“How do counsellors assess pre and post bereavement needs and implement support to children/young people and their families within children’s hospice services throughout the U.K?”

A thesis submitted to The University of Manchester for the degree of Doctorate in Counselling in the Faculty of Humanities

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Abstract

Christine Rose Buscombe

Doctorate in Counselling

“How do counsellors assess pre and post bereavement needs and implement support for children/young people and their families within children’s hospice services throughout the U.K.?”

2013

The rationale for this study arose from the researcher’s own practice as a children’s hospice counsellor, being given the challenge of providing emotional support to all those wishing to access a counselling service within a children’s hospice. How could one counsellor fulfil such a responsibility? What was meant by the term “support?” What part did the hospice’s multi-disciplinary team play within the provision of this support? Such questions, the researcher felt, needed to be put to a wider audience and the aim of this study was to examine children’s hospice counsellors’ practice of assessing needs and implementing pre and post bereavement support to children/young people and their families who access a U.K. children’s hospice service.

A phenomenological approach was adopted and in-depth, semi-structured interviews with seven children’s hospice counsellors were transcribed verbatim. The researcher identified salient information and categorised forming themes using thematic analysis. Quotes were selected that captured the semantics of these themes.

The main findings were that pre-bereavement support activities were being provided by members of the hospices’ multi-disciplinary teams. The assessment of needs during the this stage was found to be carried out by members of the nursing staff encompassing medical as well as psycho-social needs. It was also discovered that children’s hospice counsellors were more actively engaged in post-bereavement support and informally assessing bereavement needs. In addition, bereavement needs assessment was being carried out by a variety of professionals who had had some involvement with the family during the pre-bereavement stage.

Implications of the findings suggested that counsellors could be more actively involved in pre-bereavement assessment of families’ needs. It was also indicated from the results that in-depth training on anticipatory grief and the grieving process, as well as supervision of other professionals supporting family members, could be delivered by children’s hospice counsellors.

It was recommended that the subject of assessment of both pre and post bereavement needs of the diverse client groups accessing support services be opened up for wider debate and dialogue within the arena of children’s hospice services and paediatric palliative care.
Declaration

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To my children Gareth, Owen, Carys, Rhys, Aled and Elenya - I hope, in the time it has taken to achieve this particular goal, that I have inspired you all to pursue the fulfilment of your own hopes and dreams whatever they may be.

Finally, I wish to acknowledge that life being finite, I will continue to strive to live life to its fullest – my learning so far has been that without the generous support of family, friends, tutors and sometimes relative strangers, my success and joy in reaching set goals is rather hollow, since it is the sharing of my journey that brings me closer to those I love and respect. I am hooked on life with its abundance of opportunities which bring me into the presence of amazing people like all those mentioned above, and it is that delightful consequence that drives me forwards.
The Author

The author currently holds a Master’s degree in Counselling and has carried out previous research into personal development groups within counsellor training. Currently employed full-time as a counselling manager within a children’s hospice in the U.K, the author wished to re-ignite her passion for research by focusing upon counsellors’ experiences of assessing the needs of the client groups accessing a children’s hospice and the ways in which they deliver this support. Within her own practice, the author has faced and continues to face professional challenges that sit within the charity sector’s domain - of limited and finite resources, and of providing evidence of effectiveness and efficiency to service providers. Hence the impetus to explore and raise greater professional awareness of the emotional support that service users, their families and colleagues receive from children’s hospice counsellors, is a professionally-driven force that only knows how to propel its way forward, engaging in open dialogue with those who share the same commitment to improving upon practice through continued professional development.
Chapter One – Introduction

1.1 Statement of the Research Question

Picture if you will the headline – ‘Are We Getting It Right?’ - a phrase taken from the Children’s Hospices U.K. Quality Assurance Package (2008), a toolkit designed to enable hospices to examine the various aspects of their service, to help identify the strengths and to action the weaknesses of those aspects. In response to this headline I would ask of all children’s hospices the following question – what are we delivering, to know if it’s right and right for whom? Are children’s hospice counsellors able to deliver a support service that meets the needs of all its service users and their families and how do they determine who needs what help and when? Therein lies this research study’s focus – what is the current picture of pre and post bereavement counselling services within children’s hospices throughout the U.K.? What, if any, are the challenges in providing such a service and how do counsellors assess the needs of the various client groups e.g. children, adolescents, parents, grandparents? Before explaining the rationale for this particular research study I would first of all like to give a brief outline of the development and nature of children’s hospices throughout the U.K.

1.2 Children’s Hospices

The Association of Children’s Hospices (2003) states that the first children’s hospice, Helen House, opened in Oxford, England in 1982. Since then, the number of children’s hospices as charitable organisations has grown to 44, each providing specialist respite, emergency, palliative and end of life care for children and young people with life-limiting conditions. This support may extend over many years in the form of short respite visits to the hospice; nursing and psycho-social support within the home and in terminal/end of life care. Bereavement support is also offered to family members, often for as long as is needed and is deemed to be useful to and by the individual client. Regular reviews within the counselling sessions and annual evaluation of the counselling service are some of the indicators of the effective delivery of this support.
The services children’s hospices provide carry no financial charge for families, although on average, the annual running costs of a children’s hospice amounts to approximately £2,300,000. Historically, the source of funding to maintain such services came, and continues to emanate from the generosity and voluntary contributions of local communities and businesses. This has significantly allowed children’s hospices to operate more independently than adult hospices. Government funding (and their subsequent involvement in the hospices’ operational management) is greater in adult hospices compared to the current government contribution (under section 64 of the Health Service Act 1968) of 13% of a children’s hospice’s total running costs. The financial challenge that my own workplace faces today is to seek out more sources of funding from primary care trusts within the hospice’s catchment area, whilst still trying to maintain its right to function as independently as any charitable organisation operating within the health and social care sector can. These financial pressures to operationally maintain the hospice’s services unfortunately place a higher emphasis on the need to utilize resources efficiently and effectively. Therefore, the need to target resources to those most in need is not only an ethical issue but also an economical one for all managers who have the responsibility to implement their particular service within a children’s hospice.

1.3 Broad Rationale for the Research Question

Before I launch into the rationale for undertaking this particular research I would firstly like to present to you a potted history of my development as a counsellor/researcher.

I embarked upon my journey to become a counsellor in 1993 and my counsellor training was in the phenomenological, person-centred approach. I very quickly realised that the person-centred model was a very personally demanding approach, which challenged me to explore more fully the myriad of influences – social, cultural, political strands - which had shaped me into the person I had become. Never before had I put myself in such a position and felt the vulnerability that came with exposing my thoughts and feelings to others. However, in the process of revealing and understanding the assumptions I
thought of as ‘truths’ about who I was, I began to comprehend that my perceptions often reflected the convergence of past and present social, spiritual and cultural influences. The person-centred approach forced me to re-evaluate and discard some of those influences and I started, through reflection and self-analysis, to connect with what Rogers (1964) described as the ‘organismic valuing process.’ I became more appreciative of my own strengths and a little more forgiving of my weaknesses. I began to pursue academic goals, obtaining my Masters in Counselling degree in 2000 and embarking upon this Doctorate in 2006, enabling me to develop as a researcher and gratify my desire to learn and grow. This thirst for knowledge has been an innate drive, from primary school to the present day, and has always been in the quest of developing my cognitive functioning. I believe I can never know enough about a subject and what I do know has to be constantly updated. For both my professional and personal development there can be no ending, and as a counsellor I am highly committed to my profession and to the development of counselling especially within paediatric palliative care. My development has moved from an individual perspective to a more collective one. I am now more inquisitive about the counselling profession as a whole, its challenges, its progression and not just focused on my own individual advancement. Through research I believe I am able to explore more widely the issues and challenges the profession now faces and will face in the future.

Currently, I work as a full-time counselling manager within a children’s hospice. I counsel individuals and couples within their own homes and at the hospice. I facilitate therapeutic groups and workshops for adults and children. I also provide bereavement support to family members who experience the subsequent death of their child/sibling, accompanying parents to register the death, liaising with funeral directors and attending funerals. This support may be weekly, fortnightly or monthly and is reviewed regularly with the client to ensure its usefulness and efficacy. The person-centred model I believe, with its emphasis on the valuing and acceptance of the person (Rogers 1961; 1980), has enabled me to psychologically support families at the most traumatic and highly sensitive time of losing a child, a brother/sister, a grandchild. Entering my client’s frame of reference, understanding what can only be described as a
‘shattered world’ and being alongside them as they describe their pain and grief is emotionally, hugely demanding work. I would describe myself as a very resilient, compassionate, unpretentious and humorous person. Regular supervision and the support of my colleagues within the multi-disciplinary team have sustained me in my role, together with a firm belief in the quality and value of the therapeutic relationship with its three core conditions of empathy, congruence and unconditional positive regard. The regular evaluation of the support delivered continues to provide me, with the evidence and drive to promote the counselling service within my own hospice and promote its importance alongside the highly specialised medical care the hospice provides.

My professional practice of offering individual and group support pre and post bereavement has not been without its personal and professional challenges. Such challenges have raised questions for me which have spun around in my head for years but have remained unanswerable, since some of those questions needed to be placed within a wider arena. This research study has provided me as a practitioner-researcher, with that opportunity to present the following questions to a wider audience – fellow professionals working in children’s hospices throughout the U.K. These questions, which have stemmed from my position as a practitioner, will hopefully be answered through my role as researcher and are as follows.

From an individual service level, how do we, (and by ‘we’ I mean counsellors) while providing emotional support to those accessing a children’s hospice service, know if what we provide is the ‘right’ kind of support needed? Do we provide a service to all who ask for help, and if so, how is that achievable? How do we identify those most in need of our support? What do we mean by support and are there various levels or set criteria which distinguish each level? How do we go about matching the level of support required to what can realistically be provided? What formal or informal methods of assessment, if any, do we use in determining with our clients, the level and amount of support the person requires? Are there difficulties that arise in assessment or do counsellors not see a need for the use of any formal, structured assessment tool/framework within a children’s hospice? What, if that is the case, makes a children’s hospice not the place for formal assessment?
We could ask the much broader question of how service providers throughout the U.K. are evaluating existing hospice counselling services, as Walshe-Burke (2000:78) states, “to ensure more effective and efficient allocation of resources.” However, due to time and financial constraints, this study is limited to looking at how counselling services within children’s hospices are implemented and does not directly look at the issues of efficacy or efficiency per se. Rather, the study will highlight counsellors’ experiences of practice, and how they perceive and respond (individually and as part of the multi-disciplinary team) to the needs of service users and their families, with any challenges they face in the pre and post bereavement periods also being stated.

I am mindful that such a small study cannot generalise its findings about the processes within counselling support services in children’s hospices throughout the U.K. However, this study will present a unique and open account of the experiences of counsellors’ practice within children’s hospices which they have kindly allowed me to explore with them.

Counselling practice within a children’s hospice can be said to consist of pre and post bereavement support. Pre-bereavement support is offered from the time the child/young person and his/her family access the hospice and extends up to the death of that child/young person. Post bereavement support, for the purposes of this study, I define as the time period that starts at the death of the child/young person, although it should be recognised that Eiser (1996) commented that bereavement starts at the point of diagnosis of a life-limiting illness, since the family go through anticipatory grief for the loss of the ‘well child.’ Post bereavement support can extend, within my own place of work, for up to three years, and is considered by all members of our multi-disciplinary team to have continuity, being part of the holistic after-care the hospice offers. Therefore any enquiry into counselling practice within children’s hospices, I believe, has to include an exploration into both pre and post bereavement support if one is to gain an accurate insight into the work of a children’s hospice counsellor.

With reference to my particular ontological and epistemological stance, which I will enlarge upon within the methodology chapter, the stance reflects my
personal and professional beliefs about how we construct, through certain influences, our ‘realities’ and the phenomenological approach I have adopted within this study is consistent with those beliefs. Also within the methodology chapter, I will expand upon reflexivity within research. As a self-reflexive counsellor with self-analysis being a staple part of my daily diet, the continual process of being aware of my own assumptions and prejudices and suspending such preconceptions within the therapeutic encounter, has stood me in good stead in exploring what it means for me as a researcher to apply such reflexivity throughout the whole research process, from research design to final conclusions..

1.4 Aims of the Study

It has to be acknowledged that not everyone requires emotional support during a child/young person’s journey through the illness trajectory. In offering support to all who access a hospice, it could be argued that it is a waste of resources to those who do not need support (Payne, 2001). With this argument in mind, the principal research objective of this study is to discover how children’s hospice counsellors assess the needs and implement a support service to children, young people and their families during the pre and post bereavement periods. Within this objective, the following research questions will be posed:

- How do children’s hospice counsellors implement a support service during the pre and post bereavement period and what, if any, are the challenges?
- How is the assessment of needs being carried out within children’s hospices?
- How do counsellors feel about assessing needs during the pre and post bereavement periods?

Such questions are relevant to all hospices that provide emotional support and this study sets out to discover how counsellors assess and implement a service which not only has to provide support to a vastly diverse client group, but also provide support extending from the diagnosis of a life-limiting condition up to and beyond the death of the child/young person.
1.5 General Statement of Contribution

Field et al (2007), in their study of provision of adult bereavement support, argue that:

“…with the issuance of the National Institute for Clinical Excellence (NICE) guidelines on Supportive and Palliative Care for Adults with Cancer (2004), bereavement support services in England and Wales are likely to become similarly regulated.”

(Field, Payne, Relf & Reid 2007, p.428)

I believe that regulation results in the creation of guidelines for best practice which, for children’s hospices, have been produced by our regulatory body the Care Quality Commission. Regular inspections carried out by the Care Quality Commission means that children’s hospice counsellors must be able to fully account for the allocation of resources and service they provide. Therefore I believe this study, in looking at counsellors experiences of practice, is both timely and pertinent to those working within children’s hospices.

Also, with a focus on the potential future challenges children’s hospice counsellors may face, such as the need to provide evidence-based practice (Partridge 2005), the importance of conducting, or being aware of current research findings in one’s field of expertise, I believe, has become a necessary part of every professional counsellor’s practice. The counselling process and outcome research has, according to Sexton (1999) grown into an “undeniably reliable, valid and necessary source of clinical practice knowledge.” So what do we counsellors need to know about recent developments in areas that are applicable to the practice of delivering pre and post bereavement support within children’s hospices?

