findings suggest it is actually healthy for young people to revisit their bereavement at various points in their lives. Foster and Gilmer (2008) agree with this proposition and state that a continuing relationship with the deceased results in a healthy adaptation to the reality of loss. This continuing relationship, albeit not physical, is sometimes referred to in the literature as continuing bonds (Normand, Silverman and Nickman, 1996).

Whilst continuing bonds have been investigated in relation to parental death, another focus is the impact of sibling bereavement. Packman et al. (2006) present several issues from their review of literature on this topic, including situations where there may have been ambivalence or conflict between siblings prior to death. In such instances, the authors note that continuing bonds can be uncomfortable, especially if the child is struggling to cope with lingering regrets about things said or left unsaid. In addition to the loss of a sibling, the paper also acknowledges that bereaved children also have to cope with experiencing their parents' grief. As discussed previously, this aspect frequently appears overwhelming and frightening for the young person, yet may be exacerbated if they imagine their parents' distressed reactions are a sign that they loved the deceased sibling more.

The second half of the above paper relates to the clinical implications of encouraging continuing bonds with bereaved siblings. Strategies to promote coping skills are presented and include family rituals or traditions which incorporate memories of the deceased. An emphasis is placed on the qualities that professionals and carers need to foster, such as listening sympathetically and non-judgementally, offering comfort and presence. Once more, the authors stress caution in fostering continuing bonds if the siblings' relationship was negative. This point is important and one which practitioners need to be aware of when working with bereaved young people.

Empirical investigations on child bereavement also include data relating to: a child's search for meaning; their struggle to deal with overwhelming feelings; implications for social relationships and the possibility of isolation; an increased sense of risk and

vulnerability; the absence of appropriate support and a lack of personal autonomy (Ribbens, McCarthy and Jessop, 2005). Many of these issues are addressed by child bereavement organisations, particularly in relation to the development of bereavement groups.

Kennedy et al. (2008) noted from a review of services for bereaved children, that their fragmented nature makes it difficult to be comprehensive or all-inclusive when describing such provision. The Childhood Bereavement Network (NCB, 2010) estimate 3.5% of 5-16 year olds have been bereaved of a parent, brother or sister, which equates to 252,000 children in England alone. Despite this, over a third of local authorities in England lack a specialist childhood bereavement service, where families are able to access the support they require. Following a well publicised report on the subject by the Joseph Rowntree Foundation (Ribbens and McCarthy and Jessop, 2005), The Times newspaper headline reported a 'Call for Bereavement Therapy' (Frean, 2005). However, there is very little empirical evidence on the efficacy of child bereavement support (Rolls and Payne, 2003), an aspect discussed below.

2.3   Child bereavement groups

In 2003 a survey of child bereavement services in the UK uncovered several difficulties in evaluating service provision (Rolls and Payne, 2003). Out of 108 hospices (127 were approached) therapeutic interventions for bereaved children were not only located within their very specific service 'culture', they also had different organisational arrangements. Although 53% of the hospices undertook group work with bereaved children, this included a myriad of ways in which they combined facets of staffing, funding, management structures, inter-sectorial and inter-professional relationships. It becomes evident from the findings that it would be a challenge for any investigation to carry out a comparative analysis.

The above study used dated statistics from 1983 and noted that 50% of children experiencing the death of a parent are hindered in their everyday functioning within the first year. I considered the progress which has occurred within the last 27 years and reflected on a possibility that these figures may have changed. Lowton and Higginson's work (2002) helped me make sense of this anomaly. Numbers of children bereaved of a

parent, sibling, grandparent or another significant person are not collected in a systematic fashion within the UK.

A more recent study suggests approximately 4 to 7 percent of the population will lose a parent before the age of 16, with this increasing for children within public care (Ribbens-McCarthy and Jessop, 2005). When considering the potential loss in relation to a number of other significant people in a child's life, this statistic will be much higher. As an illustration, the study by Fauth et al. (2009) found that 9.5 per cent of children in their sample population had experienced the death of a parent, sibling or friend. Both papers state these figures surmount to a significant proportion of the population and argue for improved service provision.

Other reviews of child bereavement services include those of Blanche and Smith (2000), Help the Hospices (2007) and Lydon et al. (2010). Interestingly, Blanche and Smith found only one service which had referred to police checks, in respect to how they protected the vulnerability of children. With a recent emphasis on the legal responsibility to undertake Criminal Record Bureau checks with all volunteers and staff, I am sure this finding will not be as significant in future surveys.

Lydon et al. (2010) highlighted that prior to the development of child bereavement services, children who were struggling with their bereavement would probably have been referred to child and adolescent mental health services. Potentially, this would only compound the stigmatisation a young person might feel, through their bereavement and a referral to mental health services. The authors undertook a telephone survey to investigate service provision and uncovered findings which were all complementary. The data provided evidence of the parents' reassurance when working alongside staff and appreciation of the support that could be accessed. However, of the 200 parents contacted only 20 replied to the survey, thus creating a possibility that the unrepresented population may have had a very different experience.

Whilst there are differences between the various child bereavement groups, Blanche and Smith (2000) asked seven organisations to highlight their aims, as illustrated in Figure 2:

Sharing	22.4%
Feelings	13.8%
Acknowledge child's grief	12.1%
Support	12.1%
Family support	10.3%
Isolation	8.6%
Fun	5.2%
Respect	5.2%
Future resources	3.4%
Safe environment	1.7%
Encourage self-help	1.7%
Normalisation	1.7%
Gaining independence from the bereavement service	1.7%

Figure 2.   Aims of seven child bereavement groups (Blanche and Smith, 2000)

Although the range and number of aims do seem quite large, many of these are inter-linked. As an illustration, within the hospice where my own investigation took place the bereavement support group for young people offers activities that acknowledge each individual's bereavement. An exploration of feelings associated with grief is encouraged, in order to 'normalise' any particular experience a child may have. In addition, there will be discussion of coping strategies and toward the end of a session family members are invited to join the young people for a final activity. This therapeutic provision is designed to support those who may feel isolated and acknowledge their feelings as both valid and healthy.

2.4   Bereavement and people with learning disabilities

People with learning disabilities are likely to both perceive and respond to the experience of loss in an atypical way, particularly in terms of what we have come to expect from the generic grief literature (Conboy-Hill, 1992). Therefore uncovering their experience of grief, including that of people who have a profound learning disability, is crucial if we are to provide appropriate support. Whilst some literature on learning

disability and grief relies heavily on either adult or child bereavement literature (Green-Allison, 2001; Blackman, 2003), the gradual increase of empirical data will allow authors to expand and substantiate their work further. Consequently, an improvement in the evidence base will ensure publications have a more detailed source of data to both explore issues and progress practice.

Oswin (1991) highlighted in her publication 'Am I Allowed to Cry' that historically the recognition of and permission to grieve had often been denied to individuals with a learning disability. Professionals and family members believed people with limited cognitive abilities also lacked the capacity to grieve. Unfortunately, when the book was republished in 2000, Oswin noted that there remained poor support for individuals following the death of a loved one. Similarly, around the same time Duffin (2000) discovered 72% of carers within her own investigation thought the individuals whom they supported were not affected by loss. Todd (2006) suggests that perceptions such as these are the result of a longstanding inability to credit people who have a learning disability with a shared humanity and emotional life.

In the late 1970's Emerson drew attention to the scant recognition of grief experienced by people with learning disabilities and suspected that this may account for subsequent behavioural changes, possibly linked to complicated grief (Cathcart, 1995). This was explored further by Conboy-Hill (1992) who proposed that a failure to recognise the impact of loss arose from a need to believe people with a learning disability did not grieve and thereby justify the approaches used to support them. Where subsequent behaviour was identified as troublesome, quite possibly linked to complicated grief, a person was either sedated or 'trained out of it', often without reference to the possibility of an emotional cause.

In the above paper, Conboy-Hill describes her experience of working in a learning disability institution with bereaved individuals and recounts how they were frequently diagnosed as having a behavioural disorder. In reality many had: experienced multiple deaths on their ward; not been informed when a companion or friend died; told the deceased had 'gone away' and excluded from mourning rituals. More disturbingly, the author relates how some people with a learning disability were assigned to be in the

hospital 'body gang', a group of individuals who operated only at night, removing deceased residents from their ward to the mortuary.

Blackman (2003) and James (1995) assert that if we are to understand the relationship between grief and learning disability, it is necessary to first examine how the capacity to mourn develops within childhood. It is then possible to consider developmental stages in relation to people who have a learning disability. Whilst pragmatically this suggestion is informative, it is important for readers to be clear that neither the authors' nor I are proposing individuals are child-like in their grief. Not only has their life-experience been significantly longer, they will possibly have known a greater number of people and therefore experienced more deaths than their younger counterparts. In short, they may have already developed some preliminary coping strategies or adaptive behaviour.

Furthermore, an experimental study with 79 young people who had a learning disability found their cognitive level was a much better predictor of understanding the concept of death than their chronological age (Bihm and Elliot, 1982). More recently, Cochrane (1995) agrees with the aforementioned point, although both papers do not identify that the experience of grief involves much more than simply an 'understanding of death'. It encompasses learning cultural practices and rituals, in addition to interacting with potentially distressed people. This includes knowing what to say and developing ways of expressing or managing what is often a tumult of emotions, whilst still being able to function within everyday life.

In relation to the above issue, Yanok and Beifus (1993) undertook a study with 50 individuals who had a learning disability. The experimental group received a formal programme of education, provided with the acronym CALM (Communicating about Loss and Mourning), whilst the control group had no specific education on the subject. The participants were then questioned about issues relating to the concept of death, an example of which was '...if you wished hard enough, could you make a dead person come back to life?' Over half of those who had not received education about death and dying answered yes, whilst all within the experimental group answered no. A similar pattern was found throughout the other questions. The authors surmised that many of the difficulties faced by people with learning disabilities, particularly regarding the etiquette which governs the behaviour of mourners, can be supported by appropriate

death education. They suggest experiential learning, such as visiting cemeteries and having guest presentations from doctors and funeral directors. To enhance the educational experience they also recommend that this information should be taught gradually, over several months.

A similar programme of education is provided through ROC (Resource for Opportunity and Change) within their Loss and Bereavement Therapeutic Intervention (Blackman, 2003). The service is provided both pre and post-bereavement, ensuring individuals who have a learning disability *and* their carer's have at least a basic understanding of grief, thereby improving communication. A further objective is to build a skill base in the community, thus reducing the need for referrals.   Blackman suggests bereavement therapy is more likely to have a long-term effect when supported outside the therapeutic setting.   This initiative responds to the proposition that developing a continuum of support is important and should incorporate considerations not only for bereaved individuals, but at a practitioner and organisational level too (Read and Elliot, 2007).

Returning to my earlier point, in order to increase the evidence base regarding bereaved people who have a learning disability, greater flexibility may be required. Goodey (1999) suggests that we need to put aside theoretical understandings and perceptions of social reality, to trust what we encounter and learn from what individuals show us.   An illustration of how 'flexible' investigators need to be, in relation to understanding a person's experience of grief, is presented below by Summers and Witts (2003).

The authors investigated the experience of a young woman after the death of her father. When staff informed her of the loss she initially looked 'ecstatic'.   However, it later emerged that she was confused about the meaning of death, with her comments fluctuating between 'my dad's in hospital', 'he's in heaven' and 'he's not very well'. The young woman also spoke of wanting to go the funeral 'tonight' even though she had been told that it had already taken place. In line with other literature discussed in this section, the surviving family members did not allow her to attend the funeral. This very personal account of loss is highly informative. When combined with other descriptive accounts, it will allow carers and practitioners to increase their knowledge base of possible reactions to death, thus considering appropriate ways to offer support.

One of the main methodological challenges which prevents or inhibits investigators from progressing in this area relates to language and comprehension. Research questions frequently elicit what is sometimes perceived to be totally irrelevant answers, although the accuracy of the response largely depends on the meaning a person attributes to a particular word (Tuffrey-Wijne, 2003). The way I devised clear and understandable questions within my own investigation will be explained further within Chapter 5. Subsequent chapters also explore how the participants' limited vocabulary was navigated and enabled me to uncover a rich source of data.

In her capacity as Professor of psychiatry of learning disability at St Georges, University of London, Sheila Hollins has (along with her colleagues) undertaken and reviewed several investigations. These highlight some of the challenges associated with researching bereavement and people who have a learning disability (Dodd et al., 2005). In addition to the issues already mentioned within this section, the authors state that this is not a homogenous group, due to a wide range in the experience, ability and personality of each individual. A further point is made with regard to considering not only verbal discourse but also intonations, body language and communication, through a variety of artistic mediums. All these aspects were incorporated into the methodological design and, once more, are outlined in Chapter 5.

Northway (1998) acknowledges that it is not only communication issues which need to be addressed when undertaking investigations. The scope of research studies may need to be adapted to maximise the level of participation with this specific group of individuals. Rather than undertake too ambitious a project, she decided to limit the number of interviews and scale-down her original intentions. The use of qualitative approaches such as participatory research is suggested. The author notes that, frequently, traditional methodological designs have placed individuals in passive and powerless roles, a point also addressed within this thesis.

In 'Support for the Bereaved and the Dying in Services for Adults with Autistic Spectrum Disorders' (Green Allison, 2001) the author used a variety of literature to inform her publication. Within the text are valuable testimonies from people with autism who have experienced the loss of someone significant in their lives. Illustrations provide accounts of bereaved individuals who are unsure as to how they should react to loss. It is

suggested that inappropriate responses are more likely to result from general difficulties with verbal expression, rather than a wish to upset those around them. As an illustration, people with Asperger's Syndrome may visually look the same as other members of the family and therefore be expected to act accordingly. However, many individuals interpret things literally and therefore become confused with some euphemisms often utilised to describe death, such as 'gone to sleep' or 'gone to heaven'.

Haddon's novel 'The Curious Incident of the Dog in the Night Time' (2003) explored the above issue. The central character, who also had Asperger's Syndrome, struggled with an explanation that his recently deceased mother had 'gone to heaven'. He questioned a number of people about the exact location of heaven and was told it was 'not in our universe'. However, this further complicated the matter as he surmised that to arrive at another universe his mother would have needed to be fired into space on a rocket, which she hadn't. The way he came to terms with his mother's death is explained in the following way:

"…mother was cremated. This means that she was put into a coffin and burnt and ground up and turned into ash and smoke. I do not know what happens to the ash and I couldn't ask at the crematorium, as I didn't go to the funeral. But the smoke goes out of the chimney and into the air and sometimes I look up into the sky and I think that there are molecules of Mother up there, or in clouds over Africa or the Antarctic, or coming down as rain in the rainforests in Brazil, or in snow somewhere" (pp.43-44).

Although the novel was written to entertain (rather than be a theoretical text) it perfectly illustrates the challenges of explaining death to individuals who rely on accurate, pragmatic and logical information when making sense of their world. This need for flexibility when supporting a person who may communicate in an unusual manner does require much thought and time, to learn what it is they are expressing and determine a way to assist them.

Despite the growth of literature regarding the importance of inclusion in rituals surrounding death (Cathcart, 1995; Clarke and Read; 1998; Gault, 2003), there are accounts of people for whom this has not been the case. Persaud and Persaud (1997) provide an example of a young man with severe learning disabilities whose mother died

suddenly during the night, necessitating his emergency admittance into respite care. Rather than be allowed to attend the funeral, he was only permitted to visit a tree which had been planted for her in a garden of remembrance. Several opportunities to learn more about death and dying had subsequently been missed. He was not even allowed to view her body at the funeral home, an experience that could have been accompanied with an explanation of what had happened. Inclusion in an emotive ceremony (the funeral) would potentially have provided a moment in which he could meet family members and thus see individuals expressing their sadness.

Practitioners such as Dr Sue Read (2006) and Noelle Blackman (2003) have done much to emphasise the importance of this inclusion, in the rituals surrounding death and bereavement support. However, as with any emerging field of research, new evidence has come to light which questions this approach. Dodd et al. (2008) found a positive correlation between those who had been closely involved in bereavement rituals and a subsequent increase in their separation distress, including complicated grief symptoms. They discuss the implications of this finding and suggest that prior to recommending whether an individual should be involved in activities like attending a funeral, it is important to assess his or her experience and knowledge of what is involved. Whilst more research will be needed to strengthen the finding, this cautionary note is important for carers and practitioners to consider. With regard to the level and type of involvement in bereavement rituals, a more individualised prescription can then take place. A focus on more general areas of bereavement support is addressed next.

Gilrane-McGarry and Taggart (2007) undertook an investigation of the support received by 11 participants, both pre and post bereavement. The authors note a paucity of studies that have examined the effectiveness of support for people with a learning disability and state much of the literature published is descriptive. Although the participants had been involved in their family members care (during their illness), the majority were not present at the actual death. However, all were later engaged in some part of the funeral process or 'rites of passage'. Their experience following the death was varied and involved a significant amount of relocation, often into residential care. Gilrane-McGarry and Taggart emphasise the multiple losses that ensued, alongside the lack of a clear 'support pathway' and inequitable provision of services. Issues included

the participants' access to bereavement counselling and a need for front-line staff with improved knowledge and skills in this area. These two points will be addressed below.

Tuffrey-Wijne (2003) undertook a literature review within the area of palliative care and people with learning disabilities uncovering a number of crucial issues, some of which have already been addressed. These centre not only on a difficulty for individuals to conceptualise death but practitioners' poor understanding of how to communicate in return (Brittle, 2004; RCN, 2006). An empirical study which concentrated on the knowledge and skills of practitioners from both health and social care settings was carried out by Murray et al. (2000). The authors posed several questions about the grieving process to staff. Their findings indicated that whilst both groups had knowledge of the subject, it was the practitioners with *experience* of working with bereaved individuals who were more confident in their ability to provide adequate support. This finding would attest to the benefit of work shadowing and networking opportunities, thus allowing more experienced staff to educate and support those with less confidence in this area.

A number of publications balance the more negative experiences of bereaved people with a learning disability, highlighting good practice in some areas of the UK. In particular, authors focus on the benefits received from counselling (Moulster, 1998; Clarke and Read, 1998; Read, Frost, Messenger and Oates, 1999; Read, 2001; Dowling et al., 2005). Within one exploratory paper, Read (2001) describes the SHOULDER project, a bereavement counselling and support service for people with a learning disability in North Staffordshire.

In relation to the above therapeutic approach, several advantages were uncovered in an investigation by Dowling et al. (2005). Half of their group underwent a programme of bereavement counselling and the rest were supported by an integrated intervention based on the dual process model (Stoebe and Schut, 1999), as discussed in section 2.1.5. The findings showed that the counselling intervention was more successful in terms of improving the participants' quality of life. Illustrations of these changes included an increased capacity to discuss their grief, subsequent improvements in personal relationships and a greater sense of well-being.

Returning to a point made earlier, McEvoy and Smith (2005) undertook a study with 38 parents and relatives, regarding carers' views on whether individuals with a learning disability have the capacity to grieve. Over three quarters of those surveyed thought their relative would not understand the concept of death. Whilst they acknowledged that death education was important, a high proportion of carers were uncertain as to the appropriateness of counselling post bereavement. This point is interesting and perhaps overlooks the educational element which is an intrinsic part of the counselling process.

Healthcare for All (DoH, 2008) reported a poor *evidence base* when considering the overall healthcare needs of people with learning disabilities. In relation to the needs of individuals who experience loss, this broad generalisation can be misleading and fail to convey the quality of empirical work that has been undertaken within the grief literature to date. However, both Tuffrey-Wijne (1997) and more recently Gilrane-McGarry and Taggart (2007), suggest that bereavement literature tends to consist of descriptive studies and short case histories. Whilst these have clearly illustrated people with learning disabilities do experience grief, a further suggestion has been to increase the amount of quantitative data or large-scale studies, so as to generalise the findings already uncovered (Summers and Witts, 2003).

The above critique of research methodology is an important point and one which may be appropriately addressed here. The authors are quite correct as there are limitations when one method or approach is used more than any other. During the course of this review it has been necessary to identify literature based on a simple accumulation of personal accounts and descriptive literature which originates from detailed qualitative investigations. It has also been essential to find well conducted larger studies, such as the one by Fauth et al. (2009) which was able to consider patterns of grief in the general population. Both approaches to bereavement research are valid, yet aim to uncover quite different data.

Furthermore, this chapter has demonstrated that grief and individual responses are highly complex. Consequently, investigations will always need to seek an understanding of the meaning-making process within a variety of bereavement contexts. The benefits of a qualitative approach, such as the one used within this study, is that it allows

investigators to consider different ways to address and explore issues, in a way quantitative studies would not.

An illustration of the above point is provided in a case-study, as carried out by Tuffrey-Wijne (2006). Readers will note the slight deviation from considering bereavement post death to anticipatory grief, a term referring to grief which occurs prior to someone's death (Clukey, 2008).

John Davies was a gentleman who had both a learning disability and life threatening illness. Over the course of several interviews he described his experience to Tuffrey-Wijne (2006), expressing a wish to 'tell his story' in the hope that it would educate other people who had a learning disability. His message was very much about the importance of seeking earlier support with health concerns and the impact of cancer on his life. Davies described his emotional experience, "…it can be hard. Sometimes I sit in the hospital bed feeling miserable and I think: 'Right, in the next ten minutes they'll all turn up to visit me' [his family], so I take a deep breath, put a smile on, and sit there for half an hour or so talking about silly things…" He later discloses how it feels when on his own, "…if the chemo doesn't work, then it's going to kill me, so I don't know how long I've got left…" This deeply moving story has now been published in a book entitled, 'Am I Going to Die?' (Hollins et al, 2009).

The above description provides evidence as to how Davies attempted to disguise his emotions and thereby 'protect' his family. Whilst it is clear he had a relatively good command of English, the challenge still remains for investigators to find ways in which people with a more distinct or profound learning disability, are supported to 'tell their stories of grief'. Davies' account and indeed much of the literature presented in this section, completely negate the historical assumption that people with learning disabilities are not affected by grief.

2.5   Summary

Within this chapter I have explored the concept of grief and bereavement by reviewing literature specifically relating to bereaved adults, children and individuals who have a learning disability. Considering the very broad area of literature available, I have focused on work that resonates with the aims of this study. Whilst there are some

differences, many similarities are evident between all the groups, thereby highlighting that the experience of grief is an emotion shared by all human beings, irrespective of culture, gender, age or cognitive ability.

Areas where more evidence is required, in order to understand the grieving process more clearly and progress practice, includes: meaning-making within the experience of grief; the experience of bereaved individuals from complex environments; the impact of grief at various points within a young person's life; continuing bonds relating to sibling bereavement and death education. I have also discussed innovative approaches and the flexibility required within methodological designs, both of which are essential when working alongside bereaved individuals. The following chapter will continue this presentation of literature, by focusing on the therapeutic use of stories in relation to the subject of grief and bereavement.

CHAPTER THREE

LITERATURE REVIEW: Therapeutic Use of Literature about the Subject of Grief and Bereavement

A bereaved child's knowledge of death can be a burden and a source of great anxiety as she knows that nothing can be taken for granted any longer…. left un-addressed, it will lead to the child becoming inhibited and consequently unable to embrace the work of mourning.
(Hemmings, 2000, p.9)

According to Hemmings (2000), it is important that professionals help bereaved children regain the joy and spontaneity of childhood, by exploring their experience and placing it in a more balanced perspective. The author suggests one way to do this is through the use of imagination, in whatever form it may take. This approach to working with bereaved children and young people, in particular through the use of stories, will form the basis of this chapter.

Firstly, I will present an overview of the information available for young people, in relation to helping them explore and learn about the impact of death and dying. I intend to consider how this support is provided and focus on a specific therapeutic approach, bibliotherapy. Along with a review of what the literature says about this approach, I will focus on how it is used with bereaved individuals. This chapter progresses by discussing the ways in which young people access information, together with a presentation of various picture-books that are currently available. A short résumé of my visit to Seven Stories, the National Centre for Children's Books in Newcastle, will be followed by a review of some publications designed specifically for bereaved people with a learning disability.

3.1   Access to information on grief and bereavement for young people

For centuries, artists and writers have created cultural representations of human experiences such as illness, suffering, death and loss, which complement the unique and important stories created by families themselves (Nadeau, 2001). The personal

story is claimed by some to be one of the world's most cherished creations. Zuckermann (2001) states, "…in a timeless, universal way, such stories educate, inspire, and energise other people to own, tell and retell their stories of loss, joy and hope" (p.242).

Information is available for young people through the internet, books, poetry or any artistic media that provides insight, thus deepening an individual's understanding of their experience (Johnson and Jackson, 2005). The emphasis is not only on the written or spoken word but the powerful medium of illustrations and artwork (Liossi, 2000; Jordan, 2007), which are particularly helpful where individuals are struggling or unable to convey their feelings. Reasons for this difficulty in expressing overwhelming emotions may include cognitive impairment, an incredibly painful experience or not having the vocabulary to articulate emotive feelings (Delvin, 2006). Anthony Browne, illustrator and Children's Laureate (2009), is a great advocate of picture-books, although states that at the moment they are too often marginalized and forgotten, with children being encouraged to read 'proper' books (Whitworth, 2009).

Whilst booklets and pamphlets relating to death and dying have been available for many years, one of the most striking developments has been the growth of child bereavement organisations that provide information through their websites. [Further details of all the websites noted within this section are in Appendix 7]. Winston's Wish (2007), one of the foremost organisations, has an on-line site where children can access a wide range of resources to support their understanding of grief. On the very first page, a young volunteer writes in a direct, no-nonsense style "…we are very aware that you don't want to be reading this part of the site. You don't want to belong to something with a label of being for 'bereaved young people'. You don't want to be bereaved…"

Several other websites are also available, including RD4U (through CRUSE bereavement care) designed 'for young people by young people', offering support after the death of someone close. Another organisation, 'Young Voice', works with bereaved individuals to help them raise concerns and 'get their voices heard'. Their website offers resources, training, help and support, not only for children and young people but those who work with and care for them. Michael Morpurgo, a well known writer and former Children's Laureate, wrote the forward to a publication by Young Voice, in which

individuals discuss their experiences of child bereavement (Katz, 2004). Morpurgo notes:

"As a writer, I spend my life imagining how people might feel given certain situations. And I've felt very strongly that the traditional happy-ever-after ending wasn't always a necessity, even in books for young people… The stories which cascade through the pages of this remarkable book shed all kind of different lights on the way in which death can affect us… there isn't a perfect solution to help every sufferer through their sadness. All we can do is to feel our way."

(Katz, 2004, p.3).

During the course of this literature review it became evident that information, both in paper and digital formats, is widely and often freely accessible for bereaved children and their families. Reading material not only helps parents to gain intellectual mastery over their circumstances, the use of books can also offer an indirect way to approach the subject of death and dying with young people (Twycross, 1997). However, often in the stages leading up to death or the initial period of bereavement, dense reading material may be too much for families to cope with. In response to this issue, independent writers and bereavement organisations have provided several slimline publications and booklets.

In Chapter 2 I discussed a popular book which is particularly easy to read, entitled 'Someone very important has just died', written by Mary Turner (2005). Larger organisations such as CancerBACUP have published their own series of booklets, for example, 'Talking to children about cancer' (2005). Marie Curie Supportive Care offer similar resources, including one specifically for teenagers. Their range of five booklets, incorporate the following titles:

- Teenage grief: things you might want to know
- Talking to children when someone close is very ill
- Helping children when someone close dies
- Questions children may want to ask when someone close to them has died
- Books and cassettes for children, teenagers and adults about bereavement.

When investigating the available literature, it also became clear that individual practitioners and smaller organisations are creating specialist resources to help families.

One example of this is a workbook for children visiting patients within a hospice setting (Macpherson and Cook, 2003). Research on the use of this tool was undertaken, the findings of which indicated an improvement in communication, with the workbook prompting children to discuss their experience with other family members. The investigators proposed that this tool may also be beneficial within a group setting, thus supporting bereaved children to 'avoid feeling isolated', a point discussed further in both the following section and 3.2.1.

3.1.1   Exploration of information within a group setting

Bereaved young people often feel different from their peers and as a consequence mask their emotions. Subsequently, their inner life becomes disjointed and they may lack spontaneity in discussing how they feel (Hemmings, 2000). As noted in Chapter 2 (Section 2.3), one way to overcome this potential isolation is by offering opportunities for them to meet others who have also experienced loss.

Therapeutic approaches, such as storytelling within a group setting, have the potential to open up conversations about sensitive, personal experiences and inform young people that their peers also have similar feelings (Pardeck and Pardeck, 1993). When executed well, this therapeutic approach can enable them to find a framework in which to place their experience and some may even proceed to tell their own individual story (Busch, 2001). Conversely, where conversations within bereavement groups are not managed closely, I have witnessed a tendency for the session to become heavy, dark and too emotive. This situation is addressed in the literature, informing readers that when utilising various artistic and creative tools, particularly in group settings, the approach is much more likely to have a positive therapeutic outcome if carried out by a skilled practitioner (Johnson and Jackson, 2005; Berns, 2003/4). This point will be clarified further in Section 3.2.1.

Bereaved children who may initially be reluctant to talk about their feelings are often found to visibly relax when they have an opportunity to share their experience without fear of judgement (Jewett, 1994). This issue was explored in a study which interviewed bereaved young people who were listening to and exploring musical lyrics. The authors found the use of group work offered an opportunity for the teenagers to observe other people's reaction to their loss and thus allow them to experiment in 'discussing' grief

(McFerran-Skewes and Erdonmez-Grocke, 2000). It was noted that often teenagers find it difficult to express emotions, although at the same time do experience intense grief. The group setting offered a safe forum to share feelings without the risk of upsetting others, such as a bereaved parent. Within a follow-up interview one of the participants discussed how she felt when listening to a song 'Turn Back Time'. The young person said it reminded her of other people who are also experiencing grief and find themselves wishing if they could 'turn back the time'.

Hunsberger (2002) proposes that when reading and discussing literature with another individual, it is subsequently re-read in light of the other person's comments. These further discussions become a more shared landscape or at least a different one than first encountered. This educational element to storytelling (McNeilly et al., 2008) offers an opportunity for discussion and sharing, which is as necessary between a young person and adult (their carer or practitioner) as it is with their friends. In a formal setting, whilst the nature of the relationship and hence the discussion will be different (from that between friends), it is nonetheless a valuable therapeutic approach (Hunsberger, 2002).

3.2 The use of literature to support young people's understanding of grief and bereavement

During the course of this project I have presented the findings to over 200 individuals, including: palliative care professionals; staff working within learning disability services; people with a learning disability; colleagues and students. Their reaction to Rosen's book and subsequent discussion of other related stories has sometimes surprised me, especially when remarks were made about the book being too dark, depressing or upsetting. However, Gersie (1991) stresses the essential role of literature in supporting young people to understand the stark reality of death, dying and bereavement:

Not to educate ourselves and our children about our relationship with death means not educating ourselves and them about life. It is dangerous to do so, and not because of death – sooner or later we all will die – but because it profoundly affects the quality of our life, both before and after we have become bereaved. The best preparation for bereavement is death-education. The best preparation for life is to relate death to our ways and values of living.

 (Gersie, 1991, p.38-39)

The remainder of this section will explore this therapeutic use of literature (death-education) in relation to bereaved children and young people. I will also include details regarding the growth of material to explain death and dying with individuals who have a learning disability.

3.2.1 Bibliotherapy

Whilst there is a limited amount of literature regarding the use of bibliotherapy within the context of bereavement therapy, this section will present and review a variety of publications on more generic studies relating to this therapeutic approach. I will commence by presenting literature which introduces readers to the historical and practical applications, followed by a discussion of the potential benefits when utilising bibliotherapy. These include: a growth in self concept for people with learning disabilities (Lenkowskyet al., 1987); a decrease in aggression, accompanied by an improvement in social skills (Shectman, 1999); raising awareness of coping strategies (Iaquinta and Hipsky, 2006); increasing the ability to see problems from another perspective (Myers, 1998) and using this form of therapy with people who have uni-polar depression (Cuijpers, 1997). Where appropriate, I will discuss and critique pertinent findings from several empirical studies and also highlight areas where bibliotherapy needs to be cautiously considered, especially in the context of bereavement therapy.

Franklin (2006) suggests that the healing power of a story well chosen and appropriately told is evident throughout the world. Stories provide structured methods and opportunities for gradual exposure to many aspects of our lives, some of which we may be struggling to manage. According to Jones (2001), bibliotherapy is not a recent innovation with evidence of its use in 1916 by Samuel Crothers. The author also refers to a sign over the entrance of an ancient library in Greece, proclaiming it to be 'the healing place of the soul'. Bibliotherapy is described as the planned use of fictional or non-fictional literature, in order to facilitate and enhance a person's coping skills. The aim of a bibliotherapist is to mediate between individuals and their experience of reading a publication. Either individually, or as part of a group, they are supported to explore the narrative and illustrations.

Morrison (2008) discusses a bibliotherapy scheme in Merseyside, 'Get into Reading', which is implemented not only in local libraries but a myriad of settings, including: care

homes; day centres; neurological rehabilitation units; acute psychiatric wards and sheltered accommodation. This pattern is repeated throughout the country, not only within local authorities but many healthcare settings. As an illustration, Sheffield Children's NHS Foundation Trust has a dedicated website on bibliotherapy, providing details of self-help books for both children and families. Morrison progresses to state that whilst books 'take us out of ourselves', the best literature has an ability to 'take us inside ourselves, deeper than we might have expected or chosen to go'. This potential therapeutic value, where individuals are enabled to look deeper into their situation (or experience), prompted me to seek out more empirical and theoretical literature on the subject.

Pardeck and Pardeck (1993) highlight that whilst books have been used for centuries to assist individuals in coping with their lifeworld, clinically the term bibliotherapy did not emerge until the mid 20th century. Although the focus of this study is on *bibliotherapy in the context of bereavement therapy*, it is also utilised in many other clinical settings. As an illustration, the authors discuss how this approach can support children who may have experienced: family separation; divorce; child abuse; foster care or adoption. Their publication provides not only a detailed history of bibliotherapy, but many case studies of how the clinical application of reading can support young people to learn about and manage their situations better. Interestingly, the authors note that professionals (including psychiatrists, psychologists and counsellors) are more likely to use bibliotherapy, especially if they are more experienced practitioners.

Quite how the process of bibliotherapy works is introduced by Cohen (1994). He explains that the benefits of this approach centre on the intentional nature of the experience, its relational and transporting characteristics. To achieve these outcomes a bibliotherapist assists individuals to identify their problem, whilst exploring both positive thinking and self expression (Pardeck, 1993). Finally, they are presented with a range of solutions, in order to manage the issue concerned.

A much more specific focus of utilising bibliotherapy is presented by Pardeck (1993) who explores how it can be used with children who have a disability. To increase the effectiveness of the therapy, he suggests that it may be useful to incorporate further complementary activities, for example, using puppets to role play a situation from the

story-line. Pictures can also be utilised to represent the various emotions encountered either during or after reading the book. Pardeck points out that when working with children who have disabilities, bibliotherapy can result in an increased ability to deal with their lifeworld. In conclusion, the author notes this therapeutic approach will not only allow young people to develop a realistic understanding of their limitations but, more importantly, their potential for personal growth. Whilst I found the author's work inspiring, implementing any therapy within a clinical setting does require more empirical evidence to substantiate some of the claims made.

One such study was undertaken by Lenkowsky et al. (1987). Although this investigation was carried out over 20 years ago, I was particularly interested in how the authors created the methodological design. All the students (n=96) had a learning disability, were between 12 to 14 years of age and had been allocated into one of four groups. Several variations in the range of therapeutic approaches were used within each group. The findings indicated that bibliotherapy (on its own) allowed the children to explore personal problems, resulting with a growth in their self-concept. Interestingly, there was no statistically significant improvement when group discussion was added to the directed reading. However, subsequent studies do not appear to substantiate this last point.

In relation to bibliotherapy within a school setting, a more recent investigation was undertaken by Iaquinta and Hipsky (2006). Similar to other literature on this subject, the authors suggest it offers young people an opportunity to consider other individuals (characters) who face similar problems to their own, which in this instance was having a disability. Furthermore, their research indicated that this approach offers participants a variety of coping strategies. A checklist is provided to support readers evaluate the appropriateness of various publications. This includes finding a narrative which is realistic, empathetic and sensitive, thereby encouraging a positive attitude. All these aspects were considered within my own study, further details of which are in Chapters 1 and 5.

A difficulty with implementing bibliotherapy in a therapeutic context, is the absence of a database that provides details of appropriate books for specific issues or particular ages (Garrison, 2010). Whilst there are many websites dedicated to this particular form of support, the quality of the information is varied. Furthermore, there does not appear to

be any nationally agreed guidelines or procedures for a bibliotherapist to base his or her practice. In an attempt to rectify this gap, Flint et al. (2004) compiled a document on behalf of Lapidus, a national writers association. The authors proposed a number of core competencies, for therapeutically implementing the literary arts within healthcare settings. Whilst the paper is based on the authors' experience, rather than empirical evidence, it does contain many points which appear to be good practice.

Bibliotherapy is also a clinical method strongly encouraged and long practiced in counselling, utilising a variety of modalities which are influenced by practitioners own theoretical frameworks (Shechtman, 1999). As an illustration, Myers (1998) utilises this approach alongside DCT (developmental counselling and therapy), proposing that it provides the basis for developing images (metaphors) and subsequently enabling his clients to view problems from another perspective.

However, as noted in the introduction to this section, when reviewing the literature I was interested in seeking out a more balanced portrayal of bibliotherapy, including some acknowledgement of potential difficulties with its implementation. Surely, similar to other clinical approaches, it is important to apply caution in certain circumstances (Shechtman, 1999). A paper presenting a more critical review of bibliotherapy is discussed below.

Cuijpers (1997) undertook a meta-analysis of research, in relation to the use of bibliotherapy in the treatment of uni-polar depression, a study which is of interest for a number of reasons. According to the author, when bibliotherapy is used by an individual at home (on their own) it is more appropriate for patients with mild to moderate depression but should be excluded for individuals where there may be the threat of a crisis situation or suicide ideation. It is suggested that the richness and complexity of a story may be overwhelming, threatening and anxiety provoking, leading to the text and illustrations being misunderstood, misinterpreted or even distorted as a result of the reader's private experience.

Cuijpers suggests that whilst caution is required when utilising bibliotherapy, it may halt the progression of mild to moderate depression and therefore be appropriate for use as a preventative tool. This point is important with regard to the area of bereavement, particularly in relation to the use of bibliotherapy with individuals in the acute stages of their grief or those experiencing complex grief. Furthermore, the author stresses the

importance of employing a therapist to work alongside individuals, to monitor and steer the session in a positive direction. It is proposed that this may prevent a premature cessation of the intervention, ensure the person will progress in the right way and allow appropriate support if a situation deteriorates or evolves into a crisis.

Shectman (1999) undertook an unusual investigation into bibliotherapy with five children who exhibited aggression. The participants underwent a series of ten group sessions in which they explored not only books but a variety of media, including films, pictures and poems. Several benefits emerged from their exploration of stories, including an improvement in understanding and self expression. The author progresses to suggest that whilst this form of support is important in the earlier stages of aggression therapy, it should not be expected to be the only approach necessary when seeking a long term change of behaviour. Once the child is aware of their actions, it is recommended that cognitive behavioural techniques are employed for a more lasting effect.

When utilising bibliotherapy, key findings from the above study indicate that not only was there a decrease in the participants' aggression, but an improvement in constructive group dynamics. When taking into account the reported deficiency in social skills of children who exhibit aggression, this latter finding is especially interesting. As noted in Chapter 2, anger is a common experience within the grieving process, the intensity of which may be difficult to cope with. It would be interesting to undertake a similar study to that of Shectman, utilising a variety of bibliotherapy media with bereaved young people who are finding the emotion of anger a particular problem.

Returning to the focus of my own study, Jones (2001) suggests the role of a bibliotherapist within a child bereavement setting is to ensure the most suitable choice of book is found. The author suggests it should be one which closely correlates the author's presentation of death to the child's particular situation. Thereby, for a book to be effectively utilised, it should:

- Assist children to recognise that emotions can be expressed in text, from which they may extract information
- Help them to understand the concept of death
- Help them cope with the death of a person close to them
- Provide information on problems

- Provide insight into problems
- Present new values and attitudes
- Outline possible solutions
- Promote an awareness that others have dealt with the same problems and have come to terms with or overcome them

A more recent study, carried out by MacPherson and Emeleus (2007), investigated the psychosocial needs of children facing the death of a parent from cancer and their subsequent bereavement. One participant perfectly illustrated the last point from Jones' list, when she discussed the importance of reading 'Tiger Eyes' (Blume, 1983). Here we can see how bibliotherapy assisted her to become aware that she was not the only one to experience loss. As noted in Chapter 2, social isolation can be a consequence of child bereavement:

`I just loved that book. It's so good… I don't know, I just sort of could relate to her [the main character] a bit cos, although her dad had been shot… but she just felt sometimes, she felt the same ways as I felt… Yeah and she worried about stuff like her mum getting together with someone else and not thinking about her day and stuff… and if I was reading it and hadn't lost a parent or something I would have liked it but I don't think I could have, like, I wouldn't have liked it just as much"* Jenny, age 12 (p.595)

Taking into account the above, it appears bibliotherapy has the potential to help young people understand how others construct their worlds and thereby consider this in relation to their own circumstances. Irrespective of the subject, individuals utilise stories in a variety of ways and for reasons which may include:

- Solving emotional and cognitive puzzles
- Establishing and maintaining friendships
- Constructing and thereby communicating a sense of self
- Recasting events in ways that are satisfying or
- To participate in the culture
  (Engel, 2005)

Berns (2003/4) provides a detailed overview of how, as a clinical psychologist, she has used bibliotherapy within a child bereavement centre, citing various examples of the benefits to using this form of therapy. However, as with other articles or books on

bibliotherapy and storytelling (Gersie, 1991; Styles et al., 1992), there appears to be very little empirical evidence of effectiveness in this area. What tends to happen is that practitioner accounts of their teaching or practice experiences are published and whilst these are valuable sources of information, there appears to be a positive bias to them.

I was unable to find evidence in the generic, descriptive literature, of situations where practitioners had written about children for whom this therapeutic approach had not worked. Overall, it appears that we need more investigations to see whether bibliotherapy, as a therapeutic tool, is effective. Methodological approaches which could be employed, include case-study designs and phenomenological studies, both of which have the potential to explore, in great detail, the experience when reading literature.

Whilst stories may reflect a person's 'lived experience', text is necessarily selective and reveals only what authors believe to be important (Byrne, 2008). Successful writers appear to have very clear views about which elements are necessary when capturing the attention of young people. Often their stories inspire young readers, both at the initial time of reading and throughout their childhood. As an illustration, Marianne describes her favourite book, Maisie Middleton by Nita Sowter: *"I like it because of the way they put animals into it. They make them sound as if they are real human beings (well I think so anyway)…I am 9 years old and read it over and over again…[Maisie, the lead character makes breakfast]… and guess what they had, jelly and ice cream, cake, fruit, vegetables (for the animals) honey, jam and milk shake".* (Jordan, 1992, p.113)

Interestingly, the children's books read for this study (all relating to death and dying) often had both animals and delicious food within the story-line, including Michael Rosen's publication. Two further examples, include Fred (Simmonds, 2003) and Goodbye Mog (Kerr, 2003), both stories of cats who died. What the authors appear to have done is avoid producing dry and colourless stories of grief and bereavement and instead introduce the subject alongside a world the child (and adult) reader can identify with and enjoy. In the case of Fred, the story-line explores a night-time funeral organised by his fellow feline friends and attended by Sophie and Nick, two children he used to live with.

Goodbye Mog is notably different to Fred, in that she was a well-established character. Throughout a long series of books, readers may have developed a personal connection with Mog, enjoying the many adventures she got up to. Therefore, within this story arose a possibility for children to experience reading about the death of a cat they had grown attached to. Subsequently, they would have to consider that there would be no more adventures or stories about the late Mog. The book also provides an explanation of her death:

Mog was tired. She was dead tired.

Her head was dead tired.

Her paws were dead tired.

Even her tail was dead tired.

Mog thought, "I want to sleep for ever".

And so she did.

(Kerr, 2003, p. 1)

As is evident with the above text, it is descriptive, simple to understand and has several similarities to how a bereavement practitioner would explain death, especially the comment about how Mog's bodily functions ceased to work. However, it is widely recommended that practitioners and carers avoid correlating the word 'dead' with 'sleep' (Holland, 1997) or even, as with the above prose, 'dying' and being 'tired'. Within Chapter 2 I discussed how very young children may become worried that if they or other family members go to sleep, they may not wake up. Equally, if a person states he or she is tired, they may consider the possibility of them dying.

Other key themes in story-books for children include addressing a need to share worries, talking to others about how they feel and obtaining reassurance that the death was not their fault (McNeilly et al., 2008). Rosen's book (2004) skilfully captures the above concerns and presents a poignant account of when his son died. This latter, autobiographical element to the book was unique amongst the publications I found for children on death and dying. However, whilst it portrays a true-to-life situation, this does not necessarily change its genre, as it has more similarities than differences with other books discussed in this section.

Picture-books, in relation to loss, are widely utilised both within schools and child bereavement services as a therapeutic medium, thus aiming to stimulate discussion and promote understanding about a number of issues related to grief (Holland, 1997). My literature search for information regarding the effectiveness of these books, in particular within child bereavement services, did prove more difficult than first envisaged. There were plenty of recommendations for their use both locally and nationally by organisations such as The Child Bereavement Charity, Child Bereavement Network and Winston's Wish (contact details of which are in Appendix 7). However, due to the composition of lists by professionals (adults), the reviews do not appear to take into account any differences in the way adults and children approach reading stories (Tucker, 1981; Daniels, 1992). Literature suggests that children build up unique images of a story which may be very different from that of the author (Jones, 2001). Therefore, the danger arises when adults assume they know what children want or need, without asking them.

To illustrate the above issue, a phenomenological study, 'Understanding Imagination in Child's Play', observes "… true imagination or fantasies are integral to all human life, young and old…but adults have to work at capturing it (or being captured by it)" (Fahlman, 2002, p.2). On a similar point, Malchiodi (1998) offers a cautionary note within her work on understanding children's illustrations, indicating how difficult it is for adults to see drawings with anything other than 'adult eyes'. It is therefore important for professionals not to judge or interpret these from adult standards but to simply understand the child's effort and what the process means to them. This meaning-making element within bibliotherapy is an important element that my own study seeks to address.

In 'Bibliotherapy for Bereaved Children' (Jones, 2001) the author describes her extensive work within educational services and as a Cruse bereavement counsellor. I was surprised when she commented that research suggests counselling bereaved children may do more harm than good, whereas bibliotherapy has more therapeutic potential (p.7). Jones justified this comment by stating that in a structured counselling programme a professional might introduce suggestions which could prove harmful, whereas: '…books can act as a catalyst in the grieving process. They may evoke emotional catharsis, prompting overt grief, which may not have surfaced previously. This can bring relief of negative feelings or lead to attitudinal and strategy changes all

within a safe non-confrontational climate' (Jones, 2001, p.124). Whilst there are debates about how effective bereavement counselling for young people is (Harrington, 1999), I would suggest that without a substantial evidence base the same could be true for bibliotherapy.

Jones' argument appears contradictory as any intervention, either by a counsellor or bibliotherapist, could ultimately introduce harmful suggestions to a child. Whilst counselling is carried out in the presence of a trained professional, reading books (unless in a book club meeting or as part of a bereavement strategy) may be when the child is on his or her own and in a vulnerable state. My point here is that professional therapeutic support ensures practitioners are not only fully trained, they must also operate in line with their own code of conduct. As with many areas of palliative care, it is highly likely that whatever approach is taken, if carried out sensitively and appropriately, it will allow a young person to learn more about his or her situation.

In a recent survey of 108 child bereavement services, there were no details in relation to how many of these used bibliotherapy or which publications were utilised (Rolls and Payne, 2003). However, as noted earlier, most services provide 'recommended book lists', use the publications as part of their in-house support and occasionally loan books out for children to read at home. The benefit of this latter approach is that a relevant book can be suggested or loaned and thus encourage conversation between parents or carers and the bereaved child.

A further illustration of bibliotherapy in practice concerns a project undertaken to support bereaved students in primary and secondary schools (Lowton, 2004). This culminated in a booklet which offered practical advice for school staff, with an accompanying list of publications that may assist the children concerned. Disappointingly, the book titles are accompanied by either no explanation or just one sentence to describe the story. An example is given below:

Susan Varley. Badger's Parting Gifts. Published by Mulberry Books ISBN 0688 115187
"Fictional picture book in which Badger's friends are sad when he dies but treasure the memories he has left behind".

Both from the above example and the various 'recommended lists', what appears to be missing is evidence which considers the rationale for using books relating to loss or how

children actually experience reading them. With regards to *appropriate* sources of literature, this study holds the view that it is important to carefully listen and consider children's experiences of reading the stories. However, despite the scarcity of empirical evidence, more recent lists have increased remarkably (Child Bereavement Trust, 2004; 2007). Consequently, there are a growing number of books which focus on the subject of death and dying, several of which appear to be culturally bound within a Christian framework, a topic discussed next.

3.2.2 Publications with a Christian focus

In tandem with an increase in the number of books available for young people on the subject of death and dying, there is a greater breadth in how authors approach the topic. This focus appears to vary, with a number of publications either openly discussing a Christian belief in God and heaven or containing material sympathetic to this viewpoint. Waterbugs and Dragon Flies (Doris Stickney, 1997) explores what happens after someone dies by revisiting a fable the author first heard from a church minister. She felt that explanations such as 'he has gone to heaven' or 'he has gone to be with God' were no longer sufficient for children who now live in a world of 'scientific excursions into the heavens' (p. 21). According to Stickney, children's vocabulary has grown from watching TV and using computers, thereby the phrase 'gone to heaven' no longer satiates their thirst for knowing what happens when someone dies.

An example of a more recent approach to exploring death, still within a Christian framework, is 'Oscar and the Lady in Pink' (Schmitt, 2002). This book was originally written in French as 'Oscar et la Dame Rose' and has sold over a million copies worldwide. The central character, Oscar, is a ten year old boy with end stage cancer. No one is prepared to discuss his impending death until he encounters Granny Rose, a volunteer who visits patients in hospital. She suggests he plays a game, pretending that on each of the following twelve days he is a decade older. His task is to write a letter to God about his adventures. One of Oscar's letters states:

Dear God

I'm a hundred years old today and like Granny Rose I sleep a lot but I feel good. I tried to explain to my parents that life was a strange present. At first we overestimate it, this present: we think we've been given eternal life. Afterwards we underestimate it, we think its rubbish, too short, we're almost prepared to chuck it away. In the end we realise it

wasn't a present, just a loan. So then we try to deserve it… I don't know if I really
convinced them….
Till tomorrow, love Oscar

A deeply moving final letter is offered to the reader:

Dear God
A hundred and ten. That's old. I think I am starting to die.
Oscar

The very last paragraph in the book, informs readers that for the last three days of Oscar's life, he had a sign on his bedside table stating:

Only God is allowed to wake me.
(Schmitt, 2002, pp. 84–88).

This Christian approach to considering the meaning of death is not just present within literature but conversations with bereaved children. Whilst working at the hospice I have heard individuals (of all ages) discussing heaven as a place where people go when they die. Children often talk about heaven in very concrete terms, describing it both colourfully and literally, with younger individuals saying that heaven is in the sky or sometimes expecting the deceased to return.

Children's illustrations of heaven also tend to contain very human-like characters, with their relative often residing there as an angel or a spaceman (Sanderson, 1997). Recognising and understanding the above point is important for professionals working within child bereavement. It is necessary to work within the child's schema of death, rather than dismiss it as irrelevant, since their understanding is often the starting point for any bereavement support.