I believe one of those areas is bereavement needs assessment. There has been some relatively recent research that has been significant to children’s hospice services, namely childhood bereavement service provision (Rolls and Payne 2003); parents’ perceptions of hospice child bereavement support services (Wilkinson, Croy, King and Barnes 2007); children’s hospice provision (Children’s Hospices U.K. 2009, 2010); risk assessment and bereavement services (Relf, 2004); guidance on the assessment of bereavement needs in palliative care (Relf, Machin and Archer 2008, 2010); and bereavement
assessment practice in hospices (Agnew, Manktelow, Haynes and Jones 2010). Yet to date, there appears to be little research into the implementation of pre and post bereavement support within children’s hospices or the assessment of those needs within this environment. I therefore strongly believe my research focus will make a significant contribution to knowledge within this field.

This study locates itself within the current research of bereavement assessment frameworks; my aim being to identify existing frameworks and assessment tools applied within children’s hospices. This study will also aim to highlight any potential challenges to the delivery of a support service; the application or not of any assessment tools within this particular setting; and any other challenges identified by the research participants.

I hope this research will contribute to the recommendation of methods in which counsellors assess and implement a hospice counselling support service. This study’s results may also act as a springboard, opening up avenues for further research debate into assessment and the issues that may arise from the use of assessment tools in the counsellors’ particular working environments and within specific areas such as parental grief.

In a much wider context, the targeting of limited and expensive resources to those greatest in need, makes the role of assessment within counselling even more relevant in today’s climate. This study sets out to examine the use or absence of assessment processes which we, as children’s hospice counsellors, employ for those who are referred to the counselling service. In focusing upon the counsellors’ experiences of practice and in particular assessment, this study may well highlight and develop further argument on the issue of the training and competence of counsellors and other professionals to carry out assessments of pre and post bereavement support needs.

In conclusion, this study has a significant and important contribution to make to the wider debate on who receives support and who does not; on the training and skills required to carry out assessment and on the challenges of ‘proving’, often to service providers, the efficiency and effectiveness of counselling support. All of these challenges are contemporary issues involving and affecting all helping professionals who deliver a support service to people in
need of emotional support. Therefore the hope embedded in conducting this research is that this study will produce practical knowledge that will not only be of value to children's hospice counsellors but also to the wider audience of all practising counsellors employed within a variety of settings.

In many ways this research study may be likened to practitioner action research, in that I am a practitioner within the area I am researching and therefore am working with "knowledge-in-use rather than acquired knowledge" (Coghlan, 2004:6). I aim to achieve a dialogue with my research participants that will result in an outcome of knowledge that is of interest to both academics and practitioners alike.

1.6 Indication of Research Approach

This study will adopt a phenomenological approach focusing on the research participants’ experiences of practice within a children's hospice. What is most important in this study is how counsellors interpret and experience assessment and implementation of a support service, and what challenges, if any, they perceive in its delivery. As the researcher, I will focus upon assessment and implementation of that service, and through analysis of the data, what will rigorously be pursued will be the searching of a commonality amongst these experiences.

1.7 Overview of Research Thesis

The overall argument of this study is - how do children’s hospice counsellors’ assess needs and implement pre and post bereavement support within a children’s hospice? Moreover, what challenges, if any, do they face in providing such a service?

The chapters of the study include a literature review which will focus on the theoretical underpinnings of bereavement support including sections on parental grief, the attitudes to death of children in other cultures, and positive factors within bereavement. The definition of assessment within person-centred counselling will be included and assessment frameworks in bereavement support will be examined. The review will also highlight the current debate on the ethical and practical issues of assessment of bereavement needs,
particularly the issues surrounding intuition in the decision-making process of who receives support and who does not.

The methodology chapter will include the methods employed with regard to data collection and data analysis; ethical considerations in undertaking this research study; and a section on reflexivity throughout the research process. Chapter 4 will present the findings of the study followed by a discussion of those findings in chapter 5. Chapter 6 will draw together the main conclusions and state the implications from the findings of this study.
Chapter Two – Literature Review

The following chapter will take the reader through an overview of the theoretical underpinnings of bereavement, looking at parental grief and the risk and positive factors in bereavement that need to be taken into consideration when assessing the individual’s ability to manage their grieving process. It will also examine the bereavement frameworks which have been employed and developed within the knowledge and practice of supporting bereaved individuals. The chapter will then focus attention upon what children’s hospices offer in terms of pre and post bereavement support, the various defined levels of post bereavement support and the challenges that currently exist in the assessment of bereavement needs.

In order to carry out the literature review for this study, an electronic search of published literature was conducted using the databases PsychInfo; British Nursing Index; Science Direct; Scopus; ASSIA; Medline; Social Care Online and CINAHL. Key terms used were – palliative care; paediatric palliative care; hospice care; psychosocial support; bereavement support; bereavement outcome; models of grief; bereavement assessment; risk assessment and parental grief.

2.1 Theoretical Underpinnings of Bereavement

According to Currier (2001), a theoretical basis for bereavement care is essential to protect vulnerable clients from approaches based on hunches and to protect those who support bereaved individuals from over-involvement. Models of grief certainly provide practitioners with indicators as to how bereaved people may respond throughout the grieving process. Therefore we can to some extent, through knowledge of grief theory and process, roughly follow a person’s adjustment to loss and grief through the bereavement period. Having worked within a children’s hospice care setting for ten years, I can confidently say that working in a phenomenological way allows me to assist the bereaved individual to fully explore their feelings and thoughts in relation to their loss. A theoretical knowledge and understanding of the grieving process affords me some degree of assurance, a feeling of concreteness and a template
to refer to when a person experiences feelings of disorientation in the midst of overwhelming reactions to loss.

These reactions to loss are highly individualised and it has been my experience that even if a professional relationship has been well established during the pre-bereavement period, how a person responds at the moment of loss cannot be predicted. The emotional reactions to the death of a beloved son or daughter are indeed vast, intense and deeply moving to witness. A bereaved parent’s grief is, I have observed, quite particular in nature. I have yet to encounter a parent who has ‘recovered’ or ‘resolved’ their grieving. I learned early in my practice that the pain of losing a child never goes away. Rather, the bereaved parents that I have had the privilege of working with over the course of my professional career learn, over many years, to manage their grief and adapt to living without their child’s presence. As a parent myself, I have been both humbled and staggered by the sheer power and strength of human will-power to endure such an immensely traumatic loss.

At the beginning of my work within a children’s hospice in 2002, I initially struggled within my own clinical practice with my experience of witnessing how bereaved parents lived through their grief and how my theoretical knowledge of the various stage models of grief did not seem to rightly ‘fit’ with the bereaved parents’ processing of grief. How could this be? Although I did not want my clients to fit any prescribed model of grief, I could not detect any definable stages of grief, since my particular client group, i.e. bereaved parents, appeared to jump back and forth between intense feelings of grief and muddling on through their day to day tasks of living. I did not train as a bereavement counsellor and I wondered whether I was at a disadvantage somehow.

Towards the end of my general counsellor training in 1995, the renowned seminal work of Kubler-Ross (1969) on the five stages of grief was taught, which Rothaupt and Becker (2007:7) recently emphasised, developed from Kubler-Ross’s work with dying patients not mourners. My training also covered Worden’s (1991) four tasks of mourning. Such knowledge and learning was of a particular time indeed, according to Holland and Neimeyer (2010:104); stage theory as postulated by grief theorists such as Kübler-Ross, 1969; Bowlby, 1980; Parkes and Weiss 1983; has:
“...to a significant extent, become ingrained in our cultural beliefs about loss, and these models of grieving have been routinely taught as part of the curriculum in medical schools and nursing programs.”

(Downe-Wamboldt and Tamlyn, 1997)

This ingrained understanding of stage theory was highlighted recently when, giving a talk to a group of health professionals within a children’s hospital in the north-west of England, I asked what was their understanding of the grieving process. The response was some knowledge of the stages of grief – “from denial to acceptance.”

Yet in professional practice as a children’s hospice counsellor, the process of parental grief was telling me something quite different from the theory I held at that time - parents did not move sequentially through certain stages or tasks of mourning. So for a while, there was an unsettledness that sat between my experiencing of being alongside a bereaved parent in their grieving process and my limited theoretical knowledge. I felt I had no point of reference to refer to. I could only remain open to my clients’ experiencing and empathise with them, drawing upon other bereaved parents’ experiencing of grief to convey my understanding and when needed, to reassure. This struggle highlighted for me the inherent danger of trying to work with what are fundamentally hypothetical constructs, in actual practice and vice versa – trying to pin down experiences within a framework that does not seem to hold true for those experiences.

According to Machin (2009):

"Perceptions and understanding about life and death issues reflect the social climate in which they take place. Often the influence of contemporary psychological, social and ethical perspectives may be unconsciously or unreflectively absorbed into our thinking."

(Machin, 2009:3)

Consequently, without having a critical and reflective stance towards theoretical knowledge and its application within practice, I believe one can lose sight of the individualistic nature of experiencing grief and which is why working in a phenomenological way has always been vital to my own person-centred way of working. An article written by Kilcrease (2008) resonated within me, reminding me of the challenge of being aware of, but not enforcing theoretical concepts onto the experiences of individuals. Kilcrease (2008) wrote of the various
stages of grief as “artificial constructs” which the practitioner can unwittingly impose and the client accept:

“Stage models create expectations of what mourning is supposed to be like. A widely published list of stages sets people up to expect certain reactions after the death of a loved one. When those expectations don’t happen or don’t happen in the “correct” order, the bereaved individuals can think there is something wrong with them.”

(Kilcrease, 2008)

Within the bereavement literature, Holland and Neimeyer (2010:104) highlight that stage theory has had “few attempts made to empirically test (its) merits” and that those who work alongside bereaved individuals:

“…would do well to focus their assessments on how a client has come to understand or make sense of a loss, rather than trying to determine one’s stage of grieving.”

(Holland and Neimeyer, 2012:118)

Having stated the inherent danger of construing theories as ‘truths’ of people’s experiencing or as Machin (2009:5) comments, misapplying theory in practice, I would say that I prefer to have a theoretical map than no map at all, since it has been my experience that some bereaved people have required conceptual knowledge of the grieving process as we practitioners understand it, in order to make sense of their own experiencing. Also, theory, according to Machin (2009:4) defines “practice approaches for engagement with loss” and recognising and responding to the impact of loss upon the individual is fundamental to providing a counselling service within a children’s hospice. Rothaupt and Becker (2007:6) state that “bereavement research informs our clinical practice” and that theories of bereavement “continue to change and develop” as they should with the advancement of knowledge through valuable research activity.

Working with people specifically experiencing anticipatory and parental grief, the most useful conceptual ideas framed within two theoretical models of grief that have advanced my own theoretical understanding and which have appropriately encapsulated for bereaved parents their experiencing, has been Klass and Silverman’s (1996) Continuing Bonds Model. This model emphasises the negotiating and renegotiating of the meaning of the loss over
time and maintaining the presence of the deceased, in this case the child/young person, though establishing a continuing role for them within the family (Klass, Silverman and Nickman 1996), whichever way they choose to do that. The other applicable model I have found relevant to working with bereaved parents has been the Dual Process Model of Grief developed by Stroebe and Schut (1999). According to this model, Stroebe et al (2001) posit that loss-oriented coping is directly focused on the emotions attached to the deceased person whilst the restoration-orientation concentrates on stressors that result as a consequence of the death. Furthermore, Stroebe and Schut (1999; 2001) put forward the idea that the oscillation between the loss and restoration orientations, gives rise to the bereaved person confronting and avoiding these two types of stressors.

As stated earlier in this chapter, to further understand loss is to also appreciate the highly individualistic nature of mourning. Normal grief can encompass a vast array of emotional responses, so how does the practitioner distinguish ‘normal grief’ from ‘complicated’ or what is now termed ‘prolonged grief?’

Jackson (2012:4) has written of the “open conflict” within the mental health world which has erupted as a result of a draft version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) which critics say:

“…applies psychiatric diagnoses to an even greater number of what might be considered normal ranges of human emotions and behaviours.”

(Jackson, 2012:4)

With specific reference to grief, there also appears to be controversy around the pathologising of grief. According to Collier (2011:439), this new edition of the DSM-5 due to be published in 2013 by the American Psychiatric Association, is “likely to contain a new entry called bereavement-related disorder.” This diagnosis will, Collier (2011:439) continues, apply “to people whose lives are considerably impaired for longer-than-normal periods after the loss of a loved one.”

More recently, an article by Granek and O’Rourke (2012) highlighted the controversy which has erupted over this proposal to define and include complicated or prolonged grief as a disorder with:
“...fears that more people’s grief will be diagnosed as abnormal or extreme, in a culture that already leads mourners to feel they need to just “get over it” and “heal.””

(Granek and O'Rourke, 2012)

Machin (2009) makes the comment that grief theorists never intended to make grief “prescriptive” (Parkes, 2001), although Granek (2010:61) counters that Parkes provided a “rationale for the pathologisation of grief” and continues that it was Murray Parkes who claimed that grief was an illness, who justified the use of psychiatry to treat grief and who “focused heavily on the somatic aspects of grief.” Granek’s conclusion was that Parkes:

“...firmly established grief as a psychological kind within the discipline by offering both the “problem (pathological grief) and the “solution” (psychiatric intervention).”

(Granek, 2010:62).

Making the similar point Machin (2009) made about perceptions about life and death issues reflecting the social context in which they take place; Granek (2010) maintains that by:

“…tracing the historical biography of grief as a psychological kind, it becomes increasingly evident that grief, at least as a psychological object, is transient and its definition is contingent on the changing cultural, historical and social context.”

At this present time, although prolonged grief may be viewed as a pathological condition, Granek as cited in Collier (2011) suggests that:

“…Our culture needs to learn that grief is not always something people “get over.” A loss of a child, for instance, can be life-changing, creating a “new normal” for grieving parents.”

(Collier, 2011:440)

2.1.1 Role of children’s hospices and attitudes to deaths of children in other cultures

McNamara-Goodger & Feudtner (2012:3) reveal that in response to children falling ill and dying, children’s palliative and hospice care services in developed countries “have grown and developed substantially over the past three decades.” Furthermore, McNamara-Goodger & Feudtner (2012) remark that
this expansion of children’s palliative care services and children’s hospices since the 1970’s, resulted from:

“...paradigm-altering research on home care for the child with cancer...that challenged the notions that children who were dying from cancer were best cared for in hospitals.”

(McNamara-Goodger & Feudtner, 2012 p.3)

More specifically to the British Isles, Vickers & Chrastek (2012:391) remark that the UK children’s hospice movement began in the 1980’s, with their role being specifically to support families of children with “life-limiting and complex health needs.” This picture of expansion of children’s hospices reveals a provision of care for terminally ill children/young people across developed countries each with their own cultural beliefs which Brown & Dominica (2012:142) say, “profoundly affect the ways in which families experience death, dying and bereavement.”