3.2.3   Publications with a secular focus

In Chapter 2 I presented literature which indicated there was an increasing secularisation within society (Bailey et al. 2009). Consequently, it was proposed that palliative care practitioners may need to consider a variety of approaches when supporting bereaved individuals, including conversations that are independent from religious teachings (Payne, 2001). Whilst there was no literature to refute Sanderson's

observations about children's tendency to discuss heaven (Sanderson, 1997), there are an increasing number of books which explain death to children from a variety of perspectives. As an illustration, Limb (1993) offers a well-executed exploration of what happens when people die. The lead character, Bessie, has recently experienced the death of her grandmother:

Bessie's mother said that Grandma had gone to heaven. "Where's heaven?" asked Bessie. "Can she ring us up?"

Bessie looked at the stars at night, trying to see heaven, but all she saw were the lights of aeroplanes.

Daddy said Grandma was now part of Nature: the trees and the flowers. Bessie saw Grandma's face in a tree once but when she looked again it was gone.

Krishna next door said that Grandma might be born again as an animal or a bird. Bessie looked hard at all the animals she saw, but they didn't look much like Grandma, although she did see a baby chimpanzee once who looked just like Olly [her little brother!]
(Limb, 1993, pp.17-20).

There have been many inspirational books reviewed for this study. Within this section I have attempted to provide a small synopsis of those I considered pertinent to my investigation. The most striking conclusion I have made, is that whichever way the narrative and illustrations are used, they are always intended for a particular audience. The authors and illustrators 'tell' their stories and, in so doing, use specific language in a sensitive, skilled and poignant way.

3.2.4 Seven Stories, National Centre for Children's Books

Whilst undertaking background research on the therapeutic approach of bibliotherapy, I visited Seven Stories, the 'National Centre for Children's Books' in Newcastle. I have chosen to place a résumé of my visit within this literature review for two distinct reasons. Firstly, it increased my knowledge of the complex process by which authors and illustrators create and publish their stories. However, the most striking way in which it progressed my understanding, was in deepening my awareness of how pervasive and integral to all our upbringings the 'story' has become.

At times, many of the old titles in the exhibition brought my childhood memories into focus and stirred emotions that were quite unexpected. As a result, my experience of visiting Seven Stories prompted me to consider just how important it is when recommending books to bereaved children and young people. This is not necessarily just in connection to their initial experience of reading the story but the significance they may attach to the publication throughout the rest of their lives.

Quite surprisingly, the staff were unable to recommend any specific publications relating to this study. They pointed out that many story-lines within the general reading section would include some aspect of death and dying. Interestingly, Michael Rosen's SAD BOOK was not in stock, even though he had contributed to the exhibition.

One of the books I did purchase at Seven Stories was Quentin Blake's publication 'Clown' (1995), in which he tells a fascinating story without any text at all. At the time, even though Blake was the illustrator of the publication within this study, I thought the purchase was supplementary to the purpose of my visit. However, 'Clown' provided me with a new awareness of how illustrators can also be independent 'authors without text'. I will explore this aspect further within Chapters 8 and 9, with particular reference to the participants' experience of reading both the text and illustrations. A more detailed reflection of my visit to Seven Stories is located in Appendix 9.

3.2.5 Literature to support people with learning disability understand grief

In 1998 the National Network for Palliative Care of People with Learning Disabilities was formed, with the intention of influencing policy and practice in this area. As a qualified learning disability nurse I had recently chaired the local subgroup and was aware of the need for more empirical evidence, in relation to how people with learning disability experience bibliotherapy.

However, a more positive discovery was the gradual increase in literature for this client group. Some of the most popular resources appear to be a series of books published by St George's Medical School in London (Hollins and Sireling, 1989; Hollins et al., 1996, 2003). These picture-books, designed specifically for people with learning disabilities, cover a range of situations around death, dying and illness. They are utilised to explore what happens when a person experiences the aforementioned situations, thus allowing

a further discussion with family, friends or companions who have a learning disability (Read et al., 1999).

Whilst several child bereavement books may contain appropriate text for people with a learning disability, it is important to also consider the style of the illustrations. I was very aware that I did not wish to offend the young adults who took part in my study, with a publication which contained illustrations more suited to a younger age group. Fortunately, I considered Blake's work appropriate for a much wider age range and would recommend this book to other practitioners who are supporting adults with a learning disability.

Macmillan Cancer Support provides details of several national and local organisations that are able to offer not only publications, but also DVD's and advocacy information relating to bereavement. However, despite the growth of resources within this area, there remains a need to develop information for all individuals who are considered under the umbrella term 'learning disability'. A number of practitioners acknowledge that supporting *all* individuals, through either text and/or pictures, is a challenge. The answer to this dilemma appears to be the implementation of a flexible repertoire of skills, approaches and tools, to firstly understand and then support bereaved people in ways which are not only appropriate but meaningful to each person (Read, 2006).

Summers and Witts (2003) note that broad theoretical understandings of the grieving process can be adapted to meet the needs of all bereaved individual's, irrespective of their cognitive ability. Both the literature uncovered within this section and my own experience, confirm that the way forward is indeed to do exactly what the authors suggest. First and foremost, the emphasis is on considering the individual and adapting the bibliotherapy resources more generally available. Further empirical studies will increase the evidence base and thus allow practitioners and carers to substantiate their choice of resources, including publications on death and dying.

3.3   Summary

Within this chapter I have provided an overview with regard to the various sources of literature for both bereaved children and young adults, including individuals with a learning disability. As readers will note, due to the sparse empirical evidence in relation to utilising bibliotherapy within the context of grief and bereavement, I supplemented my

search with literature that considered more generic issues. This provided examples of investigations which uncovered many positive benefits for the participants concerned. These included: improved self-concept; decreased aggression; an increase in social skills and the ability to see problems from a variety of perspectives. Overall, most publications attested to the perceived benefits of utilising bibliotherapy and I therefore sought to balanced this with literature which discussed the need to apply caution when working with certain client groups.

The brevity of research, with regard to bibliotherapy in the context of child bereavement, merely reinforces a view that studies of this kind are relatively unchartered territory. More specifically, further empirical investigations are necessary to ascertain the effectiveness of this approach. Issues requiring further clarification, include instances where bibliotherapy should either be closely monitored or not utilised at all.

There is also a need to consider not only the overall experience of bibliotherapy, within a variety of contexts and modalities, but how individuals actually experience reading the publications. In so doing, we will learn more about the *meaning-making context* of reading. Methodological approaches which could be employed to investigate these issues include both case-study and phenomenological designs, both of which have the potential to explore, in great detail, the experience of reading literature. Thereby, my investigation seeks to provide much needed empirical evidence to inform practice.

CHAPTER FOUR

THEORETICAL FRAMEWORK & PHILOSOPHICAL UNDERPINNINGS

The greatest thing a human soul ever does in this world is to see something and to tell what it saw in a plain way. Hundreds of people can talk for one who can think and thousands can think for the one who can see. To see clearly is poetry, philosophy and religion – all in one.

John Ruskin (Lane, 2007)

Over the last 21 years I have frequently utilised many theories and concepts, to ensure my nursing practice has been grounded in evidence based research (Murray, 2008), thus ensuring safe practice. I was therefore surprised to find, as noted in Chapter 2, that bereavement literature relating to children and people with learning disabilities had often been adapted from adult bereavement literature, rather than empirical investigations. This alerted me to the possibility that any accepted body of knowledge is compounded by limitations of prior knowledge. Therefore, I looked for a theoretical framework which didn't take such a positivistic approach.

I became more aware that what generally tends to happen when undertaking research is for current theories to be used as a starting point and merely added to in light of new findings. Therefore, whilst it is debatable how much previous literature influences the outcome of research, in this particular study I wanted to consider a way of looking at my practice, independent of prior research, literature or my own personal assumptions. Furthermore, rather than progressing in a way that investigated the effectiveness of bibliotherapy, I wanted to consider the *meaning* of the experience. Once these two very specific criteria were identified, I searched for a theoretical framework which would be flexible enough to accommodate both elements.

Higginson (2006) asserts that choosing an appropriate design for any research study is, ultimately, the most important decision investigators make. However, far too often they concentrate on the debate of whether to use either quantitative or qualitative methodologies. Fortunately, through working in the field of palliative care I have learnt to

respect all the various orientations to research. Refreshingly, Higginson explores the challenges of both these approaches, noting that there are common issues for each to consider. As such, the ethics of involving patients, family members or their carers, together with the clinical, organizational and practical challenges, all require careful negotiation.

Constantini (2006) puts forward a strong case for utilising quantitative approaches within palliative care, for example, in assessing the efficacy of a new intervention. However, the author also acknowledges that, in this instance, it should be complemented by a qualitative approach. This would allow an investigation to consider the impact of a new intervention within the setting or context where it is implemented. Whilst I have seen both orientations to research used effectively, the particular phenomenon I wished to investigate lent itself more readily to a qualitative approach.

Although qualitative methodologies offered more scope for my ambitions with this study, on further reading it became clear that defining exactly what I mean by 'qualitative research' was much more complex than I had previously appreciated. Avis (2005) explains this dilemma, in that 'qualitative' covers such a myriad of approaches. Some focus on data collection and analysis relating to textual data, such as service evaluation, whereas others seek to uncover 'meaning' within individual experience. It gradually became apparent that a number of approaches had the potential to explore 'meaning', the focus I was especially interested in, thereby offering a possible way forward.

A further priority in my search was to find a flexible theoretical framework which would develop as the study progressed. Sandelowski (1986) states rigid rules often limit the imagination and creativity of a researcher, although offers a cautionary note regarding their need to avoid 'methodological anarchy'. With this in mind, I searched for a framework which would offer me an opportunity to uncover the experiences of the young participants, alongside a flexible, informative and robust structure. One of the first possibilities I considered was discourse analysis (Forman and McCormick, 1995; Hodges et. al, 2008), due to its focus on participant accounts of an experience.

Unfortunately, discourse analysis did not offer an opportunity to look at experience beyond verbal reflections, a point which became a crucial consideration within my

search. Even from the outset, I was aware that due to a limited vocabulary of some participants, their verbal accounts alone might not yield enough information to access the nuances of their experience. Furthermore, within discourse analysis investigators do not set aside a priori knowledge, a strategy I was particularly interested in.

Progressing through the 'myriad' of qualitative approaches I came across the work of Jasper (1994). The author explains how a phenomenological approach provides a flexible and adaptable framework, within which an investigator considers any artistic expression (for example, poetry, humour, art, photography and diaries) as sources of experiences that have meaning for individuals. Due to how central Rosen's publication would be within the investigation, and my suspicion that the participants may focus on both the illustrations and narrative, I was immediately interested in this approach. Also, when contemplating the diverse range of data collection strategies I intended to use, this prompted me to look at phenomenology further.

I was inspired by several phenomenological studies (Clark, 2002; Hopkinson and Hallett, 2001) and have since read additional work (Bevan, 2007; Rodriguez, 2009), all of which clearly illustrated important elements of the participants' experience. Within phenomenology, Colaizzi (1978) describes 'experience' as something that is very real for a person, not necessarily an internal state but a mode of presence to the world, existentially significant and a legitimate focus for understanding human psychology.

Despite my initial enthusiasm, when exploring phenomenology in greater depth I became aware of how vast the subject was, often with conflicting explanations of the terminology used. There also appeared to be great diversity in how the various practitioners interpreted its theoretical underpinnings. Some authors failed to differentiate or acknowledge the differences, a matter which has the possibility of not only misrepresenting each tradition but also confusing or misleading readers. As an illustration, Walker (2007) did not inform readers of whether she utilised transcendental 'descriptive' or hermeneutic 'interpretive' phenomenology. On closer reading of the author's paper it appears she used a transcendental framework, due to the focus on 'bracketing' and 'describing' the experience of participants (two specific terms which will be discussed later in this chapter). To blur the various traditions together, considering

them vaguely the same, appeared to create inaccuracies and confusion, with poor details of the theoretical framework utilised.

Even with the above concerns, I was constantly drawn to elements of Husserl's transcendental work and gradually developed a deeper understanding of the subtle but nonetheless crucial distinctions this had, in comparison to some of the later phenomenological positions. Transcendental phenomenology considers the whole person and is adaptable, examining the nuances of experience closely and only later re-examining these, with regard to taken-for-granted knowledge (Balls, 2009). It became increasingly clear that by using this approach, the experience of individuals and their day-to-day living are the focus, rather than utilising previously discovered concepts, categories or theories to interpret data (Van Manen, 1996). This endeavour, to capture a description of the phenomena unaffected by prior assumptions (Bloomberg and Volpe, 2008), became one of the main elements within transcendental phenomenology that I wished to emulate.

The remainder of this chapter will provide a résumé of the significant contribution Edmund Husserl made to social science, in particular his creation of the distinctive philosophy, phenomenology. Throughout his long and prolific career Husserl developed the main principles of phenomenology and his later transcendental focus provides the theoretical framework of this study. I will explore the various tenets of this philosophical tradition in Section 4.3, together with a rationale for using this approach.

4.1   Edmund Husserl (1859-1938)

In order to understand Husserl's work, I first of all sought to find out something about the development of his ideas, in relation to the context of his life. When considering his background and early academic years, it became easier to see how Husserl's philosophy was closely entwined with his personality, family experiences and status as a Germanic academic. This allowed me to understand his passionate, precise and lifelong pursuit of one goal, developing a new philosophical mode of enquiry.

Rather than focusing on Husserl's writing from just one period, the above approach allowed me to appreciate and understand how his philosophy developed incrementally, throughout his career. At times I needed to appreciate that his work was very much

embedded in the German philosophical tradition of the late 19th century. In particular, I started to understand why in Husserl's latter years, Heidegger, his protégé, became a rival not only academically but personally too. Within this section I will now offer an overview of some key developments within his life, followed in Section 4.2 by a résumé of how phenomenology evolved into a recognised philosophical tradition.

Just over 150 years ago, Edmund Husserl was born in Prossnitz, Moravia (now the Czech Republic) on April 8th 1859. His family were assimilated Jews who did not follow any religious traditions and during his formative years Husserl was not told his background was Jewish (an important point which will be discussed later in this section). At first Husserl went to a local school and then at the age of 10 onto Vienna, where he completed the school-leaving certificate. Throughout his early academic development he showed a natural aptitude for mathematics and went on to study astronomy, mathematics, philosophy and physics at Leipzig University. He then progressed to read mathematics and philosophy in Berlin (Moran, 2000).

Husserl completed his PhD in Vienna when he was 22 years of age, with a thesis entitled 'Contributions to the Theory of the Calculus of Variations'. His work stimulated an interest in the psychological basis for mathematics, although at this point he undertook military service for a year. Husserl returned to academia by attending lectures in Vienna with Franz Brentano, admiring his great enthusiasm for questioning and reflection.   Brentano's influence on Husserl's early ideas was significant and the two academics soon became friends (Dreyfus, 1999).

Husserl was a prolific writer (Sandmeyer, 2007) and produced in excess of 20 major publications throughout his career (Langdridge, 2007), with approximately 40,000 pages of manuscripts (Beyer, 2004). His lectures were described as careful, methodological and profound, leading students through a maze of subtle distinctions. Husserl's ideas reflected a man very much in tune with both his academic and social world (Moran, 2000).   Scanlon translated his lectures from the summer semester of 1925 and described them thus:
'…[they] are not simply a string of disjointed or random thoughts on the subject of phenomenological psychology. The lectures do not meander: they follow a unitary direction, a main route from which Husserl wanders afield now and then but to which he

always returns. That route is the gradual unfolding of all that is required for a thoroughgoing critique of physicalism in psychology' (Husserl, 1925: 1977, p. xii).

Husserl didn't retire from teaching until he was 69 years of age and even then continued under the auspices of Emeritus Professor. He complained that colleagues and students misunderstood his life's work, unfairly criticising his earlier writing, although surmised that this was due to the pioneering status of his philosophy. Here we can see how Husserl was insightful enough to know that his work had paved the way and would be 'cultivated' by future generations (Sawicki, 2006).

However, from the age of 73 Husserl faced several personal challenges. Due to deteriorating financial circumstances and declining health he was forced to move from Freiburg to a more rural location. This period coincided with the rise of the Nazi regime and a year later Heidegger revoked his Professorship, due to the fact that he was a non-Ayran. As I discussed earlier, Husserl had not been brought up in the Jewish faith and spent all his adult life within a Germanic culture. Therefore, this expulsion from teaching and his work with colleagues seems unjust, having little regard for the tremendous contribution he had made to philosophy. However, as the influence of Hitler within Germany increased, Husserl had his teaching licence withdrawn and his name was removed from the Freiburg faculty lists (Moran, 2000).

Following the above developments, Husserl was no longer allowed to publish anything in Germany nor attend conferences, including the 9th International Philosophy conference in Paris. Subsequently, there appears to be a decline in the use of transcendental phenomenology, with evidence of an increased interest in Heidegger's existential hermeneutic approach.   After the war, the focus on phenomenology appears to have remained firmly in the existential tradition and was progressed further by Jean Paul Sartre and Maurice Merleau-Ponty (Holloway, 1996; Langdridge, 2007).

Towards the end of his life Husserl became increasingly humiliated and isolated (Beyer, 2003). He spent his last year in poor health and died in 1938, aged 79. Apart from one colleague, no one else from his faculty at Freiburg University attended the funeral (Moran, 2000). It appears such a tragic end for someone recognised today as an

individual who made a significant and brilliant contribution to social sciences, particularly philosophy.

4.2 The evolution of phenomenology

Husserl constantly pushed his thoughts in new directions, whilst striving to remain true to the original underpinnings of phenomenological theory. He went on to progress this theoretical framework by continually identifying distinctions and conveying these through both his writing and lectures (Husserl, 1925: 1977). Introductory literature on phenomenology often starts by stating that Husserl was the founder of the phenomenological movement (Stevenson, 2002). Nevertheless, it is important to acknowledge the influence of philosophical ideas on his work which are, in essence, the forerunners to how we understand phenomenology today. As an illustration, the Danish philosopher Soren Kierkegaard (1813-1855) introduced the existential school of philosophy. He sought to understand each person's unique experience, a focus that stimulated other philosophers to explore existence from this perspective.

Prior to the above developments, Immanuel Kant (1724-1804) created the term 'phenomenal world', describing it as that which we experience, thus introducing a scientific approach to considering human experience (Becker, 1998). This particular focus has remained within phenomenological methods and is described by Giorgi and Giorgi (2008) as the way in which investigators 'make discoveries about the experiential world in psychologically significant ways' (p.26).

Franz Brentano (1838–1917) developed Kant's work further and proposed the notion of 'intentionality', a way of describing how, in consciousness, the mind directs it thoughts to an object (Holloway and Wheeler, 1996). Brentano described consciousness as a process that leads to becoming aware of an experience, which at the time was a radical approach to examining empirical instances. He identified subtle (yet crucial) distinctions when considering a conscious act and proposed that an experience is both perceived and judged, with many different orientations needing to be considered (Ashworth, 2008). Brentano was not widely recognised outside Germany, although encouraged his students (including Husserl) to develop their own philosophical direction. Both Husserl and Brentano shared a view that any worthwhile philosophy must be rigorous, rather than speculatively generating arbitrary opinions (Moran, 2000). True to Husserl's

original vocation as a mathematician, it is possible to see how their mutual ambition to create a very precise approach to philosophy appealed to them both.

As previously discussed, Max van Manen (2002) informs us that the notion of intentionality was directly attributable to Brentano, a concept which explained the intentional structure of consciousness. In progressing this idea, Husserl shifted the focus from considering separately either the 'world' or 'individuals', to the way in which the 'world' is experienced. This proposal, that consciousness and the world are entwined, became a key consideration within his approach.

Husserl's earlier attempts to establish mathematical and logical principles, in relation to how people experience the world, were superseded by an ambition to develop a philosophy which acknowledged the role of consciousness in everyday experiences (Sawicki, 2006; Moran, 2000). In so doing, he progressed away from large-scale theorization towards a careful investigation of more discrete phenomena, ideas and simple events (Marvin, 1995). Husserl developed his ideas further and thus created a scientific approach to examining human experience. By amalgamating previous literature on the concept of 'phenomenon', he dedicated the remainder of his academic career to the development of what he referred to as a distinctive philosophy, namely phenomenology (Becker, 1998).

In the position of junior lecturer at Halle University, Husserl progressed his work over a fourteen year period, often referred to as his 'struggles with psychologism'. In 1900–1901 he formally inaugurated the movement of phenomenology through the publication 'Logical Investigations', a project which had spanned ten years and was promoted as 'the universal foundation of philosophy and science'. Husserl stated that the dominant scientific view of philosophy and psychology was inaccurate, due to the reduction of 'propositions, universals and numbers, to mental states or mental activities' (Sokolowski, 1999. p.404). As can be appreciated, the publication was not popular with his faculty colleagues who viewed it as radical and a departure in philosophical tradition.

The subsequent phase of Husserl's work is frequently referred to as his 'descriptive' phase (1901–1938), a period in which he became more confident in the philosophical underpinnings and distinctions made between psychology and phenomenology. His

main argument was that the former focused on psychic processes as events in nature and therefore misunderstood consciousness (Moran, 2000). Within this descriptive phase Husserl introduced several methodological approaches, one of which was epochē (explained further in Section 4.3.7).

From 1913 until the end of his life, Husserl referred to his work as transcendental phenomenology. During this stage of his career several earlier ideas were refined and developed further, an example of which was the transition from 'universal' to 'local' epochē. Universal epochē was conceived in Husserl's earlier work and related to the way investigators suspended all prior knowledge when analysing findings. In this later transcendental phase he moved towards a more 'local' epochē, where only the relevant theoretical knowledge relating to a particular subject was suspended (Beyer, 2004). The progression of Husserl's work in this period included, 'intentionality, eidetic reduction and the constitution of meaning' (Van Manen, 2002), all of which are discussed in this chapter.

As previously mentioned, a number of philosophers continued to develop the work of Husserl, including Martin Heidegger (1889-1976), Jean Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961). Although not following their specific theoretical positions, I will complete this section by offering an overview of how Husserl's original philosophical ideas were adapted by these popular existential phenomenologists.

Heidegger was a dissident protégé of Husserl and developed his own propositions by considering that experience does not 'presence the world directly but is an act of interpretation' (Smith, 2008). In his earlier work, he focused on establishing the truth about our existence, especially through the interpretation of language. Whereas Husserl focused on how we are able to understand things about the world, a more epistemological focus, Heidegger developed his focus to consider the nature of our being in the world, often referred to as an ontological approach (Rapport, 2005). Subsequently, divisions within their work became a contentious issue, not only within their personal relationship but the wider academic sphere.

An illustration of these different approaches to phenomenology can be seen in Heidegger's critique of epochē, a concept that was integral to Husserl's theoretical

underpinnings and is explored in detail within Section 4.3.7. Heidegger, along with Merleau-Ponty and Sartre, questioned the feasibility of 'bracketing off preconceptions' about an experience. Whilst acknowledging the benefits of setting aside everyday assumptions, they believed there was a limit in the extent to which any investigator could do this. Both Heidegger and his colleagues argued that research should instead emphasise the grounded and embodied nature of our being-in-the world (Langdridge, 2007).

Heidegger's publication 'Being and Time' developed the idea of *Dasein,* which explains the nature of being and existence, and as such the concept of personhood (Mulhall, 1996). His work included the notion of 'time' and suggested that rather than simply thinking of time in a linear fashion, it could be viewed in terms of the 'now', 'no longer' and 'not yet'. Heidegger developed phenomenological enquiry into a more hermeneutic method, where interpretation rather than description was the central focus (Holloway, 1996). This approach claimed that all description involves interpretation, as description is merely a derivative form of interpretation (Moran, 2000), a point which would have been highly contested by transcendental phenomenologists.

Influenced by the work of Heidegger, Merleau-Ponty's focus was on perception and the creation of a science of human 'being' (Merleau-Ponty, 1981). He proposed that embodiment, natural attitude, experience and perception are our original modes of consciousness. As noted earlier in this chapter, Jasper (1994) refers to Merleau-Ponty's suggestion that any artistic expression, including poetry, humour, art, photography, diaries and so forth, can be used as sources of experiences which have meaning for individuals. This is one example of how some later phenomenological work inspired me to consider the phenomenon analysed within my own research, without necessarily utilising all elements of the existential approach it accompanied.

Despite the seemingly constant academic debate about the various traditions, I remained interested in utilising phenomenology. What appealed to me was its genuine and rigorous science base (Don Idhe, 1986), both very important elements to my search. In line with my ambitions for this study, Idhe (1986) suggests that phenomenology will not leave things the way they are, it will seek to make discoveries, offer a perspective from which to view things and probe for what is genuinely discoverable but not often

seen. The following section will outline how phenomenology allows these discoveries to be made, in particular through Transcendental Phenomenology, Husserl's later work which became the key influence within this study.

4.3 Transcendental phenomenology

Following my broad exploration of phenomenology, I decided that to mix the various traditions would confuse not only the methodological design but the analysis. My choice of transcendental phenomenology was largely influenced by Husserl's lectures from 1925 (Husserl, 1925: 1977), in which he provided an overview of the basic characteristics within a transcendental attitude, namely:

- a priori focus: a focus on universal structures
- pure description
- intentionality: a focus on consciousness
- epochē and
- reduction: transformation of the data

Whilst several of the above elements can be also viewed in Husserl's earlier work, during his transcendental phase they were refined, in light of both experience and further study. Therefore, within this section I will provide an exploration of the background and the above 'key principles' that are necessary when considering Husserl's particular theoretical framework.

4.3.1 Background to the theoretical framework

Husserl's use of the word 'transcendental' was criticised as loose, particularly when compared to previous philosophers such as Kant. However, he was always clear that the use of this term was in a broad sense, by way of describing his methodology. Husserl claimed phenomenology was an investigative approach, the primary concern of which was to develop a framework in which an individual's consciousness could be investigated, within the realm of 'transcendental experience' (Moran, 2000). This focus was central to his methodological approach and would, he believed, allow investigators to explain consciousness in relation to a person's direct and immediate experience.

I think it is worth highlighting a further criticism of transcendental phenomenology, as addressed by Spinelli (2005). Frequently the question, '...how can you research the act

of experience?' is asked. However, the author explains that this was never Husserl's intention, as he recognised the act of experiencing remains outside our conscious awareness. It is the subsequent awareness, namely consciousness, which is the focus of phenomenological research.

Transcendental phenomenology asserts that in order to explore and examine how individuals experience a phenomenon, certain fundamental principles require close consideration. As previously mentioned, these include: the notion of intentionality; pre-reflective descriptions; noematic and noetic reflections; universal essence; epochē; horizontalisation and the transformation of data. Within this investigation, all these principles guided the methodological design, collation and analysis of data, together with the presentation of findings. Horizontalisation, in particular, was essential to this study due to the participants' limited verbal language. Thus, a number of innovative ways to supplement the data, analyse and present the findings were required.

Husserl acknowledged that whilst it is important to primarily focus on individuals and their experience, it is also necessary for investigators to acknowledge their own subjectivity. This important and crucial element within transcendental phenomenological enquiry (Hallet, 1995) became integral to the methodological design and when writing this thesis. As readers will note, rather than present an isolated chapter on reflexivity, I have incorporated (where appropriate) my subjective reflections within various chapters. Further strategies to ensure my subjective focus was transparent will be discussed in Section 4.3.7.

4.3.2 Lived experience

When utilising a phenomenological approach, Van Manen (1996) proposes the central focus is on the lifeworld as it is experienced, rather than conceptualised, categorised or theorised. In contradiction to many other approaches to understanding human experience, phenomenology diminishes the importance of abstract theory. The author progresses to explain that phenomenology is guided by a method and attitude designed to understand an individual from his or her 'lived' world, often referred to by Husserl as 'lived experience' or 'lifeworld' (Husserl, 1925; 1977). The lived experience incorporates all experiential qualities (Todres, 2005), from those which are concrete and visible, to the more subtle experiences that happen within all our lives.

Husserl's use of the word 'intuition' describes the point at which we become conscious of our lifeworld, for example, the presence or appearance of a phenomenon. According to Todres (2005), when Husserl used the term intuition, it was in preference to words such as 'sense', 'think' and feel'. Within a transcendental framework this element is crucial, as it is by 'intuiting' the structures within an experience which provides the 'essence' of the phenomenon under study (see Section 4.3.8 for more details).

4.3.3   Intentionality

The notion of intentionality is complex and it is helpful to first consider a derivation of the word 'intender', meaning to 'stretch forth' (Spinelli, 2005). Thereby, 'intentionality' is the point at which we are first able to perceive our world. When we become conscious of a particular object, either tangible or intangible, our awareness is directed (stretched forth) towards this. Intentionality relates to the principle that consciousness is always of something, thereby to contemplate the possibility of having a state of consciousness, empty of any direction, is rejected. According to Ashworth and Greasley (2009), some critics make the mistake of supposing intentionality separates the inner and external world. The authors note that Husserl did not do this, because he regarded both the 'mode of consciousness' and the 'object of consciousness' as within personal experience, with both being situated 'in the world'.

Butt (2004) suggests, '...you cannot think experience or fear, nor can you feel anticipation in a vacuum. You always think about something, are scared of something and look forward to something. The things we are conscious of cannot be separated from our experience' (p.89). Furthermore, Giorgi and Giorgi (2008), explain, '...a perceptual act perceives a perceptual object, just as loving is directed towards a loved or treasured object'. From these two statements, it is possible to deduce that intentionality indicates all acts of consciousness precede the object.

When we reflect, it is this point of our awareness which is the focus of transcendental investigations. Ashworth (2008) observes that intentionality points to the intrinsic 'relatedness' of consciousness to the experience, irrespective of whether it is tangible or not. Considering an object, or indeed musing on a situation such as bereavement, are both equally 'real'. Another key feature of intentionality is noema and noesis, a

correlation between the 'what' and 'how' of experience, and our connection to the world (discussed further within Section 4.3.5).

A frequent criticism of intentionality is that 'to access a person's conscious experience, phenomenology will always take an interpretive stance'. However, describing consciousness in its pure form is not necessarily what is claimed (Polkinghorne, 1989). Accessing a person's conscious experience is not about accessing some private realm within their head. Intentionality relates to *how* they direct their consciousness towards an object and *how* this connects them to the world. Essentially, their consciousness is of *and* shaped by the world they are in.

The above concept can appear a little esoteric, although the following illustration demonstrates this is not so. Upon experiencing the joy of a new purchase, I perceived an antique and exquisitely carved object as a table. My cat (appearing equally joyful) perceived this new object as an exceptionally useful scratch pole. Both experiences, our perceptions and judgements of the purchase, were quite genuine and directed towards the same object. A phenomenological approach would not ask '...is it really a table or scratch pole?' It would just be interested in my own or my cat's perception of the object, that is the world that we interact with. A more frequent tendency is for individuals to force a very specific way of conceptualising the world and, in respect to the above instance, this could have influenced the investigation of the phenomenon itself.

Thereby, transcendental phenomenology aims to go beyond interpretation and uncover intentional structures (Giorgi, 2008). This approach encourages investigators to acknowledge their subjectivity and carefully utilise various methodological strategies, thus limiting any influence of bias which may be present. Through careful and systematic approaches, a sophisticated analysis takes place. Consequently, a description rather than an interpretation of what happened is provided (Giorgi, 1985). Once the findings are presented, a thorough study will then discuss these in dialogue with theoretical literature.

Husserl stressed that the perceived object could be tangible or physical in nature, intangible images or perceptions. He also acknowledged that perceptions may be very real for an individual, if not for others (Husserl, 1925:1977). Within my study this point

will be important when considering the 'meaning' of the experience, which could include an emotional element for the bereaved young people. Therefore, literature concerning how to access pre-reflective descriptions became the next step to consider.

4.3.4   Pre-reflective descriptions

The aim of a descriptive phenomenological study, according to Giorgi (2008), is not to produce a definitive statement about an experience, but a careful description of the lived experience of a phenomenon, in the context it was experienced. He reiterates that phenomenological research is 'discovery-oriented', rather than 'hypothesis-testing'. As previously explained, the aim is to produce vivid, accurate descriptions of the meaning which constitutes the activity of consciousness, intentionality. In order to access data, one of the key elements to any investigation will be the participants' pre-reflective descriptions. This is when individuals reflect and describe an experience as fully and deeply as possible, until they have no more to say (Jasper, 1994). Thereby, to undertake this task an investigator must develop a robust and appropriate strategy.

If phenomenology is to describe experience as it was lived, rather than as it was thought about later, accessing a person's consciousness through pre-reflective descriptions could be a problematic pursuit. After all, if I asked someone to stop and talk about their experience, then surely I am only accessing latent thoughts. It is this 'intangible' element that is the basis for many criticisms of a transcendental approach, especially when considering the complexity of the task and the infinite descriptions which could be posited at any one time.

Polkinghorne (1989) addresses the above issue by suggesting that phenomenological investigations increase the adequacy of participants' pre-reflective descriptions. Accessing a person's consciousness does necessarily effect a change in awareness, several times removed from the actual flow of experience. As an activity, consciousness presents itself as a 'fleeting trace or indication, a mere wisp, filled with various modes of presentations, such as perceptions, remembrances and imaginations' (Polkinghorne, 1989, p.45). Frequently, we do not focus on all these constituents, unless we 'slow down' our recollection of the experience and undertake careful contemplation of the particular moment in time. It is only by implementing a well organised and transparent methodological design, with regards to the data collection and subsequent analysis, that

the adequacy of the participants' pre-reflective description of their experience will be increased.

There are several pragmatic techniques which may be used to avoid 'worldly depictions' and focus on individual experience. Polkinghorne (1989) suggests one way to do this, is to ask questions such as 'what did you experience?' or 'what was it like for you?', rather than 'what happened?' The author proposes that the aim is to develop clear protocols and a robust strategy, thus enabling readers to see how participants arrived at their pre-reflective descriptions.

As I was about to undertake a study where some of the participants quite possibly had a limited vocabulary, this led me to carefully contemplate the concept of pre-reflective descriptions. Rather than allow the various critics to influence my choice of approach, or give up at this stage, my solution was to acknowledge their criticisms and tolerate ambiguities. This ensured I developed a robust strategy which offered a clear, detailed and precise account of how I progressed and eventually arrived at the phenomenon. Thereby, I planned to increase the adequacy of the participants' pre-reflective descriptions by concentrating on the above points, adhering to epochē (Section 4.3.7) and horizontalisation (Section 4.3.8), thus providing a high level of thoroughness in the technique utilized. Idhe (1986) reminds his readers, 'it is only by doing that a concept such as phenomenological enquiry can be fully grasped', something I will reflect on within the concluding chapter.

When individuals are asked to explore their experience of a particular situation through their pre-reflections, Husserl observed that it is not unusual for descriptions to be in a straightforward manner (noema) and also a more reflective way (noesis), two concepts that will be discussed next.

4.3.5   Noema and noesis reflections

When attempting to access an individual's intentionality, there will frequently be reflections of 'what' the focus was and 'how' he or she experienced something (Idhe, 1986). Within phenomenology, these two orientations are described as noematic and noetic patterns of reflection, both of which are entwined and take place simultaneously. Noema refers to the directional element, where we focus on *what* we perceive, and

noesis is when we reflect on *how* we perceived an experience. Noesis reflections are sometimes referred to as referential, the act of looking at an object (Spinelli, 2005).

With regard to this study I wished to uncover the participants' meaning of reading and discussing the book (noetic focus) and the way they oriented themselves towards their experience (noematic focus). However, an important point is that reflections are not exclusively one or the other. As with any experience individuals oscillate between the two foci, with the content overlapping both noematic and noetic orientations. Yet, whilst both aspects constitute our intentionality, it is possible for us to be more conscious of how we perceive something, rather than what we perceive (and vice versa).

Ihde (1986) offers readers an illustration of the above concept. If an individual focuses on a visual illusion they may be more concerned with one aspect, for example, trying to figure out what it is (noematic) or be aware of the sheer 'frustration' when trying to comprehend what it is (noetic). Here it is possible to deduce that, even though an individual may not be conscious of doing so, both aspects of the experience happen simultaneously. Similarly, when someone is speaking to us, we may focus more on 'how' they are talking, rather than 'what' they are actually saying. In this case, we would say our noetic focus was predominant. Consequently, when using this theoretical approach it is necessary to consider both noematic and noetic reflections. Only when this is achieved can the invariant structure, the universal essence, be adequately described.

4.3.6 Universal essence

When undertaking the analysis process, Husserl saw phenomenological reduction as a method of discovering what he often referred to as the immanent (Husserl, 1925:1977), more commonly known as the essential elements or universal essence of a phenomenon. 'Essence' relates to a general character of the phenomenon, which has been described and uncovered on a number of occasions. The repeated pattern of the 'essence' is deemed to be significant, without which the phenomena would not be what it is. Husserl was very insistent that 'essence' should be considered the central, crucial and important tenet to this form of inquiry.

Therefore, the task of my study was to find the essential features, or essence(s), of the participants' experience when reading and discussing a book about death and dying. A challenge was in locating an appropriate method to identify this, whilst retaining the authenticity of each person's experience. The solution to this dilemma is discussed further in Chapter 5, when the methodological design is presented.

4.3.7 Epochē

The ancient masters didn't try to educate people, but kindly taught them to not know

When they think they know the answers, people are difficult to guide

When they know they don't know, people can find their own way

Lao Tzu, c.604-531 BC

Tao-Te Ching

Johns (2002) notes in his publication 'Guided reflection: advancing practice', that the above quote perfectly represents the starting point at which any reflection should take place. I also contemplated how this might be correlated with the concept of epochē, sometimes referred to as 'bracketing' or 'suspension of belief'. Husserl preferred to use the term epochē, which Moran (2000) explains as 'cessation' of thought.

A more pragmatic explanation refers to epochē as a method by which an investigator delays or suspends previously known theories, assumptions and habitual behaviour. The purpose for undertaking this task is to gain a greater awareness of how these elements frequently influence our view of individual experiences (Spinelli, 2005) and quite possibly dictate the focus of an investigation. In my case this was certainly true and led me to find a way of ensuring that what I expected to happen, based on my theoretical knowledge and experience, did not conceal what actually happened, in short what the phenomenon was.

Since Husserl first introduced the idea of epochē it has caused controversy, with some academics appearing to dismiss the idea without fully appreciating its potential within research (Taylor, 1995). Heidegger resolutely disagreed with epochē, refusing to accept the possibility of separating a researcher's experience from the process itself (Moran, 2000). In his view, researchers should not consider themselves as separate from the

investigation because they are free and responsible individuals, determining their own development.

As discussed earlier, Heidegger strongly believed 'meaning' could not be described, only interpreted, and thus developed his own methodology, hermeneutic 'interpretive' phenomenology. This approach focused on 'sensitising', the process in which a researcher becomes immersed in the data and searches for what was missing or different about an experience (Todres and Holloway, 2006). Had I undertaken this approach, my own experience would have been acknowledged throughout the whole process of data collection and analysis.

When reading secondary sources of literature about phenomenology, I was initially persuaded that epochē was too great a challenge. Similar to Taylor (1995), I had been nursing over 20 years and during this period had amassed a large amount of experience and knowledge, in relation to working with bereaved individuals and people who had a learning disability. I questioned whether it was possible to 'suspend' this knowledge when undertaking my research. Taylor describes her reasons for not progressing with epochē in a study entitled 'Ordinariness within Nursing':
"*I did not feel able to bracket my presuppositions about nursing, given my own 26 years experience as a registered nurse. I also had a sense that I could not extract parts of myself and set them aside, for research or any other purposes*" (Taylor, 1995, p70).

After much thought, especially when reading Husserl's later work (Husserl, 1925:1977), it is clear that his position on epochē changed from an initial view of universal epochē, in which he proposed putting 'all' existing assumptions regarding the external world aside. As noted earlier, in his transcendental period Husserl proposed a more local epochē that encouraged investigators to temporarily put 'particular' assumptions aside, with respect to the phenomenon under study (Beyer, 2004). In his lectures from 1925, he clearly acknowledged there was no need for a 'socio-cultural scientist' to perform epochē in relation to nature (Husserl, 1925:1977). The Stanford Encyclopaedia of Philosophy refers to local epochē as a weaker version of the original concept (Beyer, 2004). Nevertheless, rather than being a diluted version, it is possible that local epochē is simply a more realistic version, enabling researchers to undertake the process

effectively.   In many respects, it is an example of how Husserl continued to develop his initial propositions, rather than retain a problematic concept.

Several writers, including Moran (2000), concede that some of Husserl's ideas are difficult to understand by a modern audience, especially as some words do not have an exact English translation. Husserl's original work was of course written in German and an academic style appropriate to the early 20th century. Despite this I persevered with his work, in particular this concept of epochē. It was possible that Husserl had identified a mode of interacting which I used on a regular basis. As an illustration, I wondered if this was the process recently utilised by myself whilst watching a film on television. Of course I knew it was fictional and even had a basic understanding of the story-line, yet put this fact aside and was moved to the point of tears when an emotive tale unfolded. For that particular 'moment in time' I had suspended my knowledge of its fictional status and experienced the film as though it was real.

Similarly, there are instances on a professional level where I frequently undertake this process of opening myself up to possibilities, without pre-judging situations.   When working with distressed individuals at the hospice, it is often necessary just to listen, whilst they disclose what is making them so anxious. Sometimes I supplement my assessment of the situation by considering their body language, rather than purely attending to verbal disclosures. It is often only later, when reflecting on the situation, that a dialogue with previous knowledge and experience takes place.

To illustrate the above, I was recently supporting a very distressed relative whose husband was in the terminal phase of his illness. The woman was distraught that her Christian faith, which had provided much comfort and guidance over the years, was failing to do so when she needed it most. I asked about the Church she attended and the friends who had been so good to her over the previous months. Here I put aside my own spiritual beliefs and became interested in her faith, feeling no compulsion to judge or theorise what she discussed. My previous knowledge and beliefs on the subject of religion were temporarily suspended and I learnt much from our conversation.   In summary, it was her experience of religion which was the phenomenon she reflected upon.

Thereby, even though there were sceptics who declared a 'suspension of belief' could not be achieved (Taylor, 1995), I was willing to undertake the process of epochē. Not only did I trust that it would be a worthy inclusion within the methodology, it was essential if closely following a transcendental approach. Despite my lack of experience in utilising such a contentious concept, the clear details of how to undertake this process provided adequate guidance. Consequently, this allowed me to pursue an investigation which did not start with theory or seek to 'interpret' the data.

4.3.8 Horizontalisation and transformation of the data

Horizontalisation emphasizes the importance of approaching any investigation with an open mind, considering a phenomenon from many different positions. Idhe (1986) proposes that this crucial step ensures investigators take a step back and thus avoid initial judgements. He elucidates further, by stating the process prevents a premature conclusion that sufficient information has been captured. Various strategies which are integral to horizontalisation have already been explored, such as epochē and 'describing' rather than 'interpreting' an experience.

Husserl (1925:1977) explains horizontalisation within his 1925 summer lectures:
 '… [it is by] varying perspectives in which, always according to the oriented givenness, the shape of the thing appears, and with the shape, the colour'. He continues his lecture by noting that with the '…perceptual stream of adumbrating presentations, we can then also study how the constitution of a [phenomenon] takes place' (p.118).

Sawicki (2006) observes that Husserl's use of the term 'adumbrating' is reminiscent of multiple-exposure photography, a new invention which would have been popular around the time of his lectures. This insight into Husserl's use of the modern world to illustrate his concepts is an interesting one. He encouraged students to consider the successive phases of a movement within a single photograph, thereby appreciating the many different ways to look at one particular situation. By contemplating all these different perspectives or layers within a situation, we can then start to uncover the universal structures which lie within it.

Once all the data have been captured through horizontalisation, it is then 'transformed' within the analysis stage. Transformation of data includes a gradual and methodical

pursuit, in which an investigator carefully reviews all the data available. A detailed explanation of this process is provided in Chapter 7, alongside illustrations of how it was undertaken within this study (Section 7.4.3). Sokolowski (1999) suggests that by considering the data from a variety of perspectives, a phenomenological investigator is led through transformation of the data towards eidetic intuition. Through this process the essence(s) of the phenomenon are discovered.

4.4   Phenomenological analysis

Key features of the analysis stage involved the use of phenomenological reduction, intuiting, analysing and describing (Burns and Grove, 1993; Polit and Hungler, 1993), all of which are discussed in detail within Chapter 7. Idhe (1986) cautions against casual references to these terms and notes that all the tasks are in fact highly complex when carried out correctly. I searched for a framework in which the pre-reflections could be systematically and carefully transformed, utilising a variety of approaches, including coding, categorising and making sense of the essential meanings. Ultimately, the 'essences' of the phenomenon were then uncovered, thus offering a structural description of the experience when reading and discussing with others a book on death and dying.

4.5   Summary

This chapter has explored the rationale for choosing Husserl's transcendental phenomenological framework as the basis of my study. His lifetime application in developing a phenomenological approach to the conceptual foundations of psychology is, according to Scanlon (Husserl, 1925: 1977), only appreciated when one can evaluate the character of Husserl's penetrating and orderly pursuit of his subject. Therefore, I presented information that links the man behind the theory and found a passionate, intelligent and pioneering individual. His fascination for phenomenology never waned, despite the unsettled social and political climate in which he lived, particularly towards the end of his life.

Husserl's development of phenomenology as a 'scientific approach to examining human experience' has also been presented, by reviewing the fundamental concepts and principles of his transcendental approach. Throughout this chapter I have explored several criticisms with regard to phenomenology, some of which I acknowledge.

However, after careful thought and much reading on the various concepts, it appears that most of the main criticisms can be circumvented by providing a transparent, structured, precise and detailed account of the design and analysis. All these aspects are covered in the remaining chapters of this thesis.

CHAPTER FIVE

METHODOLOGICAL DESIGN

So far within this thesis I have introduced Michael Rosen's SAD BOOK and explained the reason why it was considered an appropriate therapeutic tool for bereaved children and young adults. I then moved on to present various sources of literature, relating to both bereaved children and bereaved adults who have a learning disability. The scarcity of research with regard to bibliotherapy in the context of bereavement therapy, merely reinforced my opinion that to pursue this investigation would be valuable. In so doing, it will inform practitioners and thus offer empirical information on which to base their practice. The previous chapter introduced Edmund Husserl's transcendental theory, including the rationale as to why I was inspired to use his theoretical framework.

This chapter will commence with an exploration of how phenomenology studies have been utilised in other real world settings and the value in taking such an approach. The issues covered, include some challenges encountered and how investigators navigated the obstacles that arose. An exploration of reflexivity and my own dual role as principal investigator and practitioner will follow. My rationale for choosing to study a *slice of time,* rather than a more cumulative or protracted experience, is also addressed.

I will then progress to describe how the aims of this study were operationalised, utilising a transcendental phenomenological approach. Readers will be guided through the methodological design, alongside an explanation of the principle considerations required when working with children and young adults, some of whom had a learning disability. A résumé of the session plan will be accompanied by more specific details about the various elements incorporated within the design.

Where appropriate I have discussed a small number of accounts regarding how the design materialised in practice. Whilst I acknowledge that it is unusual to illustrate these instances at such an early point within this thesis, it has allowed me to highlight where elements of the design either did not work or required adapting and developing further.

These brief glimpses of methodological insights will not pre-empt the main presentation of findings, as situated within Chapter 8.

5.1   Principle aim of the study

The structure of this project gradually evolved and was refined over the initial fifteen months of my PhD studies. The principle aim was for the empirical methods to uncover a detailed account of all the participants' experience, thereby revealing the universal structure that adequately portrayed the phenomenon of reading and discussing together a book on death and dying. As previously noted, Michael Rosen's SAD BOOK was the chosen publication for this investigation.

5.2   Phenomenology and real world issues

In order to learn from and appreciate the complexity of managing phenomenological investigations, I undertook a wide review of published research. A number of issues which are of particular interest to this study will be explored in this section. The real world settings and topics I have chosen mainly focus on grief and end of life care (Duke, 1998; Spichiger, 2009; Rodriguez and King, 2009; Hopkinson and Hallet; Mak and Elwyn; Loftus, 1998).

To assess how phenomenological investigations consider the views of children and young people, I widened my search to look not only at their experience of palliative care issues (Finch and Gibson, 2009) but other subject areas such as rheumatology service provision (Hutchinson and Hall, 2007) and the experience of living with diabetes mellitus (Miller, 2000). I continued by reviewing research that involved adults with a learning disability (Combes et al. 2004), college students with a learning disability (Cornett-DeVito and Worley, 2005) and people with a dual diagnosis (Coombes and Wratten, 2007). To conclude, I will highlight some of the issues that Cohen (1994) describes within her research on the practice of bibliotherapy and Colaizzi (1978), in relation to his phenomenological study on the experience of reading a book.

The literature chosen for this overview was comprised of both hermeneutic and transcendental investigations. Areas I will explore include: the variety of settings and experiences; strategies utilised with regard to data collection techniques; some of the

challenges encountered; limitations imposed by this theoretical approach and a look at what the findings offer, in relation to progressing both theory and practice.

The number of participants within the studies were varied and included those with four (Duke, 1998) or six individuals (Miller, 2000), to the larger sample populations of 21 (Cornett-Devito and Worley, 2005) and 37 (Bevan, 2007). As noted in Chapter 1 (Section 1.8), the small number of participants within phenomenological investigations is frequently contested (Giorgi, 2008). However, Cohen (1994) included eight participants within her research on bibliotherapy and stated that the purpose of this theoretical approach is to obtain subjective depth in the data, rather than objective or quantifiable data. Within her own investigation the sample size was considered sufficient when the data were saturated and the same patterns recurred.

Venues for the data collection were frequently chosen by participants. These included their home, college or a hospital setting and were very much determined by the context in which the studies took place. As an illustration, in Miller's (2000) study of children with diabetes mellitus, she interviewed the participants in their own homes. Whilst the intention was to promote a relaxed atmosphere, this strategy highlighted an unforeseen issue when one of the children wanted the data collection to take place in her bedroom. Although the author knew this would be helpful (by providing additional insight into the child's interests), she was also conscious of her own professional accountability in relation to child protection. Eventually, the interview did take place in the bedroom, as it was requested by the child and there were a large number of visitors in other rooms within the house. Interestingly, when Hutchinson and Hall (2007) asked participants to choose where they would prefer to be interviewed, all chose their home rather than an outpatients setting.

Whereas my own study incorporated a group interview technique (further details of which are in Section 5.6), the investigations described in this section were mostly conducted on a 1:1 basis, utilising either semi-structured or unstructured questioning. Within Cornet-DeVito and Worley's investigation (2005), they considered the experience of 21 college students with a learning disability, focusing on how competent or incompetent they perceived their instructors' communication. In most cases, general open-ended questions were utilised, which subsequently evoked free-flowing responses

from the participants. The authors explained that at times they needed to ask follow-up questions, as a way of encouraging greater detail or where further clarification was required. During these interviews the participants also disclosed personal information, which was later utilised to provide a 'backdrop for appreciating their perspectives'.

Interviews within the various studies were audio recorded and usually lasted between 20 to 60 minutes, with the data transcribed verbatim. One exception to this was a study by Rodriguez (2009), where the interviews lasted between 1 and 2.5 hours. The author investigated the experience of both children with a life threatening illness and their parents. When interviewing the parents about such an emotive subject, an open attitude and degree of sensitivity was needed (Rodriguez and King, 2009). As the participants opened up and recounted their experience, the author noted that they found themselves reliving challenging and upsetting experiences. An illustration of this can be appreciated in the following extract of a parent discussing her anticipatory grief:

"I were just sat on my own and I remember sitting there... There were leaves falling off the trees and I can remember thinking all these trees are dying and [child] is going to die and I sat there planning her funeral" (p.10).

As the above clearly demonstrates, participant accounts may include very moving disclosures and it is evident that several of the researchers had considered this aspect when creating their methodological design. For instance, Duke (1998) undertook a study which explored the lived experience of four individuals during their spouses' terminal illness and their own subsequent bereavement. Prior to contacting any potential participants, criteria were devised to ensure certain populations would not be approached, where they were deemed to be particularly vulnerable. This included newly bereaved individuals and those who were likely to be acutely distressed by the experience.