Walter (2010:6) in his writing on grief and culture, cautions that whatever models and theories of grief bereavement practitioners are familiar with, most bereavement knowledge stems from a “western” culture. In order to understand the grieving process of bereaved people from other cultures, Walter (2010) postulates that we not only have to “free our minds of our own cultural assumptions”, but that we also have to observe and listen to the individual in order to learn about the client’s culture and how they individually experience grief. Knowledge of the cultural observations of a certain society alone does not necessarily, Walter (2010) observes, indicate the individual's needs. Valentine (2009:6) notes that traditionally, eastern cultures have tended to emphasise ritual and ceremony in creating a continuing bond with the dead whereas western societies are perceived as being more “materialist and individualistic.” Valentine (2009), in carrying out 25 interviews with bereaved individuals within the U.K. and 17 interviews with bereaved Japanese people, drew the conclusion that in both eastern and western cultures, there are “surprising similarities as well as differences” in grieving, which challenges the idea of a representative British or Japanese way of grieving. Valentine also notes that individuals:
“...do not blindly follow the dictates of culture, but rather adapt and revise these to reflect individual and personal circumstances, priorities and agendas.”

(Valentine, 2009:7)

Valentine’s (2009) cross-cultural study may reflect a picture of a growing freedom amongst people to choose what beliefs and cultural assumptions they wish to hold; and yet looking back in time, examples can be found of cultural traditions whereby the death of children and subsequent mourning was not acknowledged. For example, Goss and Klass (2005) cited in Walter (2010) describe how in China, in pre-communist times, the respect for ancestors meant that one could mourn the death of someone senior to the bereaved person but not younger, hence the mourning of children would not have been given any outward expression. With the Maoist regime suppressing the family ancestor cult, only the nation’s sacred dead were respected. However, within China now, the influence of the west, Walter (2010) concludes, has been such that families are now able to hold services for children who have died.

According to Brown & Dominica (2012 :143), in countries where infant mortality is still high, the death of a child may be considered “tragic but inevitable, with mourning lasting little longer than a few days.” In contrast to this, Brown & Dominica (2012) suggest that in societies where medical advancement has led to a decline in infant mortality, childhood death is “likely to be perceived as tragic and unfair.”

Eyetsemitan (2002) states that understanding the cultural interpretation of death in any society requires us to appreciate the religious and legal practices of that society. Eyetsemitan (2002:6) writes that Nigeria, for example, has three dominant belief systems – Christianity, Islam and the traditional African belief system known as “ancestor worship”, with some people observing more than one belief system. The principle underlying ancestor worship is the understanding that life is cyclical and not linear, with the dead “being alive in a different world and can reincarnate in new births.” The causes of death in ancestor worship may be the result of witchcraft, offending one’s ancestors or gods. The particular death of a child can, according to Eyetsemitan (2002:6), be explained within the context of Christianity as being one of reunion (parent and child will reunite in heaven); reverence (the child’s death serves as
inspiration for parents to do good works) or retribution (the child’s death is as a result of the parent’s sin). However, the death of a child believed to be caused by witchcraft practice, may bring about complicated grief reactions in those holding both ancestor worship and Christian beliefs (Eysetemitan, 2002).

Brown & Dominica (2012) state that:

*Each culture attributes unique significance to the death of a child. Individual cultures also hold a variety of beliefs about where children come from before they are born and where they go after they die. Furthermore, the age, gender, family position and cause of death may affect the meaning that is attributed to the death and determine the rites of passage for grieving behaviour within a given culture.*

(Brown & Dominica 2012, pg 143)

Walter (2010:6) highlights that few cultures are consistent and that even amongst the ethnic English in England, where this particular research study is located, there are “*class, regional, generational and gender variations in how funerals and grief should be handled.*” Therefore practitioners working with individuals who have lost a family member, be that a child or elderly relative, need to be sensitive to cultural bereavement traditions and assess the individual’s position within their own culture of origin practices. If, as Shapiro (1996) remarks, we:

“*…respect the family as the best authority on its own cultural self-assessment and coping, we are more likely to support a family’s best use of cultural resources as part of its grief experience.*”

(Shapiro, 1996:329)

**2.1.2 Individual grief reactions**

Kristjanson et al (2005) reinforce the fact that there is evidence to suggest that there is great variation in individual responses to bereavement. Research into these individual differences in grieving styles has produced further knowledge and understanding for practitioners working in the bereavement field (Martin and Doka, 2000; Nolen-Hoeksema and Larson, 1999). Martin and Doka’s (2000) research has highlighted the way “*intuitive*” and “*instrumental*” grievers experience grief and what particular therapeutic approach/strategies might be helpful to them. For instance, an instrumental griever, where thinking is predominant to feeling as an experience, may be helped by problem-solving
strategies, whereas strategies that facilitate the expression of feelings may be useful to the intuitive griever (Martin and Doka, 2000:2) Martin and Doka (2000) have also described “dissonant griever” as those who experience grief in one particular style but are prevented or “inhibited” from expressing their grief in the way they would perhaps more congruently grieve. Machin (2009:7) emphasises the fact that those who provide care to those who are grieving need to “address the way in which clients/patients are thinking about the losses.”

I believe that we capture how clients are thinking and feeling about their loss through empathic understanding. The assessment of the person’s coping with bereavement has essentially centred on risk factors that could lead to complicated grief with those individuals considered to be at high risk offered access to more “intensive support and access to bereavement counselling services” (Aranda and Milne 2000:6). Renzenbrink (2002) specified that:

“The development of bereavement risk assessment procedures and tools is now considered by many hospice and palliative care services to be standard practice which ensures that follow up is appropriate and that families who need help most will not be overlooked.”

(Renzenbrink, 2002:8)

Today, within the current literature, attention is now being drawn to how bereavement needs are being assessed and bereavement assessment practice is, according to Holland and Neimeyer (2010), moving towards mean-making perspectives and coping styles in bereavement (Machin, 2010). Prior to bereavement assessment being examined, I would like to draw attention to the levels of bereavement support that have been defined by the National Institute for Health & Clinical Excellence (2004).

2.2 Levels of Bereavement Support

The National Institute for Health & Clinical Excellence (NICE) is a health authority of the National Health Service in England and Wales that provides guidance on such issues as public health, clinical practice and clinical effectiveness. In 2004, NICE (2004:160) recommended a three-tiered system of bereavement support that any organisation providing such a service should offer. Level one recognises that not all bereaved people need support, other than perhaps information on the grieving process. Therefore level one covers
services’ provision and access to written information on the specific nature of bereavement. Level two suggests that some bereaved people may need assistance with their loss experience but may not necessarily require professional or specialist intervention, which should be available at the next level. Level three involves more in-depth psychological support and referral to counselling/general bereavement services including the “provision for meeting the specialist needs of bereaved children and young people” (NICE, 2004:161).

Incorporating all three levels of support within the delivery of a bereavement service, Agnew et al (2010 p. 3) commented that the NICE guidelines:

“...recommends that bereavement services should have robust assessment methods in place to identify those in need of services within component two and to have mechanisms in place to make onward referral to component three, where necessary.”

(Agnew et al 2010:3)

As outlined by Agnew et al (2010), other UK policy guidance and strategies exist which inform practice in standards of bereavement care such as the Department of Health’s (2005) “When a Patient Dies: Advice on Developing Bereavement Services; “The End of Life Care Strategy” (NHS 2008) and Living and Dying Well; A National Action Plan for Palliative and End of Life Care in Scotland (NHS 2008) and the Northern Ireland Health and Social Care Services Strategy for Bereavement Care (DHSSPS, 2009). However, Agnew et al (2010:3) state that these documents contain no approaches for carrying out bereavement risk assessments.

Informal methods of bereavement assessment have been challenged by Payne and Relf (1994) cited in Agnew et al (2010) suggesting that such methods may lead to “inconsistent practice and ad hoc support.” This challenge echoes Payne’s (2001) concerns about the efficacy of such services and the use of informal bereavement assessment methods may well reflect a situation where some services are perhaps failing bereaved people in their need of support at the appropriate level for them – not every grieving person requires the skills of a counsellor, and at times people want additional, professional support from outside their circle of family and friends. When this professional support is
sought, a structured procedure for identifying clients’ needs should be expected both from members of the public and the organising bodies of such services.

What is the current view of bereavement assessment within children’s hospices? How do children’s’ hospice counsellors view the current methods used, if any? Are there existing pre-bereavement assessment tools being used within hospice settings which show the potential for encountering possible future difficulties in bereavement (risk assessment) and which may help hospice counsellors identify those who might benefit from their professional input at an early stage of their bereavement? I enter my research study with a focus on discovering what is currently provided, what challenges there may be and what may improve the practice of implementing a pre and post bereavement counselling service within a children’s hospice.

Focusing upon bereavement assessment, Melliar-Smith (2002:281) suggested that risk factors or “key elements found to be associated with good or poor outcome” could be ascertained at the time of bereavement and therefore resources could be targeted to prevent complicated grief. A “risk factor” is a term Stroebe and Schut (2001 cited in Stroebe et al 2006) used:

“...to signify the identification of situational and personal characteristics likely to be associated with increased vulnerability across the spectrum of bereavement outcome variables”

(Stroebe, Folkman, Hansson and Schut, 2006:244)

These bereavement risk factors were identified by Twycross (1996), but Sanders (1993) refers to the earlier work of Parkes (1981) which led to the identification of a comprehensive list of risk factors amongst all types of bereavement. Falling under the category of situational characteristics, these known risk factors included the type of death, i.e. sudden, and characteristics of the relationship, i.e. relationship ‘dependent,’ child dying under 20, parent dying leaving children etc. Under the category of personal characteristics, the known risk factors include personality type such as “insecure,” “over-anxious”; and those with previous physical and mental illness. Parkes’ work led to the development of a Bereavement Risk Index (BRI), a check-list for risk factors to assess the probability of poor bereavement outcome (Parkes, 1981, 1993;
Parkes and Weiss, 1983). However, this formal bereavement risk assessment tool has been found to have limited reliability in predicting bereavement outcome (Relf, 2004).

A risk factor approach does not, Stroebe et al (2006:2441) assert, take into account the “processes that impede or facilitate adjustment” nor, they argue, has there been much:

“…focus placed on the relative weight of each (risk) factor or impact of interaction between factors on outcome.”

(Stroebe, Folkman, Hansson and Schut, 2006:2442)

Failure to recognise the interaction between factors or “coping variables”, they say, can lead to “faulty conclusions” (Wijngaards-de Meij et al 2005 cited in Stroebe et al 2006:2448). The National Institute for Health & Clinical Excellence guidelines (2004) suggest “risk assessment tools cannot be relied upon as a predictor of outcome” (p. 169). However, Stroebe et al (2006:2449) discuss the advantages and challenges of using an “integrative risk factor framework” that incorporates not only the intra and interpersonal factors in bereavement adjustment but also appraisal and the coping processes that contribute to bereavement outcome. The framework, the authors say, would be “difficult to test as a whole simply because it is so comprehensive.” However, what the integrative framework does provide researchers with, are questions to be explored around the interplay of factors and their impact on bereavement adjustment within adults, adolescents and children.

It is my opinion that any negative factors that may impinge upon the ability to cope with loss should not be precluded from but encompassed within the discussion and assessment of needs since they do reflect and acknowledge the impact of loss upon the individual. However, it is a more holistic and balanced assessment that takes into account not only vulnerability but also the individual’s resilience and ability to cope with the stress of losing their loved one.

Within my own counselling practice and as a person-centred counsellor, I have always adopted an encompassing approach to assessment and providing support, focusing upon the individual’s perception of their way of coping with
their feelings of loss as well as having the theoretical frameworks of grief, specifically a framework that relates to parental grief and attachment theory, to draw upon when deciding with the client, what their need of support is. In some referrals to the counselling service, it has been necessary only to provide information on the grieving process. Where people have feared being overwhelmed rather than been overwhelmed by their experiencing of such intense emotions, ‘normalising’ the process for the client using a model of grief to illustrate, has led to bereavement support rather than counselling being sufficient to meet the client’s needs. Indeed, Relf, Machin and Archer (2010) cite the findings of Schut and Stroebe (2005) that there is now:

“...general agreement that offering therapy to those who are resilient is not helpful and may be harmful”

(Relf, Machin and Archer, 2010:6)

2.3 Positive Factors in Bereavement

As previously mentioned, although much research has focused on vulnerability in bereavement, researchers have also described resilience amongst bereaved people who, over time, adjust to their loss (Stroebe, Schut and Stroebe 2007). Bereavement literature has, certainly within the last decade, expanded to include protective factors and processes that can aid adjustment to loss (Stroebe et al 2006). These protective factors include optimism (e.g. Nolen-Hoeksema, 1999, Moskowitz, Folkman and Acree 2003); perceived control over daily activities (Ong, Bergeman, Bisconti 2005); high self esteem (Haine, et al 2003; Ong, Bergeman and Bisconti 2005); and secure attachment style in relationships (Wijngaards-de Meij et al 2005 cited in Stroebe, Schut and Stroebe 2007). Religious beliefs were also found to help in some studies (e.g. Nolen-Hoeksema 1999; Benore and Park 2004; Stroebe 2004; Brown, Nesse and House 2004 cited in Stroebe, Schut and Stroebe 2007).

Further research into bereavement support was conducted by Diamond et al (2012) where helpful and unhelpful aspects of this support were considered from the perspectives of 24 bereaved adults and their volunteer bereavement support workers. Diamond et al (2012) report that the provision of hope and reassurance; continuity of support provided by the volunteers; provision of
information on grieving styles; and the quality of the relationship between client and volunteer were also perceived as beneficial.

### 2.4 Parental Bereavement

The findings of several research studies indicate that stress has been discovered to be higher in parents of disabled children than in parents of children without disabilities (Baker-Ericzen, Brookman-Frazee and Stahmner 2005; Tomanik, Harris, and Hawkins 2004). These studies found that two-thirds of mothers whose child had been diagnosed with autism experienced raised stress levels. If parents enter the grieving process at the time of the child’s diagnosis of a life-limiting condition (Eiser 1996), then looking at frameworks such as McCubbin and McCubbin’s (1989) Resiliency Model of Family Stress and Adjustment, as well as models of grief, may help children’s hospice counsellors working in the pre-bereavement period to examine how the experience of having a child with disabilities is perceived and what strategies are helpful in alleviating this stress. Such a model looks at stressors and the vulnerability created by such. It then proceeds to look at functioning patterns, appraisal of the stressor by the individual, resistance resources and problem-solving and coping strategies (Hall et al, 2012). It is evident that how the individual thinks about his/her situation is an indicator of how vulnerable or resilient they feel they are, therefore carrying out assessments would require skills in questioning and empathic understanding – skills which every counsellor needs in order to carry out his/her work.