Of the studies reviewed for this section, many investigators have been healthcare professionals with experience of their chosen subject (Duke, 1998; Hutchinson and Hall, 2007 and Mak and Elwyn, 2003). Some studies had been carried out by individuals who were both investigator and practitioner. Evidence of the strengths and limitations in relation to having this dual role is presented within several of the investigations and will be discussed next.

Hutchinson and Hall (2007) investigated the experience of 16-19 year old women who accessed a rheumatology service in the UK. During several interviews Hutchinson, a Clinical Nurse Specialist, became aware that some of the young individuals were confused about certain aspects of their care. Fortunately, additional time had been allocated in the methodological design for the investigator to discuss any follow up issues with the participants, once the data collection had taken place. Outside the research role, Hutchinson's clinical expertise allowed her to identify when a young person lacked the relevant knowledge about their condition, which ultimately could have resulted in harm (for example, a poor understanding of how to take medication). Fortunately, when this happened she was able to not only identify the problem but ensure they received the appropriate information.

Despite the benefits of working in a dual role, as both researcher and practitioner, this aspect can also cause some difficulties, particularly the interaction effect between a researcher as therapist and the participant's experience. Northway (2000) asserts that when nurses undertake research with individuals who are potentially vulnerable, they may view the process as oppressive. The author suggests that investigators should examine their own personal behaviour and be fully aware of their position, within a system that has not always supported people fairly. One way to do this is through a process of reflexivity.

According to King and Horrocks (2010), the word reflexivity implies reflection and thoughtfulness. The authors progress to highlight that this explanation fails to recognise the extensive complexity and impact of applying such a concept, both in terms of theoretical understanding and when undertaking qualitative research. Furthermore, when using a reflexive approach it is necessary to look inwards and outwards, with regard to the relationships between: existing knowledge; experience; a researcher's role and the context within which a study takes place. Equally, the attitude and responses of a phenomenological investigator are critical to developing a relationship with participants (Finlay, 2009). With regard to my investigation, these points will be discussed in far more detail in Chapter 10.

Some of the phenomenological studies reviewed, investigated topics where there is currently a scarce representation of patients' perspectives. One such example was Mak and Elwyn's study (2003), which interviewed 12 participants who had a life threatening illness and sought to understand the meaning of desire for euthanasia. The authors thought one reason for a lack of empirical evidence on this topic, may be attributed to an assumption that it is unethical to discuss such a sensitive topic with patients who are considered vulnerable. However, upon completing the study, the investigators felt a phenomenological approach had allowed intimate insights into the patients underlying desires, with both ethical and scientific rigour. The utilisation of phenomenological methodology had resulted in a sensitive and compassionate way of obtaining data. A further illustration of this approach is provided below.

Strategies that Mak and Elwyn (2003) utilised when incorporating this sensitive approach included establishing rapport with participants prior to the interview. This resulted in a situation where the patients did not have to familiarise themselves with new personnel during the data collection period. The lead investigator was a palliative care physician and therefore accustomed to communicating with the sample population. In turn, the participants related their sense of being listened to, understood and cared for. In this instance, by using phenomenological methodology and listening to patient narratives, the complexity of participants' lived experience was revealed, thereby providing a reliable indicator of their underlying needs.

Within Hopkinson and Hallett's study of patients' perceptions when utilising hospice day care (2001), one participant explained the value of attending the service. In particular, she reflected on her relationship with other patients, *"I think it's the perfect place here, because we're all in the same boat... it makes you feel closer".* The authors commented that this feeling of 'being understood' appeared to lessen the isolation of patients. Furthermore, having an opportunity to 'tell their stories', enabled them to make sense of their experience. Interestingly, due to the methodological approach used within phenomenological studies, the interviews also encourage participants to 'tell their stories'. However, as the study below illustrates, accessing this account can present certain challenges.

The issue of how to interview people with limited verbal communication was addressed by Combes et al. (2004). The authors undertook a phenomenological study with two people who had a learning disability (alongside seven members of their 'circle of support'). In order for the participants to contribute and participate in the research, Q methodology was utilised. This method is used in psychology and other social sciences, to glean participant viewpoints on a variety of issues.

Prior to the interview, a number of possible responses to a question were written on cards (in this case, illustrations were used rather than words). The participants then chose illustrations which represented their likes or dislikes and a picture of their response was gradually built up. The authors acknowledged that this approach could potentially have its weaknesses, especially if a person responded in a way they thought conformed or complied with the wishes of an investigator. Nevertheless, in an area which is incredibly difficult to progress, this involvement of people with learning disabilities in research is commendable. As the authors note, further research will substantiate their findings and may even negate some of the assumptions that are commonly made, with regard to how individuals experience their lifeworld.

Many of the studies already presented within this section have considered a cumulative or protracted experience for the participants involved, for example, the meaning of desire for euthanasia. However, when investigating the experience of bibliotherapy, it is possible that participants may focus on a very specific 'slice of time'. As an illustration, Colaizzi (1978) asked the following of his participants:

'...*please try to recall something which you read that made an impression on you, or which in some way affected or influenced you. Try to describe the impressions that it made on you'* (p.58).

Colaizzi's participants recalled the actual moment they read the book. However, upon further questioning, successive experiences were discussed. The following extract from the interview transcript demonstrates this point:

Colaizzi   *What were you experiencing before, during and afterwards?*

Participant   *Before I was just meandering along.*

While I read it I was filled with disbelief and anger.

Afterwards I felt frustrated that I couldn't change the past. I wondered when people would try to deny or suppress what I do, as they did to... [referring to characters in the story]

Later in the conversation:

Colaizzi   *Did you discuss it with someone else... after reading it?*

Participant   *I didn't talk about it right away. I was left in a daze. I have recalled the passage several times to others but no one cares as much as I do.*

From the above, it appears that the period of time investigated is largely dependent on the phenomenological questioning and aim of the study. Searching for investigations which considered a very specific slice of time proved difficult. Studies I assumed would meet my criteria did not turn out to examine such a focused point. For instance, Finch and Gibson (2009) explored how young people discover their parent's diagnosis of cancer. Whilst the authors did ask the young people to discuss how they first heard the news, the participants then expanded their conversation. This included subsequent discussions of the diagnosis with family members.

Therefore, whilst my investigation is not unique in its focus, it is unusual when compared to other phenomenological studies, as the questions remain firmly grounded in a more specific 'slice of time'. Furthermore, most hermeneutic phenomenological investigations are based on individual interviews or utilise another mode of reflection such as diaries. The interesting factor within my own study, relates to how it looked at something not only happening over a relatively short space of time, but *while it was happening.* The participants were not asked about their experience some time later but observed and immediately engaged in the interview. Asking people to recollect an experience that took place in another context, some time ago, is very different to actually being able to observe the phenomenon as it was experienced.

A comparative study to the methodological design I devised, was undertaken by Aanstoos (1985). Although this research was undertaken over 20 years ago, it is still recognised as a good example of a descriptive phenomenological study (Langdridge, 2007). Giorgi and Giorgi (2008) note that while retrospective descriptions are more frequently used because of their convenience, *ongoing descriptions* can equally be considered. Within Aanstoos transcendental investigation, entitled 'The structure of thinking in chess', five highly skilled players undertook a game of chess with a research assistant. During every game the participants were asked to 'think out loud', whilst the research assistants wore headphones. Similar to my own study, immediately following the chess games each participant was interviewed, to ensure any further pertinent information about their experience could be explored. Obviously there were some differences in the above approach, as I did not ask the participants to talk out loud whilst they read the book. However, the overall focus on a phenomenon as it was experienced does resemble my own investigation. Further details of the methodological design created for this study can be found in Section 5.6.

All the investigations reviewed within this section offered findings in relation to how individuals' experience their lifeworld, in the various contexts studied. The data frequently uncovered anomalies between the findings and theoretical literature, as illustrated in Duke's research (1998). The author found that the participants' descriptions emphasised a profound difference in how they experienced spousal illness, in relation to bereavement. Whilst literature acknowledges a change from spouse to widow, few papers identify a change from spouse, to spouse/care-giver, to widow. It is these very detailed and fine distinctions which are frequently uncovered within phenomenological studies.

Due to small population samples within the papers reviewed, the majority of authors acknowledged certain limitations in their investigations. As discussed above, Duke (1998) highlighted findings which indicated a particular issue but later acknowledged that further research would be needed to substantiate the observation. In addition, the author recounted how the participants valued the support provided by nurses, particularly those who were 'interested in them as people'. However, there was insufficient evidence in the data to make claims about this observation. Duke

suggested, once more, that further research would be needed into the effect of care-giving activities on bereavement and the support required from healthcare staff.

A further example, of both the strengths and limitations when utilising this theoretical framework, can be found in Cohen's study on the experience of therapeutic reading (1994). An important finding was the participants 'recognition of self' in the prose and text, rather than the type of literature read. The findings described how they gained both understanding and information from the publication. It was this overlap of cognitive and emotional aspects of their experience, which suggested theoretical unity between the two perspectives. However, the scope of the study was limited as it did not explore reading alongside other people (with or without discussion), thereby the author concedes that further research would be required regarding these issues.

Todres (2005) suggests that a limitation of descriptive phenomenological studies is in relation to their epistemological focus. According to the author, readers wishing to find quantitatively measurable data will be disappointed. Furthermore, the findings are not promoted as the only way a phenomenon should be considered. He progresses to explain that phenomenology presents insights about the lifeworld which can be transferred to other experiences of a similar type. Thereby, the validity of such insights is in how they promote deeper understanding of a phenomenon, thus contributing to the body of knowledge in relation to a particular experience. The very tight window of experience which investigators consider, allows them to uncover data with incredible depth and richness. The specific method I created to undertake my own phenomenological study is presented next.

5.3   Criteria for a phenomenological design

Due to the potential challenges of working with such a complex group, it was essential to create a strategy that worked for this particular study, rather than take a more traditional approach to phenomenological interviewing. In so doing, the result was a unique design which remained true to its philosophical underpinnings.

When planning the methodological design, I was aware of the possibility that due to some participants' limited vocabulary, they may struggle when attempting to both access and communicate their pre-reflections. To compound the challenges faced, not only was

I planning to undertake the group interview with children and young adults, but the number of participants was much larger than I would have preferred. Thereby, the wide range of concentration levels, different ages and cognitive abilities had a large influence on the design of the session. Strategies created to navigate these potential obstacles are detailed within Section 5.5.

It became clear that I needed to create a structure which allowed the participants to experience the book being read and then discuss it, without the session turning into a chaotic encounter. Therefore the criteria included the following elements:

1. A structured session with flexibility for any unexpected disclosures which may require attention
2. A design reflecting sound ethical principles and incorporating health and safety measures
3. Questioning with a phenomenological focus
4. A transparent process, capable of generating sufficient data for a phenomenological analysis to take place.

5.4   Preliminary practice

From a theoretical point of view there was little merit in undertaking a pilot study, as any phenomenon needs to be considered in the *context* that it appears to an individual. Nevertheless, I suspected a pilot would be useful for a number of alternative reasons. One technique I wished to practice related to accessing participants reflection of their experience. More specifically, I wanted to improve the fluidity of my phenomenological questions and verbal prompts. I also knew it would be wise to rehearse using the tools and procedural steps, as described within this chapter. In order to reflect these two requirements, the term 'pilot study' was replaced with 'preliminary practice'. Thereby, the preliminary sessions enabled me to practice various elements of undertaking a phenomenological investigation and learn from issues that arose.

Two sessions were undertaken, one with children and the other with an adult. Irrespective of which session I undertook, my focus was to access each person's pre-reflections of their experience, teasing out vivid and detailed data, in relation to the context within which the preliminary sessions took place.

5.4.1   Session one

Unfortunately, within the ethical proposal there was no provision to undertake a preliminary session that discussed a book about death and dying with children. Therefore, in the first practice session I used a different book to one about loss. I then proceeded to ask the children questions with a phenomenological focus. Due to time constraints, I struggled to find an opportunity to do this at work and therefore undertook the session with two young family members, regarding a book entitled, 'Albert Le Blanc' (Nick Butterworth, 2000).

This short session became a great learning experience for many reasons. Firstly, I had wondered if the girls would find the book childish, as they were far older than the recommended age for this type of publication, Poppy was 11 and Lulu 14 years old. However, both girls gladly entered into the experience and appeared to thoroughly enjoy the exercise. They saw it as a fun opportunity to help with my studies and discussed various meanings within the story-line, very eloquently describing aspects I had not considered before.

Albert Le Blanc was a bear from France. Upon arrival in an English toyshop, the other toys think he is "the saddest-looking bear they have ever seen". Gradually, through some hilarious encounters Albert eventually explains to his companions in the toyshop, "I am not sad at all. It's just the way I am made. I just happen to have a sad look on my face" (p.25). Initially, I was unaware of any connection between Albert Le Blanc and Rosen's book. However, it incorporated the reverse of Rosen's illustration where he looked happy but was in fact sad (as described in Chapter 1). Within this particular book Albert Le Blanc looked sad even though he was really very happy.

When questioned, the girls reflected on the book in the following way "…it's all about looking out for others and realising that your friends are always there for you. Even when you are sad, you can think of good times and happy memories". When I asked Lulu and Poppy about their 'experience' of reading the book they commented, "…it made me feel wanted; lucky; comforted… reminded me that people care about you but that they don't always show it".

Although I have only described this preliminary session very briefly, it did prompt me to be completely open to what the participants (within the data collection session) would reveal of their experience. I became aware that responses I anticipated may not transpire at all. Interestingly, Lulu and Poppy's reflections of their experience had certain similarities to those the participants made after reading Rosen's book (full details are in Chapter 8), many of which I had not expected. This point re-affirms literature described within Chapter 3, that when an adult and child read a story, their interpretation and experience is very different (Malchiodi, 1998).

One point I did need to take into account was Lulu and Poppy's settled childhood, they were both doing well at school and had excellent literacy skills for their ages. In contrast, many of the participants in the study had not experienced such a secure upbringing. There was a possibility that their education had been disrupted and they may be, quite understandably, less eloquent when discussing the experience of reading Rosen's book.

With regard to some of the practical arrangements, Poppy frequently wandered around the room as the story was being read and when talking about her experience. On reflection, I decided that if this happened in the data collection period it would be allowed to take place. Certainly the freedom to wander seemed to help Poppy listen, reflect and discuss the experience of reading Albert Le Blanc.

In the preliminary practice session there were also instances where both girls sat very close to me, especially when the story was read. Had an existential approach been taken, I would have focused on this aspect of their experience and related it to the literature on embodiment. Finlay (2009) suggests that within any research study an investigator's: presence; approach; attitude and responses, are closely related with a capacity to be emotionally and bodily present. According to King and Horrocks (2010), the emphasis on our embodied engagement with the world is often overlooked within research. Whilst I will not be relating the findings to 'embodiment' literature, these issues will be addressed in relation to my investigation of the phenomenon.

5.4.2 Session two

The second session took place with my PhD supervisor and was of immeasurable value. I concentrated on how to utilise the various tools, as incorporated within the methodological design. This involved video and digital audio recording equipment, a PowerPoint projector, several copies of the book and prompt cards. Not all the equipment worked in the preliminary practice session, thus encouraging me to make sure I double-checked everything for the session with the participants. Equally, due to the amount of time it had taken to set up the equipment, I undertook this task the evening before the actual data collection session, mainly to avoid any last minute complications.

I was aware that my supervisor's response to the questions and prompts may be exceptionally different to those of the participants. Not only was this due to her chronological age, but our discussion of the book on a 1:1 basis. Prior to the preliminary session she had experienced a close bereavement, yet generously answered the questions in an honest manner, allowing me to practice handling emotive disclosures in relation to the story-line. Another crucial point within this particular session was the opportunity to practice using prompt cards and phenomenological questioning, in short my interview technique.

Phenomenological interviewing requires a significant amount of intervention by an investigator, when supporting people to 'bring to consciousness' their reflections of a phenomenon. Whilst this involves minimal direction, it does necessitate an interventionist approach. Most of the time individuals tend to focus on the 'here and now' and it takes much more effort to step back when reflecting on their experience. When undertaking group interviews in phenomenological research, it is important to ensure that the focus remains firmly grounded in the experience that is investigated, rather than generating peripheral data (King and Horrocks, 2010).

Thereby, when creating questions for the preliminary practice sessions and data collection session, I made sure that the focus was very much on the experience of reading the book, rather than deviating into other aspects of the volunteers or participants' grief. My intention when designing the questions was to predominantly

seek out a detailed insight into their experience. They were designed in a way that would not lead the conversation but open up a dialogue, an outline of which is below:

- What did you think of the story?
- Can you remember what it was about?
- What were the best bits?
  Here I attempted to use language the children would recognise and hopefully appear less clinical than a more formal question, such as 'what elements to the story worked well?'
- Were there any bits that you disliked?
- Did any of the pictures or words remind you of how you felt?
- Do you think reading the story would help other children?

Whilst the above questions were a crucial part of the methodological design, this particular aspect did not proceed according to plan. In the actual session I lost sight of a card with the above details on, as one of the younger children had put some puppets directly on top of my papers.

Prior to the session I had read Wilkinson and Birmingham's paper (2003) on using research instruments. According to the authors, most books on research techniques fail to acknowledge that investigations are carried out in a real world, which can be messy, disorganised and full of challenging, unexpected and problematical twists and turns. They propose '...if anything has the potential to go wrong, it probably will'. I remembered this caution and simply carried on with the data collection session in the best way possible. Fortunately, the questions had been revised and re-written following the preliminary practice sessions and I was able to remember most of the points. I was therefore relieved (when viewing the recording) to find most of the above questions had been covered.

5.5   The participants

Within this section I acknowledge that the participant details are brief and mainly used as a preamble to explain, with more clarity, my rationale for the methodological design.   In general, phenomenological studies do not incorporate prior assumptions about individual participants.   If this process was undertaken, it would be similar to using 'a priori'

knowledge and thus contradict the concept of epochē. Aspects of their particular characters would be introduced, without considering the temporal element or context in which the various behavioural traits were exhibited. Therefore, in this chapter I have only incorporated a priori issues where they are of relevance, with regards to creating the methodological design.

The details mainly contain aspects known to me before the data collection period, for example, an individual's limited vocabulary or concentration difficulties. Recognition of these particular issues enabled me to *anticipate* elements which may have posed a challenge in the session and thus adapt the design accordingly. As an illustration, I used two video recorders rather than just one on a fixed tripod, thereby allowing me to capture the interactions of those who wandered around the room.

By providing these 'snippets' of participant details, my intention is to provide enough material for readers to become acquainted with some aspects of their characters, especially those which may influence the findings. In summary, brief character details introduce what was required when planning the methodological design, as a direct result of the participants' way of being.

5.5.1 Confidentiality

One complication with the design has been an ongoing issue of protecting the participants' identities. To disguise their details so much that it would be impossible to recognise them, would have necessitated the removal of essential character descriptions. Ultimately, this would have posed difficulties when presenting the findings and subsequent discussion chapters. There was a need to consistently balance the protection of their identities, without compromising the potentially emotive and insightful findings which the data uncovered. Once this position was clear, it enabled me to progress and create a pragmatic strategy for addressing the issue. After reading a significant amount of literature related to confidentiality and ethical issues (details of which are in Section 5.6), four questions were created to stimulate debate when a point needed further clarification (Figure 3).

1. What must I remove to protect the participants from potential harm, such as a breach of identify?
2. Are there any unnecessary personal descriptions which may offend the participants?
3. Am I including information that is unnecessary, in relation to the study or obtained without full consent?
4. Are identities included only where necessary, in order to make sense of and present the data?

Figure 3.   Confidential and ethical questions, relating to the inclusion of personal data within the study

A further crucial step was to ensure no photographic images were taken, due to a clause within one participant's adoption details (also discussed in Section 5.6). Viewing of the recording was restricted to my supervision team, necessitating procedures that ensured all data were securely protected (including electronically) and remained on site at the hospice. Throughout the various presentations undertaken within the course of this PhD (Appendix 9), no photographic images have been used to substantiate the findings or points raised.

To prevent identification through the participants' ages, the following categories were used: over 18 years of age; high school age and primary school age (see Figure 4). These categories were deemed necessary, due to bereavement literature that addresses issues for the various age groups. The significance of this point will become clearer within Chapter 9, when the findings are discussed in relation to developmental theory.

The participants' familial relationships to the deceased (Eleanor) were not specified, apart from one young person who was the closest relation to her. All others within the group were integral to the family unit, although had a variety of connections to Eleanor, for example, siblings through adoption. Each person within the study was asked to choose a pseudonym, with another allocated for the deceased. I ensured the

participants understood the purpose of pseudonyms and that I would be using quotes both within this thesis and presentations. An overview of the various details can be found in Figure 4.

5.5.2 Participant details

Pseudonym	Gender
Over 18 years of age	
Q B Love (QBL)	Male
Lyn	Female
Supergirl	Female
Britney Spears	Female
High school age	
Rudolf	Female
Hoover	Female
Sarah	Female
Boothy (closest relation to the deceased)	Male
Primary school age	
Flashergirl	Female
Dash	Male
Spiderman	Male

Figure 4. Overview of participant details

As discussed in the first chapter, the family were fully acquainted with the personnel involved, due to their previous bereavement support session. Chapter 1 also explained that I had met the family on several occasions, to discuss the investigation and plan their second bereavement study day, which included the data collection session.

Whilst Eleanor had been married with a family of her own, she had been closely involved in the participants' lives for many years, especially the oldest four individuals. QBL, Lyn, Supergirl and Britney all had Down's syndrome, with an accompanying limited vocabulary. Initially this was a challenge, as many phenomenological studies focus predominantly on participants' verbal recollections of an experience. Nonetheless, I also

knew that phenomenological description isn't restricted to verbatim reports or surface detail.

Within Section 5.3 I referred to Linda Finlay's work on embodiment (Finlay, 2009). The author follows a more existential approach, highlighting that phenomenological interviews are embodied experiences and, as such, should take into account the 'whole' person. In the process of understanding an individual's experience, a phenomenological investigator must not only attend to the verbatim transcript but the meanings that are present 'within' the actual narrative (Todres, 2005). I therefore considered the participants' body language, tone of speech and vocabulary. When considering these aspects of an individual's communication, it is possible that a number of meanings could be indicated. However, the most important point I had to remember within a transcendental approach was to avoid a priori theory or assumptions when describing the participants' experience.

The methodological design included extra time for the less eloquent members of the group to discuss their experience. When considering their communication patterns, it is clear from my recollections of the session and the video recording, that I was flexible in the use of epochē. In order to make sense of their reflections, I utilised my prior experience of working with people who have a learning disability.

Q B Love (QBL)

QBL was the eldest in the group, a point which the other participants both acknowledged and respected. He frequently offered opinions in the first bereavement session and his outgoing nature ensured that whilst his language may have been limited, he nevertheless spoke with great fervour about his experience of grief.

Lyn

Lyn was a very quiet member of the group, who listened to conversations and on occasion would hesitantly contribute to a discussion. Whilst I knew she would not wish to be the centre of attention, I planned to quietly ask her a couple of questions when her peers were focusing on other activities in the room. I was not sure if she could read and therefore anticipated the illustrations might be important for her when reflecting on the experience of 'reading' Rosen's book.

Supergirl

Supergirl was one of the more reticent participants in the group. Although I wouldn't describe her character as shy, she was more reserved when joining in with discussions. Her speech pattern was particularly difficult to understand, so I planned to use the laminated illustrations to assist our communication.

Britney Spears

When I visited the family to seek consent for this study, Britney was very enthusiastic about our conversation until just after 7pm. Eventually, I asked her if there was something wrong and she muttered the words 'Emmerdale'. Apparently, she was missing her favourite television programme. Interestingly, although Britney appears to be extrovert, this illustration also indicates that if something else is deemed more important, she will very quietly discontinue with an interaction.

Britney had previously related her own story of loss to the group and the impact of this on her life. She frequently referred to anger, sadness and crying. This account was repeated whenever we met and I anticipated that it may arise within the data collection session. Consequently, I planned to develop our conversation further (if required), by encouraging a discussion about various other elements within the book.

Rudolf (the female reindeer)

Both Rudolf and Hoover had known Eleanor for several years and generously disclosed their experiences of grief during our initial bereavement session. The girls enjoyed interacting with Tharpa, a young male member of the staff team, and were very much conscious of his presence. I thought this may impact on the proceedings and knew that I might need to encourage them to re-focus and respond to the discussion about Rosen's book.

Initially, I was concerned the role-play within the data collection would be too childish for the older participants such as Rudolf. However, in the preliminary practice session Lulu, who was a similar age, had appeared to enjoy this particular way of looking at her experience. I hoped this would also apply to Rudolf and the older participants.

Hoover

Hoover had previously shown great patience in waiting for her siblings to explain their thoughts and feelings. In the first session her ability to be independent of thought, whilst at the same time being modest and listening carefully to others, was often proceeded by her own 'story' of loss.

Sarah

Following the death of Eleanor, Sarah had experienced a further close bereavement and the staff team were aware that she might discuss this within the session. I found myself wondering if this subsequent bereavement, a recent occurrence, would be more prominent in her mind. Whilst Sarah was a little quiet at times, she always remained interested in conversations and joined in when prompted. As with all the teenagers, Sarah was still at school and therefore possibly used to exploratory exercises, such as those I had planned to employ within the methodological design. I had been told that following the first session she had reflected on the topics discussed and comforted a bereaved family member, informing her that it is quite 'normal' to cry and feel upset.

Boothy

Boothy was the closest relation to the deceased and, as such, his lifestyle had understandably become disrupted. Although he did not formally live with the other participants, he was a constant presence in their household and supported very much by his extended family. Throughout our previous meetings Boothy was quiet and reserved, preferring to listen to what was being said, rather than join in with the conversation. However, when asked he always offered some personal insight into his experience.

Flashergirl, Dash and Spiderman

The three youngest children would not have known Eleanor for as long as the others. All had come from a complex home background and it is possible that, as with several of the participants, the death of Eleanor was not the only significant loss to have happened in their lives. This is an important issue and acknowledged throughout this thesis.

Flashergirl

During the initial bereavement session Flashergirl frequently wandered around the room. This prompted me to use two portable video cameras in order to capture the data, rather than just one on a fixed tripod. I also suspected that she would contribute to the conversation more than her younger siblings.

Dash and Spiderman

It was hard to say if the young boys had much recollection of Eleanor. In the previous session they didn't overtly disclose any particular emotions. Complex family dynamics (prior to their adoption) appeared to have greatly disrupted their development. Even though they were the youngest within the group, it was evident that their concentration was poorer than I would have expected for their ages.

A need for physical closeness, or to be the centre of attention, was evident whenever I visited them at home. They frequently sought tactile support, attention and reassurance. I thought it could possibly be the body language and movements of the two boys which might form the basis of findings, in relation to their experience of reading and discussing the book.

As can be seen from the above details, there were a wide range of personalities, ages, cognitive abilities and experiences of grief within the group. This confirmed the need to ensure a robust design was created, to ensure that the participants did not come to any harm and remained focused on the session. The design also took into account the young participants' right to feel safe (Creig and Taylor, 1999), alongside opportunities for them to discuss any concerns with the staff team.

Additional names

The staff team were not 'participants' in the investigation, their role was purely to assist with facilitating the session. Each person was provided with a pseudonym and details of their role are provided in Figure 5.

Pseudonym	Professional role
Esmeralda	Myself (author of this work)
Katrina	Until her retirement, Katrina had been the team leader within the hospice Family Care Team and was a qualified bereavement counsellor. As she had supported the first bereavement session with the participants, Katrina generously returned in a voluntary capacity, to assist me with this study.
Tharpa	Tharpa was a volunteer within the hospice and had previously worked with the family during their initial bereavement support session.
Superwoman	Superwoman was a staff nurse within the hospice. She had prior experience of working with children, some of whom had a learning disability.

Figure 5.   Details of the staff team

5.6   Résumé of the methodological design

At this point, it may be helpful to give a summary of main elements within this enquiry:

- Group interview with 11 bereaved children and young people, immediately after they read (together) Michael Rosen's SAD BOOK

- Follow up session for the children two weeks following the data collection period, to ensure there were no outstanding issues

- De-brief session for the staff team, once the participants had finished the bereavement study day and again two weeks after the data collection session

- A thorough reflection of my own experience when reading and discussing Rosen's book with the participants

Danaher and Briod (2005) encourage phenomenological researchers to consider a 'mixed media' approach when uncovering children's experiences. Therefore, text and illustrations from the book were projected onto the wall, with additional copies of the publication provided for each participant. A member of the support team read the story out loud and afterwards the group were asked to discuss and explore what they had just experienced. Laminated pages from the book were placed on the table and a series of questions used to gently encourage and stimulate discussion. The questions were designed to gradually assist the participants to explore their own unique experience of reading the book.

The above design of the bibliotherapy session considered various learning styles, namely visual, auditory and kinaesthetic (Frankel, 2009). Participants with a visual preference towards their learning would, in this instance, focus on images projected onto the wall and their copy of the book, whereas those with an auditory learning style might prefer to listen whilst the story was read out loud and subsequently discussed. Individuals who had a kinaesthetic preference to learning may incline towards specific 'activities' within the session, such as choosing a card to discuss and giving the book a mark out of ten.

An illustrated notebook was specifically created for the participants, so that they could write down any subsequent reflections after the session. I later met up with both the participants and support staff (at separate times) for a de-briefing session. The main therapeutic session, the focus of this study, was video recorded with subsequent de-briefing interviews audio recorded. The video recording was transcribed with regard to verbal language, intonations, body language and events that were happening within the room. A detailed personal reflection completed the data collection of the session.

The first anniversary of Eleanor's death was very near and I was mindful that the participants could have been experiencing increased levels of distress. Consequently, the study required a sensitive and detailed assessment, together with a clear protocol of the various elements to be included within the methodological design.

I followed a structure frequently utilised when facilitating child bereavement sessions (Stokes, 2004), by ensuring the participants were gradually led into the discussion with general, impersonal questions. This was followed by more probing techniques, devised to investigate how *they* experienced reading the book. I ensured that links were made to some issues discussed in the participants' initial bereavement session, thus allowing the staff team to continue and further develop conversations about coping strategies in relation to loss. The final part of the session was designed to acknowledge what had been said and bring closure on a lighter note, in this case by asking the group to give the book a mark out of ten.

5.6.1 Rules for the day

As previously mentioned, several months prior to the data collection session, the participants had already spent a day at the hospice. Therefore, they were fully acquainted not only with the environment and staff but also the 'rules for the day'.

1. Put up your hand if you have something to say
2. Don't run off
3. Don't go near the pond
4. If there is a fire, wait by the door for Helen
5. Have fun and plenty of chocolate biscuits
6. Don't laugh when other people are crying
7. Don't interrupt other people
8. It's OK not to do things you don't want to do

These 'rules' were created during the initial session, as a way of introducing important issues that needed to be considered when participating in a bereavement group. They covered some aspects of grief (rule 6) and also taught the participants about assertiveness (rule 8). Health and safety issues were points which had, in the main, been suggested by the staff (rules 2, 3 and 4) and then formulated by the group. The participants' contributions were intrinsic to the exercise, which resulted in rather a lot of statements containing 'don't'. I recognise that rule 8, 'it's OK not to do things you don't want to do', could be considered contrary to a phenomenological viewpoint, as you are never '...not doing anything'. Equally, I acknowledge the questionable grammar and phrasing. Nevertheless, I left the statements as they were suggested at the time, in order for the participants to recognise, understand and 'own' the rules themselves.

It became evident when reflecting on these rules that there is a possibility of influencing young people within bereavement sessions, for example, rule 6, 'Don't laugh when other people are crying'. Several rules were suggested by the staff, thus the inclusion of this one about crying. I questioned whether we merely reinforced common cultural expectations around bereavement, one of which is, '...grief upsets people and they cry'.

However, young people have to start learning somewhere. In Chapter 2, I highlighted that situations such as loss can be bewildering and confusing for young people. According to Gersie (1991), it is not wrong to suggest or introduce certain aspects of grief but advantageous. In so doing, this can provide a language for what is happening in their lives.

The above point was illustrated in a recent interview on Radio 4 (Harwood, 2008) regarding Michael Rosen's book. In the following extract Barney Harwood, the presenter, posed a question to one of the bereaved children present:

Barney: Do you think it's a good thing that we have these sort of books to read… or do you think it's just better to stay quiet and not say anything about it?

Child: I think it's good because it just says… because I think a lot of people feel like that sometimes… it actually says that it's OK to feel like that, it's normal to feel like that… it isn't just… ooh, I don't think I should be feeling like this.

5.6.2   Preventing anarchy and chaos

Trying out any new approach in a professional capacity always has the potential for external criticism. This study was no exception and one staff member made it clear that she felt the group was too large and should be split up. Normally I would agree, although after careful thought and discussion with a senior colleague, in this particular instance I disregarded her protestations and progressed with supporting the large extended family unit as a whole. To divide the group up chronologically would have created factions, comprised exclusively of individuals who had a learning disability, were adopted or related by birth. Even though a decision to split up the group may have been pragmatic, the participants may have interpreted the rationale for this very differently.

More importantly, all the participants had experienced the tragic death of Eleanor, just as many of them lived, communicated and shared experiences alongside each other. It therefore appeared illogical to suddenly separate the group when considering the impact of their bereavement. After discussing the matter with their parents, I decided to progress with the study as planned. If required, further individual support was available.

Several strategies were put into place so that, as far as possible, the session did not turn into a chaotic encounter. Rules 1 and 7 'Put up your hand if you have something to say' and 'Don't interrupt other people' were important, although I was flexible with these up to a point. According to Creig and Taylor (1999), creating a meaningful context (rather than a sterile, stagnant one), where children are allowed to influence their environment, is paramount in research. I also wanted to capture the spontaneity, immediacy and vitality of the participants and knew it was probable that there would not be silence within the room all the time. Far from being a negative element in the design, the background noise (which was evident at the participants' first bereavement session) appeared to improve the quality of their discussion. They were possibly more relaxed with this approach, as it mirrored the activity level within their home environment.

However, I planned to remind the participants of rules 1 and 7, if the noise and activity in the session increased to a level which was detrimental to uncovering their pre-reflections. This would allow those who needed more time to put their point across, or quieter members of the group, to participate fully. By implementing this flexible approach, each person would be afforded an opportunity to contribute within the session. A further pragmatic reason for my approach was a need to transcribe the findings at a later date, a task which would have been more difficult if everyone spoke at once.

5.6.3   Accessing pre-reflective descriptions

Chapter 4 explained that effectively accessing pre-reflective descriptions is central to a transcendental phenomenological design. Therefore, I needed to include a strategy in which the participants were assisted to describe their experience, as fully and deeply as possible (Jasper, 1994). With this in mind I did not set a strict timescale for the session,

although, based on my previous experience, assumed the discussion would last about 30 minutes.

Miller (1999) noted in her paper on undertaking a phenomenological study with children, that settling the participants into their interview was important. As an illustration, she asked them to talk about their 'normal day' and then naturally progressed to discussing issues in relation to the aims of her investigation. This strategy was utilised in my own study, where we discussed the book in general, before I probed deeper about more emotive issues within the story-line. Miller also audio recorded the interviews and used field notes to provide insight into the context of their lives. In a similar fashion, I also recorded the interactions and kept a reflective diary, thus providing additional details to supplement the verbal transcripts.

The group approach provided an opportunity to gather information in a responsive way, with respect to those who had a limited vocabulary. Some of the participants also had an unusual speech pattern, due to their Down's syndrome, yet I was able to glean what they were talking about from their siblings. Consequently, the participants' pre-reflective descriptions were a combined effort, in which they all interacted and created what transpired between each other. As the video recording captured their discussion, this provided both narrative and visual richness to the data collated.

In relation to the aforementioned points, Costley (2000) emphasises the importance of encouraging participants to relax and feel at ease, especially when a group has individuals with a learning disability present. Furthermore, she states that group interviews provide a greater opportunity to access data, as their companions can encourage participation and discussion of issues. By following this advice, the participants who had a learning disability not only received support from their siblings and had their pre-reflections clarified (where necessary), they were able to listen to the unfolding discussion about the story-line.

Gilbert (2004) expands Costley's suggestions of ways to include people with learning disabilities in research. He proposes that any perceived challenges may not be due to the participants with a learning disability but: the attitudes of professionals; power relationships; limited resources and an inadequate methodological design. In order to

address these issues, Gilbert provides an informative review of various methods which have been successfully utilised, including group work. A number of the studies reviewed, highlighted the importance of: using pictures to supplement a limited vocabulary; if a question is not fully understood, varying the way it is asked; video recording as well as audio recording, and analysing body language. All these considerations were addressed when developing the methodological design for this study.

As can be appreciated, had I used questionnaires or individual interviews to elicit the relevant information, this approach may have provided very different information and quite possibly limited data (with regard to pre-reflective descriptions). Equally, it is likely that there may have been little reference to the 'meaning of their experience'. Within the study, it was interesting to compare reflections from the children, teenagers and young adults who had a learning disability. The analysis methods which were developed to uncover this information are outlined in Chapter 7.

Several strategies were implemented to provide a stable structure, where the participants could feel confident in both their support as well as the environment. As an illustration, it would have been far easier for me to undertake the interview within the education centre where I was based. However, I suspected that the participants' familiarity with their physical environment was an important aspect to the methodological design. Therefore, negotiating and setting up the same room which was used on their first visit, did increase the amount of time I had originally allocated to organising the project. Nevertheless, carrying out the study in a familiar environment appeared to reduce the 'settling down' period, something frequently experienced with bereavement groups. By investing time to ensure the participants could quickly relax into the session, may have helped them to focus on the exercise and thus improve their pre-reflective descriptions.

5.6.4   Ethical considerations

Piper and Simons (2005) remind readers that ethical decisions are rarely straight forward and largely the result of weighing up a myriad of factors within any investigation. This cautionary note perfectly set the tone for a process which required constant adaptation and negotiation, with many legal, ethical, professional and policy issues to be

addressed.   No approval was required from the NHS Research Ethics Committee because the participants were not recruited as National Health Service patients.   The Director of Clinical Services at the hospice formally signed a letter to confirm this matter.   However, several guidance documents were examined, to identify considerations which needed addressing when undertaking a study that included vulnerable young people.

Informed consent was duly obtained from those involved in the investigation.   Nevertheless, The National Council for Palliative Care (NCHSPCS, 1995) addresses this issue and stipulates that simply obtaining consent is no justification for proceeding, if a researcher is not confident about the participants' well being.   According to the guidance document, a useful test of ethical propriety is whether the researcher would consider participating or encourage their family to do so.   What appears to be suggested is something akin to the saying, 'treat others as you would like to be treated yourself'. Whilst this may seem a minor point, it was actually one of the guiding principles within my study.   I considered the above not only when planning and implementing the session, but when transcribing the data, analysing the findings, writing up this thesis and during formal presentations.

A further publication by the National Council for Palliative Care, explored research and development within hospice and specialist palliative care services (NCHSPCS, 1999).   It asserted that involvement in research is essential if services are to develop clinical practice and progress practitioners' knowledge.   As with other documents on this subject, the report states that investigators must remember to balance the fundamental principles of autonomy, beneficence, non-maleficence and justice.   Illustrations of how I ensured these principles were intrinsic to the whole study are entwined in the majority of chapters within this thesis.   According to the report, research involving patients or carers must first be approved by a research ethics committee, details of which are below.

In addition to the above specialist palliative care guidance, local and national documents, including those of the Nursing and Midwifery Council (NMC), were consulted.   Due to the sensitive practice required when working with young participants, the 'Patient's Charter and Services for Children and Young People' (Department of Health, 1996) was also taken into account.

Katrina and I had recently attended training on safeguarding children and all the staff team had undergone Advanced Criminal Record Bureau checks. Three in the group were nurses and therefore followed guidelines from the Royal College of Nursing, in relation to safeguarding children and young people (2003). Further clinical documents considered include:

- Code of Professional *Conduct (NMC, 1992)*
- *Scope of Professional Practice (NMC, 1992)*
- *Guidelines for Professional Practice (NMC, 1996)*

Relevant guidance from the above documents was implemented within the methodological design. As an illustration, The Guidelines for Professional Practice (NMC, 1996) recommended that, as a nurse, I have a duty to accurately assess, record and evaluate my practice, a point which was integral to the design and included within this thesis. [The above documents have since been amalgamated into 'The Code: standards of conduct, performance and ethics for nurses and midwives' (NMC, 2008)].

My dual role, as principal investigator and practitioner, was both recognised and monitored by my PhD supervision team and the Hospice Research Monitoring Group. In line with guidance from the National Council of Palliative Care (1999) and Research Governance Framework for Health and Social Care (Department of Health, 2001), I met with my supervisors, the Research Monitoring Group and the Director of Clinical Services, on a regular basis. Questions relating to my adherence of university procedures and hospice policies were fully answered and progress reports duly submitted.

Approval for this study to take place was sought from the University Ethics Committee and the Research Monitoring Group. This latter group included: the Chair of the Hospice Trustees; Director of Clinical Services; Clinical Development Nurse and Hospice Counsellor. After submitting reports and subsequent formal interviews with both organisations, ethical approval and permission for the study to proceed was granted. However, obtaining approval was only the beginning of a continuous process that ensured the study considered all the areas covered within this section.

There have been several occasions when I knew the data would be enriched and arguments strengthened, if anecdotes or disclosures from outside the session were included. However, to do this would have necessitated contacting the participants and their parents once more. To go back to the family and re-introduce material from a very difficult time in their bereavement would not, in my opinion, have justified my request.

The above decision was influenced by a Radio 4 interview (Harwood, 2008), in which a bereaved child interviewed Rosen and asked if many people had talked to him about the book. He answered, in an honest and insightful way:

Rosen   I was doing a show the other day and a woman came up and said it had helped her very much. Sometimes it can be difficult because my mind can be on telling a funny story and then suddenly I'm rushed off by what this person has said …into a box where I'm sad about Eddie dying …do you see what I mean ...so it's quite difficult ...there might be a queue of people and somebody saying something funny and jokey ...saying do you like this joke? ...and then suddenly somebody says thanks very much for writing the SAD BOOK because my brother died …or something like that and I'm kind of ash …and it's quite difficult, it catches my breath... you know?

Child   Oh yeah

Rosen   It's like you're going along fine and then suddenly there's the fact that Eddie died suddenly in the front of my head and I had done the thing where I've pushed it to the back so that I can get on with today and then this person has brought it right to the front and so there's a little [short intake of breath] inside me when that happens.

On consideration of the above, I decided not to contact the family and introduce any further requests for supplementary information at such a late date. Whilst it may have enhanced or substantiated some of the data further, I did not consider this either necessary or justifiable.

5.6.5   Safety precautions

I ensured full access to medical personnel and first aid resources would be available during the data collection period.   As previously noted, the study took place at a registered healthcare facility where all necessary risk assessments had been completed and were duly followed.   In addition to formal procedures, the participants were reminded of health and safety during the 'rules of the day' exercise.   This included rules 2, 3 and 4, 'Don't run off', 'Don't go near the pond' and 'If there is a fire, wait by the door for Helen'.

As the de-briefing interview with the participants took place in their own home, I was required to comply with the hospice policy for visiting families and patients off site.   The reception staff had been informed of where I was going and my expected time of arrival back at the hospice.   During this de-briefing an unexpected occurrence arose.   Whilst undertaking a creative activity which focused on coping strategies, one of the children drew a picture with the accompanying words 'a gun has shot the kid'.   Due to his previous experience before adoption, I was concerned about the possibility of any child protection issues and unsure as to whether I should discuss this with his parents.

Fortunately, after discussing the above situation with my supervision team, it transpired that the young child was actually discussing (albeit in a limited fashion) a scene from his favourite film, entitled 'Power Rangers'.   This was deduced both from his pseudonym, that was one of the characters in the story, and his drawing which had the film title written at the bottom.   Following this development, I watched Power Rangers to immerse myself in the story-line should another phrase relating to one of the characters have arisen within the transcription stage.   This scenario has been included to highlight the point at which I realised the participants' language contained both cultural and age-defined characteristics, some of which were not always immediately transparent.

5.6.6   Data protection

In line with recommendations from the NMC (1992), regarding the confidentiality of all participants and staff, pseudonyms had been utilised.   These were then incorporated into the data collection transcriptions, reports for the various organisations, poster displays, presentations and minutes of meetings.   Obtaining full consent was sought for

the use of quotes from the participants and their parents, in accordance with the Data Protection Act (1998). The confidentiality policy at the hospice explicitly stated:

"In respect of health care, there is an established common law duty of confidentiality in the following circumstances:

- where information is not a matter of public knowledge
- where information is entrusted by an individual in confidence, there is a general obligation not to disclose the information without consent…"

Access to the data was thereby restricted to myself, as principal investigator and the supervision team. All details were stored in a secure location and included: videotapes; reflective diaries; interview transcripts and artwork from the de-briefing interview. Once this study has been fully documented and examined, this information will be destroyed, under the guidance of my Main Supervisor and the Information Technology Manager at the Hospice. Before the data collection period took place, reference to this element of the study was included on the information sheets and consent forms.

A further methodological issue arose after the session when several of the younger children wanted to have their own copy of the video, perhaps thinking of the material in a similar way to their family video recordings. After much deliberation, I surmised that they did not have the capacity to fully appreciate the implications of their request, especially with regard to the sensitivity of the material. I was conscious of the older participants who had shown some discomfort with the recording and not sure how they would react to their experience being viewed by a potentially wider audience. Consequently, I sat down with the younger children and explained the reasons why it would not be possible, in this instance, to comply with their request.

5.6.7   Safeguarding children and protection of vulnerable adults

The vulnerability of the participants has been a consideration applied to all aspects of this study, especially within the methodological design. Whilst the involvement of young people, some of whom had a learning disability, was an essential component to the study, it also presented certain ethical issues (Costley, 2000). As an illustration, it was not clear whether all the participants *fully* understood what their involvement in the whole process meant. Informed consent was therefore sought from their parents, in

accordance with guidelines from the British Psychological Society (2004). Although my actions did satisfy all the formal requirements, I was also aware of the Human Rights Act (1998) which asserts that young people should, wherever possible, make their own decisions.

Therefore, whilst I knew the participants would not be able to meet all the criteria for informed consent, my endeavour to creatively present the main issues continued. For example, I introduced the subject of confidentiality to the group by inviting each person to choose their own pseudonym. Colourful badges were then created before the data collection session, highlighting their new 'confidential' identity. During this process I also explained that the tape recording would be destroyed after the study. Whilst we undertook the exercise, I reiterated the reason as to why both strategies were needed. The pseudonyms chosen were both contemporary and seasonal, including Rudolf; Spiderman; Flasher Girl and Britney Spears.

Following the data collection session, two important documents have been published that merit particular attention. The RCN document 'Informed Consent in Health and Social Care Research' (RCN, 2006), asserts that people with learning disabilities must be given the same respect as anyone else and protected from harm when participating in research. Furthermore, even though participants may not be able to fully exercise their right to self-determination, they should be offered choices within their capabilities. The use of plain language and pictures to explain the nature of an investigation, were recommendations which had been implemented within the methodological design.

The second document was 'The Mental Capacity Act (2005) Code of Practice' (Department of Constitutional Affairs, 2007). In order to consent when participating in any research activity, the report specifically states that individuals (both adult and children) should satisfy a lead investigator of their capacity to understand the study and their role within it. Furthermore, all decisions must be made in the participants' best interests.

An illustration of how the methodological design incorporated elements from both the above documents can be seen in the following examples of good practice. The first of these involves the time allocated to explain my study to the group, not only before the

data collection period but during the actual session. We discussed how their reflections would be used to help me show others about the experience of reading the book. I explained that this would enable professionals and carers to support other young people going through similar experiences. My second example concerns the issue raised in rule 8, in which all the participants were reminded about their right to choose whether or not to discuss certain matters or indeed take part in the session. This was then translated in the rules as, 'It's OK not to do things you don't want to do'.

Despite the use of pseudonyms, anonymity was one of the most challenging aspects to working with the family. Not only was their complement unique, they were easily identifiable in the locality where the study took place. Therefore, to increase the participants' anonymity, specific details of their relationship with one another have been omitted. More importantly, details of Eleanor's death were not recorded on any of the documentation, nor have they been shared with my supervision team or the Research Monitoring Group.

As noted previously, during the course of my studies I initially planned to add some images from the video into several interim presentations. The relevant parts were successfully captured digitally with faces and other identifiable characteristics suitably disguised. However, despite these measures the participants' anonymity could have been breached. As previously discussed, my particular concern was in relation to one individual who had within his/her adoption contract a prohibition on the use of any visual images that may identify his/her whereabouts. Whilst it would have been easy to remove one person from the pictures, I still had reservations about this approach and knew several of the other participants had been adopted from complex family units. Even though recognition by an academic audience would have been unlikely, I made the decision not to take any chances and erased their images. Despite a possibility that they would have added to the visual interest and quality of the presentations, once again, I thought this element to my studies was not justifiable.

5.6.8 Emotional vulnerability

In discussing death and dying, there is always a possibility that some participants may become distressed. Therefore, the staff team were briefed before the session in relation to potential issues which could have arisen. According to Stroebe et al. (2003), an

investigator is essentially 'an intruder into the world of the bereaved' and must fully respect any decision a person may take, even if it is not to participate in a research project. As previously stated, this consideration was integral to the design and during the 'rules for the day' exercise. The group were informed that if the questioning was upsetting or they didn't want to take part, then support would be provided as required (Creig and Taylor, 1999).

Before the data collection period I discussed the project with Rachel Balen, Principal Lecturer in Social Work at Huddersfield University. Balen has a wealth of experience in undertaking research with children (Balen et al., 2006), in particular negotiating ethical issues. During our meeting I became aware that the participants might feel vulnerable when talking about their experiences, especially if the book had a significant emotional impact upon them.

To address the above issue, we looked at the possibility of utilising role-play and included this within the methodological design. We asked the participants to pretend they were reporters from CBBC, giving a presentation about the book to their viewers. Initially, I had wondered if this approach would be too basic for the teenagers and young adults. Fortunately, as the findings will testify, the majority of participants seemed to find the idea fun. This approach was designed to help each person feel less pressured and more relaxed, by having an opportunity or option to speak in the third person. Once this happened, several of the group expanded their discussion to include personal experiences of grief, full details of which are in Chapter 8.

Psychological support for the participants was available through the qualified staff present and, in particular, the dual role of one volunteer who was a professional counsellor. Equally, the de-briefing session (two weeks after the data collection period), was designed to follow up any further questions or concerns that had subsequently arisen.

The issue of professional vulnerability when listening to emotional disclosures of bereaved children and young adults was addressed. The staff team all had a debriefing session once the participants had gone home, to discuss any issues of concern and reflect on what had transpired. This was followed by a meeting two weeks later, to

ensure that any further issues could be raised. Both during and after the data collection period, I experienced a feeling of vulnerability due to a family member's illness and subsequent radiotherapy. Disclosures which previously would have had little personal impact did, for a short period of time, become very uncomfortable when listening to or watching on the video. Similar to all professionals within the hospice, I had access to in-house support and utilised this over the following year.

In a completely unexpected way, the participants helped to 'buffer' some of the emotive aspects of the transcription, by their creative pseudonyms and an honest, energetic approach to the discussions. I frequently found myself smiling and reassured that despite the many aspects of their lives which potentially involved sadness, they also exhibited tremendous resilience. Their innate ability to seek out the humorous and enjoyable aspects of their lives was a pleasure to witness.

5.6.9 Transparent practice

To support the participants who required a visual prompt when discussing their experience, I laminated pages from Rosen's book to spread out on the table. These prompt cards were frequently used, predominantly as an aide-memoir. This strategy assisted those who couldn't read, thereby enabling them to discuss or describe the illustrations. Due to the requirement of compliance with copyright legislation (University of Huddersfield, 2009), I ensured these prompt cards were used only for therapeutic purposes within the session and will be destroyed once the study is complete.

In addition to the video equipment, the main session was digitally recorded to provide 'back up' verbal data. Unfortunately, once the data collection had finished the audio equipment was not turned off, thereby recording conversations from subsequent sessions. To transcribe the verbal recordings at a later date, would have necessitated all the participants' details to be kept over the Christmas period, thereby storing 'covert data'. I erased the material as soon as the discovery was made.

Whilst it would have been very easy to justify storing the tapes and only transcribing the relevant material, I knew that this would have taken some time. I also felt it was unfair to keep material I did not have permission to first of all record and then store. Kuper et al.

(2008) discuss this issue, in relation to where covert personal experiences are disclosed within the data.

Furthermore, the need to minimise harm involves not only protection from external scrutiny, but mechanisms to mitigate the potential distress of participants when their personal stories are shared with others. In this situation, I instinctively felt that neither the participants nor staff would have wanted their covertly recorded comments listened to outside the context of the session.

5.6.10   Puddle jumping and chocolates

Puddle jumping is a term used to describe how some bereaved children switch easily and frequently between discussing very sad emotive issues and being completely absorbed in another activity (Winston's Wish, 2008). It is deemed to correspond with a young person's innate ability to 'live in the moment'. Furthermore, their lack of capacity to experience grief continuously, over a protracted period of time, results in a more 'intermittent' grief. This aspect of working within child bereavement settings is one I have frequently encountered and therefore ensured the methodological design reflected this issue.

Although I knew a break would be required half way through the discussion, I didn't want to interrupt the proceedings significantly. On the first bereavement study day, the older participants and staff had a warm drink during their morning break, whilst the younger ones chose to go outside and have a run about. After much careful thought, I decided we would all have a quick 'working' chocolate break. Whilst there may be some who would question the nutritional value of the snack, I knew the group well enough to be confident that my decision would be both welcome and popular. Thus, a positive 'moment in time' was created, offering them an opportunity to puddle jump and discuss which chocolate (or how many) they would have.

5.7   Summary

In summary, whilst involving bereaved young people and adults with a learning disability in any research study does need to be carefully and sensitively considered, evidence based practice is also essential within healthcare services. The methodological design, as described within this chapter, not only enabled me to operationalise the aims of this

study but provided a safe and trusting environment for the participants. I hope the information uncovered within my project both justifies and balances the concerns noted and that the findings will subsequently inform and support carers and practitioners, ultimately benefiting a large number of bereaved children and young people.

CHAPTER SIX

COMPILATION OF THE DATA: a unique adaptation

As will become clear within this chapter, initial transcriptions of the recorded session were limited, requiring further information to substantiate what had occurred and thus increase the adequacy of the description. The data were particularly unusual for a phenomenological study, especially in relation to a narrow range of vocabulary used by the participants. Rather than rely on a verbal transcription alone, I considered ways in which their pre-reflective disclosures could be uncovered from other supplementary sources of data. A number of strategies were creatively explored to develop this option further. These included documenting contextual issues (such as what was happening in the environment), body language and intonations, alongside details of any further issues that might have influenced the verbal contributions. The final strategy was to write a very specific personal reflection of my experience when facilitating the session.

Throughout the whole process, due care and attention was paid to applying horizontalisation and epochē, thus suspending theoretical and personal interpretations. Patiently and meticulously all the data were collated, until the accumulation of material resulted in a transcription which portrayed a detailed account of the session. This chapter commences with an explanation of how I applied epochē, then transcribed and horizontalised the data. I will progress by outlining the creation of a framework to formalise my personal reflection and the way this complemented the transcription of the session. To conclude, an explanation will be provided of how all the data were merged into a substantial document, which adequately portrayed the participants' experience as they read and discussed a book about death and dying.

6.1   Epochē

As already noted, the process of epochē is pervasive and the various techniques utilised for this purpose are documented within several sections of my thesis. Here I will outline the way it became an intrinsic part of how the various sources of data were collated.

From the initial planning stages, copious personal notes from debates and discussions within my supervision meetings had been documented. These frequently related to

personal views and assumptions of events I either expected to transpire or, much later, regarding what had taken place in the data collection session. The notes contained issues I thought may influence my attitude to the data, such as reading undertaken during the course of my work, conversations with colleagues or students and issues that came to light from television programmes or newspapers.

As this process unfolded I became much more proficient at incorporating epochē, gradually developing a greater awareness of when assumptions were made. These instances were not only during the planning and facilitating stages but when the data were transcribed, analysed and transformed. As an illustration, during the planning stage I experienced recurrent thoughts of whether the participants would respond in a similar way to other bereaved children and young adults I had previously worked with. When this occurred, I turned my attention to the task in hand and ensured a variety of contingencies were in place, should they react in an unexpected way. The occurrences were recorded so that I could revisit them at a more appropriate point, once the analysis had taken place. Whilst this process was informal, it ensured I acknowledged these influences, thus reducing the impact they had on whatever activity was being undertaken at the time.

Following the data collection period, a further strategy used to incorporate epochē was by undertaking a detailed and *formal* personal reflection of the session. I noted what transpired, acknowledging assumptions and theoretical insights which frequently emerged in my thoughts (even when undertaking the reflection). Although there were periods when this task was laborious and time consuming, it provided a disciplined approach which subsequently allowed me to re-focus my thoughts on the session itself. Fortunately, as theoretical reading was temporarily suspended until after the data analysis period, I was able to re-assign time that would have been spent on this activity and use it to document aspects of implementing epochē. Thus, the detailed literature search was diverted until after epochē was applied to all the evidence collated.

Husserl's method of describing and uncovering a phenomenon, before examining the findings in relation to literature or theoretical information, contrasted to strategies I had utilised before. During the planning stage, I had not appreciated that such a small change in how the data was approached would result in an exceptionally detailed description. My previous research experience had involved teasing out themes that

frequently occurred within data, much of which had been collected in a relatively short space of time. By implementing a phenomenological approach I was able to step 'beyond' my normal assumptions of what would unfold and look at the participants' experience with an open mind, without dismissing any information at too early a stage in the analysis. In short, Husserl's process of epochē enabled me to avoid influencing the participants' pre-reflections and thus uncover new insights.

6.2   Transcription

Transcribing the data evolved over several months, providing an accurate and adequate account of the participants' experience. As discussed previously, I commenced by viewing the video on a number of occasions, sometimes writing down comments, whilst at other times simply watching and listening carefully to what the data revealed. With these preliminary notes, I designed a blank template that allowed the spoken text to be documented alongside a separate column. This latter space contained details of relevant body language, intonations, digital reference numbers or explanations of what was happening within the room. The additional contextual information offered a more holistic document, which started to increase the adequacy of the description. Figure 6 provides an illustration of how the transcript was initially created (my own comments or questions are in italics).

Spoken text	Intonation; digital reference numbers; main events of what is happening within the session
When you're sad what do you do?	[To Flasher Girl]
Flashergirl Run upstairs	
You run upstairs? Oh… do you ever talk to your sisters, your brothers?	Flashergirl shakes her head
Hoover You always talk to me, what are you lying for?	
Do you talk to Hoover sometimes?	Flashergirl nods
That's really good that you've got someone to talk to isn't it?	Flashergirl nods again

Figure 6. Development of a template to accommodate both the verbal transcription and
supplementary information.

From the above illustration, it is clear that without the information of Flashergirl's body language, the spoken text would not have fully represented the interaction. Nevertheless, whilst the transcription was becoming more detailed, I was certain it could be improved further. The document still failed to convey elements which related to the quality of the interactions, atmosphere within the room or the warmth of communication between individuals. After discussing this dilemma within a supervision team meeting, it was suggested that it might be useful to consider supplementing the data with relevant notes from my reflection of the session. Details of the structure created to formalise this personal reflection are described within Section 6.4, together with an illustration of how the supplementary data were merged with the original transcript document.

6.3   Horizontalisation

As mentioned in Chapter 4, horizontalisation emphasizes the importance of approaching any investigation with an open mind, considering the phenomenon from many different positions. In order to remain true to the underpinnings of transcendental phenomenology, this strategy became an important aspect of how I considered the data. Whilst Husserl did not necessarily follow his Jewish cultural heritage, it seems apt that the Hebrew way of looking at things is to go round and round a subject, each time using different images to illuminate what is most profound (Symington, 1992).

The above method of 'going round and round' the participants' experience became intrinsic to my approach, whereby I contemplated a variety of perspectives until satisfied that I had covered as many aspects as possible. However, due to such a different epistemological approach from those I had utilised in the past, the challenge was to avoid repeating techniques I was familiar with and confident in using. It was tempting to use a thematic approach by explaining or interpreting the data, rather than persevere with a transcendental approach and thus arrive at a pure description of the phenomena. Therefore, great care has been required at all points, especially during the period where I utilised horizontalisation.

When undertaking this process, several techniques were incorporated within the methodological design. Firstly, I was present at the data collection period and had

subsequently reflected on the proceedings by writing an assortment of notes over many months. Immediately after the participants went home, I also allocated a specific period of time for reflecting on what happened within the session. This consisted of a de-briefing meeting with the staff team and a separate period to record my reflection of what transpired. A few days later, I had an evaluation of the data collection period with my Main Supervisor at the University. All these immediate recollections were written down, generating invaluable data, which were later used in my personal reflection document and the formal commentary, as discussed in Section 6.4.

The recorded data of the session were transferred digitally to my computer, thus allowing me to periodically view sections whenever an opportunity arose. This strategy was of tremendous value when writing my formal reflection and allowed the data to be seen without sound, thereby increasing my focus of the participants' body language. I also transferred the data into a digital audio recording, allowing me to hear the voices of the participants without looking at the visual image, thereby concentrating on just the words. In the following weeks and months, I viewed the recording alone and with my supervisors, all the while making copious and detailed notes from my observations and our discussions. A further interview with the staff team provided a number of valuable insights which were subsequently incorporated into the data. An illustration of this was their observation that the participants wanted to discuss the dark, emotive pictures, rather than focus on the lighter and humorous pages within the book. They also remarked on how valuable the publication had been in stimulating the group to explore their experience of grief.

Once all details were collated, I continued to consider the information in various ways, gradually developing a strategy which enabled me to merge the various documents together. As previously illustrated in Figure 6, my first task was to note the verbal language and complement this with contextual information, including details of distinctive body language or what was happening in the room. Finally, I added a commentary to the transcription with details from my reflection, a process discussed further in the next section.

Horizontalising the data, in a way that incorporated epochē and thus avoided any theoretical interpretation was incredibly difficult, requiring constant self-surveillance.

Despite the challenge it presented, undertaking this approach allowed me to concentrate on looking at the session from as many perspectives as possible. In so doing, I learnt an increasing amount about the participants' experience, rather than my own premature interpretation. Slowly, I began to understand the data in a much clearer way, all the time remembering to only describe and confirm what happened, instead of what I expected or was looking for. The following section will provide an account of how the transcription was enhanced further by my personal reflection.

6.4 Personal reflection: utilising the Seven Hat Framework

It became evident that I needed to formalise my personal reflection, with the intention of making my notes much more integral to the data than I had originally planned. From the initial stages of this investigation, I had kept an abundance of details regarding all aspects of the study, including reflections from the session. These contained details of what I found immediately interesting, distinctive or insightful about a particular individual, or an interaction which had taken place. I also considered what the participants said about their experience and other superfluous details. As an illustration, I wrote about how the book merged into the background when the group focused on their enjoyment of the CBBC role-play, eating chocolate and playing with puppets.

My dual role, as principal investigator and practitioner, had resulted in an unstructured system for recording a myriad of details, all written in freehand style. There were so many facets to consider when formally compiling the reflection, that it was difficult to know how to undertake this task without missing any key elements. It soon became apparent that I needed to progress in a logical way, yet provide enough detail to present a thorough account of the participants' experiences. Not only did I wish to make sense of the experience and record the positive aspects, but also highlight some of the challenges.

When searching for a suitable structure to assist with the above task, I looked wider than traditional phenomenology literature or nursing texts and came across a publication by Edward de Bono, entitled 'Six Thinking Hats' (1999). The premise to the author's work was an acknowledgement of the difficulty experienced by many individuals when thinking about situations. As an illustration, when reflecting on predicaments, it is often our emotions, information, logic, hope and creativity that can lead to confusion.

According to De Bono, this is "...like juggling too many balls [in the air]" (De Bono, 1999, p.xi). The author's rationale for writing his publication resounded with my own experience, in which I needed to find a way of calming a tumult of thoughts and undertake a detailed reflection of what had transpired. I found myself contemplating questions such as 'where should I start?', 'what needs to be included?' and 'how much detail needs to be written?'

I had previously used the Six Thinking Hats within my role as hospice tutor. A teaching session with senior clinical staff, entitled 'Managing Conflict', had evaluated well. They found both the simplicity and practical application of De Bono's work helpful. This method was originally designed to help groups solve problems or differences of opinion and move forward with complex issues. Whilst it was not designed as a tool to reflect on data collection sessions, I felt certain elements of the structure offered a potential solution to the dilemma I faced. With encouragement from my supervision team, I tentatively explored various ways of applying the framework and hoped, with certain modifications, it had the potential to guide and enhance my formal personal reflection.

When utilising the 'Six Thinking Hats' within a transcendental phenomenological context, it was necessary to be very clear about how I intended to utilise the method, especially the modifications required when incorporating it within my study. I applied the same discipline and focus as De Bono's publication suggested. This strategy provided an opportunity to centre myself and consider just one particular aspect of the session at a time. The publication explained in great detail how to progress and suggested that it was possible to separate creativity from facts and figures, logic from emotion, and so forth. According to the author, this strategy maximises a person's ability to look at particular situations from a variety of directions, in a linear and ordered fashion.

De Bono's view, that logic can be separated from emotional thoughts, does appear to counter the very core of phenomenological methods. It is important to be clear that I do not subscribe to what may be interpreted as a compartmentalised view of human experience. Nor do I agree with some of the terminology referenced within the publication, such as 'brain or thought processes'. Phrases such as these do not fit within phenomenology, whereby it is not considered possible for experiences to be reduced to mere thought processes. Nevertheless, although the original method was modified

significantly and placed within a phenomenological context, it is still important to acknowledge De Bono's inspirational work, which ultimately allowed me to improve my reflection on the session.

Whilst I did not agree that it is possible to separate logic from emotion, in pragmatic terms the basic structure of the Six Thinking Hats was remarkably useful. It allowed me to freely write down elements of the session that each particular focus (hat) prompted me to recollect. However, if I thought of an unrelated issue, it was usually prompted by the section being written at the time. If I postponed documenting any unrelated points, not only would my 'train of thought' have been compromised but the context in which the issue had been remembered would have been lost. Whilst taking this approach did merge several areas, the rationale for undertaking the exercise was to increase the quality of my reflection, rather than dwell on whether all the details were in the 'correct' hat.

The framework was modified and utilised as a way of embracing 'imaginative free variation' (Don Ihde, 1986). This term, similar to horizontalisation, relates to the process of looking at a phenomenon from many different perspectives, by imaginatively varying its features (Langdridge, 2007). Therefore, by utilising De Bono's method I had 'imaginatively varied' my focus of the bereavement session, with a view to enhancing the recorded data. The most significant modification was the addition of a seventh 'Orange' hat, representing the transcendental significance of the session. A very succinct description of the Seven Hat Framework, including this additional hat, is provided in Figure 7.

COLOUR OF HAT	FOCUS FOR REFLECTING ON THE SESSION
Blue hat	Calm, controlled and organised introduction
Green hat	Surprising and unexpected elements, as created by the design

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Black hat	Things which were not perfect: a consideration of the weaknesses
Yellow hat	An optimistic view of the session: evidence of therapeutic outcomes
White hat	Outstanding pragmatic details of what happened during the session
Red hat	A reflection of the emotional encounter
Orange hat	A transcendental view: elements that created a meaningful and valuable encounter
Blue hat	A final reflection on the session as a whole: how it transpired, with a provisional summary of the outcome.

Figure 7.   The Seven Hat Framework

Interestingly, there was a similarity between De Bono's method and the strategy I utilised in the data collection period. With the latter approach, I asked the participants to pretend they were reporters for CBBC, providing a news report on the book for other young people. This 'third person narrative' allowed them to use a guise when talking about their personal feelings. Similarly, De Bono states that the process of using the 'Six Thinking Hats' is akin to de-personalising thinking, removing worries of 'exhortation and condemnation' from peers.

In line with De Bono's guidelines, I maintained a disciplined approach when directing my focus to the data collection session. At first this was more of a challenge, due to my habitual approach of reflecting in a certain, often chaotic, manner. I endeavoured to allocate a significant amount of attention towards each respective focus (hat) and found some hats easier to utilise. Whilst the publication suggested certain hats, such as the red (emotional) one, may demand less time to complete, this did not transpire in relation

to my reflection. The importance of employing a systematic approach to the process was also emphasised and De Bono suggested that the blue hat (calm, controlled and organised) should always be used at the beginning and end, almost like two bookends. In the first instance, this provided an introduction to the session, along with a rationale for why it took place and the preparations required.

When looking at the sequential patterning of the remaining hats, I consulted with additional literature on the subject of reflection, in conjunction with my own professional experience. I decided to use a little 'sandwiching', a term often used anecdotally within nurse communication training. This describes the stages within an interaction where an individual is firstly eased into a conversation, progresses to discuss more difficult issues and finishes with information and details the person is more comfortable with. The aim is to provide a sequence to the discussion, in which clarity of an issue is found. Furthermore, if the conversation is about a complex dilemma, then hope and increased knowledge of how to move forward, in a positive way, is encouraged. In consideration of this point, I progressed with the green hat which is said to represent a person's creative thinking. This centred on the pragmatic elements of the session, such as the tools utilised, pseudonyms, chocolates and puppets. I considered it to be one that would be interesting, not too emotional and thereby gently ease myself into the formal reflection.

De Bono suggested using the yellow hat (positive/optimistic) prior to the black hat (cautious/pointing out weaknesses). The rationale for this was due to a tendency for individuals to perceive many obstacles when utilising the black hat. He proposed that if all the benefits (yellow hat) had just been discussed, then an individual would be in a better position and more motivated to overcome the perceived obstacles. Conversely, if a person starts off by seeing all the difficulties, then their focus may be totally different.

However, Johns (2002) observes that within healthcare, when individuals commence guided reflection they initially tend to share experiences which are imbued with strong negative feelings and then "…like cream, the negative feeling rises to the surface of consciousness from the vast weight of experience" (Johns, 2002, p.8). According to the author, over the subsequent period they will then start to reflect on more positive occurrences.

The above observation mirrors my own experience of reflection within clinical supervision, where staff are more inclined to reflect on 'things which went wrong' rather than their positive experiences. Frequently, it is not until later that more favourable points are raised. Therefore I changed the sequential pattern of the 'hats' and placed the Black hat much earlier than De Bono had suggested. In this instance, I felt that the green hat (creative/new ideas) was a more suitable choice to precede the black hat and then follow this with the yellow hat. I progressed by utilising the white hat (neutral/objective), thus providing an opportunity to bring some 'objectivity' to the reflection, by focusing on the pragmatic details of what had occurred. This was closely followed by the red hat which supported me to acknowledge more emotive recollections from the session.

The orange hat, specifically created by myself, symbolised the transcendental elements of the session. The colour orange was chosen to represent issues which resided within my own belief system, identifying what it was that enabled me to view the experience as having value and meaning. Whilst it was quite a challenge to reflect on and describe this in a tangible way, it perfectly represented my particular transcendental experience of the session. This aspect to my work is of great importance, without which I could not envisage working within a hospice environment. Addressing this personal element to the session appeared to be a perfect ending for the reflection, alongside the blue hat overview. An excerpt from the seventh 'Orange' hat is provided within Figure 8.

ORANGE HAT

- Transcendental realm of the session

I was conscious of a certain connection to the participants and enjoyed meeting them for a follow up interview. However, whilst I felt no need to continue the relationships formed, an approach that helps to place my work in context, it was interesting to observe the recording and see how I supported this bereaved group in a caring and professional way.

All the participants and staff members were a joy to be with, as everyone seemed to appreciate interacting with one another. The warmth of their interactions reassured me that supporting them all together, in such a large group, was the right approach. At times, the session appeared to be simply a natural part of their grief journey.

Discussing various ways to manage their situation was emotive but ultimately very rewarding, transcending any material sense. Teaching and supporting the group was something which sat comfortably within my personal beliefs. Even though grief is one of the most difficult experiences to manage, I instinctively knew the participants' innate resilience, together with skilled support, would assist them in learning how to cope with their loss. Providing a setting in which they could learn from and understand reality, whilst at the same time feel supported or able to say out loud what was upsetting them, was very worthwhile.

Figure 8. Excerpt from the Seven Hat Framework: personal reflection (Orange hat)

After completing the formal reflection (see Appendix 10), it was clear this pragmatic approach offered an opportunity to methodically contemplate the session from many different angles, some of which I would not have otherwise considered. In comparison to my prior research experience, utilising this framework enhanced the way I was able to document my reflections. What transpired was a thorough and detailed account of all the elements I had experienced within the data collection period.

6.5   Development of the commentary

Gradually, the additional sources of data became available and I was able to enhance the verbal transcripts. As noted above, the reflection allowed me to access further evidence of the more intangible elements within the session. These included the quality of interactions, atmosphere within the room and warmth of communication between individuals. Previous sections have outlined other data which included documentation of contextual matters (such as what was happening in the environment), the participants' body language, intonations and details of issues that may have influenced the verbal contributions. As illustrated, this information was gleaned from a variety of avenues and comprised not only of my recollections but discussions with staff and viewing the video recording.

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The process of merging all the data took much longer than I anticipated, before I was satisfied that it provided clear evidence of what transpired within the session. This section will explain how all the information was documented and subsequently grouped under the term 'commentary'.

At first I experienced a number of obstacles, with regard to ensuring the data were presented in a way that reflected the theoretical underpinnings of this study. This concern appeared to be inhibiting the process and I found myself trying to adjust the information into a format which could be analysed in a traditional phenomenological manner. As an illustration, I attempted to modify my reflections and omit vague words or those that may be viewed as interpretive. Many sentences within my reflection contained descriptors such as, lovely, warm, touching and natural, especially when referring to communication between the participants. However, if I had continued to strive for a conventional transcript, then the essence of what transpired might have been lost. After much thought I decided to keep these intangible descriptors, as they brought richness and personal meaning to the data, without which the information did not reflect my own recollections of the experience.

Within the reflection, there were also parts where I varied the tense or commented on something which had only a vague reference to the session. As my confidence in merging the various documents increased, I was not too concerned with these grammatical points or what could be considered superfluous information. The quality of the data became my priority, which in turn lessened these anxieties and provided more fluidity to the process.

At this stage, I supplemented the emerging document with further details, in order to explain certain points, for example, Supergirl's learning disability, the young boys' short concentration span and Spiderman's limited command of language. Whilst the information was required for clarity, should anyone have needed to read the transcript at a later date, more importantly, the points were incorporated to guide and remind me of issues when considering the data as a whole. It became clear that without this supplementary information, only the more eloquent or confident speakers, such as Hoover, Brittany and QBL, would have been well represented in the document.

Interestingly, I uncovered a small number of anomalies (instances of self-contradiction), all of which were retained in the final document. Rather than view these as a weakness, the fluctuating comments represented an accurate and realistic perspective of my experience. As an illustration, at one point I documented my ability to support and listen to the participants without becoming upset. Conversely, I later wrote about how the group discussion was very moving and my appreciation of the chocolate intermission. These reflections provided key data and are discussed further in the final three chapters.

When collating the additional data, relevant details were also incorporated from supervision sessions, in which I had watched the recorded session alongside my supervisors, and subsequent meetings with the staff team. Figure 9 shows how this information was inserted within the right hand column, thereby enhancing the transcription document. The commentary revealed elements that increased the adequacy of the description, all of which were utilised within the analysis stage.

Electronically merging the commentary details alongside the spoken text required close scrutiny. Both columns needed to mirror each other and this required much patience and diligence, as they easily lost their synchronisation. I inserted gaps between the statements and points of interest, to allow for any further handwritten comments once the transcripts were printed. An unexpected bonus was in how the process allowed me to ensure that epochē was integral to viewing the transcripts. I became much more familiar with the document when continually working between all sources of the data, thus increasing my awareness of the context in which the interactions took place.

SPOKEN TEXT	COMMENTARY: intonation; digital reference numbers; main events of what was happening in the session
OK… Super Girl would you like to say anything? *Do you think the book is ….err is interesting?*	Super Girl shakes her head <u>Here I am very careful about choosing words that are not too complex. In doing this I could have been asking a leading question although Super Girl appears to answer honestly (see the underlined comment below).</u>

Do you think it's good? Would you like to take it home to read?	Super Girl shakes her head to indicate no
No? It's not one that you'd like to keep	
Which was your favourite picture in the book?	Super Girl pointed to the picture of Michael Rosen's son being bathed as a baby
That one…. ah… and what's the picture about?	
Super Girl Baby in the bath	Super Girl is smiling now (for the first time)
Katrina (s) Is that when he's remembering him?	Super Girl quietly talks about the picture but isn't loud enough for the recorder to pick up
… and that made him feel happy. So did you like looking at that picture?	No visual response is evident – it is possible that Super Girl has finished her current concentration span on the subject.
	<u>There is a lack of evidence that everyone involved in the session had enough time spent with them, to ensure they knew what the book was about and for the rest of the group to hear all they had to say. As mentioned earlier, the attention span for many within the group was limited. Certainly, some of the individuals with a learning disability would have benefited from an additional session, looking at a much smaller condensed version of the book. With this approach, it would have been possible to discuss the concepts at a slower pace and provide more time to think about certain issues.</u>
	<u>I am always fascinated by the way that the same information is received and understood in so many different ways. As an illustration, Supergirl referred to a baby being bathed in the story-line. I found out later that this was an activity she was very fond of at the time (there had just been a young addition to the family). This contributed to why the book was so interesting for her.</u>

Key to the text:

<u>Underlined text</u>   explanation of the context in which the interaction took place

Bold type   name of the participant

Italics   my own comments or questions

Figure 9. Transcript and Commentary

6.6   Summary

This chapter has provided a thorough account of how the initial transcription was uniquely expanded, collated and merged, thus providing a much more adequate and detailed description of the data collection period. All the variations used when compiling the information, allowed me to undertake what Burns and Grove (1993) describe as 'multi-sensory immersion in the data'. The whole process of developing a 'commentary' to accompany the transcripts was fascinating and provided a deeply moving 'story' of the participants' experience when reading and discussing the book. My confidence in the data was such that I proceeded to find a suitable analysis method, one which would enable me to uncover the essences and ultimately the structure of the phenomenon investigated.

CHAPTER SEVEN

ANALYSIS OF THE DATA

In the previous chapter I presented an overview of how various approaches to the data collection were firstly collated and then merged, in order to provide a good quality description of the participants' experience. This process was essential before progressing with the analysis. However, to analyse the data from a transcendental phenomenological position, I had to acknowledge that the description was unusual, particularly the way verbal transcriptions formed only a limited part of the data.

A number of analysis methods were carefully considered and, within this chapter, I will provide an overview of my rationale for utilising two seemingly contrasting approaches. Firstly, I will present Becker's 'thematic' methodology (1992) followed by the principle analysis tool, Amedeo Giorgi's phenomenological method (Giorgi, 2008). The main tenets of both approaches will be explained, before progressing to discuss in detail how the latter method was utilised within this study.

7.1   Search for a method of analysis

Todres and Holloway (2006) suggest one of the central limitations to a phenomenological approach is that it can be elitist. According to the authors, an artistic-literary capability is required of the investigator when reflecting and writing. Whilst this can be said to some degree of most research, they propose that phenomenology is on the literary side of the scientific-literary continuum. Thorne (2000) agrees with this point and forewarns readers of language, frequently utilised when referring to stages within a phenomenological analysis, which has a tendency to accentuate a sense of mystery and magic. Therefore, my aim was to find a method that would clearly inform readers of the steps undertaken and explain the process in a coherent way, thus avoiding too much of a poetic literary style which, according to Thorne, is unhelpful.

Although I agree with Thorne's criticism to some degree, there is a difference between an unnecessary poetic style and a need to provide accurate terminology for the

processes undertaken. Initially, I found it a challenge to understand phenomenological terminology, most of which I had not encountered before. However, horizontalisation, epochē, noetic and noematic reflections were all terms I needed to understand, in relation to the context of phenomenological theory. As with most philosophical traditions, Idhe (1986) refers to this as a 'tribal language', one that requires a comprehensive knowledge base, rather than a superficial understanding of the various terms. Once I had undertaken each stage of the investigation, the purpose and meaning of each term became much clearer. Gradually, I learnt to appreciate that there would be little point in *not* using such descriptors, as they all referred to something very specific.

Whilst I had followed Husserl's guidance of 'absorbing' myself in the data and was pleased with the quality of information gathered, I still required a method of analysis that would allow me to transform the participants' description, thus uncovering the invariant structure of the phenomenon. With such an unusual collection of data, I required a phenomenological method which could accommodate the description within a transcendental position. Husserl believed it was important to go beyond participants' first reflections and perceptions of their experience, by 'continual positing' of the transcendental object (Husserl, 1977).

I considered several data analysis approaches which have been utilised within phenomenological research, most notably those created by Colaizzi, Giorgi and Van Kaam, all cited in Holloway and Wheeler (1996); Parse, in Burns and Grove (1993) and Smith in Willig (2004). Each of these procedures comprised of several pre-defined steps within their particular framework. As an example, Colaizzi advocates seven steps to his analysis, Giorgi four and Van Kaam six, each of which transform data to form a classification of attributes, of the phenomena uncovered (Jasper, 1994). Very often differences in the various methods were subtle, although each contained clear and auditable lines of analysis.

7.2   Becker's 'thematic' methodology

The first method I cautiously undertook was created by Carol Becker (1992). In a similar way to Smith (2008), she recommended a transformation of data through an adapted thematic approach. Becker's work was a modified version of Giorgi's analysis method (see Section 7.4) and consisted of the following eight steps:

1 Read through individual transcripts noting themes or units of meaning

2 Colour code or note key words in the margin. *This is when the phenomenon comes into view and its salient features or meanings are identified*

3 Take each highlighted theme, placing everything related to what the individual has said about it together

4 Summarise each theme and edit, still using the person's own words

5 View the information, in order to see how all parts of the phenomenon are interrelated and make one (individual) structural description

6 Write an overall portrait of the phenomenon for each participant

7 Undertake further analysis of each portrait to find common themes

8 Develop a structural description that comprises of essential themes or qualities, regarding the phenomenon uncovered.

I followed the first three steps within Becker's structure, which clearly identified key findings that were evident in the data. After a thorough and absorbing consideration of the details from within a psychological perspective, eleven themes were chronicled and are outlined in Figure 10.

Themes within the data

1. **A fun thing to do**: design of the session and activity which transpired

2. **I know how it feels**: personal meaning and connections to the story-line

3. **More to learn**: establishing connections from a previous session

4. **This is sadness**: discussion and exploration of sadness

5. **It will help**: therapeutic value for other bereaved young people

6. **I don't know**: an absence of analogy or personal connection to the story-line

7. **I want to talk about it**: how the book stimulated reflection and conversations

8. **It made me think**: reflection on what insights the book uncovered

9. **It's my story to tell (if I want to)**: selective disclosure

10. **Together**: cohesiveness, familiarity and closeness

11. **Words and drawings**: significant text and illustrations

Figure 10.   Themes within the data

One of the most beneficial aspects to undertaking this approach was my increased familiarity of the data. I became aware that at times the participants' experience of reading and discussing Rosen's book was poignant, irritating, daunting, chaotic, fun and overwhelming. For several weeks I worked with the information, almost learning some of the sections by rote. However, the above approach had major epistemological flaws with regard to a transcendental phenomenological focus. Within my work there was a failure to contextualise what was happening and the findings were presented in a disjointed manner. Whilst this may be true of many research approaches which look at data out of sequence and in terms of 'thematic' relationships, I struggled to correlate this with the theoretical underpinnings of Husserl's philosophy. It was crucial to be clear about what had been discussed before or after a particular interaction. Furthermore, I required an approach that wasn't so much about describing individual sets of reactions but one to uncover a central structure which corresponded to the participants' experience.

Whilst Becker's method had been useful, it did not provide a clear strategy to uncover the phenomenon which had taken place in a relatively short, although complex, period of time. The participants all interacted and created what happened between themselves, rather than as a series of separate narratives. Another point of concern was the temporality of the experience (which was no longer apparent) and the data had, in my opinion, been prematurely split up. Finally, the steps undertaken were not providing a visible evidence trail, with regard to how I would ultimately arrive at a structural description of the phenomenon.

Therefore, my improved understanding of phenomenology had resulted in a certain sense of unease, in relation to continuing with this methodological approach. Although Becker's method did not meet all my requirements, undertaking what was a preliminary consideration of the data allowed me to identify what was essential to the approach required. This initial attempt to the analysis had perhaps been undertaken in haste, so I continued my search by looking for a method to transform the data into a coherent, vivid description of the phenomenon.

7.3   Resuming the search

To refine my search and find a more appropriate analysis method, I reconsidered the criteria required. As previously discussed, all phenomenological inquiry is composed of three distinguishable, though interrelated processes, namely epochē, horizontalisation and description. Rather than merely uncovering and describing certain aspects of the participants' experience, the method I required needed to acknowledge what Husserl referred to as the 'psychic, mental and subjective attributes of man' (Scanlon, 1977). A transformation of the descriptions needed to be substantiated, whilst acknowledging the data had undergone significant change. Due to this highly intricate notion, the analysis needed, as a pre-requisite, to comprise of the following:

- A sound theoretical base to substantiate the process
- An explanation of how to code, categorise and make sense of the essential meanings
- Clear guidance on how to provide an eidetic description of the phenomenon itself.

Initially I favoured a process by Colaizzi (1978), the stages of which had more clarity than Becker's and offered a completely different methodology for me to consider. Although Colaizzi's work was cited in a number of texts (Spinelli, 2005; Jasper, 1994; Hallet, 1995; Moustakas, 1994; Holloway and Wheeler, 1996), these were usually secondary sources from just one reference, a chapter in Existential Phenomenological Alternatives for Psychology (Colaizzi, 1978). Considering the period in which it was written, the late 1970's, it is understandable why Colaizzi's very clear approach became popular. Whilst there was a plethora of papers concerning the theoretical and philosophical underpinnings of phenomenology, a dearth of literature was apparent with regard to providing clear 'step by step' details of how to apply this in research.

Fortunately, the increase of literature on other methodological approaches provided an opportunity to widen my search. With such a significant study, I wanted to know much more about the origin of the methodology and be able to chart its development over a number of years. I looked for one that had been extensively utilised, with accompanying literature debating the various stages of analysis. Equally, I required more empirical examples, together with a substantial critique of its use.

7.4 Giorgi's method of analysis

After further reading and deliberation, a method which met all the criteria I was searching for was chosen. Within the field of phenomenological enquiry, Amedeo Giorgi has utilised and refined his analysis method for many years. His approach provided a clear strategy that enabled me to take the first cautious steps in transforming the data and thus uncovering the phenomenon. The quality and detail of the written material appeared good, with several illustrations to explain each of the steps proposed (Giorgi, 1985; Langdridge, 2007; Smith, 2008).

Giorgi's methodology does not claim to provide objectivity to the analysis, as it relates very much to an investigator's perception of the data compiled. This position reflected one of the defining and refreshing features of phenomenology, in that it does not claim to reveal the complete encapsulated explanation of a situation, but acknowledges how reality always bears multiple meanings. Todres (2002) reiterates this theoretical position and suggests the findings are 'possibilities with actual variations' and the results are 'expressed in a way that is not deterministic in nature' (p.2).

The question of whether Giorgi's methodology uncovered findings superior to those of other approaches, is not an issue within phenomenological studies. The important point is that the philosophical underpinnings were closely adhered to. His method typically involves four steps to the analysis, as detailed in Figure 11.

1. The entire description is read many times, in order to get a general sense of the whole statement

2. The text is read with the specific aim of identifying 'meaning units'

3. All the meaning units are analysed and through a gradual process of transformation, an expression of the psychological insight contained within them provided

4. The transformed meaning units are merged into a consistent statement to clearly illustrate the participants' experience of the phenomenon investigated.

Figure 11.   Amedeo Giorgi's four analytical steps

Within this section I will now illustrate how these 'steps' were utilised in my own study. Although I have retained Giorgi's terminology by discussing four stages of the analysis as 'steps', in practice the process became much more fluid. The steps did not cumulatively develop the analysis of data or follow a linear pattern. Instead, several of the stages were revisited at various points within the whole process.

7.4.1   Step one: familiarisation with the data

I considered the data for a considerable amount of time, gradually becoming more familiar with the details. This was supplemented by frequent discussions with my supervision team, colleagues and students. Presentations were delivered in a variety of settings and, once more, the findings were discussed, critiqued and debated with others. Both informal and formal discussions resulted in a greater awareness of alternative ways to consider the details. Not only did I gain an overall sense of what the data presented but also practiced the technique of incorporating epochē.

Were I to have followed my previous research practice, this point in the analysis would have been where issues were identified as important or not. However, this would have increased the possibility of my personal influence on which aspects of the data were highlighted. It is likely that I would have imposed my taken for granted assumptions of the world and theoretical insights, the very thing that phenomenology attempts to suspend. In short, epochē would not have been implemented. If something had been discounted because it was trivial or did not fit in with other points, I would have failed to uncover the essential 'universal' features of the phenomenon. Giorgi's method addresses this issue by considering every single word within the analysis.

7.4.2   Step two: meaning units

Once I had familiarised myself with all the data, Giorgi's next recommended step was to split up the text into meaning units, a term used for sentences, phrases or where the conversation changes direction. An important element to this step is that the meaning units needed to remain in the same temporal sequence. Giorgi (1985) cautions investigators to avoid teasing out specific units and viewing them in isolation, particularly at such an early stage in the analysis. Adhering to his methodological direction enabled

me to retain one of the main tenets of a transcendental phenomenological approach, to consider the phenomenon in the context it is experienced.

Giorgi was very clear about the meaning units not existing in the text, only in direct relation to what Husserl describes as 'continual positing'. As discussed earlier, he stated that it was only possible to go beyond a participant's first reflections, their perceptions of an experience, by 'continual positing' of the transcendental object:

"…we are concerned with something else, which also stands at the bidding of our discretion, simply perceiving, noticing, considering more closely, we are interested in the object perceived..." (Husserl, 1977 p. 144)

To follow Husserl's guidance, when identifying the meaning units, necessitated modifying Giorgi's methodology. As the transcription and commentary contained concurrent interactions and reflections from the participants, the meaning units within my own document related to points where I noted a transition in meaning had taken place. Gradually, my technique became more focused and the way I identified each unit was where the conversation took a different direction, or a particular interaction had taken place. This ensured 'all' the data were considered, in line with Husserl's theoretical underpinnings. The benefit of utilising this approach was that the data continued to retain a certain temporality, as well as being situated within the context it was experienced (Mackensie, 1994). Figure 12 illustrates how this was documented.

<div style="border:1px solid black; padding:10px;">

Meaning unit 4

How would you describe the book? Rudolf was saying that it's about somebody that's lost a family member and they were feeling sad

Meaning unit 5

Do you think other children would like to read the book?
Participants Yes

</div>

Meaning unit 6

Participant   Because there's a lot of pictures

Katrina   A lot of pictures?

There is a lot of pictures

Meaning unit 7

Participant   It's easy to read

Meaning unit 8

Rudolf   It gets you thinking more

Meaning unit 9

And what do you think other children would like about the book?

Participants   That picture, short words

Key to the text:

My own questions and comments are in italics

Participant(s) indicates that the video recorder did not show who was talking at the time.

Figure 12. Identification of the meaning units 4 to 9

Throughout this process I continued to utilise my reflective diary and note down any further issues which transpired. Frequent feedback was also sought from my supervision team, who questioned anomalies that sometimes appeared between the text and the meaning units chosen. This provided a crucial opportunity for debate and discussion within this stage of the analysis.

7.4.3   Step three: transformation

The third step to Giorgi's method corresponded with Husserl's notion of phenomenological reduction. This term describes the process by which an investigator assesses the psychological significance of each meaning unit and is mindful of epochē. As with all steps to the analysis, it was essential that I focused on what the data

indicated about the participants' experience of the session, rather than what I expected to transpire from prior knowledge and experience.

Langdridge (2007) offered two suggestions that he had found useful when undertaking this stage of phenomenological enquiry. The first was to limit the analysis of meaning units to the topic investigated, which in this case would have been death and dying. This pragmatic suggestion might have been useful if I had undertaken a project with a tight deadline and limited amount of resources. However, I was concerned with the potential impact of narrowing my focus too much. As an illustration, limiting the scope of the analysis to death and dying or bereavement, may have excluded issues such as child protection, friendship or playfulness. If I had utilised this strategy when considering the meaning units, it could have compromised the data and directly influenced my description of the phenomenon. The author's second suggestion was to read the meaning units in relation to issues that are appropriate within a social science investigation, including a psychological, sociological or educational focus. This was a useful point and I progressed to read the data by focusing on these three areas. At this stage in the process I started to clarify what the described meanings were.

In practice, there was more than one stage to transforming the data, a process which gradually transpired over several weeks. Both Ihde (1986) and Giorgi (2008) state that within the analysis stage, reflection and imaginative variation are essential. Gradually the data became more abstract and less specific to the individual versions of the participants' experience.

A further technique employed during this stage was proposed by Giorgi (2006), as a practical way to enhance and transform the focus from an individual subjective experience into a central description of the phenomenon. This involved changing a first person description into the third person, by modifying any instance where the participants had used the word 'I' for a 'P'. Giorgi claimed that this stops researchers projecting their own experience into the data and thereby makes the procedure trustworthy. Whilst I think the only way to make any analysis trustworthy is by closely adhering to theoretical principles, I did find the subtle technique was of great value. Not only did it complement the epochē process, it aided the transformation of pre-reflective descriptions, thereby enabling the phenomenon to be identified within step four.

7.4.4 Step four: uncovering the phenomenon

This final step within Giorgi's analysis method sought to identify what was essential to the phenomenon. As noted within Chapter 5, the number of participants in the study was appropriate for this phenomenological investigation, where the aim was to acknowledge diversity rather than present a grand narrative. The range of pre-reflections allowed me to find what was essential within the participants' cumulative experience, rather than merely describing the subjective experience of just one person. Husserl went to great lengths to reiterate that phenomenology strives to acknowledge both the qualities of the unique individual (subjective experience) and seek out the essential quality which corresponds to a larger number of people. Ultimately, it is the shared experiences, within this study at least, that informed the phenomenon uncovered.

A detailed account of this final stage within the analysis is provided in Chapter 8 (Section 8.3), together with the structural description of the phenomenon. After so much time reading, reflecting and learning new research skills, it was particularly rewarding to arrive at a point where the essential features of the phenomenon could be identified. I was able to utilise a more abstract thought pattern and uncover the essential and central description. As noted in Chapter 4 (Section 4.3.8), through this process of transformation and eidetic intuition (Sokolowski, 1999), the essences of the phenomenon were discovered. I was then able to present a vivid and detailed account of the phenomenon experienced when the group read and discussed together Michael Rosen's SAD BOOK.

7.5 Summary

This chapter has provided an account of the considerations required when searching for a method of analysis. Not only did this necessitate one which resided within a phenomenological framework, it needed to be flexible enough to be utilised alongside a complex collation of data. After undertaking Giorgi's method of analysis, it became clear that the challenge of embracing a completely new theoretical framework and methodology was much more rigorous and detailed than the thematic analysis I had previously employed. His very clear and precise steps were used flexibly, although the structure and rationale for each stage enabled me to take analytical control and construct the findings.   At the same time I remained firmly located within a transcendental phenomenological tradition. The last three chapters of this thesis will

present these findings, explore them in dialogue with theoretical literature and consider what they offer in relation to progressing knowledge and practice.

CHAPTER EIGHT

RESEARCH FINDINGS AND TRANSFORMATION OF THE DATA

Here may be an appropriate point to briefly consider the direction taken so far within this thesis. To begin with I explained how this study is grounded in my understanding of bereavement issues for children, young adults and individuals who have a learning disability. Whilst undertaking the literature search, it became apparent that there is a wealth of information in relation to grief and bereavement. However, I uncovered a marked contrast when searching for either empirical evidence or literature on the topic of bibliotherapy for bereaved individuals.

I then moved on to introducing the work of Edmund Husserl and his distinctive philosophy, Transcendental Phenomenology. Husserl's theory provides the background to this study and informed the methodological design. This provided a setting in which the data could uncover the participants' experience of reading and discussing together Michael Rosen's SAD BOOK. Integral to the design were strategies that ensured the environment was safe. Equally, the therapeutic methods included scope for disclosures of a sensitive and emotive nature to take place.

The compilation of data was complex due to the limited language of some participants. This became evident when transcribing the initial verbal pre-reflections and has been discussed previously. After undertaking the process of horizontalisation, with regard to documenting the participants' experience, an improvement in the transcript was visible. Rather than relying on purely the words used or body language noted, the commentary provided data that were detailed and encompassed a more holistic picture of the session. In line with transcendental phenomenological tradition, I uncovered both the noematic and noetic pre-reflections, which revealed layers of individual experiences.

I progressed by seeking an appropriate method of analysis, that would provide a coherent structure with which to consider and effectively analyse the data. Once this process had been undertaken, I sought to find a way for the findings to be presented in a clear and vivid manner. In order to do this a robust strategy was required, by which the experiences could be introduced concurrently. This significant stage of the study will be

discussed next, followed by a detailed explanation of the process undertaken to produce a structural description of the phenomenon.

To assist the reader, a brief résumé of the participant details, alongside those of the staff team, are presented within Figures 4 and 5.

Pseudonym	Gender
Over 18 years of age	
Q B Love (QBL)	Male
Lyn	Female
Supergirl	Female
Britney Spears	Female
High school age	
Rudolf	Female
Hoover	Female
Sarah	Female
Boothy (closest relation to the deceased)	Male
Primary school age	
Flashergirl	Female
Dash	Male
Spiderman	Male

Figure 4.   Overview of participant details (as first illustrated within Chapter 5)

Pseudonym	Professional role
Esmeralda	Myself (author of this work)
Katrina	Until her recent retirement, Katrina had been the team leader within the hospice Family Care Team and was a qualified bereavement counsellor. As she had supported the first bereavement session with the participants, Katrina generously returned in a voluntary capacity to assist me with this study.

Tharpa	Tharpa was a volunteer within the hospice and had previously worked with the family during their initial bereavement support session.
Superwoman	Superwoman was a staff nurse within the hospice. She had prior experience of working with children, some of whom had a learning disability.

Figure 5.   Details of the staff team (as first illustrated within Chapter 5)

8.1   To present participant experiences: an innovation

As with any experience investigated, the session was intricate with a myriad of expressions taking place at any one time.   The phenomenological method of analysis, inspired by Giorgi, required the data to be considered in much finer detail than I had undertaken before.   Subsequently, my attention was drawn to sourcing a strategy for presenting the findings in a way that accurately represented the vibrancy, playfulness, emotional tension, joy and sadness within the session.   The challenge encountered was that all these elements did not present themselves in a linear manner, but in a concurrent fashion.   At times they were fleeting and easy to dismiss, especially when compared to the more protracted discussions about grief.

Preliminary work in reviewing the data raised my awareness of a need to horizontalise the presentation and thus offer a variety of illustrations, rather than focus for too long on just a select few. Were I to have chosen only a small selection, the presentation would have been unbalanced and potentially misrepresented the participants' experience. At times, bereavement literature appears either highly emotive or light and vague. Other literature regarding bibliotherapy presents a chronological or thematic narrative (Jones, 2001).   Therefore, to find an approach which would offer a clear perspective of the session and remain firmly grounded in a transcendental phenomenological tradition, I continued my search.

I re-visited the Seven Hat Framework cautiously and contemplated a possibility of using it as a way of organising and presenting the findings. This innovative approach was tentatively undertaken and required several revisions. Finally, a process emerged that not only allowed the findings to be clearly illustrated, but ensured the presentation remained grounded in the theoretical framework I was utilising. The illustrations were presented in a way that described rather than interpreted, I was able to consider the session from a clear theoretical-free position (epochē) and present the data from as many viewpoints as possible (horizontalisation).

There were distinct differences when using the Seven Hat Framework to present the findings, instead of its previous use in substantiating my personal reflection. The main difference centred on the fact that when revisiting the framework for a second time, I had already collated the data and was familiar with the details. At this stage of the study the Seven Hat Framework was utilised simply as a tool to provide a coherent way in which to arrange and present the findings.

As with the reflection, I allowed the framework to stimulate my focus rather than neatly compartmentalise the data. What I found was that, similar to my previous experience, each of the hats did to some extent overlap with others. By now I was much more confident with the approach and prioritised certain key aspects that reflected the specific colour and meaning attributed to each hat. One exception to this presentation of findings was when considering the White hat, a point which is explained in detail within Section 8.2.8. Ultimately, the approach I undertook enabled me to gradually introduce elements of the essential structure of the phenomenon, a description of which is presented at the end of this chapter.

8.2   Findings

Key to the illustrations provided within this section:

- <u>Underlined text</u>:   explanation of the context in which the interaction took place
- **Bold type:**   name of the participant
- *Italics:*   my own comments or questions

When questioned, the integrity and openness of the participants' responses allowed me to uncover findings that highlight a variety of issues. This section will present evidence which incorporates these issues, including the participants': collaborative engagement when reading the book; limited verbal skills; supportive, cohesive relationships; confident and also reticent behaviour. As discussed above, the Seven Hat Framework was utilised to provide an unambiguous presentation of the participants' experience that can be read with ease. At no point is the structure intended to compartmentalise the findings. The illustrations will be presented in a temporal order within each subsection, to contextualise the findings and demonstrate how the participants' reflections gradually emerged over the course of the session.

8.2.1 SETTING THE SCENE: the 'Blue' hat provides an introduction to the findings in an organised, clear and succinct manner.

Within this section I will include findings that explain the context of the session and the participants' attendance (eight months earlier) at their first bereavement support day. I will commence by presenting details of where the participants established connections with their first visit and follow with instances of how the book gradually stimulated further reflections and conversations, most of which related to grief and bereavement. From the outset, it is evident that several participants connected to Michael Rosen's narrative and the illustrations by Quentin Blake, aspects of which are introduced below.

According to the participants' parents, the first bereavement support day had proved to be helpful. They were reassured to hear that their children had been well supported following the death of Eleanor. Linking issues discussed in the previous session was an important and integral part of the data collection period. Whilst this could be considered a diversion from the aim of the study (to seek an understanding of the participants' experience of reading the book), I thought it was important for the publication to be experienced within the context of their ongoing bereavement support.

The data collection session was designed to stimulate discussion of any personal experiences the participants had encountered, in connection with their loss, and explore any worries or concerns which had arisen since the last time we met. Whilst at times my

questions related to their previous bereavement support, the topic of discussion remained firmly connected to the experience of reading Rosen's book.

In the early stages of the session, Hoover commented that to understand a particular illustration, someone would first of all need to have experienced the death of a significant person within his or her life. In her own words, Rosen was "...*feeling sad but trying to appear happy because he thought people wouldn't like him if he looked sad*". I asked the group if they thought others would like the author if he looked sad, to which Hoover replied "...people who had lost someone would". I checked what had been said and asked if this meant others might understand, to which she agreed.

I continued with the interaction by reminding the group of the last time we met and discussed how 'normal' it was to feel sad. I then said "…if someone came up to you and said I'm feeling sad, what would you do? What would you do to help them?" Once more, Hoover replied that she would talk it through with them, because "…you know how you would feel, you know what it's like". This very strong connection, in relation to other bereaved people, was clearly important and one which the book enabled her to reflect upon and discuss.