Specifically looking at the death of the child/young person, the question could be posed – are bereaved parents more ‘vulnerable’ and at risk of poor bereavement outcome due to this particular type of loss? A recent review of the current literature on possible risk factors for bereaved parents carried out by Keesee, Currier and Neimeyer (2008:1146) indicated that mothers may have more difficulty than fathers in coping with the loss of their child (Rando, 1983; Scwab, 1996; Sidmore, 1999); other risk factors are parents whose only child dies (Dyregrov, Nordanger and Dyregrov, 2003); and the violent death of a child (Lehman et al, 1987; Murphy et al 1999; Murphy, Johnston, Chung and Beaton 2003). Other risk factors in poorer bereavement outcomes were
identified as being the the loss of an older child (Rubin 1991) and the experience of multiple losses (Neimeyer and Holland 2006).

Most research into parental bereavement, Keesee et al (2008:1146) conclude, has only centred on one or two risk factors at once, which they suggest may make it difficult to “...generate other explanations for the results.” More generally, Stroebe, Schut and Stroebe (2007) argue that:

“...Many potential risk factors have been under-researched... (and that)....the ways that risk factors relate precisely to the different outcomes also remain to be seen”

(Stroebe, Schut and Stroebe 2007:1968).

If the practitioner is to be the one to allocate resources and determine, along with the bereaved person, what level of support is needed, then the process of assessment becomes an important and integral part in the decision-making process as to what resources are offered and to whom. So how is assessment carried out?

2.5 Assessment Frameworks

According to Milner and O’Byrne (2004), the purpose of assessment in counselling is to provide both the counsellor and client with an opportunity to talk and decide what the client’s needs are and what can be offered by the counsellor before agreement on a particular course of action is reached. Tasker (2010) in the British Association for Counselling & Psychotherapy’s Information Sheet P13, emphasises that the counselling assessment procedure should:

“...ensure that the practitioner safeguards the client by adhering to BACP’s Ethical Framework for Good Practice in Counselling and Psychotherapy (2010) (the Ethical Framework). Referrers may not be sufficiently familiar with different modalities of therapy and assessment provides an opportunity to ensure that an appropriate referral has been made, matching client choice with practitioner and methods, and ensuring the right choice in the client’s best interests.

(Tasker 2010:2)

Assessment may include assessing “risk factors”, which may indicate a person’s vulnerability and the degree to which they have the internal and external resources to cope with their distress. Contracting with a client also
includes a contract of confidentiality which is limited by the risk of harm to self and others; and by stating such limits, counsellors take on a duty to assess and act upon the risk of harm clients may sometimes pose to themselves or others. Merry (2002 cited in Reeves et al, 2006) has argued that:

“...within the person-centred paradigm, assessment might be seen as contrary to the psychotherapeutic process as it hinders the sharing of power within the therapeutic relationship.”

(Reeves et al 2006:62)

Reeves & Seber (2004) have reasoned that assessment is a hindering factor of power within the therapeutic relationship and Worrall (1997:69) has commented that the activity of assessment within the person-centred approach is “philosophically untenable and not compatible with offering unconditional positive regard.” However Wosket (1999) has argued that the counsellor’s therapeutic use of self is a mitigating factor in the activity of assessing clients’ needs.

More explicitly within the realms of bereavement needs, the purpose of bereavement assessment is according to Relf, Machin and Archer (2008):

“...to inform decision-making so that we can make the best use of our bereavement services and offer the right help to the right people.”

(Relf, Machin and Archer, 2008:2)

When I started working at the hospice in 2002, my remit was, and still continues to be, to provide emotional support not only to the children and families attending the hospice in the pre-bereavement period but also to extend this support post-bereavement to any bereaved family member including extended family members. Clearly with such an extraordinary large remit, I needed to know the hospice’s expectations of the level of support one counsellor could provide, what levels of support were being required by service users and their families and who, amongst the multi-disciplinary team, were able to work alongside me in providing this support.

With over 160 families in 2012 now accessing the hospice service for respite and a growing proportion of bereaved families requesting continuing support from the hospice service, there is the professional challenge as a practitioner, to
manage such a workload by prioritising and identifying those who require the specific skills of a counsellor and those who can be best supported through bereavement by other members of the multi-disciplinary team. For those family members who are not experiencing any particular difficulties in managing their grieving but who wanted to share memories of their child, I refer to particular key nurses within the hospice who have previously known and supported the family – this support falls into the category of level two support as defined by the National Institute for Health & Clinical Excellence guidelines (2004). If a particular bereaved person lives at some considerable distance from the hospice, as we cover a wide geographical area, then a referral to the appropriate bereavement agencies within their local area is sometimes suggested. I undertake more in-depth work with those bereaved individuals who feel overwhelmed by their experience of loss, and for those experiencing deep distress that seems not to be lessening over time, after consultation with my supervisor and the client, a referral to their G.P or another appropriate agency may be made. Obviously, individual supervision adds an evaluative element to this work and plays a vital part in examining my own efficacy and competency in working with bereaved persons, but that initial process of assessing bereavement needs has become an important issue, since resources are finite and as Relf, Machin and Archer (2010) have commented, conclusions drawn from:

“...recent meta-analyses of the effectiveness of bereavement care\(^3,6,24,25\) that there is no evidence to support outreach support to all and that services only seem to benefit those who are “at risk” or struggling with their grief”

(Relf, Machin and Archer 2010: 6)

My own system of assessment has evolved over time. The question I asked myself when I started working at the hospice was – how is this person experiencing their grief and how can I help them through their process? It is still important for me to capture and relay my understanding of their experiencing but I do now see, in the light of the individual’s coping style, that the question I ask now is how can we as a team support you through the process?

The individual’s needs may be met by other members of the disciplinary team in terms of bereavement support, support from myself or referral to an outside
agency for further additional psychological support. In this way I believe bereaved individuals are being better served, whilst also recognising the fact that where resources are limited, no such statement of a service being available to all can be made. Parkes and Weiss (1983) commented that counselling can do “more harm than good… in stigmatising and undermining normal coping mechanisms.” Yet contrary to this statement, Larson and Hoyt’s (2007) cited in Agnew et al (2010:5) found no evidence “to support claims about treatment induced deterioration effects.” One could argue that counselling aims to bolster these coping mechanisms and whilst as a hospice service we aim to provide bereavement support and counselling to our families, the need for bereavement support or counselling, I believe, has to be clearly defined and assessed with the particular level of support matched to the needs. According to Raphael, Minkov and Dobson (2001):

“...there can be no justification for routine intervention for bereaved persons in terms of therapeutic modalities – either psychotherapeutic or pharmacological.”

(Raphael, Minkov and Dobson, 2001:587)

However, Walshe (1997) highlighted the importance of assessment through evidence which showed that support given appropriately and early on can lessen poor adjustment in bereavement (Raphael 1977; Parkes 1980; Scruby and Sloan 1989, Raphael et al 1993). This point, I believe, emphasises assessment as a significant tool within the pre-bereavement and initial bereavement stages, whereby those most in need of the right level of support can be identified.

One of the challenges of bereavement research, according to Safer, Bonanno and Field (2001) is that it is conducted after the death of a loved one and therefore the pre-loss functioning of the bereaved individual is difficult to determine. Much of my role within a children’s hospice involves working with family members, often years before the death of a child, and I therefore have some information and insight into that person’s way of thinking and coping with stressful times. This places me and other counsellors who work in paediatric palliative care settings, in a unique position of having some knowledge of the individual’s pre-loss functioning. Whilst no-one can predict the client’s response
to loss and future need of professional support, I believe a relationship with family members established prior to the death can assist in the development of coping strategies that increase resilience and which may impact upon post-bereavement functioning. In terms of bereavement research, children’s hospices do provide a potential rich source of data for longitudinal studies of the effects of bereavement on functioning.

As stated previously, an assessment of the client’s needs prior to commencement of any work takes place based upon my own and the client’s judgement of what support they need. What I do question myself on is whether the existing method of assessment is sufficient and comprehensive enough to identify all factors which may highlight the person’s resilience or the potential need for additional support.

Payne (2001) argues that there is no consensus about how:

“...judgements about potential need for support are made, many, it seems, are based on clinical opinions rather than predefined criteria.”

(Payne, 2001:108)

According to Kruglanski & Gigerenzer (2011), there are two types of judgements – those that seemingly appear out of thin air - “intuitive judgements” and those that have taken some lengthy process to arrive at “deliberate judgments.” Both types of judgements, Kruglanski & Gigerenzer (2011) comment, have:

“... been treated separately in the cognitive sciences, with analytic philosophy, economics and decision theory focused on deliberate, reflective decisions and psychoanalysis and social psychology dealing also with the intuitive, spontaneous behaviour.”

(Kruglanski and Gigerenzer, 2011 p.9)

With regard to issues surrounding intuition, Williams & Irving (1996:221) stated that within counselling, acting intuitively has been linked to what Rogers (1961) termed “gut feeling”, an organismic trusting that is both “selective and directional” (Thorne, 1990:207). Furthermore, Williams & Irving (1996) concluded that:
“...the belief that intuitive knowing is incapable of being verbally communicated is widespread in counselling. The development of intuition in counsellors is usually expressed in knowledge derived from experiential learning...and not amenable to systematic analysis. Such knowing is characterised as wisdom, the accepted product of experience and is contrasted with knowledge which results from logical (often characterised as empirical) analysis.”

(Williams & Irving 1996 p.222)

Williams & Irving (1996:222) have also argued that counsellors have owned both knowledge and wisdom as ways of understanding the world. Intuition from a phenomenological perspective, Williams & Irving (1996:228) conclude, does not “differ from any other way of making sense of the world”...and therefore reaching a decision based upon intuition can be consciously accessible and articulated.

What factors then, should I, as a children’s hospice counsellor, be taking into account when forming an opinion or judgement as to those, across all client groups, who may require bereavement counselling and for those whose needs could be met by the provision of bereavement support? Such decisions, I believe, should be made upon a thorough assessment of needs of the individual parent/sibling; and at this stage of my professional development, I find myself enquiring into others’ practice of assessment and asking what may or may not be needed within the particular setting of a children’s hospice, giving rise to my interest in researching this area.

Taking into account all the risk and protective factors in bereavement adjustment, also coping styles involved in bereavement outcome, combined with the necessity of directing resources to those most in need of support, I would suggest that it becomes apparent that good practice within children’s hospices should include some form of assessment tool that encompasses all of these aspects, and one that is flexible and adaptable to use with children/adolescents as well as adults. Melliar-Smith (2002) identified a need for families to have:

“...consistent, reliable and on-going support for carers and family members” (which she says), could only be achieved through a structured bereavement assessment programme.”

(Melliar-Smith 2002: 281)
Given that hospices have a multi-disciplinary team of professionals, the question might be asked - who is sufficiently trained to carry out the assessment of bereavement needs? If, as Wilson et al (2011) comment, the caring for dying persons and their families has been the “major responsibility of nurses” and as Relf, Machin and Archer (2010:8) point out, assessment of the need for “bereavement support in palliative care is widely undertaken by nurses”, then another question could be raised as to whether nurses’ understanding of current advancements in the theoretical knowledge of grieving is sufficient to decide the level of bereavement support required by a particular individual? Greenstreet (2004:590) states that nurses’ understanding of the principles of bereavement theory can help “promote confidence, thus enabling them to provide support.” However, if alongside providing support, they have the additional responsibility of deciding who receives support and who does not, then education and training in bereavement needs assessment becomes a more vital issue, as the emphasis is now being placed, as mentioned earlier, on the move away from the traditional focus on risk factors in bereavement to the spotlight being on the individual’s coping style (Machin 2010).

The question could also be postulated as to whether counsellors have an ethical duty of care to not only provide in-service training to other health professionals in communication/counselling skills within end-of-life and initial bereavement care, but also providing supervision to other health professionals delivering bereavement support within their caring roles? Recently, Relf et al (2008) exposed a problem with formal methods of assessment: nursing staff’s lack of time, skills and knowledge to carry out assessments, although Agnew et al (2010) suggest that:

“...formal written assessment continues to be widely promoted to ensure accurate collection of information, demonstrate decision-making, avoid subjectivity of clinical judgements and facilitate audits of practice.”

(Agnew et al 2010:5)

The assessment of needs that Melliar-Smith (2002) discusses - the gathering of basic information, would, I believe, only be adequate to assess bereavement needs at level two of the NICE (2004) guidelines. This basic assessment could be carried out by those who have a supportive element in their professional
role, such as nurses. However, given that this literature review has outlined the current knowledge on bereavement assessment, a more thorough assessment that focuses upon the person’s coping style and that captures the individual’s sensing of their grieving process, could be more appropriate for counsellors to work with, as well as perhaps being beneficial in itself to those under-going bereavement assessment.

If, as NICE (2004) state, “individual clinical judgement is currently the most effective way of identifying those at risk” (p.169), then, I believe, a framework born out of the clinical practice of working with bereaved individuals can better inform practitioners as we make those professional judgements.

A theoretical framework known as the Range of Response to Loss (RRL) Model was proposed by Machin (2001), which aims to help practitioners understand and interpret the diversity of reactions to loss and to “map” individual grief in practice. The RRL framework identified three chief reactions to loss: “overwhelmed”, a state of heightened distress by loss; “balanced/resilient”, being able to face grief with a degree of steadfastness; and “controlled”, where there is a principal need to manage emotions and stay focused upon life’s demands. The RRL framework was examined in a study of 94 people seeking counselling help from a North Staffordshire Bereavement Service. In a 12 month period, all new adult clients were invited to participate in this study and questionnaires were completed in interviews which took place after the first counselling session and six months later. Another measure, the Adult Attitude to Grief Scale (AAG) was also developed in order to place participants within the RRL framework. Six case studies were formed to examine differences in response to loss, using both quantitative data and qualitative comments. The findings of the study Machin (2001) revealed were that the AAG Scale was able to provide a good measure of the three categories of responses proposed in the RRL framework (overwhelmed, balanced and controlled). The AAG Scale was also able to provide an understanding of the combination of overwhelmed, resilient and controlled reactions occurring within individuals. The RRL matrix has since been piloted in a number of adult hospices throughout the UK (Agnew et al 2010:17) although it has not to date, or to my current knowledge, been piloted within children’s hospices.
Machin (2009:73) points out that in developing the Range of Response to Loss Model, it was important to search for “... factors which might predispose to the dominance of one grief action rather than another” and how theories such as Bowlby’s attachment theory and:

“...the wider cultural context also provides perspectives, which influence beliefs and behaviours in response to life events such as loss and bereavement.”