I then progressed to consider ways in which individuals effectively manage the experience of grief. Within formal child bereavement sessions, the exploration of coping strategies is a common element (Stokes, 2004; Gilbert, 2004). It is suggested that adults gradually accumulate a range of strategies for dealing with loss, often from observing the grief of friends or family members. Due to the limited life experience of bereaved young people, their coping strategies are frequently limited and the experience of significant loss can be both a frightening and bewildering experience. Therefore, I used the book to introduce the concept of coping strategies and asked the participants what kind of things Michael Rosen did to cheer himself up.

One participant identified (from the story-line) that Rosen thought about birthdays and things which made him happy. I confirmed his answer and another staff member highlighted a page where Rosen said it was "important to do something positive everyday" and later reflect on this at night when in bed. I then asked the participants if they had any other suggestions of what to do when feeling sad. One person proposed

writing about the experience, if an individual didn't want to speak to anyone. This suggestion was interesting as it wasn't something we had discussed before, nor was it written in the book. Interestingly, when Rosen created the book about Eddie, 'writing about it' was exactly what he did.

Later, the conversation turned to a discussion about crying and I stated that this may actually be good, as it can release pent up concerns and allow a person to share what is bothering them with someone else. This prompted a moving disclosure about one of the older participant's experience of grief, shortly after hearing about Eleanor's death:
 "When I was crying I just sat there and… in the kitchen… and just like had a big cry and then I just sat on my dad's knee…"

The closeness that the participants felt towards both parents was a significant and important part of how they managed their grief. During the rest of the day there were other similar testimonies as to how supportive they had been.

One of the youngest participants, Spiderman, found it difficult to explain his experience and when asked about the publication, his conversation was limited to "it was good". When I enquired about which picture he liked, a very emotive dark grey illustration was chosen. At this point his concentration became much less focused and our brief interaction had finished. I suspected that his reading skills were not well developed and it was the powerful illustrations which had captured his attention, thus enabling him to offer a valued contribution to the discussion.

Towards the end of the session I thanked everyone for their contribution, saying that they had all told me things which were "really special". Suddenly, Spiderman spoke up and stated "I didn't get to say a lot". I quietened the group down, so his views could be listened to, and he awarded the book 20 out of 20. Even though his concentration was poor and he needed to be physically active throughout the session, rarely joining in with the conversation, this response indicated that he still knew what was happening and we were all giving the book a mark out of 10 (or in his case out of 20). The following section provides more examples in which both the illustrations and text are discussed.

8.2.2 A CREATIVE ENDEAVOUR: the 'Green' hat presents findings that centre on creative thinking and new ideas.

This section will concentrate on how the participants utilised both the text and illustrations, to reflect on their recent bereavement experience and subsequent changes in circumstance. Utilising the book was a creative approach that touched many aspects of their lives, some of which the staff team had not necessarily expected to arise.

When I asked the participants if they thought other children would like to read the book, several stated that they would because "...there's a lot of pictures". This aspect appeared important to the group for a variety of reasons. As an example, the younger participants and those with a learning disability used the illustrations to help them discuss and explore their experience of reading the book. It was apparent that they initially focused on what the pictures represented, rather than the actual words. Subsequent discussions within the group allowed them to advance their understanding of the story-line.

Walker Books (the publishers) recommended the publication for children over five years of age, a general point which one participant appeared to agree with, by stating that it "contained short words" and was "easy to read". However, when the participants were encouraged to expand this statement, they changed the direction of their conversation and suggested one of its main strengths was how "...it gets you thinking more". At this point many of the participants were keen to comment on the book and I became more focused with my questioning. Slowly, I guided the group into a conversation about their own reflections of the publication, prompting each person to identify a favourite illustration.

Britney discussed her chosen picture by offering a description, quite unrelated to her experience of grief. She explained that it was about a 'girl and a boy', although was unable to expand on what they were doing. After a short while I interjected and asked if they were in the street and walking, to which she repeated the last word, '...walking, yes'. I was cautious of furthering this conversation, as it was possible that she was simply

echoing my words. I progressed by questioning someone else about the illustration, to give Britney an opportunity to hear what some of the others had to say.

Later in the session I asked Lyn, a very quiet and reticent participant, if she wished to say anything about the book. I introduced Rosen as the man who was telling the story and enquired about what he was doing. Quite correctly, she replied that he was talking, although could not relate this to her own experience and quickly became reluctant to interact. The video recording showed her genuine discomfort with the interaction, a point discussed further in Section 8.2.3.

Although Supergirl had followed the book carefully throughout the reading, unless prompted, she offered little to the group discussion. When questioned about her favourite picture, she pointed to one where Michael Rosen was bathing his son and explained that it was a "baby in the bath". When a staff member wanted to know if it was when Rosen remembered his son, it was not possible to hear Supergirl's reply and further attempts in encouraging her to expand the conversation were unsuccessful. I later found out that at home she was supporting her parents to look after a new baby, whom she frequently helped bathe. This illustration is of particular interest, as Supergirl perfectly described the books relevance to her life, even though it was not what I expected to be discussing within a bereavement session.

Similar to Britney, QBL was a more vibrant and enthusiastic member of the group. At first he was not sure of the story-line and reflected that it was about celebrations and parties. He thought other "kids would love it", a possible indication that he had been listening to an earlier question when I had asked if other children would like the book. I attempted to help him connect the story to Rosen's son dying, "You are quite right, that was Michael Rosen who was telling you the story, and what was he telling you about?" QBL's answer suggested there was still some confusion:
"About um, peoples lives, about, going on about celebrating things and something about role playing, games… I've seen a programme of it… but that was a long time now… a long time ago".

This interaction with QBL indicated that he did not necessarily follow the story-line as it was initially read out. However, he gradually accumulated a greater understanding from

conversations and interactions which subsequently took place within the group setting, a point discussed later in this section.

Superwoman was interested in what Spiderman, the youngest in the group, thought about the book. Similar to his young siblings, the reply was short, "…it was good" and yet he quite happily pointed to his favourite picture, one he noted again towards the end of the session. Accompanying the illustration were the words:

Sometimes I don't want to talk about it.
Not to anyone. No one. No one at all.
I just want to think about it on my own.
Because it's mine. And no one else's.

It is interesting that Spiderman chose this picture on two separate occasions. Even though he was not able to verbally explain why this was the case, it obviously held some personal meaning for him and may even explain his choice in not sharing his experience.

As discussed throughout this section, it is clearly evident that both the text and illustrations were crucial to the group's experience. Individually, some focused more on the words, whereas others sought out the illustrations.

8.2.3   NO PERSONAL CONNECTION: the 'Black' hat represents more sombre and serious aspects of the session, where necessary pointing out any perceived challenges that transpired.

The focus within this section is on findings which prompted me to question the therapeutic value of using the book. I was aware that the pace of the session was too swift for several participants, whilst for some the prompt to remember personal grief was visibly uncomfortable. Furthermore, at times my questions appeared to confuse the participants, some of whom experienced an absence of analogy or personal connection to the story-line. Firstly, I will present findings which indicated a betrayal of confidence.

As in any family, there were times within the session when having everyone together was not necessarily a positive situation. Whilst some individuals wished to be selective about what they disclosed, on a couple of occasions their siblings divulged just a few too many facts. The first time this occurred was when Sarah told the group that Britney, upon hearing of Eleanor's death, had 'cried for hours' (further details of which are in Section 8.2.6). A further instance was when Britney disclosed private details about Hoover's grief. Once I realised what was happening I changed the subject, in an attempt to restore the conversation to discussing the book, instead of disclosing family secrets.

Britney had told me that she missed her deceased sister and I proceeded to inquire as to whether the book reminded her of Eleanor. However, she still wished to expand her original comment:

Britney   Yes, miss her… a lot…sister was angry, mad. Hoover was crying, swearing…

Hoover was upset that Britney was telling everyone about her "personal life"

Britney   Sisters, hungry, mad, Eleanor, make angry…

When viewing the findings, it became evident that for the older participants who had a learning disability, it would be relatively easy to misinterpret some of their verbal pre-reflections. As an example, QBL explained how he felt about reading the book, saying "...I feel OK actually, I feel happy with it". It was possible that he either misunderstood the question or responded in a particular way to please me. On a later occasion, when I asked if there was a part of the book which was his favourite, he picked up the nearest picture, one which had previously been discussed at length. Once again, I found it difficult to gauge whether or not he had the vocabulary to explain his experience, in contrast to some of the other participants who did not have a learning disability.

However, Sarah was one participant who I knew would be able to read and understand the book, yet she also exhibited some difficulty in answering questions, frequently uttering the words "I don't know". Later in the session, I enquired as to whether reading the book might help others to understand sadness. Although, once again, she used the words "I don't know", this time she added the word "probably". Encouraged by this breakthrough in our conversation, I asked what her favourite part of the book was, to which she replied "I don't know… um". In a bid to assist my line of questioning, Katrina,

an experienced child bereavement counsellor, said "...is there a little bit of it that made you think… I felt like that or… something that you thought is relevant to you? That you thought… I felt like that?" Sarah simply and politely answered "no".

When I questioned Flashergirl about why she thought Rosen had written the book, she also expressed "I don't know". I thought that, with a little prompting, she may expand her answer and therefore varied my dialogue to include, "When you were reading it, what kind of things were you thinking of… did it make you think of something?" At this point Flashergirl continued to shrug her shoulders and mutter the words "I don't know".

I started to realise that even though the group comprised of young children and participants who had a learning disability, both Sarah and Flashergirl's reflections were no more insightful, despite their more developed vocabulary. Asking young people to reflect on their experience was certainly much more difficult than I had previously considered. However, I had been very ambitious with my design, expecting the participants to undertake a complicated task of reading, reflecting and communicating their thoughts of the experience, not only to the staff group but in front of a camera too.

Prior to the session, I was unaware of just how distracting the data collection (video recording) would be, especially for the teenagers. At various points I asked Tharpa to stop recording a particular participant and direct the camera towards myself. However, it was then difficult to know just how much the recording influenced the participants' subsequent reflections, which did not always flow freely. As an illustration:

OK, Tharpa won't video you, he'll video me

Here I was talking to Sarah who looked uncomfortable with the camera, the discussion then continued…

When you were reading the book, did you prefer to look at the book or look at the pictures on the wall?

Sarah   Looking at the book

So, ...if we were doing this with some other children ...do you think that they would like to look at the book?

Sarah   I don't know

As noted in the previous section, Supergirl showed minimal enthusiasm when exploring the book, even though she quite happily participated in the reading exercise. Interestingly, during the follow up session at home (a few weeks later) she was much more willing to join in the group discussion. It occurred to me that perhaps she was annoyed about her usual Saturday routine being interrupted and may have preferred longer in bed. Either way, in the data collection session she rarely responded to my questions. When I asked if she wished to take the book home, Supergirl firmly shook her head to indicate 'no'.

Also discussed previously was the situation where Lyn and I reviewed one of the illustrations. After she had answered one question quite happily, I persisted with our conversation a little too long. The recording shows that when Lyn turned away from me, she was visibly uncomfortable with being the centre of attention. I regretted this interaction because she was such a quiet and potentially vulnerable member of the group. Whilst happy to attend the session, Lyn showed some anxiety when answering questions she was unsure of.

Some of the participants appeared to have a short concentration span, although at the same time wished to be included in the session. Whilst they answered my questions, several gave short literal answers and were neither able to reflect further, nor expand on what they meant. Nevertheless, it was equally possible that they were guarded in their responses, choosing to be cautious or selective about what they disclosed. All the time I was aware that many of the group had potentially experienced disruptive home environments and relationships before they were adopted. This may have led to a number of losses or distressing situations in their relatively short lives.

The above consideration is illustrated by an interaction with Flashergirl. During our review of the illustrations she picked up one picture and explained "…that one looks happy and that's when he's sad". Her attention fluctuated greatly and, similar to one of the volunteers in my preliminary practice session, she needed to move around the room when contributing to the discussion. I confirmed her answer and moved on to someone else, all the while intending to re-join our conversation at a suitable time, later in the session.

When I asked Flashergirl's brother (one of the youngest participants) which picture he wanted to discuss, his body language was a little hesitant and unconfident. I decided to support him and introduced our joint interaction to the group, "…Ok, Dash and I are going to talk about this picture... and what's in this picture?" He correctly identified that there were candles, although when I ventured to enquire as to his thoughts of the book, he simply answered "...umm, cool". Here was one of my favourite short interactions in the session, illustrating a warm and enjoyable connection, concluding with me smiling and repeating his words, "It's cool… OK, thank you". These two interactions illustrate how the session was facilitated. We encouraged the participants who were a little hesitant, allowing them to express what they could and ensuring that they knew all contributions were valued.

8.2.4   THERAPEUTIC VALUE: the 'Yellow' hat relates to positive, optimistic and potentially therapeutic findings within the session.

Within this section I will illustrate how the session prompted reflections, both on the content of Rosen's publication and the participants' experience. Whilst we concentrated on sadness following the death of their sister or mother, many points were raised that reflected personal growth. Several within the group spoke of the potential therapeutic value of Rosen's book, not only for themselves but other bereaved young people. Further insights relating to how the participants coped with their grief are also presented below.

At one point in the session, QBL said he thought the book would help other young people. Unfortunately, the recording and my recollection of the moment did not provide any further detail. Sarah proceeded to expand on the therapeutic value of the book, as indicated within the following illustration. Readers will also note that it took some time before I found a way to access this information.

So, ...if we were doing this with some other children, do you think that they would like to look at the book?

Sarah   I don't know

Do you think it would help them if they were feeling sad? Do you think it would help them at all?

<u>Pause</u>

Do you think it's good for your age?

Sarah   Yes

...it's not a childish book, is that what you're saying? It's more for teenagers ...do you think that any of your friends would like to read it?

Sarah   I don't know. Probably

...if your friends read it ...how do you think they would feel… if they were reading it?

Sarah   One of my friends, err… her little brother died because… his heart… uh, I can't explain…

Rudolf   Miscarriage…

Sarah   A miscarriage, yes

So do you think reading this book might help? To understand what it feels like when you are sad?

Sarah   I don't know, probably.

Sarah was perfectly able and willing to say 'no' if she disagreed with a question, which led me to consider that she thought the book did have a possibility of helping her bereaved friend. This specific illustration is an example of the benefits when working within a therapeutic environment which wasn't too quiet. As there were plenty of other things happening within the room, it allowed some of the more sensitive scenarios and questioning to progress, without the whole group being focused on any one particular individual.   Although Rudolf was listening intently, not all the others were.

A number of the teenage participants also voiced opinions about the book. Interestingly, on one hand they said the publication was easy to read with lots of pictures and then later in the session progressed to say it was appropriate for their age group but not for the younger participants.   Rudolf repeated Sarah's point by suggesting, "…I think it would be more suitable for teenagers, rather than little children". She expanded her

comment by stating that teenagers would understand it more and "I don't think, like, Spiderman and Dash would understand it, as much as I understand it".

Not everyone was certain about why Rosen may have written the book, although Hoover answered my question with the words, "…to help people who are sad". She continued with a personal interpretation of the content and suggested that it gave readers 'permission to be happy':

Hoover   I think it's alright if you remember the good times
He did say that, didn't he? ...he said in the book that it's OK to remember ...happy birthdays.

As long as the participants were given an opportunity for breaks, not just with the chocolate but allowing them to wander whilst others were talking, they continued to volunteer information.   The following illustration from the end of the session demonstrates this point:
Well thanks to everybody. Oh, Hoover would like to say something.
<u>Hoover picked up a grey illustration of Rosen looking forlorn and read the text:</u>

Hoover   *Sometimes sad is very big.*
                  It's everywhere. All over me.

                  This one is like telling you that it's not just you that feels sad and that all people feel it not just like… people think…

The above remark demonstrates the participants' willingness to discuss the darker and more emotive pages, even at such a late stage in the session.

8.2.5   THE EXPERIENCE OF SADNESS: the 'Red' hat represents significant emotional findings within the data collection period.

Although illustrations regarding the emotive side of the session can be found within most sections, here I consider a small number of the significant or moving discussions relating to 'sadness'. These will be presented in the same temporal sequence as they occurred in the session, thus demonstrating how the subject was discussed intermittently and using a variety of emotional language.

Early on in the session there was evidence of a reluctance to discuss how they supported each other when sad. I reminded the participants of our last conversation on this topic and asked a general question about who they would go to if feeling sad. Flashergirl told Katrina that she went to her room and 'cuddled her teddy'.   I probed a little deeper and asked if they ever spoke to each other when feeling sad, to which there was a resounding "no". I remember at the time thinking this was unusual with such a close family, although it subsequently transpired that their statement wasn't completely true (a point I will revisit later in this section).

At times, it was difficult to ascertain whether the participants were being cautious in relation to divulging sensitive information. Either they were unable or unwilling to discuss their feelings, or may not have associated the content of the book with their own experience. A good illustration of this can be found where Katrina says to Sarah "...is there a little bit [within the book] that made you think… I felt like that or… something that you thought is relevant to you?" Not only had Sarah experienced the death of her sister, more recently a close family member had died. Despite this she replied "no".

When transcribing the session I was initially critical of the directive language used by myself. Phrases such as "...[it is] really good that you've got someone to talk to... isn't it", were prominent and my words appeared to suggest that there are 'correct' ways to manage the experience of grief.   However, in addition to my role as principal investigator, I was also responsible for ensuring the participants underwent a therapeutic encounter. Therefore, I needed to provide some focus in relation to issues which were likely to be important, such as the social and emotional isolation that can accompany grief. One way in which I did this is illustrated below:

When you're sad, what do you do?

Flashergirl   Run upstairs

You run upstairs… oh, do you ever talk to your sisters, your brothers?

Flashergirl shakes her head

Hoover   You always talk to me, what are you lying for?

Do you talk to Hoover sometimes?

Flashergirl nods

That's really good that you've got someone to talk to isn't it?

Flashergirl nods again

Remaining on the subject of sadness, I asked the participants what they would think if someone was crying because they were feeling sad. Even though crying wasn't specifically mentioned in the book, this topic had arisen previously. We had discussed ways in which people express grief, an issue I thought was worth revisiting. However, the sentence I used when asking the question was perhaps a little long and complex for Britney. Fortunately, she connected with the word 'cry' and replied "...I think its difficult crying… Eleanor". I was unsure of what had been said, so asked her to repeat the answer, to which she replied "crying". One of her sister's explained that she cried about Eleanor's death. Furthermore, according to her sister, Britney cried "for hours".

As discussed in Section 8.2.1, the above comment could be seen as a betrayal of confidence, if Britney had not wanted anyone to know about this. Interestingly, neither she nor her siblings seemed perturbed by this revelation and continued with their interactions as before. I later reflected on this issue and considered a possibility that due to their familiarity with each other, the incidence had little, if any, significance. Certainly as a family they were quite open about many aspects of their lives.

Later in the session, Hoover suggested that the book was to help people who were sad. Rudolf continued the conversation and said it was about someone who had lost a family member and were subsequently feeling sad. The following illustrates how the group gradually pieced together the story-line, thus indicating not all the participants immediately followed the plot.

The man in the story, how do you think he was feeling?

Boothy He was feeling sad

He was feeling sad? Mm…and why was he feeling sad? Does anyone know why?

Spiderman Because his Dad died

Flashergirl No his son and his mum

QBL also says something, although it is not clear what is said from the recording

His son and his mum had died. Mm… and so that made him feel?

Boothy Sad

The above interaction is interesting for a number of reasons, not least of which is that it shows some of the less vocal members starting to interact and support each other. I

was interested in the remark by Boothy (about loss causing individuals to feel sad) and asked if he thought it was true, "Do you think that's how someone would feel?" As sometimes happens within a group situation, my question was answered by another participant who said 'yes', to which QBL progressed by saying that it would affect "their nerves". This is a clear example of how individuals of all ages have their own vocabulary regarding the impact of grief. In QBL's case he related sadness with a psychological disturbance 'of the nerves', a phrase I could envisage him hearing from some older members of his family.

Following on from the participants' previous conversation, I became interested in what other parts of the story-line they related to and enquired "…did anybody think there were bits in the story that were very true?" Hoover responded by drawing attention to the first page. I asked her to read out the words, although strongly suspected that it was the accompanying illustration which had captured her attention. Several members of the group also referred to this in the next session, even though the book was not used. Rosen's text explains:

This is me being sad.
Maybe you think I'm being happy in this picture.
Really I'm being sad but pretending I'm being happy.
I'm doing that because I think people won't
like me if I look sad

As discussed in Chapter 1, of all the illustrations that Quentin Blake has created throughout his career, he found the one above extremely challenging. His difficulty was in creating a complex drawing, of which he explained, "I did it 15 times, but I just couldn't get it right…. it wasn't so much that he was sad, it was that he was sad, but trying to look happy. I did it once and he looked too cheerful, another in which he looked too sad. It was a matter of trying to dose the happiness" (Jeffries, 2007). The perceptive and descriptive text, alongside the illustration, appeared to offer several participants a strong personal connection to the story-line. Our conversation continued:

Gosh, that's interesting isn't it… and has anybody here felt like that?

Hoover puts up her hand

Yes? ...let's have a look, let's find that card ...this card says… this is me being sad, so this is the man writing the story. Do you think that people would like him if he looked sad?

Hoover   People who had lost someone would

So they might understand?

Participant   Mm…

Because it's very normal isn't it….

I found this connection very moving and did ponder, once again, that these young people may have experienced tremendous sadness, not only due to the loss of a sister but the incidents or loss that led to their adoption.

<div style="background-color: yellow; color: red;">

8.2.6   TO KNOW 'GRIEF': the 'Orange' hat represents how the experience was both meaningful and valuable

As highlighted within this chapter, many of the participants made connections to the story-line, indicating an on-going experience of grief that was tough and at times resulted in several seeking support from family members. This section will focus on instances which suggest the experience of exploring their grief was both meaningful and valuable.

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At certain points in the session, I distinctly asked questions that prompted the group to focus on how it feels when someone dies. An example of this was when I discussed the last page of the book, featuring an illustration of Rosen completely without any text. I enquired as to how the author looked at the end of the story and a quiet member of the group, who did not often join in the conversation, explained "...it's in-between". Another participant confirmed this view, with the words "...it's in between, because like he's not happy but he's not sad like he was…"

This illustration contrasted with many of the picture books I had read on the subject of death and dying. Often, at the end of a story-line the characters were much happier and moving on with their lives. In this study, the participants certainly connected with Blake's picture and when I asked if they were saying it represented "how it feels when someone dies", QBL answered very eloquently: "Sometimes we do, yes… things we get upset about, different characters… all growing up and go to the sky like an angel". Here it is interesting that although the book itself does not indicate any particular belief about what happens when people die, QBL introduces the subject within our conversation, by stating his spiritual beliefs about life after death.

Later, following a discussion about crying and emotions, I probed a little deeper regarding the significance of the book and asked how the participants felt when they were looking at the pictures:

When we were reading this book, did it remind anybody of those kind of feelings, when you were looking at the pictures?
Participant   Yes
...you know, I cried when I read it once
Hoover   It's just like… it's just like what other people feel…

Unfortunately, the video did not capture any specific verbal details about Hoover's subsequent comments. However, the recording did provide evidence of several participants hiding their faces from the camera and being visibly moved when various parts of the book were read. Interestingly, after the 'reading' had finished there was no evidence of this emotive behaviour within the discussion.

Whilst the video recording provided a good amount of data, it did have an impact on the way several individuals participated in the session. When I visited the family in their own home, a few weeks later, they were much more relaxed, although still conscious of the digital recording. In the data collection period, Rudolf appeared uncomfortable with her discussion being recorded. When I realised the significant impact it was having on her reflection, I asked Tharpa to point the camera towards myself. However, it still took quite some time for her to relax into the discussion, as the following illustration demonstrates:

...after Eleanor died ...if you read this book, do you think it would have helped?

<u>Although the camera wasn't picking up anything, Rudolf was communicating in subtle body language, therefore I persisted with the line of enquiry</u>

…so did you actually find it quite difficult to read it?

<u>Although the recording didn't pick up her answer, Rudolf probably nodded before I progressed</u>

Hoover said that there were times whilst reading the book that she felt like crying

<u>Rudolf spoke quietly and therefore I paraphrased</u>

You felt like that?

Rudolf [nodded]   I did… I did, it was the bit where…

Due to Rudolf's quietly spoken voice, the recorder did not pick up her full explanation, although it was good that she had finally chosen to contribute to our discussion.

8.2.7   LAUGHTER, CHOCOLATE AND TOGETHERNESS: To conclude, the 'Blue' hat will provide an overview of the main findings in an organised, clear and succinct manner.

All the illustrations within Section 8.2 have provided evidence of key findings. Two recurring elements weaved throughout the data collection period and will form the basis of this final section. 'Togetherness' illustrates the cohesiveness, familiarity and closeness of the participants' family unit.   'Having fun' relates to the activity that transpired from the design of the session and includes reference to their laughter and thorough enjoyment of the chocolate intermission.

Firstly, I considered the methodological design and wondered how the participants experienced this, especially whether they preferred to read the book in paper form or by watching the images on the screen. As expected from such a large group, their response varied, with the teenagers more able to carry out both activities, as opposed to the younger ones. Throughout the recording it was possible to see the teenagers not only managing to look at the book and the screen but appearing emotionally moved by the content.

A number of touching moments are evident, particularly where the siblings subtly and naturally support each other, often in a seemingly unconscious way. These instances were fleeting but significant, possibly contributing to all the participants being able to understanding at least one part of the exercise, if not all. As an example, when Britney started to get confused, Sarah very naturally helped her by pointing to the page that Katrina was reading. Later in the session, Sarah gently touched her sibling's arm, this time to support her cope with the pace of the session. It was a wonderful moment that conveyed an unconscious action which was warm, freely given and without any expectation of her actions being seen or acknowledged by anyone else.

The participants also sought assistance from staff members, as indicated just after the reading when Superwoman stated, '…that was very nicely read'. In response to a question from one participant, she replied '…we're all going to work together'. In fact this phrase of 'working together' was evident throughout the data collection period.

Irrespective of the participants' age or cognitive ability, each seemed to have a personal preference for the reading activity. For example, Hoover stated that she chose to read the book rather than look at the screen, whereas Flashergirl preferred to look at the projected image, as the following illustrates:

When you were reading the book, did you like to watch it on the screen or did you like... the book?
<u>Flashergirl nodded and smiled</u>
Flashergirl   On the screen
You liked it on the screen… so did it remind you of going to the pictures?
<u>Flashergirl nodded</u>
And when you were reading it, what kind of things were you thinking of… did it make you think of something?
<u>Flashergirl shrugged her shoulders and the brief interaction was finished</u>

At certain points in the session it was difficult to understand what everyone had said, especially the participants with a learning disability. Completely unprompted, several members of the family patiently allowed the older participants to finish their explanation and then offer a translation or explanation of what had been said. As an example, after

QBL expressed his understanding of the book, which was at times a little hard to follow, Hoover waited for him to finish and then explained:

Hoover   He's talking about…

That's very clever QBL, it's very good

Hoover   ...and the last pictures like to show that sometimes you can feel that….

QBL   That's what I mean

Although not all of Hoover's explanation was recorded clearly, the most striking aspect was the fluidity of the interaction, the even tone in both participants' voices and the mutual respect they offered one another. However, it was not just the individuals with a learning disability who had difficulty in explaining what they meant. In a previous section there is an illustration of where Rudolf helped Sarah to explain about her friend's mother who had recently experienced a miscarriage. Flashergirl also helped her brother work out who (within the story) had died.

I quickly surmised that for some of the participants I was not going to reap eloquent reflections of their experience but, at the same time, wanted each person to know their contribution to the session was valued. Below, I have chosen to highlight an interaction which ensued between Flashergirl and myself. It is clear from the verbal transcription that she does not say anything apart from helping with the sound effects. However, the recording shows us both communicating in a relaxed way and laughing at some of the text and illustrations, despite not really achieving much (in relation to what the page was about).

Right, we've got five more minutes and we are all going to answer one question each for the viewers… we are going to take it in turns and Tharpa is going to be videoing us, as though we are news reporters… we are going to start with Flashergirl

At the time she was playing with one of the toy puppets (a kangaroo)

OK, Flashergirl and her kangaroo… now you can choose your own card... and just talk a bit about it.

Hesitant pause

I'll do one with you?

<u>Flashergirl nodded</u>

Flashergirl and I are… what about this one?

<u>Flashergirl nodded once more</u>

... Flashergirl and I are going to talk about this card.

OK, it says… shall I read it or [will] you read it?

<u>Flashergirl was hesitant at this point and I was unsure of how good her reading was</u>

I'll read it….

> *Sometimes because I'm sad I do crazy things, like shouting in the shower...*
> *Banging a spoon on the table*
> *Or making my cheeks go whooph, boooh, whooph.*

<u>Flashergirl helps with the sound effects for whooph, boooh, whooph. A warm interaction ensued with both of us helping each other, communicating with ease and giggles</u>

Several people, including myself, made mistakes in the session. Within the following illustration I incorrectly stated that Rudolf was the oldest. It was in fact QBL, as noted by one of the participants:

Participant   No QBL is… QBL is the oldest…

Sometimes it is the absence of things which are the most informative. My mistake was swiftly resolved, with the session resuming quite naturally. It was good to see that there was no laughing from the others, QBL did not appear perturbed and our discussion continued without any visible detrimental impact.

Another example of potential conflict was discussed within a previous section and is expanded below. Whilst Britney and Hoover had an emotive disagreement, it was soon over and, once again, none of the other participants laughed, encouraged further conflict or even added their own comments to the interaction. In many ways Britney did make a mistake when she inappropriately disclosed something about Hoover. However, due to her learning disability, she was possibly not aware of the possible effect this could have had on her sister.

<u>Britney was talking about Eleanor:</u>

Did the book remind you of her?

Britney   Yes, miss her... a lot… sister was angry, mad, Hoover was crying, swearing…

<u>At this point I didn't fully understand what Britney was saying</u>

Will everybody listen to Britney, she's telling us something very, very important here

Hoover   Tell them my personal life

<u>Perhaps due to her learning disability, Britney carries on doing just that</u>

Britney   Sisters, hungry, mad, Eleanor, make angry….

<u>Realising what was happening, I changed the focus of the conversation to Britney</u>

Right... and what do you do when you're feeling sad?

Britney   I end up crying …because Eleanor died.

No more was said on the subject, either in the session or during the rest of the day and Hoover certainly didn't seem to take offence.

Occasionally, I wondered if the data collection period was an exemplary bereavement session and came to the conclusion that perhaps this was the wrong question to ask. In order to be exemplary, surely a robust criteria would be required, which in turn would be a great challenge given the complexity and variety of each therapeutic session that takes place. With hindsight, I may have changed some of the design, especially by providing more time for those who had a learning disability to read and discuss the book.

However, what these findings offer is a glimpse at what did transpire, a session in which there was evidence of the participants jumping about, opening up and sharing their reflections. The younger ones sat on our knees, gently tugged my hair for attention, listened to the story and ate chocolate… in short, a healthy balance of emotions and behaviour. A mutual love of chocolate within the group was evident, not necessarily from the verbal transcriptions but the body language recorded on tape. My reflection written shortly after the session illustrates this point:

Chocolates were used half way through the session to good effect, in fact taking a short chocolate break actually increased the length of the session by far more than I had hoped. Although the level of activity and noise continued to fluctuate, even after the

consumption of chocolate, the participants carried on with their discussions for a significant amount of time…

It was also interesting that one participant made a connection between the discussion of coping strategies and eating chocolate, even though this was not in the book:
So crying is good for us… and what else can we do when we are feeling sad and we're crying
Participant   Eat chocolate
<u>Laughter from a number of the participants</u>

After approximately 30 minutes I became aware that the participants' concentration span was starting to wane (the session itself lasted 43 minutes). I asked each person to take it in turns and answer one question each for the viewers, in their capacity as CBBC news reporters. This reminder of the 'role-play', which they all quite happily embraced, brought a fresh surge of motivation to the group. Even though some of the answers were neither audible nor clear, I politely acknowledged each response. At certain points in the discussion, when I thought a participant would be comfortable with the attention, I asked the group to listen to what they were saying.

Both playfulness and gaiety were intermittent throughout the session and did not appear inappropriate at the time. Some of the younger ones found the recording a highly enjoyable part of the session. There was evidence of the children puddle jumping in and out of deep emotive discussions with lighter and more playful behaviour, as the following illustrates:

Has everybody said something now to the camera?
<u>One participant noted that Tharpa hadn't said anything and Dash, one of the youngest</u>
<u>participants, decided to interview him</u>
Participant   Tharpa hasn't because he's been filming… Yes, Tharpa
Dash   Give it a mark out of 10
Tharpa   I think it's a great book… I'd give it 9 out of 10
<u>Claps and cheers from many of the participants</u>

Towards the end of the session several participants wanted to have their own copy of the book, even the quieter ones who said very little within the session:

Participant   Can we take the book home?

You can take the book home. Would you like to take the book home to have a look at it?

<u>Question directed at an unknown participant</u>

Lyn   I'm taking mine home

Flashergirl   We've got one here

When bringing the session to a close, I asked the participants what news reporters would say when finishing off their reports and quite unprompted the rest of the group took over the scenario:

Hoover   This is the six o'clock news, goodbye.

Superwoman   You've got to say who you are.

Hoover   I'm Hoover Girl…

<u>The whole group then followed in a similar manner, each taking turns and looking towards the camera</u>

To emphasise the link between their use of pseudonyms and confidentiality I had asked Tharpa to record everyone speaking to the camera and stating their chosen name, a point illustrated by the above scenario. The strategy appeared to be successful, as all the participants (and staff) accurately stated their chosen name.

I offered my personal appreciation, to ensure the group were clear about how the recording was going to be part of my PhD:

…I'd like to thank you all for helping me with my course work, thank you very much. I think you have really participated well and you've all told me things that are really special.

When using this therapeutic tool, a particularly rewarding element was the participants continued willingness to discuss the book. This lasted after the data collection session had finished, with latent thoughts arising periodically during subsequent therapeutic activities. Furthermore, they wanted to read and discuss the book all over again, when I returned to see the family a few weeks later.

The very last part of the session was recorded by Dash and Spiderman, who had asked if they could use the camera.   A scenario ensued in which they decided to interview myself:

Dash and Spiderman   Esmeralda, Esmeralda, stick your tongue out
<u>To which I replied</u>
Oh, I can't do that. I would get sacked!

> **8.2.8   EPOCHĒ: the 'White' hat encourages a neutral and objective focus on situations.**
>
> **The White hat represents a neutral and objective focus, suggesting a more positivist approach to presenting the findings. For this reason the hat was not included in the main body of the 'presentation' (Sections 8.2.1-8.2.7), details of which are explained below.**

Previously, I adapted De Bono's framework and used the White hat to reflect on the pragmatic, overt details of what happened in the data collection session, without being concerned about any accompanying emotional or negative elements.   However, I realised that to present findings of the participants' experience which denoted their neutrality, was not in line with the epistemological focus of my study.   Nevertheless, rather than abandon this part of the framework altogether, I considered alternative ways to use this hat (focus).

Although the White hat did not appear to offer an option when presenting the findings, it did seem to have some connection or similarity with the process of epochē. Interestingly, both De Bono and Husserl encouraged their readers to view situations with a certain detachment, albeit in very different ways. De Bono encourages individuals to look at a 'dilemma' (often in a business setting) and view the various elements or consequences without feeling emotional. In this section I am not attempting to do this. Instead, the focus (hat) has been adapted and applied in line with an element of Husserl's philosophical underpinnings, epochē.   Whilst Section 10.4 provides a more

general account of my experience when suspending theoretical knowledge and experience, here I will concentrate for a brief moment on the challenges of implementing epochē when presenting the findings.

One of the first challenges was to present the data independent of any particular position, especially my role as a palliative care professional, with prior knowledge and experience of supporting bereaved young people. The way I navigated this dilemma was to consistently focus on what the findings uncovered. By undertaking this approach I presented information that described the participants' experience clearly and fully, thereby allowing subsequent chapters to reflect on the universal elements of the phenomenon, in dialogue with literature and my own points of view.

As an illustration, much of what I have read about grief and bereavement discusses the powerful emotions that many individuals experience. Within Chapters 2 and 3 I discussed several sources of literature that identified emotions such as anger, denial, shock and despair, which frequently accompany the death of someone significant in our lives. However, due to Husserl's insistence on the process of epochē (see Section 4.3.7 for a full explanation of this term) it was important to put aside this expectation when considering and presenting the findings.

Due to my role within palliative care, I have been very conscious of writing about such an emotive subject and, at the same time, discuss how the participants had fun, laughed and ate chocolate, even though this is exactly what transpired. However, phenomenological methodology insists that investigators consider each element of the data. Thereby, I had to ensure that *all* the findings were included, instead of omitted because I felt uncomfortable or perceived they did not fit within the area under investigation.

At various points I thought about splitting up the findings into elements of the experience that related to discussing Eleanor, followed by a discussion on the laughter and chocolates (which were possibly more to do with the design of the session and the staff approach). However, this would have altered the philosophical tradition I was following, which states that any experience is a combination of many facets (Idhe, 1986) and, as such, the findings should reflect this. Furthermore, it was important for the details to

reflect the temporal element of the session, rather than offering a disjointed, 'thematic' account.

I very quickly identified elements within the data which were expected, due to my knowledge and experience, not only in palliative care but also from working with adults who had a learning disability. My supervision team ensured that when I presented these aspects only the findings were highlighted, without any comments about my expectations, past experience or the literature uncovered. This constantly reminded me to put 'all' the essential details into the presentation, in preference to providing a snap shot of the various interactions, without an explanation of what was happening at the time. Had I not carried out this approach, the presentation of findings would have been very different indeed.

8.3 Transformation of the data

Due to the Husserlian focus within my study, Section 8.2 has presented a pure description of the research findings, unadulterated by any theoretical literature on the issues explored. I will now progress by revealing how, through a further process of transformation, the layers of individual experiences were merged, thus highlighting the essential findings of the participants' lived experience. As explained in Chapter 4 (Section 4.3.6), essential findings are often referred to as 'universal essences', describing the 'root' or 'common' elements of an experience and representative of more than one individual experience. This key feature of phenomenological analysis acknowledges Husserl's position, in which every experience, without exception, has universally common inner properties (Husserl 1925:1977).

Through transformation, the data is synthesised and presented within a statement relating to the structure of the experience, referred to by Giorgi (1985) as 'a consistent description of the psychological structure of the event' (p.19). Furthermore, Todres (2005) notes that a structural description is concerned with 'establishing what is typical of the phenomenon and expressing such typicality in an insightful and integrative manner' (p.113). To undertake the proposed process, I considered both commonalities and differences in the participants' experience. This included frequently occurring traits or reflections and general features within the data. Most idiosyncratic variations were

removed to identify relationships within the findings that were universal, rather than specific to just one or two individuals.

There were times when I found the above process a great challenge, as some individual findings were potentially crucial when formulating the final description of the phenomenon. I was therefore relieved to read a pragmatic book by Langdridge (2007), entitled 'Phenomenological Psychology: theory, research and method'. In line with previous literature, he encourages readers to aim for a description containing the invariant properties of an experience. However, according to the author, it is sometimes necessary to acknowledge that it may not be possible to achieve a structural description, without referring to *some* individual experiences. By following his advice, I ensured that throughout this transformation stage, the experience was described accurately and sought to focus on the universal structures *wherever possible*.

I was forewarned about the process of further transformation being complex (Todres, 2005) and therefore undertook this stage of the analysis cautiously. Several drafts were written and each summary scrutinised, to ensure it was a clear and concise portrayal of the findings. Deciding which data to highlight within the final statement was difficult. I concentrated on details that were superfluous and those which needed to remain, in order to adequately portray the participants' experience of the session.

The above task was at first overwhelming, due to so much data and once again I realised the need to break this down into manageable steps. I tentatively considered the structure utilised when reflecting on the session and presenting the findings, namely the Seven Hat Framework. This strategy had not been used before (with regard to transforming the data) and I was mindful of a potential criticism that the process would force an overly a priori structure to my thinking.

However, after undertaking a preliminary exercise in utilising the framework for this stage, I was reassured to find it had produced a more complete summary. As can be seen from Figure 13, the range of essential details within this descriptive summary (an intermediate stage of the transformation) provided a balanced and increasingly vivid overview of what transpired. Had I not used this approach, there may have been a possibility of focusing on aspects of the session that stood out for me and an omission of those which did not appear essential. As discussed in Section 8.2.8, the white hat had

been utilised to portray my experience of undertaking epochē, therefore the penultimate transformation was derived from each of the six remaining hats.

The lived experience of reading and discussing Michael Rosen's SAD BOOK included the following essential elements:

The Hats	Transformed universal, essential findings
Blue hat *Introduction*	… a continuation of learning: establishing connections from a previous session
Green hat *Creative elements*	… words and drawings: significant text and illustrations
Black hat *Unexpected elements*	… no personal connection for one person with little reference to the deceased from the younger participants
Yellow hat *Optimistic elements*	… it will help: therapeutic value for other bereaved young people … it made me think: reflection on what insights the book uncovered
Red hat *Emotional elements*	… this is sadness: discussion and exploration of sadness ... an opportunity to explore personal struggles with grief ... coping strategies for managing grief were an important part of the discussion
Orange hat *Transcendental elements*	... I know how it feels: personal meaning and connections to the story-line
Blue hat *Summary*	… laughter, chocolate and design of the session … it's my story to tell (if I want to): selective disclosure … togetherness: cohesiveness, familiarity and closeness

Figure 13.   Descriptive summaries from the Seven Hat Framework

As can be seen from Figure 13, the majority of statements were now starting to resemble 'universal', rather than specific individual elements of the experience. One exception to this was the Black hat, which reads '*No personal connection for one person with little reference to the deceased from the younger participants…*' At this stage the individual descriptors were retained, as I felt they were essential to the overall experience of reading and discussing the book. However, in the structural description [presented at the end of this section] the details were transformed further and influenced the statement, '… **for some** there is a personal connection to the story-line…'

The final stage of the transformation involved condensing the descriptive summaries even further, to make them more articulate and indicate the psychological meanings that were present within the data (Giorgi and Giorgi, 2008). Creating a more *articulate* statement was a challenge and required several revisions, before it revealed the *universal elements* of the phenomena investigated. I read through each of the descriptions and used imaginative variation to understand which elements were essential to the phenomenon. At the beginning of this study I had thought a structural description would be highly condensed, a little like a mission statement. However, I soon came to realise that when transforming the data, a key consideration is for it to accurately portray the totality of the participants' lived experience.

I continuously returned to the data, transcending specific details and instances of each individual, thereby concentrating on providing an account they were instances of. As an illustration, at first I started the statement by identifying the book by name, instead of 'a book of death and dying' as it later became. Had I left the name of Rosen's book in the structural statement, it may have detracted from what the experience was actually about, that is 'reading a book about death and dying'. I repeatedly questioned whether a particular sentence was 'essential' to describing the participants' experience, intermittently seeking clarification from my supervision team, who had viewed the recorded session on many occasions.

Finally, the point arrived where I recognised that to transform the information any further, would have restricted my ability to capture the 'essence' of what the session was about. I was resolute that the description would not be a disjointed statement describing the participants fluctuating understanding, their focus on the story or their limited concentration. My aim was for the structural description to represent not only what

happened but also offer the reader a sense of rhythm, a clear illustration of what transpired within the session.

Transforming the summary from what appeared to be a historical account, into a description of the essential features, was the next challenge. Whilst some may argue that the difference is debatable or at best minimal, this fine distinction was crucial if I was to portray the phenomenon in line with the philosophical underpinnings. It was important for readers to understand that the essential features could be expected if they undertook a similar therapeutic approach, thereby allowing not only a greater insight into the session itself but a possibility of comparing it to other situations. Consequently, I changed the statement into the present tense, to emphasise the 'universal essences' of the phenomenon (Figure 14). Finally, it was possible to see that I had created a statement reflecting more than one particular instance. The description of the phenomenon clearly illustrates features which are not purely incidental but have great relevance to similar experiences, beyond those of the participants.

The lived experience of reading and discussing with others, a book of death and dying, involves a discussion that gradually opens up the subject of grief and bereavement. Participation, concentration and understanding fluctuate throughout the group.

The discussion of death and dying in a bibliotherapy session is fluid and increases in depth. Whilst participants are selective about what they disclose, the focus of the conversation is on the impact of loss. For some there is a personal connection to the story-line and other bereaved individuals.

A warm and caring atmosphere contributes to a setting in which personal insights can be generously shared. Remembering personal grief, prompted by parallels within the story-line, may be difficult to experience and result in an exploration of personal struggles, conflicting emotions and ways in which grief is managed. These poignant reflections of grief and sadness are 'puddle jumped' with a focus on the present moment, frequently intermingled with gaiety and laughter.

Figure 14.   The phenomenon of reading and discussing with others, a book about death and dying

In order to uncover the phenomenon of reading a book on death and dying, this study focused on the experience of one book, rather than a larger sample of publications. By utilising a transcendental phenomenological design, I was able to explore the participants' experience in fine detail and from a number of perspectives. Rosen's book contributed to the group's experience and in turn allowed them to discuss certain issues, such as the lack of a happy ending and coping strategies for managing grief.

Nevertheless, this study does not suggest the publication was so unique that it generated completely distinct experiences to anything else. The structural description allows readers to see aspects of the experience they could expect in practice, irrespective of which particular book on the subject of death and dying is used. Further research in this area, specifically with a number of different publications, will allow for a comparison to be made and thereby identify any contrasting findings in relation to the respective books.

8.4 Summary

Within this chapter I have highlighted findings which offer a range of pre-reflections and observations of the participants' experience. Wherever possible, illustrations have been used to substantiate the data, including selective disclosures, the experience of sadness and grief. Section 8.3 progressed by offering an overview of how the structural description was produced.

Despite some of the participants' limited language, I became increasingly aware of similarities rather than differences in their experience. What emerged was a shared experience and gradual understanding of the issues contained within both the text and illustrations. For each finding uncovered, another became apparent which refuted stereotypes often referred to in the literature. This and other aspects of the phenomenon will be explored in the final two chapters.

CHAPTER NINE

THE FINDINGS REVISITED IN DIALOGUE WITH THEORETICAL LITERATURE

In a timeless, universal way… stories educate, inspire and energise other people to own, tell and retell their stories of loss, joy and hope
Zuckermann (2001, p.242)

Similar to the quote from Zuckermann (2001), this penultimate chapter will discuss the way Rosen's book inspired the participants to explore their own stories of loss, joy and hope. The structural description of the phenomenon highlighted a number of key areas: bibliotherapy; grief and bereavement; a connection to other bereaved individuals and personal insights, generously shared. This chapter will explore these issues and related findings alongside theoretical literature, some of which was introduced in Chapters 2 and 3.

The methodological design revealed aspects of the participants' experience that are not always predominant in literature and the relevant points will also be expanded in this chapter. I will focus on areas where the data confirmed or cast doubt on previous work, particularly where it added something significant to the literature currently available. Through critical engagement with work available to date, I intend to underline the distinctive contribution that this study offers.

As noted in Chapter 5 (Section 5.1), the principle aim of this study was to uncover a detailed account of all the participants' experience, thereby revealing the structure of the phenomenon when reading and discussing together a book on death and dying. For the purpose of this investigation, Michael Rosen's SAD BOOK was the chosen publication. This chapter will firstly consider findings that cast light on literature relating to bibliotherapy, the therapeutic technique utilised with the group. I will follow with the broader areas uncovered, including grief and bereavement (the context of the study), puddle jumping (a specific orientation towards exploring issues on death and dying) and a strong connection that bereaved individuals frequently discuss, in relation to others who have experienced loss. To conclude, I will explore findings that contribute to

literature regarding the personal insights of bereaved individuals and specific issues relating to the participants who had a learning disability.

9.1 Bibliotherapy

The findings, as outlined in Chapter 8, illustrate how important it is to consider the experience of bibliotherapy in the context of bereavement therapy. They provide much needed evidence about the therapeutic impact of storytelling, especially the unexpected elements that arose. The data and particularly the structural description, refer to the way bibliotherapy was experienced within the group, *'…the lived experience of reading and discussing with others, a book of death and dying, involves a discussion that gradually opens up the subject of grief and bereavement'*. This therapeutic approach supported the participants to discuss their grief, whilst at the same time allowed them to be '…*selective about what they disclosed*'. It is these findings, in relation to the theoretical literature available, which will be discussed next.

The role of the book in stimulating a discussion about loss, prompted me to think carefully about the therapeutic impact of storytelling (in the context of grief and bereavement). Firstly, I reflected on my own experience as a child, when I attended wakes and heard many stories about deceased relatives. Todd (2006) explains that wakes were a common bereavement ritual and usually involved friends and relatives visiting the deceased's home, to pay their respects and offer support to the surviving family. I remember the open coffin in the sitting room, with older members of my family drinking tea and discussing the deceased, especially the funny or poignant tales relating to their life. This experience enabled me, at a relatively young age, to see adults becoming upset, crying and laughing at their recollections. Upon analysing the findings, I was constantly drawn back to the similarity of the participants' experience alongside my own, when I attended wakes and listened to these stories of death and dying, albeit verbal accounts, all those years ago.

In relation to how young people access their own stories of loss today, it is less likely to take place at wakes. Presently, most deaths take place in hospital with only 18% of people dying in their own home (Department of Health, 2008). It is now common practice for the deceased to be transferred to a funeral home, rather than remaining or returning to their family abode. Literature suggests that a deskilling of the local

community has ensued, with most activities (in connection to the dying) carried out by professionals. Thompson (1993) argues that by enlisting the help of others, families concede they lack the relevant knowledge and skills to manage death, with only a 'professional' able to carry out this role.

However, there appears to be an idealised or romantic picture of the past, in which communities supported each other and had more respect for the bereaved (Fanthorpe, 1986). Interestingly, accounts of grief many years ago show this was not always the case (Holland, 2001; Katz, 2004). Families struggled to discuss death with young people and either through ignorance, or as a coping strategy, denied that children or individuals with a learning disability experienced the impact of grief at all. Stokes (2004) suggests one reason for adults discomfort in discussing death with children, is a belief that they need to be protected from the harsh realities of life.

Findings within this study are not in line with the above literature, as the parents had clearly supported their children and discussed the impact of Eleanor's death on the family as a whole. When enlisting our help, it was to ensure no issues had been missed and for us to ascertain if there were any fears or concerns that the participants had concealed from them. Therefore, rather than contributing to deskilling the family, our session was complementary to the care already provided and, as such, enhanced the bereavement support received. I was reassured when the parents stipulated that their older children with a learning disability should be fully involved in all aspects of the support offered to everyone else. When considering the impact of death, there is plenty of literature regarding the exclusion of both young children and people with a learning disability.

In Chapter 3 I emphasised the work of Nadeau (2001), who stated that for centuries writers and artists have created 'cultural representations' of human experiences such as loss. These stories are said to complement those which families create themselves. When initially reading this literature, I was unaware of its significance in relation to this study. However, Nadeau had perfectly described what unfolded within the session, where Rosen and Blake represented the 'experience of loss', a story which the participants expanded further.

Prior to the publication of Michael Rosen's SAD BOOK, Quentin Blake had created a story-book entirely with illustrations (1995) and Rosen wrote a poetry book comprising of mostly text (2002). However, in the data collection session both the story-line and illustrations appear to have been of equal importance. Firstly, the participants focused on Rosen's story, graphically illustrated by Blake, then slowly progressed to discuss aspects of the story-line in relation to *their own* experience of loss.

There were numerous ways in which the participants oriented themselves to the task of reading the story and their subsequent discussion. When analysing the data, often the illustrations appeared to capture the participants' attention first, followed by Rosen's accompanying text. This was certainly more evident with those who had poor literacy skills, where the illustrations allowed them to have an equal contribution when discussing the book. However, at other times it was impossible to prioritise one medium over the other.

With such a varied group, in relation to their: personality; age; cognitive level; concentration span and reading ability, utilising a picture-book certainly enhanced the design of the session, irrespective of whether the participants could read or not. Johnson and Jackson (2005) suggest that any artistic medium has the potential to provide insights and deepen understandings about complex and existential aspects of human experience. I considered this in relation to the wide range of abilities within the group, particularly with regard to whether the book deepened their understanding of death and dying. Whilst this study does provide evidence of a substantial discussion, subsequent research would need to be carried out in order to investigate whether the session *deepened* the participants' understanding of their situation.

Jewett (1994) states that when children are uncomfortable or not familiar with talking about their feelings, combining discussion with an external activity, such as using visual props, often helps them to open up. This suggestion was also made by Pardeck (1994), in respect to encouraging discussion in a bibliotherapy session. The findings certainly seem to substantiate the above, with the book and particularly the illustrated cards, promoting an exploration of loss. This allowed those who did not have a wide vocabulary or were unable to express their experience, to choose one of Blake's

drawings, thus helping them to feel part of the session and satisfied with their contribution.

Liossi (2000) and Delvin (2006) progress the above point and observe that drawings are also helpful for individuals who struggle or seem unable to express their feelings. As discussed in Chapter 8, it wasn't until Spiderman pointed to his favourite picture and had given it a mark, that he was pleased with his involvement in the session. In many ways, the picture gave him a voice and enhanced his participation within the group. Furthermore, the illustrations not only helped those with a limited reading ability but, more surprisingly, the teenagers who had excellent literacy skills. The main difference was that the teenagers commented on the accompanying text too.

A very tough challenge for bereaved young people is that they often feel different from their friends at school (Lydon et al., 2010), which may lead to a perception of having to mask their emotions (Hemmings, 2000). This certainly seemed to have been the experience of some participants who focused on the image and text of Rosen 'looking happy but feeling sad'. Whilst I will discuss this in Section 9.3.1, it is of particular interest here because, once more, the older participants drew just as much attention to the visual image as the words. At this point, I realised a symbiotic relationship between the text and illustrations. Without either medium I am not sure if the page would have been as captivating and poignant for the group as a whole.

According to Colaizzi (1978), 'genuine learning radically re-structures our world-view'. At many times in the session there appeared to be evidence that it was not just reading the book, but the group discussion which contributed to the participants 'genuine learning'. What transpired was an exploration of personal struggles, conflicting emotions and reflections of how they managed their grief, with one participant choosing to discuss her friend's loss.

Over the course of analysing the data, I have at times wondered what the experience would have been like for the participants if they had first read the book in isolation, as happened within Jones' study (2001). Whilst Lenkowsky et al. (1987) found no statistically significant benefit when comparing individuals undertaking bibliotherapy alone or in a group, findings within my own study suggest that it was beneficial to

discuss the book with others, especially for those who took some time to understand the story-line. Therefore, it appears that further investigation is required into these two very different approaches to utilising bibliotherapy.

In consideration of the above, this experience of reading and discussing the book in a group stimulated not only private thoughts, but offered an opportunity to listen and learn from each other. I was certainly moved by several disclosures the participants made, especially when listening to the way they supported each other when upset. I learnt about not only their experience of reading Rosen's story but also their life together. In turn, they listened to staff contributions, such as the time we disclosed how the book provoked our emotions or the instances where we found the text and illustrations amusing.

Most of the significant publications about bibliotherapy and loss appear to present this therapeutic activity in a positive light (Jones, 2001; Gersie, 1991; Berns, 2003/4). Reasons for this are possibly due to the infancy of research in this area, which is frequently carried out by practitioners who utilise bibliotherapy within their professional role (Delvin, 2006; Jones, 2001 and McNeilly, 2008). As an example, Jones had worked as a Cruse Bereavement Counsellor (in educational settings) and published 'Bibliotherapy for Bereaved Children' in 2001.

The above study by Jones (2001) was undertaken with 10 children, four of whom had experienced a significant bereavement (over two years prior to the investigation). Each child read Squib, a book concerning the plight of an abused child and reasons for his strange appearance and behaviour. Jones clearly informs readers as to which aspects of loss are present within the publication and her investigation asked the participants several questions, including '...how did you feel when you were reading the story?' Each child progressed to individually record their answers. The findings showed that only the bereaved children recognised the subtle references to loss and subsequent emotional effects of grief. This point correlates with data from my own study, where the participants both recognised and discussed many aspects of grief in Rosen's story-line.

Packman et al. (2006) highlight a certain maturity which, in their experience, frequently results from a child's experience of grief, accompanied by an increased ability to be

flexible and adaptable within their lives. The authors propose a greater capacity for empathy, cooperation and compassion often transpire. This was also demonstrated in a study by Van Epps et al. (1997), when they interviewed a group of young people about their experience of grief. One participant explained that if a friend needed someone to talk to, she would be there for them. Once more, it was interesting to relate this to findings within my own investigation.

As an illustration of the aforementioned point, Hoover stated that if someone came up to her and said they were feeling sad, she would talk it through with them because she "knew what it was like". In a professional setting, the phrase 'I know how you feel' is usually avoided, due to the individuality of grief being recognised. Although we can share concern for another person's distress, saying we 'know how they feel' is much more difficult to substantiate. However, when Hoover used this statement, it was perhaps a reflection that she would recognise some elements of her bereaved companion's grief.

Jones (2001) suggests one benefit of using bibliotherapy is that bereaved young people can become their own therapist. According to the author, by reading and re-reading a book, perhaps discovering new levels of meaning, interpretation and understanding, individuals can apply the relevance of a story-line to their own situation. My concern with this view relates to the instances of 'imagined' realities that I have heard bereaved children disclose before, which can have a negative impact on their ability to cope. If provided with the option to read alone, it is possible they may fail to identify or correct this, a point reiterated by Cuijpers (1997) and discussed further in Chapter 10 (Section 10.1).

Furthermore, Berns (2003/4), an American psychologist who works in a children's bereavement centre, is very clear about the need for skilled guidance within bibliotherapy. The author states that when carried out in the context of grief and bereavement, contemporary bibliotherapy should be conducted by practitioners who are suitably trained, not only in relation to literature (the language of arts) but also therapeutic bereavement support.

Another factor not highlighted within Jones' (2001) investigation, was the benefit of using group discussion to stimulate a shared understanding of the story-line. As can be seen throughout the findings in my own study, it was these shared moments which enhanced the participants' understanding of Rosen's book and its relevance to their situation. After the data collection session the participants took their book home, thereby having a further opportunity to re-read it on their own. However, I ensured an additional session (a few weeks later) was provided, so they could ask any questions or discuss latent thoughts, worries or concerns.

The cohesiveness within the group reflected literature that attests to the advantages of bringing young people together, to read and discuss literature. Shectman (1999) undertook a bibliotherapy study with five young people who exhibited aggression. Not only did the children improve their self expression, this was accompanied by a consistent improvement in constructive group dynamics. Nevertheless, despite the benefits with regard to group work and bibliotherapy, the need to effectively facilitate a session is paramount. Within my own investigation, the data highlighted several conversations which could have developed in a negative way, if they had not been facilitated firmly. As an illustration, upon realising that Britney was divulging too many secrets about her sibling, I immediately re-focused the conversation to her experience. Fortunately, within the group there were very few instances of this and, as already mentioned, the participants did not seem perturbed, it was simply a part of their normal family communication.

When reading and discussing something with another, it is subsequently re-read in light of the others comments, with the discussion becoming more of a shared landscape (Hunsberger, 2002). Within bereavement groups for young people, listening to the discussion of others can sometimes be uncomfortable, as one teenager notes, "...although group discussions are helpful, they can sometimes be difficult because they make you realise what's going to happen, and you talk and listen to some difficult and sad emotions" (Popplestone-Helm and Helm, 2009, p.220). Thus, there is a need to be sensitive and receptive to the potential impact of disclosures on bereaved young people and the subsequent support they may require following a group discussion.

Returning to the data collection session, Engel (2005) proposed that children utilise stories in a variety of ways, for example, by solving emotional puzzles, recasting events in ways that are satisfying or constructing and thereby communicating a sense of self. The findings show that Rosen's story resonated with several participants, who utilised it to explore their own 'puzzle' of grief. I asked the group if parts of the story were true, to which the reply was a resounding "yes". A further individual noted that Rosen wrote the book to help people who are sad. The text also appeared to offer the group a 'language' for their experience of grief and this, in turn, enhanced their ability to discuss how loss had affected them.

Within the above publication, Engel (2005) suggests several points which should be addressed when facilitating a bibliotherapy session. The findings show that some of these were covered, such as promoting awareness that other people have experienced loss. However, a number of the author's suggestions were not evidenced, especially the recommendation to '...present new values and attitudes when helping bereaved children cope with their loss'. Prior to the session I did not envisage all of Engel's suggestions could be achieved in one meeting, to have expected this would, in my opinion, have been naive. As a practitioner, I have always considered bibliotherapy to be one in a range of therapeutic tools which may be utilised in bereavement therapy, a point underlined below.

In clinical practice, Schectman (1999) recommended that bibliotherapy can be used alongside other approaches, such as cognitive behavioural techniques. Certainly, in relation to bereavement therapy, if it is complemented by other approaches or tools presently available (Stokes, 2004), findings within this study indicate that bibliotherapy does offer great potential. As an illustration, it assisted the participants to explore a range of coping strategies and thereby enhance their knowledge of grief and bereavement. The phrase 'one size rarely fits all' appears appropriate, considering the many therapeutic approaches that are available.

Byrne (2008) states that text is necessarily selective and reveals only what the author believes to be important. This became evident when I read Rosen's story of loss in his poetry book for adults (Rosen, 2002). The depth of his despair was palpable and much more graphic than in the picture-book for children. As noted in Chapter 2, when adults

experience grief it is often different from that of children. One reason is because adults are aware the experience of very intense grief will pass and eventually they will adapt to a change in their circumstances. In their relatively short lives, children have no concept and little (if any) experience of this, and may worry about their lives remaining emotive and distressing. This helped me to appreciate Rosen's approach when writing his book for children. He was honest, descriptive, yet not too graphic with regards to the challenge of grief. The author also wrote about coping strategies, in relation to how he lightened his day, which thus allowed him (and potentially readers of the book) to reflect on these more pleasurable moments.

Similar to many picture-books, Rosen's story had illustrations of delicious food, young people looking happy, a cat and reference to football. However, despite these aspects, it was usually the dark, grey pictures which the group wanted to discuss, rather than the lighter ones. When they explored the illustrations and text, their conversation tended to be more factual and inquisitive, rather than emotional or depressing. Perhaps, as adults, we try to protect young people from exploring the more difficult areas in life, even though bereaved children not only have experienced this (Katz, 2004) but, as the findings in this study suggest, wish to talk about it too.

Chapter 3 presented an overview of several publications that professionals and carers may wish to use. Both the number and range of books have increased since this study commenced, with a wider array of resources for bereaved young people of all ages. This range of publications will hopefully assist them to manage the complexity of beliefs they may encounter, in relation to death and dying. Some of the books contain a complementary note for carers, regarding what questions may be expected or how to discuss issues within the text and illustrations (Gilbert, 2004; Stickney, 1997). Whilst this may be appropriate for some, I didn't think it was either necessary or would have enhanced Rosen's book. Following my own experience of undertaking this research, had I read a preamble on what to expect, it may have limited my ability to be open to whatever transpired. I doubt very much if a note from the author would have included the possibility of a discussion on bathing a baby.

According to Watson, books 'make it possible for children to negotiate a cultural space for themselves' (Watson, 1992, p.11). Certainly the bibliotherapy session encouraged the participants to explore Rosen's book and relate their own cultural experiences to

those within the story-line. The findings provide many instances where they had indeed 'connected' to the story. As an illustration, the group focused on the way candles were used to remember Eddie, a similar ritual to that utilised within their own family unit, thereby allowing them to identify with this particular part of the story.

Within Chapter 1, I noted that Rosen's book was intended for children from the age of five. In the data collection session the youngest participants all commented on their favourite illustrations. On one occasion Spiderman raised his voice to let me know that he "didn't get to say a lot". However, when given a further opportunity he struggled with finding a vocabulary to expand his conversation, although did point to a dark grey picture he thought was "good".   Interestingly, the teenagers proposed that the publication would be of more value to individuals their own age and at no point appeared to consider it a book purely for young children. This encouraged me to be much more flexible with how I interpret the 'recommended ages' often advised by publishers. Instead, I would suggest that the focus should be much more on the appropriateness of the illustrations and text, in relation to the individuals and context in which a bibliotherapy session is to be situated.

As previously mentioned, discussing difficult issues in a group setting often enables young people to realise they are not the only ones who experience loss. They are then able to acknowledge that there is not something wrong with them (Kraus, 2005). However, for many young people there may be little (if any) access to child bereavement groups, potentially resulting in an isolating experience of grief (Katz, 2004). Fortunately, on this particular occasion, all the family were able to access support together.   To prevent the experience of isolation, the design of the session incorporated an exploration of their connection not only to each other but other bereaved individuals.   This latter point will be explored further in Section 9.3.

Whilst the opportunity to access support together had many positive elements, there were some challenges for the staff team. Within a bereavement session specifically designed for younger children, we would have allocated more time for activities that are created to engage this age group (Stokes, 2004) and thereby discussed concepts from the book at a much slower pace. However, an important factor in the methodological design was to involve the younger children, so they would feel part of the whole group. My rationale for this was mainly because the youngest participants were recent additions

to the family (by adoption). I wanted them all to feel valued members of the group, irrespective of whether they had strong memories or recollections of Eleanor. Therefore, had I heeded protocol or advice, on the age range or recommended number within a group, I would in this case have omitted to provide a valuable learning opportunity, as the findings within this study clearly show.

9.2   Grief and bereavement

Several distinct issues relating to the impact of loss merit particular attention and are covered within this section. As acknowledged throughout this thesis, prior to the data collection period I did know a significant amount of theoretical information regarding grief and bereavement. However, when relating this to the findings, much of my 'taken for granted' knowledge has been challenged. The structural description included reference to a session where the discussion was '*fluid and increased in depth'*. I also noted that *'whilst participants are selective about what they disclose, the focus of the conversation is on the impact of loss'.* In dialogue with literature uncovered within Chapters 2 and 3, I will also address the broader areas of grief and bereavement that emerged from the findings.

Although the participants came from the same family unit and knew the deceased well, each had a very unique story of their loss. Whilst some participants chose to discuss their personal experience of grief, Sarah and Supergirl appeared to be more concerned with current happenings in their lives. Furthermore, the two youngest individuals were ambiguous with regard to their experience of loss or that of others. Consequently, almost one year following the death of Eleanor, it was apparent that each of the participants had a varied approach to reflecting on and discussing their 'state of bereavement'. However, as the structural description reveals, there were several universal elements, all of which can be related to current literature.

It is important to acknowledge that the session wasn't designed to explore *all* aspects of grief and therefore the findings merely confirmed 'some' of the reported emotional responses noted in the literature. Equally, some issues I anticipated may transpire within the session did not materialise. As an illustration, none of the children reported any somatic symptoms which are frequently reported in bereavement literature (National Children's Bureau, 2007). For readers who require further information on either somatic

illness or any other issues highlighted within Chapter 2, details of various organisations to contact are in Appendix 7.

As noted in the previous section, in addition to the group's wide chronological age, there were four people who had a learning disability. Several sources of literature, including Summers and Witts (2003), Green (2001) and Cathcart (1995), imply that people with a learning disability frequently struggle to understand the concept of loss. Within Summers and Witts account a bereaved young woman fluctuated in her conversation, perceiving that her late father was alive or, at other times, dead. Although this difficulty in understanding death may occur for some people with a learning disability, my own data did not substantiate this point.

Throughout the findings there continued to be differences in the experience of bereavement for the participants with a learning disability, compared to the literature. More specific illustrations pertaining to this issue will be presented in Section 9.4. However, at this point I offer a preliminary speculation as to why there appears to be this anomaly. Rather than the participants within my own study having a higher than normal ability to understand the concept of mortality, it is possible that they were illustrative of a silent population of bereaved individuals who are not fully represented in the literature.

Often professional accounts or case studies are based on referrals that have been made, due to a person's difficulty in coming to terms with their loss (Holland, 2001). This led me to question whether literature (including books, journal articles or published research studies) is written more about bereaved individuals who have problems, rather than those for whom there are no complex or complicated issues. There is a possibility that many individuals with a learning disability have adapted well to their loss, in line with their cognitive abilities and in relation to their understanding of death and dying.

Complicated grief is a *complex* term, largely due to the negative connotations associated with it, especially the implication that individuals have failed to grieve in the 'correct' way (Payne et al., 1999). Machin (2009) refers to this descriptor as a socially constructed concept, yet to be defined as a clinical syndrome. However, in order for readers to understand some of the symptoms commonly classified under this term, it may be useful to consider diagnostic criteria, as created by Neimeyer et al. (2002). The authors

suggest that complicated grief relates to individuals who have been experiencing a significant disturbance in their lives for at least six months.   Several acute symptoms are listed, for example, a feeling of life being empty or meaningless, excessive irritability or anger related to the death.   In addition, some individuals assume somatic symptoms or harmful behaviours which mirror those that had been experienced by the deceased.

In contrast to bereaved young people who have experienced difficulties with managing their grief, all participants in this study had been referred to the hospice so that their parents could be certain no issues of concern had been overlooked.   Consequently, there is a need to balance the accounts of challenges faced by bereaved individuals who experience complicated grief, with those who do not.   It is possible that we can learn just as much from more resilient grievers (Relf et al, 2008) when seeking to progress our knowledge about the impact of loss for people of all ages and cognitive abilities.   This would necessitate professionals within a variety of palliative care settings, to develop research questions that consider those who have managed their grief and adapted well to subsequent life changes.   If this is not done, bereavement literature may offer a distorted and misrepresented account of how people grieve.

I next considered literature on how individuals understand the concept of mortality. There were many instances within the data that indicated all the participants had a 'concrete' understanding of death (Phillips, 1969), more commonly seen in children above the age of 7.   As most of the participants were above this age, this may not appear to be of significance.   However, when relating the findings to child development literature, I found chronological guides did not account for or recognise the various cognitive or development levels within the group.   Whilst some authors (Gilbert, 2004) did encourage readers to be flexible when considering specific levels, others presented more rigid stage or age descriptions (Dyregrov, 1990).   Certainly, in relation to the mixed ability group within my own study, publications which focused on levels of understanding in relation to chronological ages were less applicable or useful.

Furthermore, Gilbert (2004) proposes that it is not until 11 years of age when a child will *fully* realise the deceased will not return.   Chapter 8 provided evidence of the participants good understanding as to the wider concept of death, even though some were younger than 11.   Fortunately, as Gilbert encouraged readers to be flexible with

this point, I thought it may be the amount of time since Eleanor's death (almost one year) which allowed even the younger children to realise she would not return. This point is significant for practitioners who will be working with young people at a variety of different stages in their bereavement.

However, it was not only the amount of time that had elapsed since Eleanor's death which may have contributed to the participants' good understanding of mortality, but the support received from their family. As an example, one of the children had been told before the funeral that in the church he would see Eleanor in her coffin, yet at the service the young boy said he couldn't hear her *coughing*. Small but significant instances such as this, in which his mother explained to the young boy about what a coffin is and why it was needed, will have contributed to his understanding of death. Interestingly, the young woman within the earlier account by Summers and Witts (2003) had not been allowed to attend her father's funeral and subsequently missed a valuable opportunity to learn about the concept of death.

Whilst the above issues may seem superfluous to discussing findings within the session, they demonstrate the time and energy that the parents had spent discussing death and dying with the participants. It was this knowledge and experience which formed the *context* for their reading and discussion of Rosen's book.

Bereavement refers to a state, a consequence of loss and grief is the process, our affective reaction to the loss (King, 2003). Whilst these terms seemed clear enough when compiling the literature review, when considering the findings several points of interest emerged. Firstly, understanding the participants' experience of grief and bereavement was complex and not only influenced by their age or cognitive level, but their past experience and lifeworld. Developmental theorists, such as Piaget, acknowledged that a child's development is not purely age dependant but highly varied (Phillips, 1969). Whilst generally the ages provided are good indicators of what to expect, as previously noted, I had to be more flexible with the participants who had possibly experienced other instances of loss.

It may seem unusual within a phenomenological investigation to encounter a discussion of the findings in relation to such rigid, stage based developmental theory. However, as

a direct result of this research the data highlighted that, without flexibility, it is easy to misinterpret a bereaved person's understanding and fail to see why they may not quickly grasp all the issues discussed about death and dying. Fortunately, as some authors recommended a flexible approach (Goodey, 1999; Gilbert, 2004), this corresponded well to phenomenological research, where investigators are required to set aside theoretical understandings and learn from what transpires.

In Chapter 2 I discussed a substantial study by Fauth et al. (2009). The authors found that children from the most disadvantaged backgrounds were more likely to have experienced loss. In connection with this finding, I was aware that the three youngest children had most likely experienced an unsettled period before their adoption, which may have affected their development and understanding of grief (Holland, 2001). It was also not clear if any of them had experienced other significant deaths, as multiple losses would probably have impacted on their experience of Eleanor's death and the priority this had within their lives.

The findings indicated that the young children's vocabulary for expressing their experience of loss was very limited. However, even though several were not at an expected developmental 'stage', in relation to their chronological age, the order they progressed through appeared to be in keeping with literature. Thereby, for these participants, they will possibly just take a bit longer before they become more eloquent in describing their feelings of grief.

A further illustration of how the findings challenge developmental literature is the instance where QBL spoke about people going up to the sky like 'angels'. It was possible that his words could have been interpreted as 'immature understanding' or 'magical thinking', due to his learning disability or cognitive level. This raised an interesting point regarding how people use their belief systems to make sense of and understand death. The topic prompted much debate within both my supervision sessions and presentations.

Practitioners' with knowledge of the psychological theories regarding child development, may classify QBL's reference to 'angels' purely in terms of an abstract developmental level. However, the content of what he said is not radically different from some adult

religious beliefs. For example, when considering a mature adult belief about what happens when a person dies, angels do frequently enter a Christian reflection of death (Marušic, 2002). Thereby, to say that any reference to angels can be understood as an indicator of a person's developmental level, is to omit the cultural context in which it is said. This inconsistency was found in literature which correlates a child's reference to angels with magical thinking (Sanderson, 1977; Krementz, 1991), in marked contrast to when an adult mentions angels and it is assumed that this indicates elements of their religious culture.

Furthermore, in the forward to 'When Uncle Bob Died' (Althea, 1982), Dr Hugh Jolly forewarns young readers, *"I hope your Mother's and Father's don't make up stories about what happens when someone dies, like saying that Grandpa has become a star…"* This very narrow viewpoint of how young people 'should' consider death, points to a weakness in assuming an individualistic cognitive developmental approach, in this instance indicating that any reference to angels *or stars*, is a consequence of magical thinking.

Thereby, to assume OBL's reference to angels relates to magical thinking and that he could not think in an abstract manner or consider 'adult' ways of understanding death, is merely one way of considering this instance. There are many other valid reasons why any of us may use similar language. From a phenomenological perspective, QBL's description of what happens when a person dies was simply a reflection of his belief or understanding, in terms of certain kinds of phenomena. According to Mystakidou et al. (2003), grief is influenced by the meanings which every culture lends to death and loss. Certainly, there was evidence within this study that whilst no one disagreed or took up QBL's reference to angels, there were discussions about other symbolic rituals, such as the use of candles.

As noted in Chapter 1, Quentin Blake's final illustration was of Rosen looking at his deceased son's photograph, accompanied by a candle on the table. The participants described this scene and stated "...it's in-between, because he's not happy but he's not sad like he was…" Whilst perhaps not related to a specific religion, this link to the hope of finding some resolution or happiness seemed to add a further spiritual dimension to the session. The family had used candles in both remembering and commemorating

Eleanor's life and, once again, this was an aspect of the book which the participants connected to.

Candles are often seen as a safe point of reference, with many religions utilising them not only to symbolise death but new hope. Whilst Rosen's book did not portray any overt spiritual belief systems, neither did it refute any. The author and illustrator used candles to signify both emotive and lighter aspects of the story, including celebrating birthdays and the moment when Rosen remembered his son. Therefore, similar to the flexibility used around the representation of a family unit (see Chapter 1, Section 1.5), there appeared to be a flexible and adjustable element to this spiritual dimension too. When books are designed in this manner, it potentially widens the scope for an intended audience, allowing readers who follow a variety of different religions or belief systems (Cowles, 1996) to identify with the story-line.

The use of candles as part of a mourning ritual would potentially have been quite emotive for the participants. This element of child bereavement was raised by Neimeyer (2002), who highlighted that young people not only have to recognise and cope with their own grief, but experience the impact of loss on other members within their family unit. At times, young people can be confused or bewildered when seeing family members emotionally distraught and I therefore linked the discussion about candles to the subject of crying. Even though this was not within the book, it was something we had previously addressed.

Within the literature there appears to be contrasting views of how a person *should* react to loss. Way and Bremmer (2005) discuss how, in their experience, young people are sometimes referred to bereavement services because they have not 'cried'. In the data collection session, although a discussion about crying took place (described earlier within this section) there wasn't unanimous agreement on this subject, a point expanded below.

Raising a topic such as crying often appears to give some individuals an arena in which to discuss their emotions. As this aspect of grief was potentially emotive, I ensured that the subject was introduced only once the participants had settled into the session and were starting to discuss more challenging issues in greater depth. A moving disclosure

from Hoover followed our discussion, "...when I was crying, I just sat there and… in the kitchen… and just like had a big cry and then I just sat on my dad's knee". Here I became more aware that the bereavement support received by the participants was in sharp contrast to that received by a number of other children. As an illustration, in Chapter 2 I noted an investigation by Van Epps et al. (1997), with eight bereaved children. The authors found only one participant had someone with whom they could discuss the experience of grief.

Remaining on the issue of emotional responses to grief, Stokes (2004) suggests that questions such as, 'why do some people cry and some not, even when they both knew the dead person?' are valuable points of reference for young people. Within my own experience, children have disclosed that they cry into a pillow at night, to avoid upsetting their surviving parent or family member. This reluctance to share overt, acute emotions in public, is often reported to be culturally defined (Holland, 1997).

An illustration of the above point is made by Collins (2003), who describes how in certain countries, for example Italy, individuals are much more comfortable with an outpouring of grief and actively show their emotions in public. Whilst this is not an unusual view, if it is taken as a normative expectation, there is little room for any acknowledgement of variations within cultures, as the data in my own investigation suggests. Whilst stereotypes usually have a sound evidence base they are only averages and were unhelpful for this study. The participants discussed several emotional reactions which did not correspond to reserved grief, often reported to reside within an English culture (Holland, 1997). Therefore, by implementing epochē and suspending any pre-conceived expectations of how the participants would express their grief, I allowed for the variation that transpired within the group.

According to the literature, bereaved children have a tendency to focus on scary, negative aspects of their situation (Lindsay and Elsegood, 1996). In order to check that the participants did not have any concerns or worries, I ensured there was room for plenty of reflection and discussion within the methodological design. Had an issue been raised, any unfounded negative beliefs could have been explored further and the reality of the situation emphasised. This was one of the reasons why, within the findings, there are details of both myself and Katrina encouraging the participants to acknowledge the

benefits of sharing their concerns with another person. As an illustration, when Hoover told us that Flasher Girl talks to her when she was sad, I reinforced this behaviour by saying "...that's really good that you've got someone to talk to, isn't it?"

Raveis et al. (1998) found a high correlation between the level of distress experienced by bereaved children and their parent's ability to offer support and discuss the loss. This point is particularly important, as the death of someone significant in a young person's life may be bewildering and scary, an experience that would be compounded if they do not have access to appropriate care.

Whilst the findings within my investigation did not immediately indicate 'scary' or negative aspects, the participants did wish to discuss several dark illustrations within the publication, possibly indicating their struggle to manage such an emotive experience. I also wondered if this element of grief could relate to most of the discussion about 'feeling sad but pretending to be happy'. Hoover pointed out that Rosen was feeling sad but trying to appear happy, because he thought people would not like him if he looked sad. She continued with the words, "only people who lost someone would like him, if he looked sad", a comment several of the participants agreed with.

This belief that one should 'look happy rather than sad', is in contradiction to some of the Victorian mourning rituals, as discussed within Chapter 2. Clark (1993) discussed a 'period of mourning' which included the closing of curtains and wearing black clothes for a specified period of time. The symbolism of Native American Indians was another illustration, where a bereaved person's hair was cut, thereby indicating to fellow community members that he or she was grieving and thus required special care and attention (Haberecht and Prior, 2006).

After reading an assortment of bereavement literature, there does appear to be strong and conflicting opinions as to what is a 'normal' way to grieve. Wallbank (1996) suggests it is not only carers or professionals who become concerned about young people grieving incorrectly. In her experience, it is the children and young adults themselves who worry that their experience of grief means they are uncaring or did not love the deceased. Hindmarsh (2000) explored this issue a little further and explained that teenagers are a particularly vulnerable group. In addition to their loss, they are also

experiencing the ambivalent feelings of adolescence. During this time, they may have conflicting emotions and rather than discuss the loss with their parents, choose a friend or another adult (for example, a teacher) instead.

Popplestone-Helm and Helm (2009) interviewed a teenager about the experience of attending a therapeutic group, specifically for young people whose parents had a life threatening illness (anticipatory grief). The young person replied, "...I find it hard to talk to my friends sometimes because they don't know what to say to me. Whereas people in my group have said they feel the same things. It helps to know you're not the only family going through a sad time, which is how it feels sometimes..." (p.220). This account indicates that for teenagers who prefer not to discuss grief with either parents or friends, yet do not have access to others who have experienced similar situations, the isolation of their situation would be exacerbated. Therefore, as happened within the bibliotherapy session in this study, offering bereaved young people an opportunity to discuss their grief appears crucial.

When progressing through the findings, it became clear that not everyone wished to discuss their grief. Certainly Supergirl's response to the session could be representative of bereaved individuals who choose not to spend time discussing their loss, or participate in bereavement studies (Holland, 2001). One possibility of why individuals decline to take part in research may be that, similar to Supergirl, they prefer to concentrate on more pressing concerns, rather than dwell on what has happened. Within more recent bereavement literature, this approach to managing grief is referred to as resilient or restorative grief (Relf et al, 2008; Stroebe and Schutt, 1999), a point discussed below.

Often individuals cope with grief in their own authentic way (Walters, 2004). Fortunately, recent literature draws our attention to a much more flexible view, with both restoration orientated and loss orientated grief being recognised (Stroebe and Schutt, 1999). Within the findings there were a variety of expressions used to describe loss, mirroring both the above orientations. As noted earlier, Supergirl exhibited a more restoration-oriented approach to the session, in which she preferred to focus on issues for her at present, rather than discuss the experience of grief.

Illustrations of loss orientated grief (Stroebe and Schutt, 1999) were expressed by Hoover and Rudolf, who contributed to the conversation about feeling emotive when reading the book:

When we were reading this book… did it remind anybody of those kind of feelings [crying] when you were looking at the pictures?

Participant   Yes

And do you know, I cried when I read it once

Hoover   It's just like… it's just like what other people feel

Rudolf also indicated that she felt like crying when reading the book and the video recording showed that Boothy was very moved too. When I explored this further with the group and asked how it feels when someone dies, QBL replied, "Sometimes we do, yes… things we get upset about, different characters…"

Continuing with the theme of emotional responses to loss, Kübler-Ross (1969) described how the patients she was caring for commonly discussed anger when reflecting on their situation. Within my own study there was a particular reference to this psychological reaction, when Britney discussed her experience of loss and the anger she felt. She expanded this to include the impact of loss and the dawning reality that Eleanor was not coming back, "...missed Eleanor and [she found] it difficult crying". Upon asking the group how someone would feel if their son or mum had died, as in the story-line, Boothy said "sad" and QBL said 'their nerves', further psychological reactions to loss.

9.2.1   Puddle jumping

Within the session there was evidence of a fluctuation in the participants' experience, ranging from discussing highly emotive issues, to clamouring for a favourite chocolate and playing with puppets. Winston's Wish (2007) describe this behaviour as 'puddle jumping', something I have frequently observed in bereavement sessions for young people and individuals with a learning disability. However, whilst I have referred to puddle jumping in this thesis, there were few references in the literature.

Findings within my investigation showed only *brief amounts of time* between the participants' discussing very moving, emotive issues and the lighter moments. Couldrick (2001) relates this to a young person's tendency to fluctuate between talking about

highly emotive aspects of their grief and suddenly asking if they can go out and play. When working with bereaved adults, Kübler Ross (1982) observed 'we cannot look at the sun all the time, we cannot face death all the time'. The empirical evidence within this study indicates that the participants, especially the younger children, fluctuated much more than I have ever noticed when supporting adults.

By reading a book, the door is opened for insight, clarity, understanding and a sense of camaraderie (Berns, 2003/4). This point was clearly evident in many of the findings, including the instances of laughter and gaiety at appropriate points in the conversation and confectionary break. In the story-line Rosen also fluctuated when discussing aspects of his grief and his memories of Eddie, frequently depicting their happy times together. Hoover commented on this and said "...I think it's all right if you remember the good times".

Within several publications (Wallbank, 1991 and Holland, 2001), the authors appear to omit information relating to times when bereaved young people laugh and enjoy school or being with friends. As highlighted above, this element of the participants' discussion was important and offered an insight into not only the darker, emotive aspects of their lifeworld but the joy they still experienced *alongside* their grief. I would propose that, as adults, we often write books or even undertake research from our own perspective, forgetting that young people often puddle jump and may not experience grief continuously, for the elongated periods of time that we do (Couldrick, 2001).

9.3 A connection to other bereaved individuals and personal insights, generously shared

This section will focus on what I referred to within the structural description as *'…a warm and caring atmosphere [that] contributes to a setting in which personal insights can be generously shared''.* The literature review discussed a number of publications which attested to the importance of relationships for bereaved individuals and the willingness of many to share their personal stories. I will concentrate on these two elements, alongside literature which discusses the strong connection that bereaved children often feel towards other individuals who have experienced loss.

One of the main aims for child bereavement groups is bringing together vulnerable children who have experienced the death of someone close in their lives (Stokes, 2004). As noted in Chapter 2 (Section 2.3), the lack of role models or other bereaved young people with whom to share their experiences, often results in a feeling of being 'different' (Katz, 2004). Thus, an opportunity to connect with other individuals who have experienced loss, allows a sharing of 'stories', improved awareness of grief and potentially a greater ability to manage what is happening within their lives. Due to the fact that all the participants knew each other, I did at first wonder if there would be little to gain from this approach and whether it was really necessary for the whole family to attend. However, the findings indicate that they listened to one another, joined in the discussion and explored Rosen's book, in much the same way as any other group of bereaved young people I had worked with.

When executed well, story-telling can enable a bereaved person to find a framework for what has happened to them and thereby tell their own individual story (Busch, 2001). The findings indicated that the bibliotherapy session provided an opportunity for the participants to practice saying words out loud, such as '...when Eleanor died' or '...when I am upset I talk to'. Thereby, in a safe atmosphere, the participants were able to be honest about their grief and practice phrases or explanations of their loss. The group also had an opportunity to experience their peer's reactions to what they were saying. For some individuals, this may have necessitated using a totally new vocabulary. Jewett (1994) proposes that providing an opportunity to speak out, without fear of judgement, is paramount. As discussed earlier, this did transpire even though there were some minor breaches of confidentiality.

Within Chapter 2 I presented literature which stressed the importance of exploring coping strategies in formal child bereavement sessions (Gilbert, 2004; Stokes, 2004). This is an important element within bibliotherapy and was integral to the methodological design. As noted earlier, one participant identified from the story-line that Rosen thought about birthdays and things which made him happy. She progressed by suggesting that bereaved individuals could write about what was worrying them, if they didn't want to talk to anyone else. Evidently, the book appears to have stimulated the participant to learn from what was within the text or illustrations and consider other possibilities too.

Gradually, I began to wonder if the value of story-telling may not only be connected to the words and illustrations on the page, but the subsequent expansion of young people's imagination. In so doing, the participants navigated their own way around a relatively new and at times difficult experience. Furthermore, if feeling overwhelmed by either their own grief, or in Sarah's case that of a friend, sharing stories of loss may contribute to the 'tools' they can utilise in the future. Consequently, these stories will provide bereaved individuals with potential coping strategies, thus lessening the impact of grief within their young lives.

In the context of palliative care, *resilience* refers to whether or not an individual demonstrates effective coping strategies, both internal and external, whilst being able to acknowledge the impact of their loss (Relf et al, 2008). As the findings have shown, there were a number of instances where the participants talked about their management of grief. These included discussing feelings with each other, venting emotions through being angry or crying and seeking physical comfort from their parents. They also reflected on other possible strategies, such as eating chocolate and writing down what was worrying them.

Furthermore, those most closely related to the deceased, not only contributed to the discussion but were also able to experience obvious delight in other aspects, especially the confectionary break. These findings are good indicators to suggest a resilient approach to managing grief and consequently an absence of complicated bereavement (Neimeyer et al., 2002). The participants' ability to puddle jump, potentially allowed them to balance the emotive elements of their experience, with expressions of gaiety and laughter.

At other times, some of the group were more reserved in their contributions, embarrassed by the video recording or had difficulty in understanding the text. When this happened, it was the more outgoing members who removed any unwanted attention from quieter participants, with behaviour that was buoyant, talkative and sometimes attention seeking. The family knew each other well and helped one another enormously, in an instinctive rather than overt philanthropic fashion. When someone got a question wrong, there was an absence of the person looking embarrassed or anyone focusing on

their wrong answer, it simply became a part of the conversation that required further development or clarification.

An illustration of a 'fluid' communication pattern within the group can be found where Hoover patiently waited for QBL to finish his discussion and then explained what he said. This finding indicates that the participants both respected and complemented each other's contribution, rather than one half of the group becoming frustrated because the rest needed more time to express their views. Once more, I reflected that this mix of individuals, with their different ages, abilities and experiences, would have been seen years ago at wakes (Todd, 2006), in which there were not segregated rooms for adults, children or individuals who had a learning disability.

The group dynamics within the session appeared to mirror those I had witnessed in the participants' home environment. Frequently, they waited for each other to finish having their say, supported each other *and* complained about each other, in much the same way as any other family would. I strongly suspected that their willingness to share personal insights was more to do with the way they had been encouraged to communicate at home, over many years, rather than my skill as a facilitator. This cohesiveness was not necessarily determined by age or cognitive ability, as Costley (2000) notes, but by familiarity, closeness and respect for each other.

The closeness within the participants' extended family appears to have been advantageous in relation to managing their grief, as opposed to the experience of isolation so often found with bereaved young people (Ribben's McCarthy and Jessop, 2005; Van Epps et al., 1997). Furthermore, Holland's investigation (2001) uncovered findings that attested to a sense of powerlessness, with most decisions made on behalf of children. This was not a feature within the findings of my own study, as the whole family had been involved in so much of the proceedings since Eleanor had died. Unlike the experience of many other bereaved children, the participants' routine had remained much the same as before, due to the tremendous support within their family unit.

The literature suggests that bereaved parents frequently struggle with touch, which in turn can give messages to children that they must be good (Abrams, 2000). Thereby, rather than express appropriate feelings they may suppress their inner state. Faced with

the total disappearance of a family member and a perceived lack of warmth from the surviving parent, young children are often anxious and may develop tantrums and negative behaviour patterns. Touch is such an integral part of any young person's development (Maxwell Hudson, 1988) and, if used therapeutically, allows healing to take place (Macrae, 1988).

Whilst I always advocate appropriate touch, I was concerned that professional safeguarding children advice (RCN, 2001) cautions practitioners about this aspect of care and recommends they must ensure any actions are *not* misinterpreted. When working with young children, I have found adhering to this advice can be complex. The dilemma I have seen in practice is one of over-caution, where a child who seeks physical comfort is gently moved aside, rather than allowed to sit on a practitioner's knee. It is possible that this awkward and unsympathetic response can be more harmful than what the recommendations are trying to avoid.

As evidenced throughout this chapter, the group had received excellent emotional support from their parents. When visiting them at home, it was evident that touch was a natural and frequently used source of comfort. Therefore, I confidently 'followed the lead' of their parents and allowed the participants to approach us if they required reassurance, especially whilst discussing such an emotive publication. However, I did not expect to witness the tactile support they offered each other. Throughout the findings there were frequent examples of the participants helping one another, for instance, when Sarah gently touched Britney's arm to draw her attention to the book. The dash for the chocolates, half way through the session, also demonstrated their ease with physical contact, as they all scrambled over each other and raced to choose the best one.

At times, I was concerned that my encouragement to revisit and follow up ideas from the participants' first bereavement session may have been a distraction from the focus of the book. However, as stated in Section 8.2.1, all interactions take place within the context of our life experience and the discussion was integral to their experience of bibliotherapy.

Within my personal reflection, I wrote about my unease when observing some of the participants' apparent discomfort when reading the book. I questioned the therapeutic value of raising such emotive issues, after what must already have been a very difficult year for them. However, Ribbens McCarthy and Jessop (2005) suggest it is healthy for young people to revisit their bereavement at various points in their lives.

Foster and Gilmer (2008) are in agreement with the above paper and propose a continuing relationship with the deceased is important, rejecting the notion that any bereaved individual 'gets over' a death. This continuing bond (Normand, Silverman and Nickman, 1996) was evident within the group, with most of the participants wanting to discuss Eleanor and explore how they felt about her death. It appeared to be something that had relevance and interest to them, albeit a year after she had died.

Whilst not evident from my own findings, I do think it is important to once more address a point made by Packman et al. (2006). The authors encouraged practitioners to be aware of a possibility that bereaved children may have experienced an ambivalent or negative relationship with the deceased. If this does transpire, they may struggle to cope with their grief, a situation which would need addressing and managing in a sensitive way.

9.4 Findings relating to the young people who had a learning disability

After working with people who have a learning disability for over a decade, I was surprised by Duffin's investigation (2000) which found 72% of carers believed those whom they supported were not affected by loss. Todd (2006) suggests inaccurate statements such as these arise from a longstanding inability to acknowledge that individuals with a learning disability also have a shared humanity and emotional life. A further explanation for these perceptions, may relate to the exceptionally wide range of cognitive and communication abilities amongst the group referred to (Dodd et al., 2005). This includes people with both profound physical and cognitive impairment, to individuals with a mild learning disability who are married and work full time.

Certainly, with individuals who have a profound disability it is difficult but not impossible to recognise the impact of their loss (Read et al, 1999). Conboy-Hill (1992) suggests the assumption that people with learning disabilities do not grieve, has a purpose of

reducing the need to offer them support and understanding. This literature was in contrast to the inclusive approach used by the family in my investigation and is evidenced throughout the findings. Chapter 8 offered an overwhelming number of illustrations to refute the notion that a person with a learning disability lacks the capacity to grieve. Even though Supergirl and Lyn spoke very little within the session, I had met them both on several occasions and know they were very aware of their sister's death. Equally, there are instances within the findings where Britney and QBL had plenty to say about their feelings and experience of grief.

As noted previously, despite my enthusiasm to support all the family together, there had been some concern from a colleague who thought the group was too large. The main issue was in relation to the older participants with a learning disability, who potentially needed more time than the others to explore various issues. Whilst acknowledging my colleagues opinion, I instinctively felt the planned methodological design was the way forward. I knew that some aspects of the session might not work for 'all the participants, all the time', yet was comfortable enough to progress with my plans.

Interestingly, the findings provide evidence of more similarities than differences, with regard to how the participants experienced the session. Once I had started to piece together not only the verbal feedback but the gestures and commentary of what was happening at the time, any differences associated with their learning disability started to fade into the background. Britney spoke about crying in a similar way to Hoover, Supergirl preferred to speak of a current activity in her life, in the same manner as Sarah who was more concerned with her friend's grief, and Lyn struggled to discuss her experience, as did Flasher Girl.

When designing the session, I had wondered if it would be necessary to allow extra time for understanding the speech pattern of the participants who had Down's syndrome. I knew from experience that their responses could have been a little more stilted and slower than the rest. When undertaking the literature review I also read an investigation by Bihm and Elliot (1982). The authors found that when they interviewed 79 participants with a learning disability about the topic of death and dying, only six individuals asked any independent questions. Overall, the participants showed little interest in the subject and the authors reported that they appeared 'indifferent'. However, findings within my

own study clearly demonstrate that, contrary to the above investigation, two out of the four participants who had a learning disability were interested in discussing death and dying. Furthermore, in the periods outside the data collection period, all four individuals quite willingly discussed the death of their sister with me.

Despite the *potential* challenges that could have transpired, all the participants naturally followed one another when discussing either the publication or their experiences of loss. Costley (2000) suggested that this 'cumulative discussion' often happens when utilising a group design with people who have a learning disability. The author emphasised the importance of encouraging individuals to relax and feel at ease. Whilst I agree with Costley, I do not think it was any more important for the participants with a learning disability, in fact the methodological design benefited the group as a whole. It was interesting that child bereavement literature made similar recommendations (Berns, 2003/4; Stokes, 2004), thus providing an illustration where, despite the authors' very different rationale for writing their books or journal articles, both fields offered similar reading material.

Within the literature review, details were provided of a study by Yanok and Beifus (1993). The authors investigated a programme of education for people with learning disability on the subject of CALM (Communicating about Loss and Mourning). They found that for those who received the education, an improvement was clearly visible in how much they understood about death and dying. The authors also proposed a gradual introduction to the various concepts, accompanied by experiential learning, in order to assist individuals understand the etiquette which frequently surrounds death.

Chapter 8 illustrated that the vocabulary used by the participants with a learning disability when describing their experience of grief, was representative of other bereaved individuals. This included references to anger, sadness and crying. Whilst they had not received formal education in relation to their loss, one possibility for this quite developed vocabulary may have been the inclusion and support received from their family.

It was interesting to see that, in line with Bihm and Elliot (1982) and Cochrane (1995), a better prediction of how the participants in my study understood death and explored their grief, was less to do with chronological age and more to do with their cognitive level. As

highlighted in Section 9.1, the cultural environment in which they resided was also paramount in progressing their understanding of loss. A further predominant finding within this study was the link between a willingness to express grief and each participant's personality, a point also noted by Dodd et al. (2005). Certainly the two individuals who were more outgoing showed less hesitancy to share their experiences of reading the book and their personal grief.

Read (2006) emphasises the importance of including people with learning disabilities in all aspects of the rituals that surround death and their subsequent bereavement support, an endeavour which was an integral part of this study. However, it is also important to consider a more recent finding from an investigation carried out by Dodd et al. (2008). The authors found a positive correlation between those who had been involved in bereavement rituals and a subsequent increase in their separation distress, including complicated grief symptoms. Therefore, it was suggested that prior to recommending *all* individuals should be involved in activities relating to their loss, a full individual assessment of the persons experience and knowledge should take place. This point was considered prior to my own investigation.

Tuffrey-Wijne (2006) proposes two of the main methodological issues which preclude people with learning disabilities from taking part in research, relate to their language and comprehension skills. For example, their responses when questioned may be unusual. Irrespective of the question asked, some individuals are likely to smile and offer a positive response to questions (Green Allison, 2001). They are also more likely to discuss the last thing they have read or looked at. A good illustration of this point was found when I asked QBL what the book was about. He chose an illustration directly in front of him and replied 'celebrations and parties'.

When the above interaction transpired, no-one laughed or told QBL he was wrong, it was simply not the main theme of the story-line. A further example of an unexpected response was when Supergirl chose to discuss bathing a baby, rather than her bereavement. Without focusing too long on the detail of both their replies, I continued the session. Although Supergirl remained focused on her topic, QBL later expanded his conversation to include the impact of grief and bereavement, in line with other conversations taking place at the time.

Whilst Britney answered some of the questions in an unexpected way, by discussing one particular illustration of a young couple walking in the street, she was also very keen to point out her anguish at the loss of Eleanor. The important point I wish to make here, is that her contributions were very independent and did not simply 'follow my lead' or discuss an illustration others had previously mentioned. These findings show that whilst the literature was very useful when supporting QBL and Supergirl (Blackman, 2003; Green Allison, 2001), I had to be very careful not to assume it would apply to all the participants who had a learning disability.

According to Tuffrey-Wijne (2002), a crucial factor when carrying out research is to know the person well and use a vocabulary they will recognise and understand. The findings in this study indicate that it is also beneficial to persevere with conversations, periodically returning to a particular subject. This approach allowed the participants to relax into the conversation and gradually piece together their own 'stories'. Where these conversations contained minimal verbal recollections of an individual's experience, supplementary data of their body language, the context in which the discussion took place and my own recollections of their interactions were utilised.

The above approach allows investigators to ascertain what is happening at any one particular time and ensure descriptions of the data collection sessions are adequate (Gilbert, 2004). Certainly the findings within my own investigation uncovered a unique picture of how four family members with a learning disability interacted, shared their personal reflections, offered support to their family members and, in return, were supported themselves.

9.5   Summary

As illustrated in this chapter, the findings did confirm much within the literature, with regards to the grief of young people and bibliotherapy. However, further critical engagement with the literature also offered several instances where the data did not substantiate what had previously been written, which led me to question several 'taken for granted' assumptions. I hope all the issues that have been explored will stimulate debate and provide practitioners with a greater understanding of the approach taken. By continuing to investigate this topic, a more informed picture of bibliotherapy in the

context of grief and bereavement will be accessible and thus ensure therapeutic practice takes place. In conclusion, Michael Morpurgo, writer and children's laureate, perfectly summarises many of the issues which have been presented within this penultimate chapter:

"Life, which is what stories of any kind are about, isn't about happy endings. Every life has its share of sadness, contentment and joy, and all the bits in between".
(Morpurgo, 2004, p. 3)

CHAPTER TEN

THE PHENOMENON DISCOVERED: a conclusion

The last chapter provided many valuable insights into the use of bibliotherapy and working with bereaved young people. Within this thesis I have also explored several areas in relation to the chosen philosophical framework and my creation of the Seven Hat Framework. This concluding chapter will draw together all these elements and consider what the findings offer, with regards to progressing knowledge and practice.

Readers will note that there is an absence of a section on the limitations of this investigation. As an alternative, the relevant issues are merged within various topics as they arise, thus applying greater coherence to this chapter. A résumé of particular points include: the small number of participants and their unique composition; a possibility that other publications may yield very different experiences for bereaved individuals; the need to research bibliotherapy with individuals at various timescales in their grief *and* with those who experience complex grief; ethical issues that arose when audio and video recording the participants; difficulties encountered with understanding the verbal discourse of some individuals and, finally, my dual role as both principal investigator and practitioner.

I will start by focusing on bibliotherapy, the phenomenon itself, proceeding with a discussion on research studies that involve bereaved young people and individuals who have a learning disability. A consideration of the methodological contributions which have been made will follow, relating to the transcendental phenomenological approach and, more specifically, the Seven Hat Framework. A personal account of the challenges and achievements encountered will precede any outstanding recommendations for practice and future research. The conclusion offers a final word to the author, illustrator and participants, without whom this study would not have taken place.

10.1   Bibliotherapy

This section will focus on the substantive contributions my study has to offer, in relation to using bibliotherapy with bereaved young people. As identified within Chapter 3, bibliotherapy in the context of grief and bereavement is an under-utilised research topic,

yet ripe for uncovering so much, not only about the experience of young people but the carers and professionals involved. I also noted the increase in publications which explore death and dying for bereaved young people and individuals who have a learning disability.