(Machin, 2009:73)

Within my own practice, during the very early years, I became increasingly aware that the theories of grief that I knew of did not fit with my experiences of working alongside bereaved parents, and it was only when I applied the Dual Process Model of Grief, developed by Stroebe and Schut (2001), that I felt this theory reflected a more consistent picture of the grief experience for parental bereavement. Machin (2009:76) describes “the theoretical fit between the RRL framework and the Dual Process Model of Grief as striking.” This would suggest that the RRL framework would be applicable within the children’s hospice counsellor’s practice as an assessment guide and tool when working with bereaved parents.

The Adult Attitude to Grief Scale (AAG), a self-report attitudinal scale also devised from Machin’s study (2001) to capture the various individual grief reactions, enables both practitioners and clients to track a person’s progress through their grief experience. Two research studies carried out by Machin and Spall (2004) and Machin (2007) examined the AAG scale, the first study being conducted to further understanding of

“...how far the responses to the nine items on the AAG scale would provide pertinent information about clients’ grief, facilitate the telling of the individual story of loss and provide the clinician with useful indicators to guide the therapeutic process.

(Machin, 2009 p.84)

The second study, Machin (2009:84) states, was carried out in order to explore “counsellors’ experience of using the scale... through a questionnaire.” The findings of these studies resulted in a revision of the AAG scale and guidelines were produced for practitioners making use of the scale in practice.
Machin (2009) also comments on the:

“...possibility of using the AAG scale as an outcome measure.... and that a revised version of the scale for use with young people was employed to assess the efficacy of an intervention in a Child Bereavement Service.”

(Machin, 2009:90)

Such versatility would suggest that such a tool would be highly appropriate in a children's hospice environment where there are client groups of children, young people as well as adults. It would allow assessment of pre and post bereavement needs to be naturally integrated into the therapeutic process, aiding counsellors' decision-making in providing bereavement support and/or counselling.

However, it has to be acknowledged that within a children’s hospice, there are many children/young people with communication difficulties and cognitive impairments/learning disabilities. How to assess and address their emotional needs during the pre-bereavement period is, I believe, a much under-researched and neglected area. A research report published in 2005 “Making Us Count” by The Foundation for People with Learning Disabilities highlighted the mental health needs of young people with learning disabilities. The findings were that the young people needed mutual peer support; family support; someone to talk to; and a single point of contact to which they can be referred for other sources of support. The report also highlighted how those person-centred approaches:

“...that incorporate attention to health can identify and address some of the causes of mental health problems, including isolation, boredom and physical health problems.

(The Foundation for People with Learning Disabilities 2005, p.3)

Given that these young people have the diagnosis of a life-limiting condition, I believe I have a duty to focus on addressing and delivering emotional support to those who may need to communicate their feelings about death and dying. Although often working alongside parents in order to understand the child/young person's communication, I believe it is also my responsibility to be able to convey my understanding of their perceptions, thoughts and feelings through the use of aids such as communication boards and Makaton sign language.
Returning to Machin’s adapted Range of Response to Loss Model, Relf, Machin and Archer (2010:2) point out that this model has been developed “for use in settings where a bereavement service is an integral part of the organisation” I would now like to emphasise the specific provision of services within a children’s hospice that has psycho-social support as an integral part of the care provision.

2.6 Children’s Hospice Provision of Support

A report, carried out in 2010 by the Children’s Services Mapping Team on behalf of and with Children’s Hospices UK, collected data from 41 out of 44 children’s hospices in the UK. Their findings identified and measured the type of service provided to children/young people with life-limited/life-threatening conditions and their families. Since this research study is focused upon the practice of counselling within children’s hospices, the particular aspects of the report significant to this study were the report’s key findings in relation to bereavement support and assessment, which will be specifically referred to at various points throughout this chapter.

The percentage of services offering the various types of psycho-social support to three client groups of parents, siblings and extended family members, were summarised in the above report, with 36 of the 41 children’s hospices providing 100% pre and post bereavement support to parents and siblings alongside 80% of pre-bereavement support and 94% post- bereavement support being delivered to extended family members.

So what exactly constitutes pre and post-bereavement support within a children’s hospice and more precisely, what role do counsellors have in assessing needs and implementing this support?

2.6.1 Pre-Bereavement Support

Pre-bereavement support is the assistance that is offered from the time when a child and his/her family access the services of the hospice. From the time of diagnosis of a life-limiting/life threatening illness and at any point along the course of the child’s illness trajectory, practical, financial, social and emotional issues may arise which can impact negatively upon individual and family
functioning. Parkes (1990 cited in Payne & Relf, 1994) has argued that palliative care is:

“...in a unique position to offer preventative support, that assessment of need should be routine and that it promotes the efficient utilization of resources.”

(Payne and Relf, 1994 p.292)

However, Randall and Downie, (1999; 2006 cited in Agnew et al, 2010), have questioned the need for psychological and social interventions as part of specialist palliative and end of life care, although Reith and Payne (2009 also cited in Agnew et al, 2010) have argued that family life is often “chaotic due to impending or actual bereavement”. Amidst such chaos, the child/young person and family members may require a level of support that is tailored to meet their specific needs at any particular time. Consequently, the delivery of pre-bereavement support within children’s hospices has to be flexible and responsive in terms of matching the support at the appropriate level with the most relevant professional within the hospice’s multi-disciplinary team who can provide specific help in the particular area of difficulty being experienced.

The term psychosocial support is also often used within hospices to describe the provision of holistic care undertaken by hospice staff, which aims to focus on the quality of life thereby promoting the child’s/young person’s personal/social well-being as well as family functioning. This pre-bereavement/psychosocial support, the collaborative report by the Children’s Mapping Team and Children’s Hospices UK (2010:9) identified as comprising: end of life care; symptom management; telephone advice; emergency care; residential short breaks; family support; sibling support; practical support; psychological therapies; community nursing/care at home; and complimentary therapies.

In providing this variety of care and support to families, hospices view this provision as addressing the holistic needs of the child/young person and their family. Yet Payne (2001) focuses on only one particular aspect of pre-bereavement support (that of preparing people for their relative’s death) when calling into question the issue of efficacy of pre-bereavement support, making the comment that there is minimal evidence to support the assumption that:
“...the holistic and person-centred care delivered by hospices and specialist palliative care services helps to prepare people for the grief and loss of bereavement and produce a better outcome in terms of subsequent adjustment, than conventional care.”

(Payne, 2001:108)

Payne (2001), I believe, in raising doubt over the efficacy of pre-bereavement support based upon preparing people for grief, has not taken into account the rationale for providing such support within paediatric palliative care services, and does not seem acquainted with the uniqueness of children’s hospices’ provision of such support to families prior to bereavement. Pre-bereavement support within the setting of a children’s hospice is not considered solely a time for helping people and their families prepare for grief and loss as Payne (2001) comments, although such support during end of life care when it arrives for the child/young person, is a very important aspect of hospice care. So what makes pre-bereavement support within a children’s hospice different to that within an adult hospice?

The admission criteria for a children’s hospice covers four categories of life-limiting/life threatening illnesses, some of which may have been diagnosed pre-natally or at birth. Also, with the advancement of medical interventions, children/young people with some life-limiting conditions are able to live longer lives, hence for some families, the pre-bereavement period may extend over many years, unlike adult hospices where the point of admission and subsequent death is usually only a matter of weeks or months. This period within children’s hospices, is centred upon helping the family adapt to living with disability; providing opportunities to enhance the quality of life that remains for the child/young person, and helping families to create happy moments and special memories of time spent together. It is also, from a psychological perspective, about recognising that at times during this period, crises will occur as the child/young person’s condition deteriorates, and this may cause a relative to become very distressed. Responding to individual family members as and when they require emotional support is the remit of hospice counsellors. During the terminal/end of life stage, nursing staff are on hand to provide medical care for the child/young person and to assist the family in preparing for the death to the extent of answering their questions and giving comfort, which I think is very
different to the task of preparing them for their grief that Payne (2001 p.108) refers to. I have had my hand gripped as a mother watched her son pass away; and I have held another mother’s body as it shook forcibly under the intense pain of raw grief. Yet I do not profess to know how I could prepare anyone for their individual grief reaction, since that would imply I would know what their reaction would be when the death of their loved one occurred, and that would be very presumptuous of me to claim.

Studies that have been carried out on the phenomena of anticipatory grief (Billings and Kolton, 1999; Costello, 1999), Main (2002:795) concludes, have suggested that providing emotional support during end of life care is a “key component in the period of mourning”; and yet Costello (1999 cited in Main, 2002) found that nurses received little training in bereavement skills. For Main (2002:785), this lack of education and skills training “could be argued to apply to the pre-bereavement period.” With regard to nurses providing support, one of the findings of Main’s (2002) study was that these professionals:

“…often felt ill-equipped to deal with issues around death and dying. Both qualified and unqualified staff thought that training in this area was not generally available for them, although most acknowledged the need for it.”

(Main, 2002:799)

This further supports the argument that hospice counsellors are in a position to be able to provide training and supervisory support to other hospice staff, as they too have the task of managing a time that is both traumatic and emotional for people suffering the devastating loss of their child.

2.6.2 Assessment in Pre-Bereavement Support

Initial assessment of the child/young person’s needs within a children’s hospice is carried out by members of the nursing team and documented within a care plan that seeks information on all of the physical, psychological, social and spiritual needs of that individual. Care plans are carried out in conjunction with the main carer/parent with young people over 18 and with mental capacity, having the option to complete the care plan with or without the parents’ being present. If this assessment indicates a need for social, psychological/emotional, or spiritual support, then the staff member would make a referral to the
appropriate professional within the team, such as the social worker, counsellor or minister who share skills in providing psychosocial care.

Within the Children’s Hospice Provision Survey (2010:13) it was noted that assessments of needs were being carried out jointly with other agencies in 20 of the 39 hospices reporting their practice in this area. Their findings were that 51% carried out co-ordinated assessments with other professionals, but 31% did not and 18% did not complete joint assessments. Moreover, it was discovered that the process of assessment covered particular areas of need which were defined as nutrition; emotional well-being; communication; siblings: respiration; mobility; continence; seating; housing, equipment; education; carers assessment; access to leisure and recreation and self-assessment. The report did not specify which professional/s within the multi-disciplinary team carried out these assessments; therefore, whilst a significant number of hospices reported carrying out assessment of needs including emotional well-being, no specific assessment tool to determine or highlight emotional distress was revealed.

Within my own counselling practice, no formal pre-bereavement assessment tool is employed, although information gathered through the use of such psychosocial tools as genograms, which assist in forming a picture of family functioning; family roles and current conflicts, may be included within any counselling notes that the client is made aware of. Also, where parents are seeking support for a child, a joint detailed assessment of the parents’ perspective of the child’s issues, together with the child’s understanding, is obtained. The use of genograms, Richards et al (1993) state, can extend to include information on the client’s supportive networks within his/her community and from such information, an assessment of family needs and possible intervention prior to and during bereavement can be made.

Carrying out assessments in practice raises the matter of informed consent. Informed consent should always be obtained prior to conducting any assessment, pre or post-bereavement, in order that the person is fully aware that their needs and level of support required are being assessed. Agnew et al (2010) cite Relf and Payne’s (2009:6) findings that hospice staff’s observations of relatives’ distress at the time of death may not be reliable; that relatives may
not even be aware that they are being assessed; and that staff may be hesitant in asking what may be perceived as “intrusive” questions. In order to address these concerns, Agnew et al (2010:6) cited Relf et al’s (2008) proposal of using a particular framework, Machin’s (2009) Range of Response to Loss (RRL) matrix, which has been designed, according to Agnew et al (2010):

“...to inform the development of documentation for continuous assessment from the point of admission into early bereavement. Information may be gathered through observation and discussion with the family, both pre and post bereavement, and through discussion with the multi-disciplinary team.”

(Agnew et al 2010:6)

For me as a practitioner, the assessment of needs should cover not only the child/young person’s needs but also that of his/her family, since The Association for Children’s Palliative Care (2003) established that children’s needs were interdependent with their family’s needs. Assessment should therefore be a multi-disciplinary matter throughout an illness trajectory, thereby enabling a service to be more responsive in identifying the level of need and level of support required. Whilst evaluation by those who have received the support provides an indicator of a service’s efficacy after delivery, the earlier stage of adequate assessment of what Jeffrey (2003:2) describes as “the domains of physical, psychological, social and spiritual need” of the child/young person and their family and “meeting those needs within the limits” of the multi-disciplinary team’s areas of professional competence is a significantly important practice issue when looking at the delivery of a service, targeting resources and actually providing the support to those most in need of it.

2.6.3 Post-Bereavement Support

Put at its simplest, bereavement support is the “understanding and recognition of a person’s grief and need for psychological support” (Melliar-Smith, 2002:281). The types of bereavement support ascertained within the children’s hospices provision report (2010:10) were: individual one to one bereavement work; hospice support post-death; support and information re post mortem and funeral planning; memorial days; bereavement support groups; counselling: drop-in sessions; befriending; bereavement weekends; play therapy and e-listening. All such interventions allow the bereaved person to express their grief
with someone who has some degree of proficiency in listening and attending skills, has experience of the helping relationship, and holds knowledge of the boundaries that exist within that relationship. Within my own counselling role, individual and group-work with bereaved children/parents is offered; and I would say that this role very much concentrates on providing the in-depth psychological support defined as level three of the NICE guidelines (2004).

The provision of such support within hospices is an established aspect of care with nurses and other members of the multi-disciplinary team all providing a certain level of support. Although my place of work is currently looking into the use of trained volunteers in the delivery of bereavement support, we do not, at this time, have the resources to utilize them in this way. Other children’s hospices throughout the U.K and bereavement organisations such as CRUSE do provide trained volunteers in a supportive capacity within bereavement services. Payne (2001:108) highlighted this “diversity” of provision and reported there has been little research into “...the right mix of professionals and volunteers to provide a high quality and effective bereavement service.” Nor, Payne (2001:108) continues, do we know whether this diversity means “there is something for everyone or whether there is unmet need, or even wasteful provision.

When it comes to the provision of support within hospice care, Payne (2001) cites a study by Ragow-O’Brien et al (2000) carried out in the USA, which compared the bereavement outcome for families cared for in hospices and those cared for in hospitals, with those provided for in hospices faring better. In addition, a more positive result of providing bereavement support was highlighted in a study by Wilkinson, Croy and Barnes (2007) looking at parents’ experiences and perceptions of a support service for families with bereaved children. The parents commented that they did find the service useful in:

“…providing advice and reassurance; support for their children while they grieved; advice on ameliorating behavioural difficulties at home and school...(and) benefited from talking to a non-family member and being involved in social events that reduced feelings of isolation.”

(Wilkinson, Croy and King, 2007: 401)
Working in this field, I would say that bereavement support services are now firmly established within palliative care settings, although Relf (2000 cited by Roberts and McGilloway, 2008) observed that there was no general accord on the nature or delivery of these services. Does this still hold true in 2011? More recently, Agnew et al (2010:1), in their study of bereavement assessment practice in hospice settings, cited a national survey carried out in 2007, which focused on ten Marie Curie Hospices within the UK providing hospice care for adults and supporting families. The survey found that “there was no standardisation of service across sites.” The findings of this study, Agnew et al (2010:2) point out, led to the “development of a post-bereavement service model implemented across Marie Curie Cancer Care.”

It must be said that each children’s hospice service is unique, in the sense of delivering a provision of support which specifically caters for children/young people and their families, and therefore cannot be fully compared to adult palliative services. A children’s hospice is not a statutory service but provides, in addition to what statutory services offer, medical and psychosocial support to children with life-threatening illnesses and their families. With very limited government funding, and relying heavily on the charitable donations from their local communities in order to maintain their operational costs (80% of which are staff salaries), children’s hospices, whilst being relatively free to decide what support they can offer, constantly face the challenge of keeping their hospice fully functioning and need to be prudent in their budgeting. Therefore cost efficiency is positioned highly on a children’s hospice’s agenda, and demonstrating the impact of provision of counselling support is certainly a professional challenge within my own practice.

The uniqueness of a children’s hospice environment shapes its practice, and therefore other hospice counsellor practices will, to some extent, share a commonality with my own, given our similar working environments. We may all share the same challenges of evaluating and measuring the impact of our services upon those who access it. However, the delivery of that service and what they choose to prioritise will be very individual to that hospice, and based upon organisational decisions that are not necessarily shared with other hospices. Therefore how practitioners assess needs and target resources may
not be such an issue as it is for others, and therefore no standardisation of service across sites, or development of a pre or post bereavement service model as has been developed with the Marie Curie Cancer Centres, currently exists for children hospices.

Simply providing a counselling service, whether in palliative care or elsewhere, does not indicate its efficacy. It cannot be left to chance that the service offered is less than effectual and helpful to those who access it. However, as previously stated in the discussion of pre-bereavement support, I feel that a dynamic system of assessment of bereavement needs and allocation of the appropriate level of post-bereavement support is warranted, to ensure that the right level of support to cater for the specific needs of all client groups that access a hospice service are met. If a service claims to be available to all families pre and post bereavement, then it is incumbent upon the service to have a process in place that unites the differing needs with the various levels of support. So what are these levels of support?

2.7 Conclusion of Literature Review

In summary, this literature review has given a brief outline of bereavement theory and bereavement assessment methods, and provided a description of pre and post bereavement support within children’s hospices, highlighting the levels of support that should, according to NICE (2004), be offered – from providing a sympathetic, listening ear to in-depth psychological support. As to who delivers this support, it was noted that within palliative care, nurses also provide bereavement support. It was suggested that such provision does not indicate the efficacy or efficiency of such a service. Payne (2001) drew attention to the diversity of bereavement support provision and argued that there was no agreement amongst services as to how decisions about potential need for support were made.

Some of the questions that arose from examining the literature on bereavement assessment and which led onto the development of this research study’s focus of enquiry were as follows:
• What current assessment methods are being used in determining the level of emotional support needed by those who access a children’s hospice support service pre and post bereavement?

• Who carries out such assessments and what is the difference between “formal” and “informal” assessment?

• Are the current assessment tools sufficient and comprehensive enough to identify all known factors which may not only highlight a person’s vulnerability but also their resilience and ability to cope with their grief?

Theoretical frameworks were examined in this literature, including the integrative framework as outlined by Stroebe et al 2006, which not only encompasses intra and interpersonal factors but also includes the appraisal process and coping mechanisms of bereaved individuals. Machin’s (2009) Range of Response to Loss Model and Adult Attitude to Grief Scale were also examined as a new and innovative model and tool for extending practitioners’ understanding of people’s responses to grief. In addition, it has been suggested that this tool may act as a guide in informing practitioners’ decisions in offering the appropriate level of support, thus enabling the matching of level of need to those who most require psychological support.

This research study sets out to address some of the questions raised during the literature search on how pre and post bereavement support and the assessment of bereavement needs is carried out within children’s hospices. The methodology chapter will delineate the methods used to carry out this investigation.
Chapter Three: Methodology

The following chapter presents the methodological considerations, methods employed to gather and analyse the data, trustworthiness and the ethical issues that were considered within this research study.

All research, whether quantitative or qualitative in nature, starts with an attempt to explore a particular phenomenon and carries the hope of creating new or further knowledge. Parahoo (2006) states that:

“...the nature of science and knowledge is such that no one school of thought can have a monopoly on the definition and the production of knowledge, although the dominant or favoured paradigm tends to influence what is researched and how.”

(Parahoo, 2006:45)

However, Holden and Lynch (2004:397) go further and contend that rather than research being “methodologically led,” methodological choice should arise from the researcher’s own “philosophical stance and the social science phenomenon to be investigated.” Therefore, an examination of the researcher’s own beliefs about the nature of reality and the study of knowledge – their ontological and epistemological stance, needs to be integrated within any research study. These beliefs must be made explicit and must also be congruent and consistent with the research question and the research methods employed. Such clarity, Bradbury-Jones (2007) argues, is necessary in displaying rigour throughout the research process. This chapter begins with these methodological considerations and subsequent chosen research methodology.

Of significance to this specific qualitative study is the gaining of knowledge to develop and enhance counsellors’ professional practice. I have chosen to embark upon research in the field that I professionally practice in – the assessment and implementation of a pre and post bereavement support service to children and their families accessing a children’s hospice. Although I did not invite work colleagues within my own setting to participate in this study, the research participants were all employed in the same counselling role as myself within a children’s hospice working environment. Therefore I deem it appropriate to discuss within this chapter, the term “insider researcher,” its benefits and disadvantages and its potential impact upon the research process.
The aim of this chapter is also to include researcher subjectivity, along with my understanding of reflexivity and its place throughout the research process. I will describe the data collection methods used and how the data was analysed. Ethical considerations will be discussed, and although appearing at the end of my methodological chapter, these considerations were part of my initial deliberations when deciding to carry out this research enquiry.

3.1 Epistemological Stance

Patton (2002:66) in his depiction of reflexive triangulation, poses the question to the researcher - “How do we know what we know?” This not only invites us personally to explore our ontological and epistemological position, but also draws our attention to the distinctions between the quantitative and qualitative research paradigms that have been previously been made and argued. Clark (1998:1243) contends that:

“Philosophically, the qualitative and quantitative paradigms are not as diverse or mutually incompatible as is often conveyed... (and that)…staunch identification of methods with particular paradigms may not be as accurate or even useful an endeavour as past trends would indicate.”

(Clark, 1998:1243).

However, an exploration of the various philosophical assumptions is useful in order to position the researcher and this study within the existing theoretical frameworks.

Amongst those who carry out research, there are individuals who embrace an objectivist/positivist philosophy, essentially quantitative researchers, who hold assumptions of an objective reality existing which operates outside of human experience. Scientific truths and laws are said to be present that relate to given facts about this external reality (Clark 1998; Crossan, 2003; Topping, 2006). The goals of quantitative research, according to Genevro et al (2003:18) are said to be the need to identify and establish “causal factors” relating to the phenomenon being studied; hypothesize outcomes and produce findings which can be generalized beyond the particular research study. Positivist approaches assume researchers can remain detached and separate from the focus of the inquiry and can remove their preconceptions whilst testing their hypotheses with
such objectivity deemed to be the ensuring of validity of results (Johnson and Onwuegbuzie 2004).

A constructivist/interpretive philosophy on the other hand, holds assumptions of human reality being rather more complex. The qualitative researcher recognizes that:

“...the world of human perception is not real in an absolute sense, but is “made up” and shaped by cultural and linguistic constructs.” (Patton, 2002:96).

Therefore, the assumption that there are numerous realities and our understanding of the world being “…contextually embedded, interpersonally forged and necessarily limited” (Neimeyer 1993:1) leads the goals of qualitative research not to hypothesize about the outcomes of the research, but to focus upon and capture the individual’s unique worldview and experience of the research phenomenon. This allows findings to be presented not as “scientific truths” as in the positivist sense, but as a representation of the “truths” of the researched. The qualitative researcher also acknowledges the complexity of the interaction between the researcher and the researched (Bradbury-Jones 2007). Therefore the researcher has the challenge throughout the course of the study, of identifying his/her subjective voice through the process of reflexivity – a process which will be more fully described later on in the chapter.

Positivism has, according to Clark (1998:1242), been presented as an “outmoded and rejected philosophy which should cease to significantly shape inquiry.” Clark (1998:245) also argues that post-positive thinking has moved away from the dichotomy between quantitative and qualitative methodologies to a more gradual acceptance that whilst the two paradigms have their own particular and distinctive assumptions, that these “truths inherent within each….are valid.”

Whatever path one chooses, do we not all start with the same challenge – to create or advance knowledge for the benefit of ourselves and others? I think it important to note that in positioning oneself, taking a particular stance is not to dismiss the other philosophical viewpoints, and concur with Johnson and Onwuegbuzie (2004) in that both quantitative and qualitative research, with their
various philosophical underpinnings, have their rightful, equal and valuable
place in expanding our understanding of the world in which we live and work.

In examining the range of philosophical and theoretical perspectives within the
qualitative tradition, there now seems a mind-boggling array, or perhaps
phrased more correctly, a plethora of methodologies. According to Patton
(2002:79):

“There is no definitive way to categorize the various philosophical and
theoretical perspectives that have influenced and that distinguish types of
qualitative inquiry”

(Patton, 2002:79)

However, given the broad outlines of the philosophical viewpoints and thinking
of where I position myself epistemologically, I align myself between the
constructivist/constructionist viewpoints. I do not see constructionism and
constructivism as contradictory but a matter of emphasis. Constructivism as
defined by Crotty (1998:58) takes into account the many diverse perspectives
and focuses upon “the mean-making of the individual mind” which, as a
phenomenological trained counsellor, I attach much significance to recognising
and appreciating. The social constructionist viewpoint is one that highlights
cultural conditioning and which:

“…emphasises the hold our culture has on us; it shapes the way in which we
see things (even in the way we feel things!) and gives us a quite definite view of
our world.”

(Crotty, 1998:58)

Therefore, a constructivist/constructionist position recognises the individual’s
contribution to making sense of the world whilst recognising the power of
cultural, political and social influences upon individual mean-making. This
position holds validity with my own personal beliefs about human nature – that it
is inherent within us all to want to understand our world and be understood by
those in our world. This human desire to understand, to know ourselves and our
world is, I believe, life’s unique challenge. Grasping the myriad of influences
that to a greater or lesser degree, shape our thinking, our interactions with
others, our world-view, is no simple undertaking.
Patton (2002:79) states that each epistemological stance has shaped the various theoretical perspectives of positivism, interpretivism, critical inquiry, feminism and post-modernism “...in varying degrees.” In the vast array of theoretical perspectives that inform qualitative study, this study adopts an interpretivist/phenomenological perspective which I believe is consistent with the epistemological stance of the social constructionist.

The phenomenological method within qualitative research design aims to uncover the reality of human experience, to capture the deeper meanings of the participants’ lived experience, i.e. a rich description of reality, as articulated by those being studied (Emery, 1983, Creswell, 1998; Thomlinson 2002). Phenomenological research, Moustakas (1994:57) believes, also holds the challenge for the researcher of “…establishing the truth of things” which, according to Creswell (1998:52), starts with the researcher’s own “…intuition, imagination and universal structures to obtain a picture.”

Qualitative researchers would acknowledge that they are inextricably intertwined with the focus of their enquiry. Our own biases, what Patton (2002:65) describes as our “…cultural, political, social, linguistic and ideological origins” need to be brought into consciousness and openly discussed in relation to the research findings. This study, through the process of reflexivity and recording one’s own thoughts and feelings throughout the research study’s progression, espouses an open exchange of the researcher’s engagement with all aspects of the research process and the writing of this thesis.

The advantage in adopting a phenomenological perspective as the research focus is the existing degree of familiarity I have in concentrating on an individual’s subjective experiencing. Consequently, transferring my practitioner skills as a counsellor to conducting research, the research methods used to gather data were selected to capture and describe an individual’s view of their practice of working in a children’s hospice.

However, this transfer of phenomenological practice to research is a cautionary venture. Paley (2005:106) claims that phenomenologists are “saddled with a philosophy that is disabling”, since the sole focus is on “perceptions, meanings and uniqueness.” How then, Paley (2005) argues, can this unique experience
be also something that is shared with others? I believe that the word ‘uniqueness’ has a much broader definition than something which is ‘singular’ or ‘exclusive’ to the individual as Paley (2005), in this particular instance, is referring to. Surely one could argue that uniqueness can also apply to groups as well as individuals? For example, a group of parents who have a disabled child will all have their individual “stories” to tell; however, the commonalities they share within that particular group make them ‘unique’ or ‘distinctive’ from parents who do not have a child with a life-limiting condition or from a group of bereaved parents whose child has died.

Paley (2005) also states:

“...rhetoric claims that generalisation is beside the point but the majority of researchers – unobtrusively and, as it were, unself-consciously – contrive to generalise anyway.”

(Paley, 2005:113).

This study’s focus is deliberately limited to a specific group of counsellors who work within children’s’ hospices. It does not set out to make sweeping generalisations from the findings nor does it attempt to generate new theory. Rather, the emphasis is on extracting the counsellors’ perceptions of delivering a pre and post bereavement counselling service. Choosing a phenomenological approach best served the intention of delving into the research questions I formulated, which related to the individual’s knowledge of practice within a children’s hospice working environment. Exploring each research participants’ experiences, and making links between other participants’ experiences, Lester (1999) argues, can dispute “structural or normative assumptions.” Also, the growing emphasis on the value of practitioners-as-researchers carrying out research within their area of practice may enable research findings:

“…to be used as the basis for practical theory, allowing it to inform, support or challenge policy and action.”

(Lester, 1999:1)

Far from being ‘disabling’ as Paley (2005) suggests, the qualitative phenomenological researcher, utilising whatever interpretative tools are available to complete a task, could be viewed as a:
“...bricoleur, a maker of patchwork, a weaver of stories; one who assembles a theoretical montage through which meaning is constructed and conveyed according to a narrative ethic that is neither naively humanistic, nor romantically impulsive – but rather one that stimulates an inclusive and dynamic dialogue between the researcher and her audience” (Yardley, 2008:1).

According to Denzin and Lincoln (2000:4) there are numerous types of bricoleurs – “interpretive, narrative, theoretical, political and methodological.” The bricoleurs’ end product, the bricolage, has been described as an attitude towards a problem (Wangelin, 2007); an emergent construction (Weinstein and Weinstein 1991:16) and something which signifies “interdisciplinarity – where the researcher employs more than one analytic framework” (Kincheloe, 2001:685).