There are many reasons why the book worked so well with this particular group of participants and may with other bereaved young people too. Whilst Quentin Blake's illustrations were created predominantly for children, they also had great appeal for a much wider age group. The illustrations succeeded in capturing the interest of all participants within the study, including Supergirl. Whilst not very interested in discussing the story-line or the death of her sister, she sought out an illustration which related to something of great personal consequence. This finding indicates the broad appeal of the publication, even for individuals who may not wish to conform and participate within 'expected' discussions, thereby allowing them to focus on a topic other than bereavement.

Many story-books relating to loss portray what for many is a traditional family unit of mother, father and children (Kerr, 2003; Limb, 1993). Within Rosen's story there was an omission of this structure, which worked much better for the group where several individuals had not experienced a consistent 'family unit' from birth. This point leads me to propose that the publication may also transfer well when working with bereaved young adults who live within public care (Penny, 2007), some of whom may have a learning disability. Furthermore, Rosen recalled the loss of his mother (in addition to his son), an element which potentially widens the story-line. By incorporating these familial losses over a wide age range, readers may find it easier to consider elements of the story in relation to their own circumstances.

The omission of any reference to a religious context also worked well with the participants in this study. As noted in Chapter 9, this could potentially widen the readership catchment, by avoiding any disagreement in relation to a specific ritual or cultural statement. It thereby allows a larger and more diverse number of people to identify with the basic premise of the story. For the above reasons, I propose that Rosen's book merits a place amongst the more specialised titles on the subject of grief and bereavement and one that may well be a useful 'tool' for practitioners to use.

Chapter 3 offered an overview of several descriptive papers and empirical studies relating to the clinical use of bibliotherapy. The findings from this study are in agreement with Iaquinta and Hipsky (2006), who discussed the value of offering children a story that introduces other individuals facing similar problems to their own, thus providing a number of options for managing their situation.

Nevertheless, there are several important issues which this study did not investigate, yet are crucial for safe and effective practice in the field of bibliotherapy. As an illustration, a problematic issue arose when I discussed Rosen's book with two groups of adult students. Daniels (1992) forewarns practitioners that discussing publications with young people does need to be carefully organised and executed. If skilled facilitation is present, there is more opportunity for participation by all within the group, where 'seeing things from someone else's point of view' can be encouraged. According to the author, without this intervention, a dominant personality may have the potential to portray a blinkered view of the story-line. Indeed, whilst discussing the publication with healthcare professionals (who were undertaking a diploma in palliative care), a situation arose which echoed Daniels' warning.

Within the first group, a number of negative comments about the book (from one particular student) appeared to have a profound impact on the way the session progressed. The individual concerned (a nurse) had recently experienced the death of a close relative and said he wouldn't give Rosen's book to his children, due to the illustrations and text which were "depressing and dark". Later, I considered this remark and thought he may have found it difficult to contemplate the possibility of his children experiencing similar moments in their grief. On reflection, the publication may have been inappropriate for the student, who had only recently experienced a significant loss. Perhaps in his initial stages of grief, it was difficult to read the story-line. Interestingly, following the student's strong opinion, a cascade of *similar* comments from his peers transpired. This reminded me of the above point made by Daniels (1992), about the possible effect of a dominant personality within a group setting.

Conversely, the next year I carried out a similar presentation to a second group of healthcare practitioners and the session couldn't have been more different. The students said there was a poor selection of bereavement literature for teenagers and they thought Rosen's publication was an excellent and much needed resource. The group did not describe the book as 'dark and depressing' but instead commented that it contained a more realistic ending than the 'happy ever after' premise which other books offer (Limb, 1993). In order for bibliotherapy to be therapeutic, Berns (2003/4) reminds readers that it does not happen 'just by chance', but requires careful thought and raised awareness of issues which may arise. The above illustrations prompted me to consider that, when reading a book in a group setting, skilled facilitation is just as necessary with adults as it is when working with children.

Whilst it is my hope that all the findings related to this therapeutic approach will support carers and practitioners to reflect on the issues uncovered, it is also important to point out a possible limitation. Publications such as Goodbye Mog (Kerr, 2003) and Fred (Simmonds, 2003) were not written to be therapeutic tools and are, quite rightly, concerned first and foremost with how they work as a story for a general audience. Therefore, many books used within bereavement services do not conform to a neat check-list of whether they will meet therapeutic outcomes. The whole nature of reading and responding to any artistic product is incredibly subjective and this needs to be acknowledged in any investigation of bibliotherapy, including my own.

Furthermore, I recommend that more research is required into how bibliotherapy is experienced, not only in relation to the timescale of a person's bereavement but the severity of their grief. In Chapter 3, Cuijpers (1997) highlighted that for some individuals the richness and complexity of a story may be overwhelming, threatening and anxiety provoking, thus leading to a misunderstanding of the text and illustrations. In turn, this may lead to misinterpretation or a distorted view of reality, as a direct result of the individual's personal experiences and state of health. Therefore, research into the experience of bibliotherapy with individuals experiencing complex grief would further increase our knowledge base, particularly regarding safe and effective practice within this area. An overview of how such an investigation could be designed will conclude this section on bibliotherapy.

In order to proceed with any future investigation, the amount of funding will determine to some extent the methodological strategies used. However, in-depth studies similar to my own or interview based approaches could provide much needed qualitative data. This would then enable investigators to frame the focus for larger scale effectiveness studies, possibly carried out over a more protracted period of time.

Within Chapter 2 (Section 2.1.4) I highlighted the issue of unrepresented populations in bereavement studies, with a variety of reasons why some individual's choose not to participate in research. Furthermore, I found out that some potential participants are not approached, if they are deemed to be particularly vulnerable (Duke, 1998). However, the very nature of complex grief means that the vulnerability of these individuals is clearly present and any research study would need a clear strategy which incorporated appropriate ethical safeguards.

Designs more suited to investigations with bereaved people experiencing complex grief, would typically comprise of participants being offered a variety of therapeutic approaches. Each individual would then be recruited into one of the following groups:

Group one: bibliotherapy with 1:1 facilitator support

Group two: bibliotherapy and group discussion plus facilitator support

Group three: bibliotherapy and counselling

Group four: counselling

In considering a design for the above population, I was inspired by several investigations noted in Chapter 3 (Section 3.2.1), especially those of Lenkowsky et al. (1987) and Myers (1998). The reason why all the proposed groups incorporate an element of professional support is due to the paper previously mentioned by Cuijpers (1997). It was suggested that employing a professional to work alongside individuals may help to monitor and steer the session in a therapeutic direction. A qualitative design utilising individual or group interviews (King and Horrocks, 2010) would provide enough data, thus allowing investigators to make sense of the complexities and meaning-making processes which transpire. However, this data can also be utilised to inform larger scale evaluation studies that consider the number of individuals who have complex grief and wish to access therapeutic support.

Other possibilities for researching bibliotherapy include the consideration of more longitudinal studies, using a variety of books and interviewing participants at various stages in their grief. Whilst I acknowledge that no one person is ever at the 'same' point in their grief (at any one specific period of time), larger scale studies will have a substantial sample population which should even out individual variations, thereby uncovering common patterns. However, the argument and evidence regarding common patterns in the way people experience grief is complicated further when incorporating a therapeutic approach such as bibliotherapy. If relying on purely quantitative designs, one challenge would be that whilst reading a book may be more effective at one stage in a person's grief than another, within each period of time there will also be much variation. Therefore, the need to focus on the concept of meaning-making becomes a priority, in order to make sense of the data.

In conclusion, I would argue that one method is rarely enough and researchers will always need to look at the complexity of investigating bibliotherapy within the context of bereavement therapy. Mixed method designs offer an ideal opportunity to uncover more evidence, especially if anomalies are found using one specific approach. Whilst there are limitations to any methodological design, the important point is that a combination of approaches will provide much needed evidence to inform practice.

10.2   Involving bereaved young people within research studies

Chapter 5 discussed the implications of involving young people within research studies. However, despite the potentially problematic nature of pursuing this form of enquiry, my study has succeeded in presenting a unique picture of the participants' experience. Within this section, I will review several issues that were navigated when overcoming some of the challenges encountered.   The first of these was a limited range of vocabulary used by the participants and the need to create a method of collating and managing the data. In addition, several individuals displayed reticent behaviour when answering questions and were visibly uncomfortable with the session being recorded. Two additional points that will conclude this section are the absence (in the discussion) of any reference to Rosen's deceased son and the use of role play.

Due to the phenomenological focus, I was very aware of a need to look at both noematic and noetic qualities of the participants' experience. As mentioned within Chapter 4, I use this distinction as a heuristic and recognise that it is impossible to separate the how and what we experience, after all everything we do is concerned with experiencing something in a certain manner. Nevertheless, I utilised this strategy to undertake a very detailed investigation and thereby understand the participants' experience better.

The findings illustrate that the children with a limited concentration span wandered around the room and only occasionally asked a question or made a statement. However, their remarks were perfectly in tune with the discussion at the time. An example of the above was when Spiderman spoke up towards the end of the session and stated "I didn't get to say a lot". It transpired that he actually did not have 'a lot' to say but offered a valuable contribution by awarding the book 20 out of 20. As I have just noted, although his verbal contribution was minimal, the remarks were both appropriate and timely.

Whilst the participants appeared to be very conscious of how other bereaved individuals felt, there was evidence that some found it difficult to express their own emotions. As discussed in Chapter 9, information which related to specific developmental levels in relation to loss was difficult to apply, specifically when considering their short concentration and restricted range of vocabulary. However, to say a particular individual functioned at an expected level of age five to seven years, would have presented certain difficulties. Although some participants had difficulty in *expressing* their experiences, this does not necessarily equate with an inability to understand at a certain level, an important point for practitioners to consider.

The data also showed that at times the participants were reticent in answering or responding to my questions. After some thought, I acknowledged this was quite understandable and a natural part of their position when being asked questions in relation to loss. During our conversation they were requested to focus on issues which were both difficult to manage and explain. It is possible that this hesitancy was positive and showed some selection of what the participants wished to disclose, in short, a possible coping strategy. When facilitating bibliotherapy with bereaved young people, other practitioners may also experience this reaction.

As noted in previous chapters, when all the transcripts were complete, a further challenge within the analysis stage was deciding how to circumvent the limited verbal discourse. When I first started working with the data, I thought the participants were generous with their reflections of 'what' they read, yet had only provided a small number of reflections in relation to 'how' they experienced the session. Fortunately, once I considered the data more closely, in particular the non-verbal data and commentary, I was able to glean a much more detailed account than I initially thought. This methodological insight leads me to recommend utilising not only a reflection diary but also video recording equipment, when undertaking qualitative work with people who have unusual or limited communication. However, as the information below will highlight, this should not commence without first addressing certain ethical issues.

Despite my concerns with the recording, the opportunity to collect visual data was invaluable and uncovered aspects which would otherwise have been overlooked. Unfortunately, the data showed a significant number of the participants were uncomfortable with the session being recorded. This finding was in contrast to literature which suggests most individuals will, after a short period of time, become comfortable with the use of a video recorder (Murray, 2008). As noted in Chapter 8, when I became aware of any discomfort, the equipment was immediately repositioned away from the person concerned.

A specific issue needing to be considered with this group was that some of the participants had been adopted and therefore possibly experienced taped 'interviews' before. At the de-briefing session, one individual became perturbed by the audio tape recorder and asked for it to be turned off immediately after we had finished. This situation was something I was not aware of beforehand, yet would consider carefully before designing a session with adopted children in the future. Despite their visible discomfort with both forms of recording, the participants persevered in supporting me with this study. Their generosity prompted me to be very cautious when presenting the findings to students and professional staff. I was fastidious in applying my own moral and ethical reasoning, in line with the national and local professional standards.

I noticed deeper reflections of the participants' experience usually took place after a certain amount of time had elapsed, which in this case was towards the end of the data collection session. The findings show that it took quite a while for the group to start discussing their experience of reading the book, perhaps an indication of a need to feel secure, before exploring emotive issues. This initial reticence when exploring our experience is a common feature within both individual and group interviews (King and Horrocks, 2010). The aforementioned issue should be considered when undertaking future research on sensitive topics. Firstly, I recommend that professionals need to allow a certain 'warm up' time for young people. Equally, ethical permission should be flexible enough to include relevant details which have been shared once the recording is finished. This last point assumes consent will be sought from the participants, for any additional details. In my own study this was not done and some valuable material that transpired after the session was omitted from the findings chapter.

Whilst several participants were reluctant to discuss their experience of grief, the dynamics within the group allowed other more confident and vocal members to take 'centre stage'. Knowing when to probe further or leave a line of enquiry alone was difficult, especially with such a large group. Fortunately, if an individual became upset due to a disclosure made about them, the rest of the group simply left the subject alone. Whilst at times a number of participants corrected each other, there were no occurrences of someone laughing or demeaning another person's contribution to the discussion. Nevertheless, in groups where participants do not know each other, practitioners should be alerted to a possibility of the reverse happening.

Whilst most participants were able to relate the subject of the book to their own experience of loss, it was interesting that they didn't refer to the deceased character (within the story) by his name, Eddie. A possible explanation for this could be that the story was read in its entirety on just one occasion, thereby providing only a small amount of time for the participants to identity fully with the characters. An illustration of how readers may form a greater connection with lead characters, can be found in the picture book about Mog (Kerr, 2003). As noted in Chapter 3, 'Goodbye Mog' was the last in a long series of books about the adventures of a cat. For young people who have followed Mog's exploits over the years, there would possibly be a different reaction to the loss of a well-loved animal (real or not).

Using group interviews to explore sensitive areas, such as bereavement and loss, have been shown to be useful (King and Horrocks, 2010; Balen et al., 2006). Despite my initial doubts about whether the participants would share their experiences of reading Rosen's book, their attitude to the design (that is, listening to the story and then discussing it) surprised me. Not only did the group appear to quickly understand what the exercise was about, they seemed to find the session interesting and enjoyable. However, using role-play or group discussion is frequently utilised in schools and therefore a familiar experience for many in the group. Even with the participants who were above school age, two were quite extrovert and appeared to enjoy speaking in front of their peers.

The above points were reflected in the findings, which uncovered data revealing a bibliotherapy session which involved a myriad of experiences. These included aspects that were emotive, enjoyable, embarrassing and without exception, a thoroughly enjoyable chocolate break. Whilst this section has provided information relating to all the participants, there remain a small number of significant issues I wish to highlight, specifically relating to people with learning disabilities.

10.3   Involving people who have a learning disability in research studies

Much of the literature and service provision appears to separate supporting bereaved individuals who have a learning disability from those who do not. In avoiding this approach, I have uncovered findings that are of relevance to both theory and practice. The main points will be explored below.

My professional experience before working in palliative care involved supporting people who had a learning disability. As a result of this prior experience, whilst I employed epochē with regard to transcribing, analysing and presenting the data, I did not suspend my expertise when supporting the four young adults who had Down's syndrome. In fact by utilising this knowledge and experience, I was able to effectively facilitate the session and much later consider the findings in relation to theoretical literature.

A central feature within the study was that of inclusiveness, with the four older participants featuring alongside other members of their family. Whilst the approach I took is interesting from a research perspective, it also has much wider theoretical

implications. As an illustration, many people with learning disabilities will experience grief alongside family members, friends, companions and carers. This contextual focus is in contrast to theoretical literature which appears to segregate the issue of grief for bereaved people who have a learning disability (Green, 2001; Blackman, 2003; Tuffrey-Wijne, 1997). Whilst I acknowledge that a segregated focus can have many benefits, such as identifying key issues for practitioners to consider, this study sought to redress this unbalanced portrayal and consider the context in which people with learning disabilities grieve. In so doing, I was able to consider similarities in how they experienced loss alongside their family.

One strategy I utilised to portray this inclusiveness was by allowing the data to emerge jointly between all the participants, rather than segregate the findings. The details were then presented in a contextual and temporal manner, appropriate to a transcendental phenomenological position. However, at times there were some exceptions to this, for example when it was relevant to put a few illustrations together that were pertinent just to the individuals concerned. As an illustration, I noted how QBL's mode of speech was sometimes difficult to understand, yet enhanced by the 'interpretation' from Hoover. Gradually, it became evident that had the group been segregated, it would have been more of a challenge to understand QBL's verbal contribution, without the valuable assistance from his sister.

Throughout the findings there were similar instances, where the participants who did not have a learning disability expanded their sibling's contribution to the discussion. This was done not only by supplementing the clarity of their words but adding important contextual information to explain a particular remark. For example, when Britney discussed her grief and said she "cried for Eleanor", Sarah expanded her statement and disclosed that she 'cried for hours', to which Britney responded by nodding her head.

It could be argued that perhaps the participants who did not have a learning disability interjected the conversation with their own expressions, rather than supporting their siblings. However, there are two points which lead me to refute this suggestion. Firstly, I had observed the dynamics of the family over several occasions and had witnessed the individuals with a learning disability disagreeing with others, or preferring to tell their own account of what happened. Whilst they all had very different personalities, each had the

ability to either quietly or vocally put their point across, even though I did not understand all they said. My second point is that from a phenomenological perspective, how the group interacted was in context of the world they lived in. To consider reflections of those who had a learning disability in isolation, without any mention of how their siblings had helped, would have presented inaccurate data. Furthermore, this would fail to portray the collaboration that appears to be a natural part of their lifeworld.

In utilising the above approach, what transpired was an emphasis on similarities rather than differences, with regard to the group's shared experience and understanding. It was at this point that I started to question some of the theoretical literature on supporting people with a learning disability who were experiencing grief. For example, in the above illustration we learnt of Britney 'crying for hours', yet this was not any more remarkable than the rest of her siblings, in relation to the way they spoke of their grief. Later in the session, another participant (who did not have a learning disability) spoke of the time when, after being told that Eleanor had died, she sat on her father's knee and just "had a big cry".

The data also provided evidence of several participants struggling to find a vocabulary when explaining their emotions or experience of grief (very few adjectives were used). Whilst this was a significant issue for those who had a learning disability, others appeared to find this aspect difficult too. However, when considering the temporal element of the session, once several clues to the plot were provided by some of the teenagers, the younger children and those with a learning disability started to piece together the main tenet of the story. This evolving development in the session, is often what happens when individuals with different abilities work together for a common goal (Costley, 2000). Not only was this evident in the findings, it is something I have experienced within my own clinical practice.

A further instance of where I considered the group to have similar needs was connected to their vulnerability and my wish to ensure the ethical principles were upheld (see Chapter 5, Section 5.9). As previously mentioned, on one particular occasion Britney divulged a little too much information about one of her siblings, which at the time I assumed was due to her learning disability. However, on close analysis of the data

there was an almost identical instance between two participants who did not have a learning disability.

One distinct difference the findings did uncover was in relation to the emotive elements within the book. The individuals with a learning disability did not appear to have an instant reaction to the story-line. For example, where the text or illustrations moved some of the teenagers to tears, it was not evident that the four older participants experienced such a reaction. Whilst I am not saying they did not experience this (it is always possible I could have missed something from the recording and my observation), I do think they probably needed more time to have the illustrations and text explained, before fully considering the emotive details.

Another finding, more specifically related to those who had a learning disability, was in how they exhibited great openness with their interactions. This was in comparison to the potentially more developed ability of some participants when 'filtering' what they wished to share with the group. As an illustration, on analysing the data I noticed that Supergirl appeared slightly uninterested with the session, especially when I asked what the book was about and she pointed to the illustration of Rosen bathing Eddie (when he was a baby). At first I thought this 'perceived' confusion was a result of her learning disability. However, later in the evening I found myself watching a crime drama on television. Instead of focusing on the story-line, my attention was taken up with the architecture, garden design and interior furnishings. Similar to the experience of Supergirl, I was drawn to aspects of the experience that were more relevant to me at the time (I was in the middle of extending my home). Despite this, if someone had asked me about the programme, I would probably have 'filtered the truth' and discussed some aspects of the drama.

In considering the above, it is possible that over the years I have not only developed the ability to sometimes disguise my experience but also multi-task. Perhaps Supergirl's learning disability prevented a concealment of the fact that bathing a baby was of more interest than discussing the book. Alternatively, the story-line may have been too far removed from her experience of grief. However, to substantiate either of these points, further enquiry would be necessary.

In conclusion, it became apparent that the participants with a learning disability did not dilute the experience for the others, nor did they enhance it any more than the rest. They all participated equally within the session and as such their experience contributed to the universal finding, the structural description as outlined in Chapter 8 (Section 8.3).

10.4   The utilisation of transcendental phenomenology

The reason I chose this theoretical basis for my study was due to Husserl's continual persistence in focusing on a person's unique experience of a phenomenon (Husserl, 1925; 1977). Idhe's comment that phenomenology probes for what is genuinely discoverable and potentially present, but not often seen (Idhe, 1986), led me on a journey of exploration which has been intricate and challenging, yet always fascinating. My ambition was to find out not only what the participants experienced, the historical event, but through the process of transformation, the essential features which would transcend this one session of bibliotherapy. I wished to uncover issues that practitioners may also experience, were they to undertake similar work in the future.

In many ways this study is almost autobiographical, as the session was shaped by my experience. I created the context in which the data session transpired on the basis of professional assumptions, in that I chose the book and developed the methodological design. Therefore, one of the challenges became a need to make sense of, and incorporate, the concept of epochē (Langdridge, 2007), especially regarding how I facilitated the session and interacted with the participants. Whilst I did not suspend my professional knowledge in how I made sense of the participants' experience, utilising the process of epochē became an essential component within the methodology. In truth, this did cause some tension as I actually helped to co-create the data, working from a position of experience, which I subsequently set aside when undertaking the analysis. However, this enabled me to suspend a premature analysis of the findings, in relation to both my theoretical knowledge and experience.

As previously noted, there were some pragmatic exceptions to the above, for instance when I analysed the findings of the participants who had a learning disability. As an illustration, due to QBL's limited vocabulary I needed to transcend a literal transcription of his discussion and look much deeper, by utilising the recording of his body language. When I asked '...how did you feel when reading the book?' he replied 'yes, it was alright,

I felt happy'. Whilst this could be an accurate description of his experience, I knew from practice that some individuals often answer questions in an almost institutional, positive way (Green, 2001). It appeared possible that his words required expanding into a more sophisticated expression of his experience and I therefore considered several alternatives, such as, he 'felt comfortable' or it was 'good reading the book with his family'.

I acknowledge that the above approach may be labelled as interpreting text, it is certainly not akin to the transcendental phenomenological approach I had chosen. However, by drawing on my practitioner knowledge and experience to facilitate the session, it appeared inappropriate for me not to use this in the latter stages of the process, especially where I transcribed and analysed the data. Ultimately, I believe this approach enhanced the quality and richness of the findings. Further issues related to the transcription and analysis stages are discussed next.

Husserl constantly reminded his students to keep looking at the phenomenon from different perspectives. He asserted that they would then arrive at a more adequate description, although at the same time still need to acknowledge no one statement is ever the end of the story (Moran, 2000). This encouragement to constantly review and analyse the data, did at times require great patience. Progression through the analysis stage was much slower than I had encountered with other methods. Nevertheless, in persevering with this approach, I was confident that the structural description presented the participants' experience in a clear and insightful manner.

A further crucial issue when transcribing the data involved finding a way to accommodate information, where a substantive part was based on observation. Usually when undertaking phenomenological studies, interviews contain detailed verbal descriptions, with only smaller instances where the participants imply certain aspects of their experience. In this instance, the balance within my own study was reversed and I needed to find out how to uncover all aspects of their verbal and non-verbal descriptions during the transcription process.

As noted in Chapter 6, to make sense of and describe the things which were not said, including the implied or absent, I needed to supplement the data. The way I navigated

the dearth of explicit verbal findings was in completing a substantial personal reflection and transcribing aspects of the session from the visual recording. To ensure the authenticity of the transcription, regular discussions with my supervision team became essential. They had watched the recording several times and monitored how I undertook this stage of the research.

In order to arrive at the structural description, the phenomenological method was painstakingly lengthy and, as Giorgi (2006) noted, it could not be done partially. Whilst the process of horizontalising and transcribing the data took many months of intense work, the detail and attention to remaining within a transcendental phenomenological position resulted in an insightful piece of work. It is possible that research studies completed in haste, with tight deadlines and large cohorts of participants, do not have an opportunity to view experiences and analyse them in so much depth. Fortunately, due to the nature of my PhD study, I was able to invest both time and resources in pursuit of my enquiry.

One methodological contribution within this research has been the way in which I sought to examine experience through a combination of both video and audio recording. Within Chapter 5 (Section 5.2) I reviewed several phenomenological studies and noted that the data collection methods frequently consist of audio recorded interviews. These are usually undertaken individually, although there are instances of where group interviews have been utilised (Van Epps et al., 1997). Whilst written transcripts and field notes are frequently used as the method of choice (Duke, 1998), capturing non-verbal data is not common practice within phenomenological studies.

However, video recording is sometimes used within more general qualitative interviews (King and Horrocks, 2010) and also recommended for enhancing research designs with people who have a learning disability (Gilbert, 2004). This approach allowed me to view the phenomenon as it was occurring over a set period of time and, more importantly, review over several occasions at a later date. The benefits to emerge from this approach have been discussed within previous chapters. Not only was the quality of the transcription document improved, the way in which I compiled the data could be closely monitored by my supervision team.

10.5   Originality: the Seven Hat Framework

Without doubt, the development and use of the Seven Hat Framework became one of the most distinctive contributions to this study. As previously explained, the framework was a heuristic tool, inspired by De Bono's publication, 'Six Thinking Hats' (1999) and Idhe's insistence that experiences must be considered from as many viewpoints as possible (Idhe, 1986).   Idhe explains that this crucial process (horizontalisation) encourages investigators to consider data without describing or concluding what the essential features are too soon. He proposes that stepping back and avoiding premature assumptions will allow them to view the phenomena more clearly. To undertake this process, various strategies were incorporated within the study, the main one of which was the Seven Hat Framework.

The framework was initially created to find a solution to completing a detailed reflection on the data collection session. Initially, I was overwhelmed by the amount of information that needed documenting and found the Seven Hat Framework a creative way of capturing and explaining my reflection of the experience. To remain firmly within the philosophical underpinnings of transcendental phenomenology, it was crucial not to impose a rigid structure whilst using the framework. Therefore, each 'hat' was used flexibly, enabling me to retain my focus on the session and consider what was essential to the phenomenon, rather than being concerned about which reflections should go where.

It quickly became evident that most of the details documented had the potential to be in several hats at the same time. I started my reflection with the blue hat which was very much an introduction, a summary of the experience. This included, how the session started, implementation of the design and the participants' response (in short, a surface level description). Subsequently, each colour was used as a platform, to launch my focus of the experience from a different perspective. This first attempt at using De Bono's framework resulted in a much more detailed and holistic personal reflection than I had expected. What I didn't foresee at the time, was that the framework I devised would also be utilised for both the analysis (transformation stage) and presenting the findings.

When considering various possibilities of how to analyse the data, I was inspired by the work of Peter Ashworth. Within the papers read (Ashworth, 2009; Ashworth and Greasley, 2009), it was his work in analysing data from various perspectives that enabled me to envisage how this approach may work within my own study. Ashworth's strategy considered seven perspectives, with each described not as a 'hat' but 'fragment of the lifeworld'. This structure represents seven pre-defined theoretical constructs, namely:

- Selfhood
- Sociality
- Embodiment
- Temporality
- Spatiality
- Project and
- Discourse

Were I to have applied these 'fragments of the lifeworld' to my own study, I would have analysed the participants' experiences by considering the way that reading the book enabled them to express their individuality (selfhood), connection to other bereaved individuals (sociality) and so forth. At this point, I started to see comparisons with my own use of the Seven Hat Framework, especially the idea that you can take a different slice through an experience, none of which are more accurate than the other, or of greater importance.

Ashworth has successfully combined ideas from both Husserl and Heidegger, particularly in the way that several of the fragments such as selfhood, embodiment and project have a close philosophical relationship to existential phenomenology (Moran, 2000). This approach considers not only the nature of knowledge and knowing about the world in a certain way (Husserlian focus) but also the nature of being (Heideggerian focus). Whilst Ashworth does not approach his investigations from an interpretive stance, he does acknowledge the existential shift from epistemological to ontological.

In consideration of the above, I felt that the structure did not sit comfortably within my theoretical focus. At this stage in the research, it would have diverted the study away from its strong Husserlian transcendental focus and any methodological continuity would

be lost. However, despite my decision not to utilise Ashworth's structure, it was of immense value, allowing me to consider the possibility of mirroring his 'framework' and utilising my own 'fractions', with seven hats, rather than selfhood, sociality or embodiment. Initially, I was unsure as to whether it would work but progressed cautiously whilst combining it with Giorgi's analysis methodology (Giorgi, 2006).

For this crucial stage in the analysis, I was aware that utilising the Seven Hat Framework was an unusual step to take. Fortunately, the success of the method in the reflection and its close link to horizontalisation encouraged me greatly. Not only was the framework a pragmatic tool but during the transcription process it had resulted in a much more detailed piece of work than I would otherwise have produced. Therefore, I decided to progress and soon realised that each time I utilised the tool, the framework became more refined and I was much more adept in navigating the challenges encountered. As previously mentioned, at first I hesitated too much about what hat the data should be addressed under, as it was apparent that the various findings could have been appropriately placed into several hats. Gradually, I came to realise the strength of this approach was more to do with the way it stimulated my thoughts in certain directions. Ultimately, it was the *combined data* that uncovered the phenomenon of reading and discussing Rosen's book.

As an illustration of the above point, it became apparent that there were a wide range of emotive elements to reflect upon. On the one hand there were a series of findings related to a sense of comfort and togetherness, which seemed pivotal to the experience, yet equally there were issues around discomfort and betrayal of confidence. It was possible that the red (emotive) hat might have included seemingly contradictory findings. The way I navigated this dilemma, was by utilising the Seven Hat Framework flexibly, working through the data methodically from each perspective. Thereby, I reserved significant emotional findings for the 'red hat', such as where the participants focused on Rosen's description of "being sad, but pretending I'm being happy". Alongside this I included findings which appeared to sit comfortably with the subject of emotion and then follow on from this focus.   As mentioned before, individually each 'hat' description did not capture everything 'essential to the experience', nor did I expect them to.   The purpose of this approach was that it enabled me to horizontalise my position, rather than standing in just one place.

The third (and final) way I utilised the Seven Hat Framework was in presenting the findings. I wanted to add a certain coherence to this thesis, thereby enabling readers to have a direct comparison between my initial reflections and aspects that emerged from all different stages of the analysis. The challenge was in finding a way to do this, without it resembling a thematic discussion. After many drafts, I decided to emphasise an important philosophical underpinning of transcendental phenomenology, epochē. I presented the findings first before progressing to look at these in dialogue with theoretical literature. Within each 'hat', the findings were also presented in a temporal manner.

It would no doubt have been easier just to write a typical structural description, closely followed by a presentation of the findings. However, the framework firstly fragmented the session and then, by placing all the various descriptions together, provided a holistic sense of the phenomenon, the structural description. What transpired was a coherent link from an earlier stage of the process by using the same framing device only for a different task, an endeavour that appeared to be appropriate and worthwhile.

Supported by my supervision team, I realised that alongside the substantive findings, this methodological innovation offered a comparable contribution to the academic body of knowledge. In many ways, the repeated use of such a creative approach provided a certain consistency that I found improved both the quality and clarity of this thesis. The end result was a fluid and 'relatively' swift way to reflect, transform the data and present the findings. Ultimately, the time taken in constructing a unique heuristic tool was, I believe, a good investment. This approach enabled me to remain true to the philosophical underpinnings and included: horizontalisation; retaining a temporal line to the experience; describing rather than interpreting the data and incorporating epochē. I would encourage other researchers to consider the Seven Hat Framework, to experience its potential within phenomenological research and develop it further.

10.6   Dual role and reflexivity

Within Chapter 5 (Section 5.2) I addressed the issue of working both as a practitioner and investigator, more frequently referred to in the literature as a 'dual role'. I discussed

the potential benefits of this approach, for example, an opportunity to use clinical expertise and circumvent any issues of concern in an appropriate and timely manner. Whilst carrying out my own investigation, I was able to address topics discussed in the previous session, whilst maintaining a steady focus on the research agenda. Equally, due to my familiarity with the participants, I was able to access disclosures which may otherwise have been more guarded and also knew that any outstanding issues could be addressed later in the day.

Nevertheless, my dual role was not just about the data collection session and influenced many aspects of the research process. In Chapter 5, I highlighted a possibility that the participants might find the research oppressive, particularly due to their vulnerability. Whilst they did not show any indication of this, I considered their vulnerability throughout my work. Furthermore, as this section will outline, a more general awareness of my dual role was integral to the study. Northway (2000) suggests that in order to navigate this issue, investigators need to monitor their behaviour. Therefore, I addressed my influence on the research through several strategies, one of which was utilising the process of reflexivity.

Langdridge (2007) proposes that reflexivity is an essential component within phenomenological studies, allowing investigators to inform readers of any prior knowledge and experience they may have, in relation to the topic investigated. Consequently, information about their position is provided throughout the study, alongside an acknowledgement at the end about how this may have influenced their work. As readers will note, within many of the chapters I have followed Langdridge's advice and incorporated elements of my personal journey whilst undertaking various elements of this investigation. I will now explain how I documented my 'developmental period' and highlight issues that emerged, incorporating those I had expected with some of the more surprising elements to transpire.

Phenomenological researchers often keep a very detailed research diary, methodically writing down aspects of their experience. In line with this approach, I recorded a wide range of points and through using these personal reflections, gradually developed the ability to step back and look at what was emerging both critically and analytically. This

process had a positive impact on my practice, particularly the way I approached literature and considered research methodology.

I have previously discussed several difficulties which arose on the day of the data collection, such as exhaustion and concern in relation to prompting unnecessary distress for the participants. As such, it would be foolish to say the day was without any challenging issues. However, I do think the bibliotherapy session ultimately provided an opportunity for the young people to: explore; discuss issues; ask questions; listen to and debate the reality of their grief for Eleanor. In a society that finds the subject of death and dying difficult to address, providing this opportunity was, I believe, the right thing to do.

Following the session, I noted my initial confusion with regard to managing the data, a significant amount of which was visual. Initially, I thought the data collection period may not have provided enough detail with which to undertake a phenomenological analysis. Fortunately, formal discussions with my supervision team allowed me to recognise the quality of the information available and be creative in how all the data were transcribed. Through carefully adhering to the principles within a transcendental phenomenological approach, I was able to progress with more confidence. The structural description uncovered was not only clear and detailed, in terms of the content, but one I could carefully trace over the many years of considering and analysing the session. Consequently, I developed my ability to research an area which others may have discounted, due to the potential challenges it presented.

I have often discussed my experience of undertaking this investigation within formal presentations and more frequently during informal discussions with colleagues or fellow PhD students. The tension experienced between the rate at which I wished to progress and the reality of undertaking such an intensive and demanding study, alongside other responsibilities, has been constant. When transcribing and analysing the data, the greatest dilemma was one of frustration, knowing that due to work and personal commitments, it was sometimes necessary to put the study aside before progressing with the next stage. Fortunately, a quiet perseverance has enabled me to remain focused, despite encountering many unforeseen circumstances. Interestingly, on completion of such a sensitive piece of work, it is apparent that there have been several

pragmatic benefits to progressing at a slower pace, an illustration of which is provided below.

As discussed throughout this thesis, I have always been concerned at the vulnerability of the participants, particularly in relation to their anonymity. Due to the structure of the family unit this remains an issue that is uppermost in my mind. On one specific occasion, I was asked to undertake a presentation to approximately seventy regional learning disability professionals. Despite taking several precautionary measures to protect the participants' identity, I was surprised when a member of the audience approached me (afterwards) and said she recognised the family.

To avoid a repetition of the above situation, I reviewed both the presentation and material within my thesis. Further non-essential details were removed, such as specific ages and the participants' relationship to the deceased. Whilst there will always be a possibility that readers may recognise the family, they are requested, through their 'professional code of conduct', to appreciate the participants' right to anonymity. In so doing, it is envisaged that practitioners will appreciate the tremendous effort which has been made to protect the family and thereby follow this through with their own practice.

Despite so much time elapsing since the data collection session, I still wondered if the acuteness of the participants' grief, so visible within the first year, had settled down a little. Therefore, whilst I was concerned about the above recognition of the family, it was reassuring to hear from the practitioner that they were all adapting to their loss and progressing with their lives. In many ways, this discovery was an appropriate point at which to proceed with the final stage of the study and complete writing up my thesis.

10.7   Looking Forward

This investigation has retained a steady focus, looking exceptionally closely at one particular 'moment in time', acknowledging diversity, rather than concentrating on a grand narrative which proposes strong, dominant ideologies. Many recommendations with regard to the significance of the phenomenon have been merged within previous sections of this chapter. This penultimate section will now consider outstanding elements of the study, in relation to progressing both knowledge and practice.

The relevance of this study will be communicated in a number of ways. Both the parents and participants will be given an opportunity to have a brief synopsis of the findings either verbally or in a written format, including a pictorial version for those who prefer illustrations rather than dense text. An electronic version of this thesis will be available in the British Library and Repository at the University of Huddersfield. Paper copies will be donated to: The Florence Nightingale Foundation; Help the Hospices; the local adult hospice and regional children's hospice, all of whom have generously supported this project.

Presentations have already been carried out with over 200 professionals working within the field of palliative care or learning disability, in addition to a small number of people who have a learning disability (Appendix 9). Two posters were created to explain the findings (Appendix 5), one of which received first prize at the Trans-Pennine Palliative Care Research Network Conference. Once this thesis has been examined, a more detailed overview of the research will be submitted to a minimum of two nursing and social care journals (a practitioner oriented publication, together with a more theoretically oriented one). It is envisaged that the findings will be published, thus contributing to the body of knowledge on the subject of supporting bereaved children and young people through literature.

The issue of whether a session, lasting no more than 43 minutes, can produce a valid and legitimate investigation has frequently been asked. Whilst I applaud many longitudinal and much larger studies (Bruera et al., 2006), I also believe other complementary approaches are required, to provide detailed evidence within all areas of palliative care. Readers, who have considered this thesis in detail, will be aware that the findings actually denote not just 43 minutes but an insightful account from 11 individuals who experienced bibliotherapy, much of which relates to their personal loss.

In consideration of the above, this project offers a detailed and sensitive research document which, I believe, merits a place within the realms of investigations at this level. The illumination and presentation of the phenomenon will thereby contribute substantially to the body of knowledge on sources of literature and therapeutic approaches that may be utilised to support bereaved children and young people, including individuals with a learning disability. In turn, this will inform and support

professionals, by raising awareness of the various issues to be considered when selecting literature and facilitating bibliotherapy sessions, thus providing safe and effective practice. Furthermore, in line with other phenomenological studies, the structural description emphasises what individuals have in common, thereby enabling the findings and new insights to be applied in other areas. These may include utilising bibliotherapy in a variety of contexts, such as supporting children to understand divorce, bullying or violence.

Within the methodological design, one particular point does need addressing in this final chapter. The reading and discussion of Rosen's book appeared too swift for several participants, although by the end of the session most of the group had a general idea of what the publication was about. This understanding resulted not only from the initial reading but their subsequent discussions on a variety of issues. The way I came to terms with this potential weakness in the design, lies in an acknowledgement that for some participants the session was not just about reading a story. Those who did not fully understand the story-line were able to have fun and be involved in various aspects of the discussion. For example, the youngest participant did not discuss his experience in great depth but was able to point out his favourite illustration and give the book a mark out of 20.

Whilst some of the session did focus on Rosen's publication, plenty transpired from the more unexpected issues. After reviewing all the findings, I surmised that whilst in this particular case I would not necessarily change the design, there is a need to take into account the *context* in which bibliotherapy sessions are facilitated. Aspects to consider include the time allocated to various elements of storytelling and the level at which concepts are discussed.

In Chapter 2 (Section 2.1.4) I highlighted that theoretical literature often relates to bereaved individuals who struggle with their grief, possibly because it is this population that professionals support and thereby have access to. However, within the general population, Neimeyer (2004) stated that recent studies indicate there is actually a substantial percentage (over 60%) of individuals who have a good adjustment to their loss. Machin (2009) continues this theme, proposing that a new theoretical focus is emerging, which identifies the way people successfully meet life's adversities. The

author links this to resilience, a topic discussed in Chapter 9 (Section 9.3). Interestingly, the elements of resilience, as identified by Machin, also reflect many of the qualities inherent within the findings of this study. These include the participants' optimistic outlook, a capacity to make sense of their loss and knowing they do not have to experience grief in isolation but alongside other family members.

With regard to the participants' experience of the phenomenon, the findings show that those who had a learning disability did not neatly fit into the 'norm' of the 'forgotten people', so often represented in the literature (Oswin, 1999; Read, 2001). Individuals within the group were cherished, valued members of their family. Whilst they did not exhibit remarkable knowledge of grief or provide exceptional stories of their experience, they presented a picture of what is perhaps the unreported 'middle ground'. As such, this study has balanced the more commonly reported case studies of people who experience complex grief (Katz, 2004; Green, 2001). I would strongly recommend practitioners to consider documenting and promoting their own positive accounts of individuals who have been able to learn from, and share, their experience of loss with family and/or friends. These accounts would then provide a more balanced and holistic picture of how young people grieve.

To complete this section, I will now consider the methodological approach utilised within my study. Whilst undertaking such an advanced academic piece of work, I always intended to progress my research skills. Initially, I thought this would be realised by undertaking a 'traditional' approach within phenomenological research, as it encompassed a completely new theoretical framework to those I had previously used. However, whilst I did learn much from this transcendental approach, a more surprising element was the unconventional route I took when considering the data. Although the Seven Hat Framework has been discussed in detail within Section 10.5, here I will reflect on the conception of this innovative method and its contribution to research practice.

When taking the first cautious steps in planning the study, I had not envisaged that there would be a need to develop a completely new methodological tool, yet the Seven Hat Framework has become one of the key developments to emerge from this work. It has increased my knowledge in the field of research and enabled me to undertake an investigation with participants, some of whom had limited verbal communication. Whilst

De Bono's method, the Six Thinking Hats (1999), is usually carried out within management and business environments, his framework has, in this instance, been utilised alongside Husserl's theoretical framework. The challenge of creating a heuristic tool and the subsequent creative merger has been very rewarding. Not only were the data enhanced but the framework encouraged and facilitated a process in which I reflected and considered the findings, in directions which may not otherwise have been taken. In turn, this has uncovered insights that would not have been visible or evidenced had I relied on a more traditional phenomenological method.

Although I have explored the concept of adequacy within phenomenological research elsewhere in this thesis, it would be appropriate at this point to provide a résumé of the main issues. The number of participants within this study was relatively small compared to many other quantitative and qualitative investigations. Within Chapter 5 (Section 5.2) I described how this factor is frequently contested in relation to phenomenological studies. However, it closely adheres to the aim of this theoretical approach, which is to obtain depth within an analysis rather than objective or quantifiable data. Whilst my ambition for the study has always been to provide a clear and insightful account of the participants' experience, the structural description of the phenomenon (as presented in Chapter 8) applies much more generally than the very specific case investigated.

Jasper (1994) proposes that whilst phenomenological investigations do not generate theories, the descriptive data of a phenomenon can be used to provide wider and larger-scale investigations with an *informed* starting point. What this study does offer are detailed insights into the lifeworld of the participants, which can be transferred to other experiences of a similar type. The validity of these insights results from the adequacy of the description and how the findings will promote deeper understanding into the experience of reading a book about death and dying, in the context of bereavement therapy.

Nevertheless, it is important to acknowledge that there will always be many ways to consider any data collected and this study is no exception. In keeping with phenomenological tradition, this thesis has presented a glimpse at possibilities and ultimately emphasised what we all have in common as human beings. My research journey has, through careful methodological steps, offered a statement which is

representative of the participants' experience and one that I consider to be the invariant structure within the findings. As highlighted above, I do not claim to offer a definitive account or incontestable truth, rather a *glimpse at the possibilities* of what happened within a bereavement session for young people on a very cold December morning.

10.8   A last word to the author, illustrator and participants

Ultimately the greatest honour we can do those we love who have died is to take the best of what they gave us and carry it forward into our future, with respect and appreciation. If we are monitoring ourselves carefully then we will recognise when we reach the point where we need to give ourselves permission to move forward, a time when it is right to take on new responsibilities, make new relationships and create the new future that belongs to us and us alone. To do this is not a denial of the importance of the person who died but rather a celebration of their life and of the rich inheritance of learning, thoughts and memories they gave us.
(Wallbank, 1996, p.125)

It seems to me, that all the individuals who have supported this project, perfectly reflect Wallbank's insightful words. My study has brought me into contact with individuals who have not forgotten their daughter, son, mother or sister, yet at the same time are 'moving forward with their lives'. The generosity of Michael Rosen and Quentin Blake in creating their book on sadness, following the untimely death of Eddie Rosen, is to be commended. As this study has shown, the integrity of the book instantly connected with the participants and ultimately enabled the staff team to gently guide them through the concepts contained therein.

Without the children and young adults who participated in this study, I would not have uncovered yet another poignant and illuminating story, their own. At times I have smiled and even laughed when I remembered their delight with the session, the gaiety and warmth of their interactions. Equally, there have been exceptionally emotive moments when I pondered on their circumstances and knew that the future would never be the same for them or the rest of their family. At the most difficult times along my journey I was determined to complete this study, if only to honour all the above individuals.

Together they have taught me so much, about the power of storytelling on the subject of grief and bereavement.

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Appendix one:

Michael Rosen's SAD Book

A copy of Michael Rosen's SAD BOOK is enclosed with this work.

For readers accessing this work electronically, further details of the publication are in the reference section.

Appendix two:

What do you think of the story?

Following the data collection session, the participants took this additional sheet home.

What do you think of the story?

Please write down anything about the story or how you feel when you read it, either next to the pictures or on the pages at the back of the book.

You can write BIG and small or draw other pictures that help you explain what you are thinking.

You can tell me all about what you have written or drawn when I visit you after Christmas.

Thank you for helping me with my work.

From, Helen.

Appendix three:

Star reporter aide-mémoire

MICHAEL ROSEN'S SAD BOOK

You are a star reporter for CBBC Newsround, giving a report of the book to children watching your programme.

What would you tell children about the book?

How do you think children might feel when they are reading the book?

Which bits do you think they would find the most interesting?

What mark out of 10 would you give the book?

What pictures would you choose to show them?

Thank you Star Reporter for your help.

Appendix four:

Consent forms - staff and parents

Additional information sheet is also enclosed

Exploration of ' Michael Rosen's SAD BOOK'

This study aims to interview a number of bereaved children, in order to find out what their experience is when they read one of our child bereavement books (Michael Rosen's SAD BOOK) in a group setting. At the bereavement session on ...., I will be using video recording equipment to capture the experience of each child when reading the book. This will help me to record more accurately the children's interactions and will enable me to uncover what it was that they remembered and understood from the story and more importantly what the experience 'meant' to them. The information will enable both ourselves and other child bereavement workers to know if using bereavement books are actually helpful to children.

I will read the book to all the children and then ask them what the story was about. We will provide art materials for the children to use when telling us about the session. Also, each child will be given his/her own copy of a picture book based on the story. This may be useful after they return home, if he/she wants to tell you more about what they have done. Children may even write down questions that they would like to ask me later.

The following week I will contact you to arrange a date to meet the children so that we can discuss anything that they would like to tell me about the book or their visit to the hospice.

In order to highlight certain points from the interviews, quotes from your child may be used. Every step will be taken to make sure that when I write up my study, your child will not be identifiable to other professionals who may read the report. I will also ask you to comment (if you wish) on the sections relating to your child before the final document is completed. All information from the session will be securely stored at the hospice throughout the study period. Details about the interviews, including the video tape, will be destroyed once the final report has been written.

When we discuss death and dying to any child, there is always the potential that they may become distressed. As a precaution, the interview can be stopped at any point if the child wishes and a fully trained bereavement counsellor will be available to offer support (if required).

If you have any questions about the study, please do ask me at work Monday to Friday (8.30am to 4.30pm) on 01484 557900.

A signed copy of this form will be attached to your child's hospice notes and a photocopy provided on request.

Staff agreement to the proposed study

Surname   …………………………………………

First name(s) …………….. ……………………………

Date of birth …………………..……………………….

☐ I understand that the person conducting the interview has the relevant skills and qualifications.

☐ I have read and understood the information described above on the benefits and potential risks of the proposed study.

☐ I agree to the study proceeding, with the involvement of myself.

☐ I give permission for quotes to be used in order to highlight important points.

☐ I understand that I will have the opportunity to discuss the details of the study at any time with Helen Dudley.

Signature ……………………………. Date ………………………

Name (please print) ……………………………………………..

Confirmation of consent

As the Principal Investigator I have confirmed with staff that they have no further questions and wish the study to proceed.

Signature ……………………….. Date ………………….

Name (please print) ………………………………………

Parental/guardian agreement to the proposed study for their child.

Child's surname/family name……………………...............................………..

Child's first names……………………………………………………….....

Date of birth………………………………………………….......................

- ☐ I confirm that I have 'parental responsibility' for this child.

- ☐ I understand that the person conducting the interview has the relevant skills and qualifications.

- ☐ I have read and understood the information described above on the benefits and potential risks of the proposed study.

- ☐ I agree to the study proceeding, with the involvement of my child.

- ☐ I give permission for quotes to be used in order to highlight important points.

- ☐ I understand that my child and I will have the opportunity to discuss the details of the study at any time with Helen Dudley.

Signature……………………......…………….....   Date ………………………

Name (please print) …………………………………………………................

Relationship to the child ......…………………………………………………..

Child's agreement to being interviewed (if the child wishes to sign)

Signature …………………………………….   Date ……………………………

Name (please print)…........……………………………………………………

Confirmation of consent

As the Principal Investigator I have confirmed with the child and his or her parent(s) that they have no further questions and wish the study to proceed.

Signature ………………………………..   Date ……………….…………..

Name (please print) …………………………   Job title ....

Appendix five:

Posters:-

- Chocolates with Rudolf and family
- Embracing imaginative free variation

Chocolates with Rudolf & family: a phenomenolgical exploration of a children's fictional book on the subject of death and dying

Eleven children and young adults (some of whom had a learning disability) attended a bereavement session, one year after a close family member had died. In common with most child bereavement services, literature was utilised in order for the children to explore their grief. The uniqueness of this study, is the opportunity provided for the children to talk about their experiences of reading Michael Rosen's SAD book, alongside their discussion of grief. A phenomenological framework provides the structure for the data collection and analysis period.

Each child was asked to choose their own pseudonym as a way of teaching them how their identity and comments would remain confidential. Chosen names included Rudolf, Dasher, Hoover, Superman, Flasher Girl and Brittany Spears.

Video recordings from the session offer a vibrant and rich assortment of behaviours and emotions when reading the book, such as embarrassment when tearful, absorption in the storyline for the older children and more attention to the illustrations for the younger participants and those with a learning disability.

The participants were then asked to pretend that they were presenters for CBBC, giving a report on the book. This approach was not only fun and enjoyable, but created an environment in which the children felt more comfortable discussing their experience.