The “interpretive bricoleur” as defined by Denzin and Lincoln (2000:6) is the one I, as a qualitative researcher, most identify with. The interpretive bricoleur acknowledges the collaborative nature of the research relationship, and through the process of self-reflexivity, identifies the innumerable influences that go into producing a complex and unique bricolage.

This research study can be likened to an artist beginning to paint a picture, where I as researcher/artist using the various brushes/tools, will paint for you a portrait of counselling practice within children’s hospices. It will have broad strokes and finer detail. It will have luminosity and transparency and it will originate not just from my own mind’s eye but also from the words of my research participants who provide the paint with its various tones and hues. The portrait will be a unique piece by the conclusion of this study; but like any other artist, I do not think that one portrait will be satisfactory to advance one’s art. I firmly believe that having acquired the appropriate research skills and identified a need to further develop findings, the results of this study may act as a precursor to further research. This hopefully will then lead to the possible future development of an area of counselling practice, within a children’s hospice – another portrait to hang in a gallery of counselling research studies that enable practitioners to view, be inspired by and promote the development of one’s own practice.
3.2 The Practitioner as Researcher

McLeod (1999:12) asserted that in order to create practical knowledge and carry out research that is relevant to practice “it is necessary that investigations are placed in the context of practice.”

I arrived at the point of wanting to carry out research as a result of providing emotional support to families who had faced and were facing the death of their child. As a counselling manager, I now have the responsibility for not only identifying pre and post bereavement supportive strategies, but also their implementation and the evaluation of a counselling service via a small team of people working within a larger multi-disciplinary team of nursing staff. Reflecting on my own individual practice always produces questions – Was I getting it right? Was I getting it wrong? How could I improve? How did other counsellors’ manage such a service? These self-absorbing questions, and surely any research starts with such, led me to consider counselling practice within a hospice environment. This inspired me to discover what was being delivered in other children’s hospices and which compelled me to conduct research, not as an academic exercise, but as a practitioner wanting to understand more about counselling practice within this specific paediatric palliative care setting. I highly respect the work carried out by all hospice staff and the potential to enhance professional practice through advancing practical knowledge is the raison-d’être and motivating force behind this study.

There are several advantages to carrying out research in the area one works in, and these centre around the pre-existing level of engagement in this field. Firstly, I am already “immersed” in the practice of counselling, having worked for ten years within a children’s hospice environment. I have therefore, a good understanding of how these organizations operate internally, the constraints and challenges facing them, and how my practice as a counsellor fits within a multi-disciplinary team. Secondly, being part of the same culture as the research participants could be construed as being fully engaged in that culture, which is essential if the researcher is to attain a full appreciation of the research topic (Kuhn, 1970: Wuest, 1995; Hewitt-Taylor, 2002). Thirdly, being perceived as a ‘fellow professional’ can have its benefits. Findings from a study of fellow professionals (Chew-Graham, May and Perry 2002:288) found that the
respondents recognised the research interview as a “communication between equals…led to rich and intuitive responses.”

There are also disadvantages to insider research which the investigator needs to be aware of. With regard to power dynamics between the researcher and the participants, Hewitt-Taylor (2002) raises the point that even if the researcher perceives him/herself to be in an equal position to the participants, the research process itself shifts the power dynamics within the relationship. The degree of familiarity I have with the research participants, and them with me, is a potential block to full engagement in the research process. Therefore in order to minimize this potential limitation, I aimed to select research participants that practiced within children's hospices throughout the U.K.

There are also potential drawbacks to researching other people's professional practice; Chew-Graham et al (2002:289) highlight the fact that such research studies are not regarded as “…professionally or politically neutral.” The authors argue that for the research participants there is:

“…an element of assessment or adjudication of quality in studies that seek to explore clinical practice” (and therefore resistance through) presenting partial accounts or through being selectively silent about particular topics – is not uncommon in such work.”


In addressing resistance, I believe the nature of the job, as a counsellor, regularly working with people’s defences, can help the practitioner/researcher to identify resistance more readily and therefore be in a better position to identify it when or if it occurs. Also, the task of transcribing allows the researcher to re-connect with the interview, enabling him/her to not only physically see the words that passed between the participants and themselves, but also what could have been explored more in-depth. A follow-up interview, with the agreement of the research participant, could be one way of addressing this issue.

3.3 Subjectivity

Subjectivity is also an important subject matter for the researcher to consider. The fact that a researcher may have shared with research participants, experiences within the realm of the research phenomenon, has been
highlighted within literature as having potential amplified significance and negative consequences on the data (Schulz, 1994; Crotty, 1996; Drapeau, 2002). Drapeau (2002) draws attention to any research project being influenced not only by external factors but also the internal motivations of the researcher. Drapeau (2002:1) recommends exploring our own biases whilst also being “cautious when analysing data” as he warns of subjectivity having the potential to throw findings “off-track.” Chew-Graham et al (2002:288) also warn of creating within the research relationship, “a case of shared conceptual blindness allowing the interviewer’s own feelings and opinions about the field to govern the dialogue and interpretation.”

If subjectivity is interpretation based upon personal opinions and feelings, then our cultural history and identity comes into play when carrying out research. Etherington (2004) writes of social constructionism motivating:

“...us to view the world and ourselves as embedded within historical and cultural stories, beliefs and practices and reality and knowledge as depending upon socially defined stocks of knowledge available at the time.”

(Etherington, 2004:46)

West and Talib (2002) writing of the researcher’s cultural identity influencing the interpretation of the data, suggest that researchers can only aim for “critical subjectivity” as suggested by Rowan and Reason (1981). If this is so, then as researchers carrying out qualitative research, we not only have to consider how the interpretation of data can be influenced by our social and cultural identity, but how the whole research process can be shaped by who we are and what we believe. My practitioner status within this particular working environment serves as a source of understanding that informs me as a researcher. However, it is only one aspect of my identity, and a commitment to visibility within the research means an exploration of other influences which may impact upon this study.

3.4 Social and Cultural Identity of the Researcher

My social and cultural identity as it is today could be described as that of a white, British, middle-class mother/grandmother, doctoral student/researcher and full-time children’s hospice counselling manager. This identity has evolved
over the years and is not just confined to how I see myself but also how others perceive me. It has developed as a result of pursuing my personal and professional goals and ambitions. My achievement in gaining academic qualifications and gainful employment has put me into a different social/class position from the working-class position I was born into. The educational influences and opportunities throughout my life have brought me to this point where, placed in an individual context, the internal drive to strive for academic achievement and the need to improve upon my own professional performance has taken a major leap forward. I desire, through research, to look at ways of improving not only my own professional development but also counselling as a general practice within children’s hospices.

I have come to realize how significant this individual and cultural context has been on my research choices. My professional links with Children’s Hospices UK and their assistance in helping to identify counsellors working in children’s hospices was valuable in the early stage of this study. My position as a hospice counselling manager allowed me to gain easier access to the research participants and more rapidly establish a rapport and trust with them. I chose to research a subject, and to hopefully produce something, which will be of some value to a group of people who occupy the same professional role as myself. In reflecting upon my choices here, I have to ask myself the question - was there a presupposition on my part that the participants of this study would be more open and more at ease in exploring their practice with someone who has an understanding of hospice work, rather than with an ‘outsider’ with no knowledge of children’s hospices? To suppose participants would feel more at ease talking with a fellow professional could hint at nepotism – that the participants in some way prefer to talk to someone who understands more fully the internal operations of a children’s hospice. This is of course pure conjecture on my part and not necessarily the case; they may have felt equally or more at ease discussing their practice with someone with no knowledge of the hospice environment. Turning the argument around, was it myself who wanted to make things ‘easier’ by talking to participants who would “understand more” where I was coming from? The thought cannot be dismissed, but in returning to my initial keenness to embark on the Doctorate Course, I remember the excitement
of being given the opportunity to look at my own area of counselling practice within pre and post bereavement support. Not only this, but to share with others (the research participants) this journey and exploration into what is happening within other children’s hospices and to identify possible challenges and areas for improvement in practice.

Research, before I became a researcher, was personally viewed as a remote activity carried out by very scientific people with whom I could never hope to compete academically. Taking the plunge of applying for this Doctorate Course to discover what research actually entailed from a practitioner’s viewpoint, and exploring the various research approaches, enabled me to challenge my own view of self and my perception of research. Whilst remaining an enormous cognitive challenge, I believe research, like personal development, whilst challenging, needs to be embraced as part of on-going professional development for those who wish to contribute to the advancement of counselling practice. Because I started out as a novice on the research path, examining an area in which I practice is not without its pitfalls, as discussed earlier. However, my skills as a person-centred counsellor have fitted in quite well with the qualitative researcher’s task of searching for more knowledge through gathering people’s perceptions of their world. Furthermore, the practitioner’s desire to improve their knowledge and skills has given this study its momentum. Therefore my current identity as a practitioner/researcher could be said to have brought me to a greater appreciation of the many internal and external factors which go into shaping the individual’s view of reality, and to approach research from a qualitative rather than quantitative angle, thereby putting the emphasis not only on the research phenomenon itself but also on my own impact upon the research.

In acknowledging the need for informed awareness of our own subjectivity, the many researcher influences on the research, and their impact upon the validity of research findings, the next step was to find out how I was going to achieve openness and transparency within this study.
3.5 Epoche, Bracketing and Reflexivity

Epoche in phenomenological research, according to Patton (2002) is a process whereby the researcher attempts to:

“…become aware of, prejudices, viewpoints or assumptions regarding the phenomenon under investigation”


Bracketing, Patton (2002:485) states, is the next step where the researcher, having segregated those preconceptions, then faces the phenomena “as much as possible, on its own terms.” However, Bednall (2006) argues that the definition and applicability of both processes have not been, within the literature, fully defined and are lacking in consistency of standards “particularly when critical engagement occurs with the issue of researcher subjectivity in data interpretation.” According to Ihde (1979) cited in Patton (2002:485), epoche requires suspension of judgment: “until all the evidence (or at least sufficient evidence) is in.”

Bednall (2006:125) adds that bracketing occurs: “at those interpretative moments when a researcher holds each of the identified phenomena up for serious inspection.”

Bracketing, Gearing (2004) argues:

“…remains undefined, as researchers tend to focus on specific components and less on the entire process of bracketing.”

(Gearing, 2004:1434)

Continuing, Gearing (2004) defines bracketing as having three distinct phases: “abstract formulation; research praxis and reintegration.” Each phase has essential components within it. The initial phase of abstract formulation refers to the influence of the researcher’s epistemological and ontological position and theoretical framework upon the research design. The second phase, research praxis, refers to what qualitative researchers tend to know and carry out in terms of bracketing i.e. suspending pre-suppositions. However, Gearing (2004) details within this phase:
“...five fundamental elements of foundational focus, internal (researcher) supposition, external (phenomenon) supposition, temporal structure and parenthesis (boundary) composition.”

(Gearing, 2004:1433)

The third phase, that of reintegration, occurs when:

“…a researcher then allows those personal ideas and feelings held in epoche to synthesise with those observations as interpretative conclusions.”


Clearly there is much for the researcher to consider when thinking of bracketing. Gearing (2004:1434) believes that bracketing places demands upon the researcher to make “clear, methodologically sound decisions,” and given the three phases he outlines, those decisions are clearly presented not just at the data analysis stage but throughout the research process.

McLeod (2001:195) poses that the dialogue around the issue of the “personal” within qualitative research has come to be known as reflexivity. More specifically, Etherington (2004) defines reflexivity within research as:

“...being aware of what influences our relationship to our topic and our participants. Those influences inform personal, cultural or theoretical constructs that we can use to guide our interactions as we engage in the research and represent our data.”

(Etherington, 2004: 46)

As self-reflexive researchers, our task is to record these influences, enabling those who have participated and the wider audience, to fully view the study in its entirety - a representation of experiences as written by the instigator of an exploratory journey into a research phenomenon. Having kept a personal reflexive journal throughout the research process, in order to record and incorporate into this thesis some of those personal influences, and regarding attention to reflexivity as important in qualitative studies, I question how much reflexivity is warranted to do justice to my position as an “interpretive bricoleur” (Denzin and Lincoln 2000:6). Is it a case of 'how much?' Or rather, do I need to be, in my self-reflexive writing, less introspective, less subjective and more aware of the wider influences that shape the emerging creative bricolage? I
noticed a preponderance towards introspection and recording feelings in my personal journal which led to a re-examination of reflexivity:

“Will I truly be able to make something out of this data that will be useful, something of real value to me, to the research participants, to the wider arena? Time is ticking away and I have to get a grip, get on with what I set out to achieve. How much introspection is needed without it becoming the self-indulgent, navel-gazing ramblings of a woman who fears she cannot produce anything worthwhile? Is this reflexivity taking me back in time instead of helping me to concentrate on how I am relating to the research now? Old messages, old feelings, they don’t belong here. I think I am being self-indulgent and not in a good way. Is this reflexivity useful if all I do is to get into negative feelings? Where will this lead? Maybe I need to go back to the definition of reflexivity and adjust my understanding of it. How much of ‘me’ needs to be in this research?”

(Personal Journal, 2011).

Finlay (2002:209) describes the process of engaging in reflexivity as:

“…full of ambiguity and multiple trails as researchers negotiate the swamp of interminable deconstructions, self-analysis and self-disclosure.”

(Finlay, 2002 p.209)

Now that reflexivity within qualitative research has evolved, debate, Finlay (2002: 212) states, “revolves around competing accounts of the rationale and practices of reflexivity.”

Numerous typologies exist, but Finlay (2002:213) in Fig.1 details five variants of reflexivity within current practice and concludes that each provides its “own particular opportunities and challenges.”
As a counsellor with a phenomenological background I have tended to favour introspection as a variant of reflexivity. However lately, as my personal journal entry above indicates, I have begun to question not only how much introspection is needed but indeed, whether I need to think more widely and more critically; and certainly Gearing’s (2004) work on bracketing, discussed previously, has given me much to consider with regard to this research enquiry.

McLeod (2001:201) highlights the concept of “critical reflexivity”, pointing out that the “subjectivity of the researcher does not command a privileged position.” The meaning of reflexivity McLeod (2001:201) frames within the constructivist and constructionist viewpoints and argues that, whereas the constructivist’s world-view is achieved through “individual cognitive ability”, the constructionist’s world-view is shaped by “historical, micro-social and cultural collective action.” Therefore, McLeod argues, critical reflexivity sets out to:

“…place a piece of research within a cultural tradition, so that what becomes visible includes both the way in which the tradition constructs the topic and the way in which an engagement with the topic changes the tradition.”

(McLeod 2001:202).