Preliminary analysis indicates a connection for the children to many of the illustrations and words within the book. In particular, Hoover discussed the following quote at some length, describing the similarities with her own experience:

This is me being sad
Maybe you think I'm being happy in this picture
Really I'm being sad but pretending I'm being happy
I'm doing that because I think people won't like me if I look sad
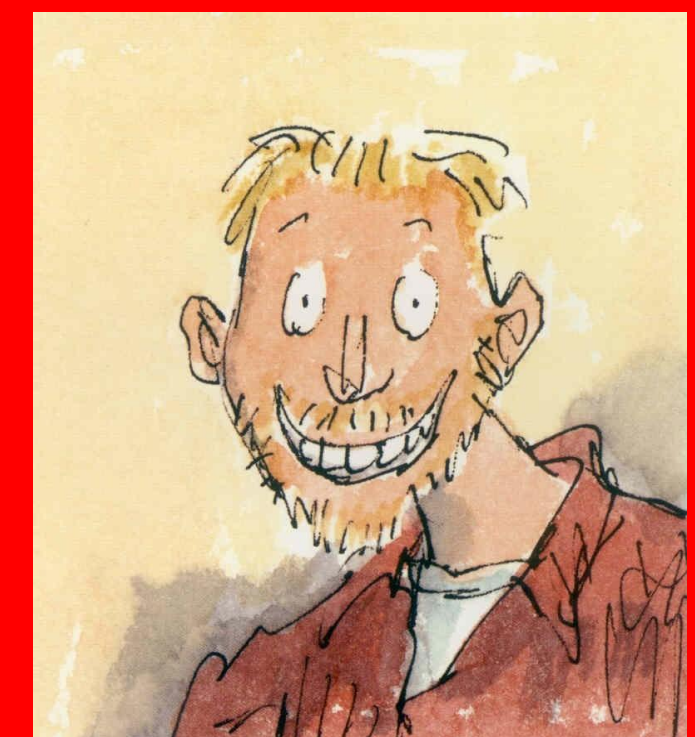
The pages of the book had been copied and laminated, to use as an aide-mémoir during the discussion. Brittany, who has Downs Syndrome, picked up a card that was being discussed and spoke of her own sadness when her sister died. Whilst her language was not instantly understandable, it was spoken with great fervour. It appeared that listening to the story had created a setting in which she felt that it was safe and appropriate to share her own very significant feelings.

Flasher Girl said that when sad, she didn't share her feelings with anyone else. Immediately, her older sister said "...you always talk to me". Her decision not to share this point with all the group, was an indication that even at such a young age, she was cautious and selective about what to disclose.

Chocolates (kindly donated by Waitrose) were utilised half way through the session when the children had started to lose focus – to great effect.

Helen Dudley, PhD student, University of Huddersfield,

Supervised by Dr Nigel King and Trish Durkan, University of Huddersfield

EMBRACING IMAGINATIVE FREE VARIATION:
a personal reflection on a child bereavement session

A personal reflection of involvement in a research study with eleven bereaved children was proving a challenge. There were so many elements of particular significance to consider: emotions uncovered; disclosures by the children; interactions observed - all interspersed with pragmatic considerations that had been required on the day.

A personal reflection was undertaken utilising a structure originally devised by Edward de Bono entitled `Six Thinking Hats' (1999). Certain modifications were made, the most significant of which was the addition of a seventh `orange' hat which represented the transcendental significance of the session.

It could be argued that de Bono's ideas are counter to the very core of the phenomenological methodology employed within the study, as it suggests a compartmentalised view of human experience. However with this study it was utilised as a way of embracing `imaginative free variation' (Moran, 2000) which encourages a researcher to find ways of opening up new aspects of an experience that may not immediately have come to mind. Each hat guided reflections on various aspects of the experience which were undertaken systematically one at a time, namely:

Hat	Description
Blue hat	Organised, calm and controlled aspects to the experience
Green hat	Creative thinking and new ideas that were employed
Black hat	Sombre and serious; cautious and careful; weaknesses in the session
Yellow hat	Sunny and positive; optimistic; hopeful; positive aspects of the experience
White hat	Neutral and objective; concerned with objective facts in the session
Red hat	This section focused on the emotional experience and feelings uncovered
Orange hat	Transcendental. This new hat focused on the intangible experiences and what it was that gave the experience meaning and value

The structure was utilised in a flexible manner by writing freely once a topic had arisen, with little concern for the appropriateness of its inclusion within the particular section. Those sections that the author had anticipated would be more difficult such as the black hat were not, whereas the orange hat (focusing on intangible experiences and describing what gave the session meaning and value) was the most challenging of all.

The final document contains a rich assortment of personal recollections of the child bereavement session, uncovering far more aspects of the experience by embracing `Imaginative Free Variation' with the `Seven Hat Reflection'.

Helen Dudley, Ph.D. student, University of Huddersfield

Supervised by Professor Nigel King and Trish Durkan, University of Huddersfield

Appendix six:

Radio 4 interview with Michael Rosen

Children and Bereavement: a Go4it special

Radio 4 FM 16:30 – 16:56

http://www.bbc.co.uk/radio4/factual/

Barney Harwood **(B)** presents the children's magazine show to discuss the experience of bereavement with Michael Rosen **(M)** and three children. Anna **(A)** (no age given) recently experienced the death of her brother Benny; Jack **(J)** (age 7) and Chloe **(C)** (age 8) both had experienced the death of their father. [Where it is not clear from the interview which particular child is talking, '**Child'** is used as a form of identification].

M   To start with I couldn't write anything at all about Eddie or how I felt that he had died and then just suddenly the dam broke. It was as if I had to and I sat down and wrote this in what felt like about 3 minutes. I suppose it was a little bit longer than that but it just went 'whoosh' straight away... and the only picture that springs to mind is of a dam that all the water …tears and feelings built up and built up and then the dam broke and then I just sat down and went scribble, scribble.

I like to think of it as a book that grown-ups and children can share and talk about. Children haven't actually said that much about the book, they have just sort of looked at me, kind of rather intently and said …"I've read your book" and then they've just left it at that really.

B to A How did you feel when you read it?

A   Well it kind of reminded me of how I felt when he died and it helped me realise how my dad felt at that time because I think he had a bit of a cloud over him and it helped my younger brother Jacob by looking at the pictures. Especially the ones where there are plenty of pictures of Eddie and then just a blank box and I thought that really fitted into the book.

B   Do you think it's a good thing that we have these sort of books to read, or do you think it's just better to stay quiet and not say anything about it?

Child I think it's good because it just says …because I think a lot of people feel like that sometimes. It actually says that it's OK to feel like that, its normal to feel like that ...it isn't just ooh I don't think I should be feeling like this.

B To J and C
How did you feel about reading the book?

C   Felt like a bit better because that is how my mum actually felt.

J   Happy because that book's helpful and helps you think about it ...so you see pictures that maybe you can relate to because you remember how you felt.

C   Yes

B   Is that what you were hoping to do Michael or was it just a release for you when you wrote it?

M It was a release but it was also ...and I always think of books as starting points for conversations. So I just think if someone opens a book, reads it and then starts talking with someone else or even just talking to themselves, then I think hooray, I have done a piece of writing that is good and has said something. But it is the first thing you said that it was the release and 'whoosh' …I had got it out. I spat out what I felt and there is a kind of magic you know, when you start putting into words, something happens that helps you sort out how you feel at the moment. I don't know how that is because you can have all those feelings …you know, like when you listen to music and there's all those words in your head and you've got these happy, sad or amazing feelings ...but when you put things into words, I can only describe it as magic, it just sort of helps you realise what you feel …that's it.

Child to M
Have many people talked to you about the SAD book and has it helped you and helped them if they've lost someone close to them?

M I was doing a show the other day and a woman came up and said it had helped her very much. Sometimes it can be difficult because my mind can be on telling and funny story and then suddenly I'm rushed off by what this person has said …into a box where I'm sad about Eddie dying …do you see what I mean ...so it's quite difficult ...there might be a queue of people and somebody saying something funny and jokey ...saying do you like this joke? ...and then suddenly somebody says thanks very much for writing the sad book because my brother died …or something like that and I'm kind of ash …and it's quite difficult, it catches my breath... you know?

A Oh yeah.

M It's like you're going along fine and then suddenly there's the fact that Eddie died suddenly in the front of my head and I had done the thing where I've pushed it to the back so that I can get on with today and then this person has brought it right to the front and... so there's a little [short intake of breath] inside me when that happens.

Child to M
Do you like the book that you made?

M I like the book a lot and mostly because of the absolutely incredible pictures Quentin Blake did. I'm overwhelmed every time I look at the book, I scarcely read the words, I just look at the pictures and think *these are incredible... this is what art is about*.

B They are amazingly powerful, for me the last picture is the most powerful. The last few pages talks about birthdays and celebrations and the happy times and the fact that its always great to get together and have a cake, candles, you must have candles. You turn over the page and there is obviously a picture of you staring at Eddie, lit by a candle. Did you have any input into that or was it just something that Quentin [did]?

M Absolutely nothing from me at all, I thought it was going to end with the one before, there's a big party and everyone is looking at hundreds of candles. I thought that was the end and then I turned over the page and there is a picture of me staring at this candle and I thought …it just took my breath away again …you know I just thought you know …wow, where did that come from? ...and I was quite overwhelmed by that actually.

B Yes me too, it was amazing ……

At this point I realise that I had wrongly accredited the book to MR when in actual fact it was a joint endeavour with Quentin Blake, especially as the last illustration was one that

the children commented on and instigated a later disclosure by a participant within the study.

J   Do you think about him?

M   I do, yes I often think about him, he was a very funny boy ...a bit like you actually. Yes, I liked to see you mucking around. I was once in a studio, just down the corridor from here with him and we were making a programme and he was supposed to be reading things out with me and instead he kept scratching his bum [laughter from those present] …and I said 'what's up, what's the matter Eddie, we're supposed to be doing this recording' ...and he said 'my pants are too tight dad' ...and this became a little thing, we always used to say to Eddie 'are you all right Eddie or are your pants too tight?' So I kind of miss those things with him and I miss the fact that I can't go to Arsenal with him as well.

Child   How are you?

M   How am I? Yeah, I'm OK actually, thank you for asking. Yeah, I'm actually OK …um …I've been very lucky, because I've had two children since Eddie died and …we talk about filling up the space …and you can't fill up the space more than having to be worried, concerned and loving with two other children …so it's just incredible really.

B   Do you think adults try to over-protect children by not talking about death?

M   Yes, I suppose so and I think probably in the past. I know someone, who when her dad died, she wasn't allowed to go to the funeral or graveyard. So she didn't go to see it until she was about 40 years old and yet really death is part of life. Butterflies die, we die …we have to know that, we can't kid ourselves.

B   You mentioned earlier about being angry Jack. Why do you think you were angry?

J   I don't know.

The children then talked about some of the activities they do at a local child bereavement group such as making a friendship bracelet. This involves making a bracelet using different coloured silk threads and identifying each colour with a person they know, who they could talk to if they needed support or someone to talk to.

B   How does it help you? [Referring to a variety of activities that the children have undertaken, sometimes in a group and one with 1:1 support from a child bereavement counsellor]

Child   It helps me by thinking about it.

B   After all that you have been through and the things that you have spoken about [i.e. child bereavement group activities] ...and someone was going through a similar experience, what would you say to them?

A   It's OK to cry and if you have someone you trust. It could be an aunt, friend or teacher, sister, that it's OK to talk to them because I'm sure they would listen, even if you do feel like …jealous or something like that. If you do actually talk to someone... you will probably realise that lots of people feel like that.

B   Chloe, what would you say to someone listening right now?

C   I would say that …just think about the happy things that you did together and that it's OK to cry.

B   OK, it's good to get your emotions out and start to learn about how you feel.

Barney introduces another book that those present have read, 'Wenny has Wings' (Carey, 2002). The premise of the story relates to a boy called Will whose sister died when she and Will got run over by a truck. Will survived the accident and the following extract was read out from the book:

How have things been going at home? Asked Mr James
These questions made my insides squirmy, I knew I had to be really careful, I mean if I told him how bad it was at home, how the air feels as though it weighs a thousand pounds, how I'm angry with mom and dad for being so sad, how you totally screwed up my life by dying…..what would happen then?

B   So what did you think about that story Chloe?

C   I think it's really sad and when I heard it, it started making everyone cry.

B   Do you think it's good to listen to sad stories about what you've been through?

J   I do, but you don't have to listen to it all of the time because sometimes you just feel guilty for being happy. If you're always going to be sad, there's not really a point in life. I think you should listen to sad things but have a break and listen to happy things sometimes.

B   One final suggestion for things you can do to make yourself feel better when you are feeling sad ...what do you do?

A   I like to chat, so I chat to my mum about happy memories I have and I like to talk about things I've done with my brother Benny.

J   I tell my mum things and then to make me feel happy I watch videos and DVDs and read my favourite book.

M   Yeah, watch videos, DVDs, Arsenal and playing cards on the floor with my three year old.

Personal reflection

Prior to listening to the above interview, I had intended to contact Michael Rosen and ask him about the book. However, the children interviewed him with a refreshing forthrightness and asked questions that I would perhaps have been hesitant to use. In turn, Rosen seemed to connect with the children, perhaps due to their mutual experiences, the tragic loss of a close family member.

Appendix seven:

Bereavement services that provide:-

- Lists of recommended training and books on death and dying
- Further training in childhood bereavement
- Support for bereaved individuals who have a learning disability

Contact list for supporting bereaved young people

Details of services that recommended books alongside further information on death and dying for young people:

Child Bereavement Charity (formerly Child Bereavement Trust)

www.childbereavement.org.uk

This charity provides a variety of services for bereaved families. These include a support and telephone information service; education provision for professionals and families; support through their website and a variety of publications, DVDs and information leaflets.

Child Bereavement Network (CBN)

www.childhoodbereavementnetwork.org.uk

This is a national (multi-professional) federation of organisations and individuals who work with bereaved children and their families. The overall aim of the CBN is to improve the quality and range of bereavement support, thus increasing access to information, guidance and support services. Similar to the above organisation, this national charity is very much involved with education and provides a recommended book list for bereaved young people, including some produced by the organisation itself.

Winston's Wish

www.winstonswish.org.uk

The resources provided by this child bereavement charity have been widely used at the hospice where my study took place. The lead counsellor attended child bereavement training through Winston's Wish and many of the activities used within the bereavement study day were based on ideas from this organisation.

Winston's Wish has raised the profile of bereaved children, with several television programmes that have highlighted its work. The recommended book list also includes material for professionals and family members on supporting a child bereaved through suicide.

CRUSE: RD4U

www.rd4U.org.uk

Cruse Bereavement Care has developed a website for children and young people, with a focus on the experience of bereavement. The website was designed predominantly by young people.

Undergraduate Diploma and Postgraduate Certificate in Childhood Bereavement

childbereavement@helpthehospices.org.uk

These two programmes of learning offer a practice-based qualification for those working with bereaved children and their families.

National Council for Palliative Care (NCPC) [formally the National Council for Hospice and Specialist Palliative Care]

www.ncpc.org.uk

NCPC is the umbrella organisation for those involved in providing, commissioning or using palliative and hospice services in England, Wales and Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life-threatening and life-limiting conditions. NCPC promotes palliative care in health and social care settings across all sectors, ranging from government, national and local policy makers.

Young Voice

www.young-voice.org.uk

Young voice is a project that has been supported by the Family Policy Unit (formerly the Home Office) DfES and works with young people to help them raise concerns and get their voices heard.

Macmillan Cancer Support

www.macmillan.org.uk

This service offers telephone and email support to provide details of national and local organisations, for both bereaved young people and individuals who have a learning disability. In particular, they have a list of organisations and resources to support people with learning disabilities who are experiencing loss.

The Learning Disability Help-line, MENCAP

http://www.mencap.org.uk

The Learning Disability Helpline is an advice and information service for people with a learning disability, their families and carers.

The National Network for Palliative Care of People with Learning Disabilities

http://www.helpthehospices.org.uk/NPA

This network was developed in 1998 by a small group of practitioners from services in both learning disability and palliative care. The aim is to promote high quality care for people with learning disabilities, who are either accessing palliative support or experiencing the illness or death of a significant person in their lives. The organisation provides information for people with learning disabilities or their carers on issues relating to palliative care. A network of regional groups has been developed around the UK, where practitioners share resources and research, with many groups facilitating study days and conferences.

Appendix eight

Learning encounters during the PhD period

LEARNING ENCOUNTERS TO DATE: seminars, conferences and presentations

18.10.04	Meaning Reconstruction and the Experience of Loss (study day) Speaker: Professor R. A. Neimeyer, University of Memphis Venue: University of Huddersfield
September - December '05	Qualitative Methods within Psychology Series of lectures that included interviewing techniques, narrative research and phenomenology Venue: University of Huddersfield
29.11.05	Dr Rachel Balen, Senior Lecturer in Child Health: meeting with regard to interviewing children Venue: University of Huddersfield
26.4.06	Palliative Care and Bereavement Issues in Learning Disabilities Yorkshire Universities Learning Disability Nursing Research and Development Forum Venue: University of Huddersfield
28.4.06	Postgraduate Conference Venue: University of Huddersfield
19.06.06	Seven Stories: the national centre for children's books (experiential visit) Newcastle upon Tyne
9.6.06	Consulting with Children and Young People: the where, the why and the wherefore. RCN Research in Child Health conference. Venue: RCN, London
27/28.6.06	Communicating Effectively with Children and Young People through Play (2 day course) Venue: Social Services Learning Centre, Cliffe House, Huddersfield
29.11.06	Trans-Pennine Palliative Care Research Network Poster submission (first prize) Venue: University of Sheffield, Trent Palliative Care Centre, Sheffield
24.8.06	The Florence Nightingale Foundation: interview for a fellowship award. This study was one of only 30 projects out of 200 entries to be granted an award. Venue: The Florence Nightingale Foundation, London
5.12.06	Story Telling in Palliative Care: research and creative practice Venue: St Christopher's Hospice, London
27.2.07	A Celebration of Five Years Support for People who have a Learning Disability and Palliative Care Needs Oral presentation on the emerging findings within this study Venue: Kirkwood Hospice, Huddersfield

4.4.07	Yorkshire Association of Palliative Care Educators Meeting: oral presentation with regard to carrying out a PhD study alongside the role of Hospice Tutor. Colleagues at the meeting included lecturers and education managers from a variety of universities and palliative care settings. Also discussed was the importance of PhD study within nursing, research strategies and advancing evidence-based practice. Venue: Kirkwood Hospice, Huddersfield
7.9.07	The Florence Nightingale Foundation, London Successful interview for a second fellowship grant
23.10.07	Thesis Writing (study morning) Speaker: Dr Rowena Murray, University of Strathclyde Venue: University of Huddersfield
27.11.07	Making Research Accessible (study morning). Speaker: Professor Colin Robson Venue: University of Huddersfield
5.2.08	Taking Everyday Experience Seriously: qualitative psychology in the real world: professorial inaugural lecture Speaker: Professor Nigel King Venue: University of Huddersfield
11.2.08	The Needs of People with Learning Disabilities who are Dying or Bereaved 10th Anniversary Conference for the National Association of Palliative Care for People with Learning Disabilities Oral presentation: Chocolates with Rudolf and Family Venue: Dove House Hospice, Hull
12.2.08	Chocolates with Rudolf and Family (Oral presentation) Diploma in Palliative Care session: University of Huddersfield students Venue: Kirkwood Hospice, Huddersfield
6.2.08	Striking and Sticky Moments: learning through narrative and reflective writing. Speaker: Dr Alison Donaldson Venue: University of Huddersfield
28.2.08	Preparing for the Viva (study session) Speaker: Dr Rowena Murray Venue: University of Huddersfield
3.3.08	Situating Learning in Practice: tales from the field. Speaker: Dr Sue Duke Venue: Help the Hospices, London

| 10.3.08 | Research Open Day: Department of Human and Health Sciences
Poster Presentation: Chocolates with Rudolf and Family.
Also attended:
Health Care Assistants Working in Nursing Homes: results of an evaluation study.
Speaker: Professor Annie Topping
Venue: University of Huddersfield |
| --- | --- |
| 11.4.08 | Writing for Publication (study session).
Speaker: Professor Eric Blyth
Venue: University of Huddersfield |
| 3.08.08 | Qualitative Psychology: real world relevance (study session)
Venue: University of Huddersfield |
| 11.3.08 | Diploma in Palliative Care: Aspects of Grief: University of Huddersfield
Presentation of PhD research to date
Venue: Kirkwood Hospice, Huddersfield |
| 7.5.08 | Into the Swamp: reflexivity in qualitative research (study session). Speaker: Dr Linda Finlay
Venue: University of Huddersfield |
| 23.6.08 | Child Bereavement study day
Presentation of PhD research to date
Venue: Kirkwood Hospice, Huddersfield |
| 3.9.08 | Qualitative Methods in Psychology Section: inaugural conference
The British Psychological Society
Poster accepted and displayed
Venue: University of Leeds |
| 24.2.09 | Phenomenology Workshop:
· Ambiguous encounters: a relational approach to phenomenological research: Linda Finlay
· The phenomenology of 'approach to studying': the idiographic turn: Peter Ashworth and Kay Greasley
Venue: University of Huddersfield |
| 1.7.09 | Improving Patient Care: provision in palliative care for people with learning disabilities
Presentation: Undertaking Research with Bereaved Young Adults who have a Learning Disability
Venue: Hudawi Centre, Huddersfield |
| 22.7.09 | Examining PhD students: research forum meeting
Speaker: Professor Annie Topping
Venue: University of Huddersfield |

Details of the study have been presented to approximately 200 people from 2007 to the present date.

Appendix nine:

Reflection of a visit to Seven Stories, National Centre for Children's books

Reflection of a visit to Seven Stories, National Centre for Children's Books, Newcastle upon Tyne

Seven Stories was opened on 19th August 2005 and became the first British centre to celebrate children's books. It hosts an exhibition dedicated to the work of writers and illustrators, bringing together original manuscripts and artwork from some of the nation's best loved books. I did not think it possible to undertake a review of children's literature without going to see the centre. Therefore, together with my PhD supervisor and a colleague, I visited Seven Stories in June 2006.

Within the publicity material, Seven Stories is promoted as 'one of the most prestigious children's bookshops in Britain'. It is described as offering a comprehensive and diverse range of titles, from folktales to poetry and contemporary fiction for all ages. The staff team were able to offer advice on the most appropriate books for different age groups and interests. After searching for publications on death and dying, I was a little surprised when the library staff could not suggest any dedicated books on the subject. Instead, they pointed out that many story-lines within the general reading section would include some aspect of death and dying. It was particularly interesting that Michael Rosen's SAD BOOK was not in stock, as it was a fairly recent publication and the author had contributed to the exhibition.

Whilst it may seem an unusual idea to have a specific children's section in libraries or bookshops about loss, Gersie (1991) makes the following observation:
"Not to educate ourselves and our children about our relationship with death means not educating ourselves and them about life. It is dangerous to do so, and not because of death – sooner or later we all will die – but because it profoundly affects the quality of our life, both before and after we have become bereaved. The best preparation for bereavement is death-education. The best preparation for life is to relate death to our ways and values of living". (Gersie, 1991, p.38-39)

Overall, the visit to Seven Stories was tremendously worthwhile. It was the first time I had seen the 'scribbles, drawings and notes' from authors such as J. K. Rowling, all of which had subsequently been transformed into successful publications. The tremendous skill, background research and planning needed to create the books was evident and the

displays contained personal testimonies, video and voice recordings from a number of well known authors. My visit also offered an opportunity to read accounts from illustrators and see the development of their drawings, executed with enormous talent and detailed perception of everyday life. I wondered if any of the most popular children's picture-books would have been so successful without their genius.

Crewe (2004) interviewed a group of authors and illustrators, to find out how they worked together. Whilst she discovered a particular chemistry between the respective individuals, there appeared to be no magical recipe or high-flying corporate venues in which they met. Often meetings took place in motorway service stations or their respective homes. Some of the group barely communicated at all, or spoke only on the telephone, with the writers granting illustrators' free creative licence. Nevertheless, Crewe noted that the mere mention of many titles will 'leap out from the rest and make the heart sing'.

One of the books I did purchase at Seven Stories was Quentin Blake's publication, 'Clown' (1995), in which the illustrator recounts a fascinating story without any text at all. At the time I thought my purchase was supplementary to this study. However, it prompted me to consider that illustrators also work independently, as 'authors without text'.

In summary, the visit to Seven Stories increased my knowledge of how authors and illustrators create both narrative and illustrations. One of the most striking aspects was a deepened understanding of how pervasive and integral to all our upbringings storytelling has become. At times, the old titles brought my childhood memories into focus and stirred some quite unexpected emotions. This prompted me to consider that when recommending books for bereaved children, it is not just their initial experience which is of consequence, but the significance they may attach to the story throughout the rest of their lives.

[1] An abridged version of this reflection can be found in Chapter 3, Section 3.2.4.

Appendix ten:

The Seven Hat Framework: personal reflection

The Seven Hat Framework: personal reflection

THE BLUE HAT

- Calm, controlled, organised thinking that provides an introduction

This hat offers an introduction, focusing on why my study took place, the issues investigated and an overview of some elements within the methodological design.

During the initial stages of this project, I considered a number of areas to investigate, not only in relation to supporting a group of bereaved young people within a therapeutic setting, but the experience of bibliotherapy. Parents of a family I had previously worked with generously agreed to support this research. Reasons for assisting with the study included the approaching anniversary of when their daughter had died and a desire to access further assistance from the bereavement team.

At first I was hesitant to involve such a vulnerable group, especially when (for various reasons) it was necessary to protect their identity. However, several safeguards were put in place, thus enabling me to progress with the investigation. These included restricted access to the video recording and the creative use of pseudonyms. The idea of pseudonyms had been discussed with the participants when I visited them at home. This approach allowed me to make certain that, as far as possible, they were aware of what I was doing and its relevance to my PhD. I am now much more comfortable with the study, as the participants will be growing up fast. By the time this thesis is published, I am confident that the likelihood of their identity being compromised will be greatly reduced.

Preparations for the session had to be navigated around other commitments, such as a full time job, several family concerns which required attention and Christmas. I had not envisaged the session taking place in late December, but this was arranged to fit in with the anniversary of Eleanor's death. Whilst organising lunch was an additional task and not part of the data collection period, it was required for the session to take place. This was true of so many other issues, especially ordering the technical equipment, many items of which I had not utilised before. As I note in subsequent sections, certain situations transpired which I'm sure would not have happened had circumstances been less rushed. In many ways, the study is simply an account of everyday practice and I suspect will ultimately have similarities to other professionals' working practice, the events of which are often far from perfect.

With so much organisation required, two of the main considerations were health and safety issues and ethical safeguards. Whilst the participants needed to follow certain guidelines, in order to be safe, it was important for me to ensure all their holistic needs would be met during their time at the hospice. The rules for the day, created at their first bereavement session, reflected how this was formally addressed. The following rules had been agreed by all those present:

1 Put up your hand if you have something to say

2 Don't run off

3 Don't go near the pond

4 If there is a fire, wait by the door for Helen

5 Have fun and plenty of chocolate biscuits

6 Don't laugh when other people are crying

7 Don't interrupt other people

8 It's OK not to do things you don't want to

On reading the above, I am very conscious of how easy it is to influence others. In the original session, staff at the time (myself included) guided statements such as 'don't laugh when other people are crying'. After subsequent discussion with my PhD supervisors, I am more aware of the possibility that we introduced common cultural expectations regarding loss, for example, it is upsetting and people may cry. Other points incorporated statements to ensure the participants were aware of their right not to take part, to respect others and of course health and safety issues, for instance, what to do in case of fire and not going near the pond.

The participants were fully supervised throughout the session, although the staff ratio was lower than usual. This had been hampered when one member of staff cancelled her attendance a few days before the session. Fortunately, one of my PhD supervisors was familiar with the hospice environment and had prior experience of working with children. She offered to be available, should another member of staff be unable to attend on the day. Subsequently, permission to proceed was granted by the Director of the hospice. Had this situation been anticipated earlier, another staff member would have been recruited, although the day progressed without any unforeseen incidents.

I knew a certain familiarity with the physical environment was important and therefore planned to open the same room which the participants had used for their first session. This merely added to my list of things to do, which included: ensuring all the equipment and supplies were transported to the building; changing the heating so the rooms were warm and organising catering for the refreshment breaks. In short, the checklist was long and varied, reflecting my dual role of principal investigator and practitioner.

My emotions throughout the data collection period varied greatly and will be discussed in subsequent sections of this reflection. I had an instinctive feeling that the study would be important, a reflection of 'nursing in the real world' and was ready to accept whatever happened, thereby moulding my practice around the events which transpired. This approach is one I have slowly developed over the years, when working with individuals who are experiencing distress or grief. However, it does not mean that I sailed through the whole experience without fleeting moments of anxiety.

One particularly anxious moment was when the prompt cards, so carefully and thoughtfully prepared, went missing. They were an important guide, to ensure the discussion remained within a phenomenological framework. As soon as the session was finished, I found them underneath some toys the younger children had been playing with. I had a fatalistic approach when this happened, considering a possibility that the investigation would have the same merit as other situations, where conditions are perfect, with few (if any) mishaps.

THE GREEN HAT

- Creative thinking and new ideas

For this hat I am adapting de Bono's original structure, where he emphasised finding creative solutions to a set problem or task. In this reflection, I have focused very much on the creative side to the data collection period, especially how the approach worked with the various age groups. My reflection will encompass the surprising and unexpected elements to the session, especially issues which transpired as a result of these creative features. Also presented will be a discussion of pseudonyms, having to remember these (in addition to the participants' own names) and how chocolates 'resurrected' some enthusiasm towards the end of the session.

As mentioned earlier, the pseudonyms were very important and not only provided an educational element to the session but one that was fun, largely due to the festive and fascinating names chosen. As a researcher, the amusing pseudonyms supported me in coping with such an emotive set of data. Shortly after the session, due to personal circumstances, I found the material difficult to work with and am certain this would have been even more so, were it not for the frequent references to Rudolf, Britney Spears and Hoover.

I am always fascinated by the way individuals read a book, with the same details received and understood in so many different ways. For example, Supergirl pointed to a baby being bathed, an activity she was very fond of at the time (as the family had recently adopted a young baby boy).

When discussing the story-line, this was the only individual contribution she made, whereas many of the others spoke of their emotional feelings and experience of loss.

It is impossible to conclusively say all the participants enjoyed the whole session, as the video recording appeared difficult for some. However, on the whole, those involved (including the staff) appeared to take delight in such a creative approach to exploring bereavement. Asking the group to be reporters for CBBC helped to open up a discourse, in a less threatening way than simply questioning them about their experience of reading the book. Interestingly, once the participants started talking, their conversation naturally evolved into disclosures about their own experience of grief. Using a 'third person' narrative appeared to help the group and it was also grounded within their 'lifeworld', where they watched CBBC at home.

With such a large age group, it was important to use a variety of approaches and, although some of the participants were probably too old to appreciate the CBBC approach, they didn't appear offended by this. One person in particular, QBL, was interested in acting and therefore appeared comfortable with the role play scenario. Obtaining a toy microphone, to use as a prop, may have enhanced the session, although perhaps this would have made the design too childish or even threatening for those who were more hesitant about speaking in a group or recorded session.

Pages from the book were transferred into a PowerPoint presentation and projected onto the wall (as in a trip to the cinema), an element that may not have been necessary. However, with such a large group, this provided a variety of things to look at. It was possible that the two younger boys would have found it difficult to sit at a table quietly and read a book. In the data collection period they quite happily sat by the projector, glancing at the wall every now and again.

One popular and creative addition was the chocolates, used towards the end of the session when some participants appeared to be losing focus. Although the level of activity and noise continued to fluctuate, even after the consumption of a chocolate, the break appeared to extend the session and allow more time to discuss the book.

One of the most rewarding aspects to this study has been the participants' generosity in sharing their ideas, reflections and memories within the session. They showed remarkable honesty, discussing some very emotive issues. All responses to our questions were acknowledged as important and their respect for each other was one of the most moving aspects of the transcription process. Often, when a person with a learning disability says something out of context or unusual, other individuals will either discount their contribution to a conversation or be amused at what they have said. Within this group, the participants simply listened and responded. Whilst on one occasion they appeared to be

ignoring Britney, she was actually stating something we had all heard many times before. Due to a limited vocabulary, her explanation was noteworthy, even if repetitive. A particularly touching scenario was captured on the video, where QBL described what happens when someone dies. His conversation was not immediately understandable, so Hoover very patiently let him finish and then translated what he was saying for those present. Subsequently, QBL agreed with her comments.

It could be suggested that I should have exerted more discipline with the group, to quieten the session down. However, by allowing the young participants freedom to explore their environment, an opportunity arose to discuss issues with those who were still focused on the book. Thereafter, the younger children fleetingly returned to the group and contributed to the session, in their own unique way

Within the room there was plenty of stimulation for younger members of the group, especially when they wished to leave the table and have a look around. The puppets were a popular choice and on one occasion I used them during a discussion with Flashergirl. This technique is frequently used within child bereavement sessions and, although I had not envisaged it would happen in the data collection session, the toys did add to the variety of props utilised.

Trying out any new approach, in a professional capacity, brings with it a certain awareness that some colleagues may not agree with the methods used. This study was no exception and one member of staff thought the group was too large and should be split up. After much careful thought and discussion with other colleagues, I decided to progress with supporting the family as a whole. To have divided the group up chronologically, or distinguish between the individuals who had a learning disability, would have separated birth siblings from those who had been adopted. I felt the family experienced the tragic death of a family member together, lived together, communicated and shared experiences together and therefore it appeared illogical to suddenly separate them, when looking at how loss had impacted on all their lives.

I was conscious that the session was under scrutiny, not least because it was due to be part of my PhD study. After the session had finished, I knew the data would not portray a perfect session (assuming this was possible). However, as far as I was concerned, there was an overwhelming array of positive occurrences, which ultimately the staff team and I were pleased with.

THE BLACK HAT

- **Sombre; serious; cautious; careful; points out weakness**

The purpose of this section is to focus on occurrences which (with hindsight) I possibly would change. Ensuring the participants were going to be safe, not only physically but psychologically, will be encapsulated within this section. At times, keeping the group on track was a challenge. The younger ones were very active and, as noted in the previous section, I was aware that having such a large group could be considered inappropriate for a therapeutic encounter.

My experience of meeting the participants to discuss ethical approval was very different to how I imagined it may transpire. Several of the participants wanted to sit immediately beside me, the young ones fought over who would sit on my knee and one particular individual decided to rearrange my hairstyle from a strategic position behind the sofa. I recognised this as attention seeking behaviour, although, after watching their parents, knew they would soon settle down and let me get on with what I needed to discuss. If unaware of the context in which this happened, it would be easy to consider this approach inappropriate.

Approximately a month before the data collection period, I distinctly remember a University session on research techniques. The lecturer said there were just two things to avoid when interviewing, groups and working with children. Apparently, young people are by their very nature unpredictable and especially so in groups. Marvellous I thought. Undeterred, I continued with my plans, not only due to all the arrangements which had been made, but because supporting bereaved children formed the basis of this investigation. To address this issue, I built certain contingencies into the methodological design, in relation to the range of materials and resources in the environment. An additional factor to consider was the wide span of ages and abilities within the group.

When transcribing the video, there was evidence of several younger members losing concentration and not really joining in with the verbal conversation about Eleanor's death. Even less evidence was found in relation to any acknowledgement of what had happened or the impact of this on their lives. However, several participants had already experienced circumstances which necessitated adoption and it is possible that the sudden death of a family member was not the worst thing to have happened within their short lives. Writing about these issues is perhaps harder than transcribing the bereavement information and has evoked much personal sadness. Although no disclosures took place, the vulnerability of the participants and their negative experiences, at such a young age, are difficult to comprehend.

Following the first bereavement session, Sarah had experienced the death of another close family member (unrelated to the rest of the group). Within the data collection period she didn't mention this and whilst it could be surprising, I did not assume she had openly discussed the experience with all those present. Sarah was a very quiet member of the group and perhaps did not feel able or willing to share such personal information in the session or with the staff team present. Interestingly, she did speak about her friend's unborn sibling who had died (a possible indication of selective disclosure in the session).

Although Sarah did not interact much within the group setting, her mother told me that following the first bereavement session she had noticed Sarah's increased understanding of the bereavement process. When her relation died, she was heard comforting a family member, saying that it is OK to feel upset and quite normal to cry. Therefore, she possibly internalised what was being said and used this later when an appropriate situation arose.

All the staff had been notified of the participants' background and prepared for other disclosures that may have unfolded. Katrina and I had recently attended child protection training and therefore acquired the necessary knowledge and skills to manage disclosures of a sensitive nature. The training cautioned against too much physical contact, in keeping with professional guidance from the RCN. Nevertheless, I took my lead in how to work with the participants by watching their parents. On the two occasions when I had visited them at home, it was a privilege to watch their approach. Even though the two youngest children were over 5 years of age, they still needed to be held, touched, picked up and occasionally sit on someone's knee. However, in the session these were fleeting moments and the boys soon settled down, became quieter and joined in with activities, in a manner more appropriate to their chronological age.

During the session, there were occasions when I suspected the recording was having a detrimental impact on some of the participants' experience. Several of the teenagers disliked being video recorded, a point which cannot be ignored and is visible within the data. Whenever I became aware of this happening (with at least three individuals), Tharpa stopped recording them and pointed the camera towards myself. When visiting the family just over two weeks later, to follow up on any subsequent issues, the atmosphere was more relaxed (a small tape recorder was all that I used). At this session, some of the younger participants requested a copy of the video recording. However, I explained why it would be unfair, especially to those who were not comfortable with being recorded. Equally it would have meant that other individuals may view the content. As discussed before the session, the data was confidential, a point agreed by all.

Once I realised the timescale of the data collection period was very close, the preliminary practice sessions were hurriedly arranged. The first was with two children whom I had known on a personal basis all their lives. I read a story and asked questions regarding their experience, including what it meant to them.

On a positive note the exercise was good, as it helped me work on prompts to use when teasing out what 'the experience of reading the book' was like for them. Similar to some of the younger participants, the girls sat very close, perhaps, in this case, influenced by the times when I had read to them at bed-time, when they 'snuggled' up and became engrossed in the stories. Their ability to grasp concepts and discuss the 'meaning' behind the story was a pleasure to listen to. This provided me with great hope that the data collection session would yield some rich and meaningful discoveries.

However, in my haste I missed out several fundamental issues, which very much weakened the effectiveness of this strategy. It was only later when I realised the significant difference in their background, compared to the participants in the study. Both children (aged 11 and 14) were very comfortable in my company and had experienced little disruption in their lives. Apart from very elderly great grand-parents and family pets, they had experienced no significant bereavement or personal trauma. Also, their uninterrupted education provision to date had provided them with a good vocabulary to explain their experience.

Furthermore, in the practice session I read a different publication to Michael Rosen's SAD BOOK. I had only received ethical approval to read Rosen's publication in the data collection session (as there was a trained counsellor present should any complex issues have emerged). In carrying out the preliminary session this was not the case, so another book was utilised instead, Albert Le Blanc by Nick Butterworth (2003). The story-line appeared simple when I first read it, although the two girls delved deep into the meaning and discussed some touching insights, generated from reading both the text and illustrations. Interesting though this was, it would have been better to consider using Michael Rosen's book and included this in the research proposal.

Having a further preliminary session with an adult participant was equally mixed with regard to its usefulness. The main benefits were in setting up a digital audio recorder and using the PowerPoint equipment for the first time. One element I didn't practice was using the video recorder. Had this been done, I would have realised the importance of loaning any equipment much earlier than a few days before the session and thereby avoided the following situation. It was too late when I realised my spare tapes for the camera were the wrong size. Therefore, as I only had two correct tapes, it was only possible to use one for the participants' session, with the remainder for the staff de-brief. In

hindsight, what I should have done was to audio record the staff interview, keeping the two video tapes for the participants' session.

Some mistakes in the session, with regard to following the phenomenological methodology, were evident. As an example, I kept reverting to my role within the child bereavement support team, rather than purely focusing on the investigation. There are instances where I questioned the participants about their experience of reading the book, although we spent an equal amount of time discussing coping strategies for managing grief. I frequently referred to issues discussed in their first bereavement session (several months earlier). This illuminated my dual role as principal investigator and lead professional for the session.

As noted in the blue hat section, within the session I could not find the prompt cards which had been carefully prepared beforehand. So many small mistakes happened on the day and were possibly linked with having too much to remember. All the staff undertook the session in their own time and for this reason I did not delegate tasks as I would normally have done. Overall, it was a good lesson to learn, in relation to the danger of juggling too many tasks all at the same time.

There is a lack of evidence that everyone involved in the session had enough time spent with them, in order to make sure they knew what the book was about. As mentioned earlier, the attention span for many individuals was limited. Equally, the individuals with a learning disability may have benefited from looking at a much smaller, condensed version of the book. With this approach, it would have been possible to discuss the concepts at a slower pace and provide more time to think about certain issues.

On several occasions, I felt uncomfortable when some participants looked upset and spoke of feeling tearful when reading parts of the book. I questioned whether it was a good thing for the family to spend their Saturday before Christmas looking at loss. Furthermore, I wondered if there was a genuine evidence base to show that this would help their grieving process.

In summary, the purpose of this section was to allow myself to remember things which were not perfect, without needing to justify my actions. I have undertaken similar reflections within supervision sessions, although not in such a formal way. However, doing this in a stark way (with my black hat on) has been the most uncomfortable reflection to write, perhaps revealing a strength when utilising the Seven Hat Framework. Had I not considered or created the framework, it is possible that my reflection may have failed to recall the more controversial or negative elements to arise, as documented herewith.

THE WHITE HAT

- Neutral and objective

Within this section I focus on being neutral and objective, reporting on facts and figures from the session, the time it lasted, its structure, the number of participants and what transpired.

Overall, the data collection was organised well. As requested, the staff came half an hour before the session and the participants arrived on time.

Two of the teenagers chose not to attend for personal reasons. This did present an immediate concern, as they were going to do the video recording and I had not asked anyone else to do this. I made a quick decision, choosing Tharpa and Superwoman to do this task, mainly to prevent any jealously with the participants (as several wanted to have a go, especially the younger boys). It was such an important part of the methodological design that, on reflection, it would have been better to have allocated staff to do this from the outset. They would have been better prepared, had formal instruction on how to do the recording and an opportunity to practice. More importantly, it would have afforded time for a discussion on the need to stop recording when anyone appeared uncomfortable.

In total there were 11 participants present and four staff, the pseudonyms of which are:

Participants:
Q B Love (QBL); Lyn; Supergirl; Britney Spears; Rudolf (the female reindeer); Hoover; Sarah; Boothy; Flashergirl; Dash and Spiderman

Staff:
Katrina; Tharpa; Superwoman and Esmeralda (myself)

The session was structured in a way that gently eased the participants into the proceedings. Rules of the day were agreed and the book was read out loud by Katrina. Each person had their own copy, alongside an opportunity to view the pages which had been projected onto the wall.

To start the discussion a general question was put to the group, "...if anybody was doing a news report and you had to say what the book was about, would any body like to start? How would you describe the book?"   Later, when the participants were talking freely I was much more direct and started asking individual questions. One example was when QBL had been discussing the book for a while, I asked:
'……you are quite right, that was Michael Rosen who was telling you the story and what was he telling you about?'

There is evidence that I focused for too long on Lyn who was very shy. Whilst in the session I could not see her face, on the video recording she looked uncomfortable with the questions put to her.

At one point Rudolf spoke about how certain parts of the book were difficult to read and she "felt like crying". When reviewing the video recording, I thought this remark could have been explored further. However, in the session I reverted to discussing coping strategies for sadness, some of which are referred to in the book. The swiftness with which I did this indicated that either it was to move the discussion on, or because I felt uncomfortable with Rudolf's remark about the book making her feel so emotional. My responsibility for creating a session in which the participants were in a situation they found upsetting, was definitely something I pondered on (as already discussed), especially whether this was deemed to be therapeutic or not.

I followed a structure frequently carried out when facilitating child bereavement groups and ensured that the session had a mixture of addressing difficult issues, discussing topics like coping strategies and highlighting the importance of sharing feelings with another person. Throughout the transcripts, there is evidence of every person being given an opportunity to say something about their experience. Equally, I thanked each of them for their contribution, no matter what it was. I finished the session on a lighter note, by asking the participants to give the book a mark out of 10 for CBBC viewers.

Chocolates were used towards the end of the session to good effect.

THE YELLOW HAT

- Sunny and positive; optimistic; hopeful; positive thinking

This hat provides an optimistic reflection of the session, including the value and benefit for all involved. Contrary to what I had originally thought, this was a much harder section to undertake in a positive light, especially when I had just spent the last couple of hours looking at the black and white hat issues.

There are several points from the session that worked extremely well. A couple of weeks after the data collection period, I spoke to the participants' parents and was pleased to hear there were no negative issues which had arisen. Although it seems a strange thing to write, on the whole, the participants appeared to enjoy the day, including the data collection period. They even asked if it was possible to come back for a further day.

When visiting them at home for a follow up interview, they wanted to repeat the exercise all over again. I suspect that if it had not been an enjoyable activity, they would not have wanted to either return to the hospice or repeat the exercise once more. On this follow up visit, Dash was distressed about something which had happened during his day at school. I felt it was a positive sign that he had not shown any distress within the main data collection session, where he appeared relaxed and entered into the exercise with good humour. Additional family members also joined in our discussion of reading Rosen's book.

Whilst I did question whether or not the session would be therapeutic in the long term, it is possible that this may transpire for some of the participants. Following the initial bereavement session, Sarah showed great maturity when a close relative died. This was important, as it allowed me to see the possibility of similar outcomes occurring after the data collection period. I instinctively felt the issues discussed would be of help to some (if not all) of the participants in their future lives.

Within the staff team there was an experienced counsellor and other members with equally valuable experience, skills and personal qualities. They were comfortable talking about difficult emotions with the participants, an important aspect in child bereavement sessions where emotive disclosures frequently take place. Personally, the ability to discuss death with bereaved young people has resulted from my work within the hospice, attending several child bereavement sessions and accessing the relevant education.

THE RED HAT

- **Emotional experience**

This section will discuss issues related to: exhaustion; concern when the participants looked troubled; reassurance when the conversation appeared to be therapeutic and a certain relief when the session was finished.

It is quite natural and common for therapists to be affected when listening to people relate their sadness and experience of loss. I have found this true, especially when supporting young people. Reasons for this include:

- Acknowledgement of my own mortality. In this instance, Eleanor was only a few years younger than myself
- The aim of the session was not to make everything right. This would not only have been impossible but unhelpful, in relation to the natural order of inherent emotions for each bereaved individual. It is widely acknowledged that latent grief can actually be more traumatic for a person, than experiencing and working through loss as it transpires.

There were several components to the session which helped balance some of the highly emotive disclosures. The young boys were amusing with their diversionary activities, such as the Scooby Doo (puppet) sub-plot. Their background noise avoided any clinical quietness in the room and the steady chatter had little, if any, detrimental effect. All involved appeared able to function well, without being distracted from conversations. At various appropriate intervals, the boys were asked questions and their answers contributed to the overall data collection period. Had the session been too formal, quiet and structured, it may have been an awkward experience for the group. I sometimes question whether 'peace and quiet' is truly necessary for therapeutic encounters or research interviews.

Young participants can also offset the emotional impact of bereavement work with their need to puddle jump. This term is used to describe situations where, for example, they disclose very emotive issues then go outside and happily play a game. It is deemed to correspond with an innate ability to 'live in the moment' and linked to a lack of capacity to experience grief continuously, over a long period of time. Intermittent grief is therefore exhibited.

It is clearly evident from the analysis, that the words "does anyone want some chocolate?" helped to inspire, re-focus, cheer and bring the group to order. After discussing and reflecting on some very emotive issues, I found the enjoyment and laughter when deciding which and how many chocolates to have, a welcome relief. As discussed earlier, I do find that watching and listening to participants discuss distressing experiences can be emotive and it was good to see their ability to put this aside for a moment and consider their chocolate dilemma.

Appropriate use of touch has a quality within bereavement sessions to soothe, ground and comfort, in even the most upsetting situations. There was evidence of this in the study, not only with the younger participants but many of the others, often between themselves. This very natural way of communicating was equally reassuring to the staff team. When working with children, I interpret appropriate touch as an indication that they are comfortable with my presence. In the session they often tapped me on the back, almost in a primeval way, perhaps to make sure I was there, real and to be trusted.

Just before the session I had received news that a close family member had been diagnosed with cancer and required radiotherapy. Whilst it is not unusual for staff at the hospice to manage family health issues in addition to their work, I did find it a struggle to concentrate. Not only was my usual work based in a hospice setting, but this project was also on the subject of death and dying. My sleep was definitely affected, as I tried to work out how I was going to fit everything in. Although this did impact on the quality of my preparations and performance, what transpired was simply a realistic account of managing hospice work alongside everyday life. Whilst the data collection period had to progress within the allotted time-scale, flexibility was afforded to me the following year. Thus, I was able to work through the acute period of managing an emotive and complex situation.

Due to my disturbed sleep pattern, I had been awake since 5am on the morning of the data collection period and did feel exhausted. The responsibility to support the participants and ensure they were safe was an element I found both daunting and rewarding. It was reassuring to know I had captured the necessary data and a great relief when they returned to the care of their parents, safe and well.

ORANGE HAT

- Transcendental realm of the session

The colour orange was chosen to represent my transcendental reflections of the session. This section will explore how the study resided alongside my own belief system and the reasons why it was valuable and meaningful on a personal level. Although it has been quite a challenge to reflect on and describe this in a tangible way, the following aspects reflect my experience.

A recent television programme, in which J. K. Rowling discussed her own experience of writing the Harry Potter novels, prompted me to add this element to my formal reflection.   She discussed how writing was closely linked to her personal beliefs on mortality, good and evil, and the imperfect, fragile, vulnerable, yet wonderful parts of being human. This stimulated me to consider how facilitating the session was exactly that. I was prepared to accept whatever happened and felt inspired when listening to the participants' discussion.

Twenty years prior to the data collection period, a close relative (who had several young children) died suddenly. I distinctly remember the support that each child received and often recall this when working with bereaved children. In many ways, I utilised this personal experience in the data collection session to complement my professional skills, along with an inherent belief that supporting bereaved young people is a valuable thing to do.

I was conscious of a certain connection to the participants and enjoyed meeting them for a follow up interview. However, whilst I felt no need to continue the relationships formed, an approach that helps to place my work in context, it was interesting to observe the recording and see how I supported this bereaved group in a caring and professional way. All the participants and staff members were a joy to be with, as everyone seemed to appreciate interacting with one another. The warmth of their interactions reassured me that supporting them all together, in such a large group, was the right approach. At times, the session appeared to be simply a natural part of their grief journey.

Discussing various ways to manage their situation was emotive but ultimately very rewarding, transcending any material sense. Teaching and supporting the group was something which sat comfortably within my personal beliefs. Even though grief is one of the most difficult experiences to manage, I instinctively knew the participants' innate resilience, together with skilled support, would assist them in learning how to cope with their loss. Providing a setting in which they could learn from and understand reality, whilst at the same time feel supported or able to say out loud what was upsetting them, was very worthwhile.

THE BLUE HAT

- Conclusion

Throughout my reflection the focus, in the main, has centred on how I facilitated the session. This included a flexible approach, thus enabling the participants to have a therapeutic encounter, rather than purely being part of an experimental research study.

The complexity of my dual role within the session has been illustrated, including both positive and negative aspects of what transpired. The session demanded organisational skills in a wide range of areas, from pragmatic issues, such as ensuring there were refreshments and a warm room, to having a correct mix of professional skills within the staff team. This reflection has covered the myriad of areas that I feel represents the data collection period.

Two main factors contributed to an effective session. Firstly, the personal as well as professional qualities and skills of the staff team ensured all participants were holistically supported (physically; emotionally; socially; psychologically and spiritually). Secondly, the participants were receptive, within their own limits of concentration, followed our requests and respected the 'rules of the day'. As a family, they were not necessarily any different from others I have known or worked with. They simply responded to the warmth and kindness offered to them and shared their experiences within the group setting.

The difficulties that I experienced, including exhaustion and concern about initiating any unnecessary distress, have previously been discussed. It would be foolish to say the day was without any negative components. However, the session was valuable, in that ultimately it was an opportunity to offer the participants a 'moment in time', where they explored, discussed, asked questions, listened to and debated the reality of grieving for a young family member. In a society which finds the subject of loss difficult to address, providing this opportunity was, I believe, the right thing to do.

To conclude, the overall aims of the session were achieved. The data provided adequate details that will contribute to the body of evidence, in relation to supporting bereaved young people through the use of group work and literature.

LIST OF FIGURES