Having fully explored my own positionality and the subjects of practitioner/researcher; subjectivity and reflexivity, I will now focus upon the research participants, data, collection and data analysis.
3.6 The Research Study

I will now outline how I conducted this research study, looking at the participants chosen for this study, data collection and data analysis.

3.6.1 Research Participants

In looking to select suitable participants for this study, a purposive sampling method was employed. As the most common sampling method used in qualitative methodology, it allows the researcher to actively recruit research participants in order to provide “rich” data (Marshall, 1996) i.e. those who have experience of the research phenomenon who are most likely to respond to the research question in more detail and depth.

Particularly within phenomenology, Corben (1999) states that:

“…the sample has naturally to include only those who have experienced the phenomenon.”

(Corben, 1999:59)

Therefore the research participant inclusion criteria were: qualified counsellors, male and female, aged 18-65 and a principal inclusion criterion of counsellors employed within children’s hospices who are responsible for assessing and implementing a support/counselling service during the pre and post bereavement periods. After consideration of appropriate sample selection for this methodological approach, the exclusion criteria included those who, although they coordinated and had responsibility for implementing bereavement support, were not qualified counsellors. An email to all Heads of Care outlining my research proposal, together with a few questions for potential research participants, was sent via Children’s Hospices UK – the nationally recognised organisation representing all UK Children’s Hospices. Each Head of Care was requested to forward the email which included: participant information sheet 1 (Appendix I), consent form 1 (Appendix II) and short survey (Appendix III) to the lead person within their organisations providing pre and post bereavement support. In addition to this, a list identifying the named persons providing pre and post bereavement support/counselling, compiled by “Children’s Hospices UK,” was emailed to me, which proved useful in following up those who did not respond. Another email was sent from me to those who fulfilled the inclusion
criteria but did not respond to the initial email sent out by Children’s Hospices UK.

One of my first discoveries from the compilation of this list of counsellors was that not all children’s hospices throughout the UK employ counsellors to provide pre and post bereavement support. Emotional support is being delivered by an assortment of senior staff or bereavement co-ordinators, many of whom have a dual role within the hospice.

This discovery impacted upon the recruitment of research participants, and much time was spent in directly telephoning all children’s hospices throughout the UK, in order to enquire into the counselling qualifications of those providing pre and post bereavement support. This investigation found that although they had counselling skills, these co-ordinators were not fully qualified counsellors. These exclusion criteria significantly reduced the number of potential participants for this study, since its focus was to be solely on counsellors’ experiences and not on other professionals’ practice of delivering a support service within children’s hospices.

In trying to establish the number of participants that would be considered a reasonable figure for this qualitative study, the most suitable sample size according to Marshall (1996), is one that responds to the research question adequately. A proposed sample figure of ten participants was originally hoped for but, given that not all hospices employ qualified counsellors to deliver a support service, I was still fortunate to recruit seven qualified counsellors across the UK. This breadth enabled me to provide this study with a broader overview of the support services within children’s hospices throughout the country.

3.6.2 Data Collection Methods

Qualitative data was collected in two ways for this study. Firstly, a short survey (Appendix III) was emailed to participants who met the research participant criteria of providing a pre and post bereavement support service within children’s hospices in the UK. Secondly, from those who returned the survey who met the research criterion of being qualified counsellors, and who had agreed to further participate in the study, a telephone call was made to each
participant and a date and time was agreed for a semi-structured recorded interview to be conducted in their place of work, in order to assist me in gathering more in-depth data for this study.

3.6.3 Survey as Recruitment Tool

Potential participants were initially contacted by email. I attached a Participant Information Sheet 1 (Appendix I). I also attached the Consent Form 1 (Appendix II) and Research Survey (Appendix III) for them to complete online. A note at the end of the survey was added that a certain number of returned forms would be selected and used to identify those who would be willing to further participate in the study by undertaking a research interview.

The short survey was intended to take no longer than 15 minutes to complete and was employed as a probing tool only, designed to collect factual information and elicit responses that would give a broad picture of those delivering a support service within a children’s hospice. The questions asked were:

- level of qualification and training
- professional role within the hospice
- theoretical model of counselling
- client groups supported
- use or not of an assessment tool, (to identify the levels of support needed within the particular client groups).

This initial data-gathering was not intended to produce ‘rich data’, where the responses are more descriptive of the participants’ thoughts or feelings. However, it did provide an opportunity to identify those who would be willing to further explore their practice. From the 34 hospices throughout the UK that the survey was emailed to, nine surveys were completed and returned, giving a response rate of 26.4%. In order to determine the possible causes of the low return rate, i.e. hospice not receiving the form, questions too ambiguous etc., I telephoned all the hospices listed by Children’s Hospices UK as providing pre and post bereavement support, to speak to the lead person delivering this support service. It became apparent from the conversations that took place that
those who had a dual role within their hospice and had only a counselling skills qualification, did not see the relevance of completing the form, since they did not see themselves as qualified counsellors and the wording on the form proposed that a selection of these qualified counsellors would be selected and invited to further participate in the study. Despite this low response rate however, eight of the nine respondents were qualified counsellors and these were selected for interview although one participant withdrew from the study due to leaving her position within a children’s hospice, leaving me with seven research participants to interview. The following table shows the participants’ profiles:

**Table 1 : Research Participants’ Profiles**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Counselling Approach</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Female</td>
<td>Person-centred</td>
<td>NE Wales</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>Person-centred</td>
<td>North Wales</td>
</tr>
<tr>
<td>P3</td>
<td>Female</td>
<td>Person-centred</td>
<td>South Yorkshire</td>
</tr>
<tr>
<td>P4</td>
<td>Female</td>
<td>Integrative</td>
<td>West Midlands</td>
</tr>
<tr>
<td>P5</td>
<td>Female</td>
<td>Person-centred</td>
<td>SE England</td>
</tr>
<tr>
<td>P6</td>
<td>Female</td>
<td>Person-centred</td>
<td>NE England</td>
</tr>
<tr>
<td>P7</td>
<td>Female</td>
<td>Family centred</td>
<td>Central England</td>
</tr>
</tbody>
</table>

**3.6.4 Research Interviews**

Interviewing, according to Wimpenny and Gass (2000:1485), has become “synonymous with qualitative research” and in order to achieve my aim of exploring counsellors’ experiences of practice in a children’s hospice, face to face interviewing was deemed the most appropriate instrument to collect data.

Kvale (2007:173) writes of the interview being a place where people are able to “...organise their own descriptions, emphasising what they themselves find important.” However, in this particular instance, the interviews carried out were qualitative research interviews, the purpose of which Kvale (2007) describes as:
“...to gather descriptions of the life-world of the interviewee with respect to interpretation of the meaning of the described phenomena.”

(Kvale, 2007:174)

According to Scheurich (1995), the research interview encompasses not only the researcher carrying out the interview by posing the questions and taping the responses, but also interpreting the interview, both of which he believes are subject to the interviewer's and the interviewee's:

“...conscious and unconscious thoughts, feelings, fears, power, desires and needs....and that an indeterminate ambiguity...lies at the heart of the interview interaction.”

(Scheurich, 1995:249).

Scheurich’s (1995) point emphasises the importance of reflexivity within the research process, something on which I go into further detail later on in this chapter.

Within a qualitative approach, an open-ended interview with a loose structure, according to McLeod (1994), minimises assumptions made about the participants’ subjective experiences. Semi-structured interviews were chosen over structured interviews as I believed these offered a degree of freedom to the participants to freely talk about their practice within what Gerrish and Lacey (2006:341) described as “predetermined topics and open-ended questions.” Structured interviews, Gerrish and Lacey (2006) comment, give the interviewer “the balance of control” which may not have allowed the participants to more fully explore the research focus.

A general interview guide approach to the design of the interview allowed interview questions to be formulated prior to the interview taking place, and certain areas were identified prior to the study. Kvale (2007:174) describes the qualitative research interview as “theme-oriented not person-oriented” and the interview schedule design arose from thinking about previous doctoral assignments that looked at the specific working environment of a children’s hospice and counsellors’ practice. What became important for me to find out, as a result of reviewing all findings from my previous writing on the doctoral course, was how counsellors decided who needed support and how they
determined what level of support an individual needed. Also, the responses given in the brief survey that formed the first part of this research study informed and focused the interview schedule design, focusing the questions around what existing pre and post bereavement assessment frameworks were being used within children’s hospices and how, given the participants’ stated theoretical counselling approach, they were being implemented within the research participants’ practice.

In previously conducting a pilot study for one of my assignments, a participant had commented on how useful it would have been to have seen the questions prior to the interview in order to be better prepared. Therefore in this study I emailed a copy of the Interview Schedule (Appendix VI) to every participant for their perusal prior to the interview taking place, thereby giving them time to consider how they might wish to answer. Alongside the Interview Schedule (Appendix VI) I also emailed to each participant a Participant Information Sheet 2 (Appendix IV) and Consent Form 2 (Appendix V).

The interview schedule consisted of the following discussion areas:

1. What are the images/thoughts/feelings that spring to mind when you think of the word “assessment?”

2. During the pre-bereavement period how do you determine what level of support you give? Are there levels of needs and support? What kind of support is given?

3. How do you implement the support offered to the various client groups?

4. Are there any challenges in providing support in the pre-bereavement period? How might these challenges be addressed?

5. In the post-bereavement period, how do you assess or determine the level of needs of the various client groups?

6. How is post-bereavement support implemented?

7. Are there any challenges to providing post-bereavement support? How might these challenges be addressed?
8. Does the level of need pre-bereavement determine the level of support offered post-bereavement?

9. Are there any particular factors you believe any formal assessment framework should include if being applied within a children’s hospice?

10. Is there anything else you would like to talk about?

My task as the researcher was to focus the participant upon the above areas, to obtain a rich description of the participant’s experience of their practice within a children’s hospice and avoid leading the participant to specific meanings through the use of leading questions. Kvale (2007:190) warns of the danger of leading questions and how, “in principle (they) are impossible to avoid.” However, Kvale (2007:190) goes further and states that rather than trying to achieve “technical objectivity in questioning” the researcher should work towards a “reflected subjectivity with respect to the question-answer interaction.”

All the interviews were approximately of 90 minutes duration, were conducted uninterrupted in the participants’ places of work and in environments that were conducive to recording. Consent to record at the various hospices was obtained by the research participant, in discussion with their own Heads/Directors of Care. After each interview the participant was thanked and reminded to contact me at the number provided should any questions or concerns arise from the study. I also obtained the individual participant’s permission to e-mail a transcription of the recorded interview for them to amend or delete any data they did not wish to be included and to verify the accuracy of the content. Each participant was satisfied with the transcript’s accuracy and I did not attempt any data analysis until all feedback from the participants was received.

Kvale (2007:177) raises the point that interviews carried out by another researcher using the same interview guide may not be the same due to “varying sensitivity by the interviewer.” It has to be acknowledged that as a children’s hospice counsellor myself, my sensitivity and knowledge of the research phenomena had its advantages and disadvantages, as discussed earlier. This
study is set within the particular margins of practitioner-based research/insider research.

3.7 Data Analysis

According to Thorne (2000):

“...data analysis is the most complex and mysterious of all the phases of a qualitative project...”

(Thorne, 2000, p.68)

Qualitative research can produce large volumes of raw data which require in-depth systematic analysis in order to produce interpretations and overall themes (Pope, Ziebland and Mays, 2000). There are numerous methods of analysis but whatever method is chosen, Foster and Parker (1995) argue that analysis has to convince the reader of a conceivable line of reasoning.

Therefore in order to determine which method of analysis is going to convince the reader of the plausibility of this research study’s argument, I have to return to the aim of this study. What have I set out to achieve? My aim is not to generate theory from the phenomena, as in grounded theory, but to increase knowledge that informs practitioners. I wish to work with the data rather than go too far beyond it into nuances, in which case a method like Interpretative Phenomenological Analysis would have been more appropriate.

In achieving this aim, I believe, the data analysis had to focus upon descriptions of the phenomenon and search for commonalities, consequently thematic analysis was deemed an appropriate method of analysis. The justification for my use of thematic analysis was a pragmatic one. As an effective method of analysis it worked for the purpose in hand and it produced a significant contribution to knowledge.

Thematic analysis is described by Braun and Clarke (2006) as having six phases:

1. Familiarisation with the data through reading the transcripts
2. Initial coding
3. Searching for themes – bringing together codes into broader themes
4. Reviewing the themes

5. Refining the themes – on-going analysis

6. Producing a report of the analysis

(Braun and Clarke 2006:87 summarised table 1)

Unlike content analysis of transcripts which “attempts to identify core consistencies and meanings” (Patton, 2002:453), applying thematic analysis to my data allowed me to form and represent the participants’ data under categories which transpired from my own engagement with it. I concur with Braun and Clarke (2006:205) that thematic analysis incorporates themes which are “anticipated” through reviewing previous literature, and themes that dwell not only in the data itself but “in our heads from our thinking about our data and creating links as we understand them.”

Having received verification of the accuracy of each transcript I read each one and started to extract sentences and phrases which pertained to the areas we had explored. I read through the other transcripts and gathered similar phrases together. These excerpts were then pasted onto a large sheet of paper, establishing a broad theme. I worked through all the transcripts until all the data was categorised under broad themes. I was then in a position to study the sheets of paper and look for other themes, their connection with each other and with the literature I had read. The themes identified are more fully presented in the findings chapter; however, before I present these findings, two very important considerations in any research undertaking are those of trustworthiness/validity and ethics.

3.8 Trustworthiness/Validity

The term validity can be said to relate to the claims one makes from an enquiry into a phenomena and how ‘true’ or believable those claims can be in the light of evidence presented within a particular study. Therefore it is the responsibility of the researcher to demonstrate, within a thesis, the steps taken that led to the assertions made. Validity has its roots in quantitative research, whereas the term trustworthiness is often used within qualitative research to denote validity. Lincoln and Guba (1985) believe that trustworthiness carries certain criteria
which Gerrish and Lacey (2006:169) summarise as those of “credibility, transferability, dependability and confirmability.” These criteria focus upon the connection between what the participants have said and the researcher’s portrayal of such; the findings’ transferability to other similar situations; and the links made between the data and the researcher’s findings/interpretation.

In order to establish trustworthiness within this study I incorporated member checks after I had finished transcribing the interviews. Each participant in the study was asked to peruse the transcription and to feed back their satisfaction or not with it. A member check at this stage allowed for my proficiency in capturing the participants’ entire recording of their experiences to be verified, giving participants the opportunity to volunteer additional information or to delete any they did not wish to include in the study. After the data analysis took place, I also invited the participants to examine the findings, again permitting them to challenge me on possible wrong interpretations and to confirm my reconstruction as being recognisable and sufficiently representative of their experiences of practice within children’s hospices. Regular de-briefing with a colleague, not involved in research, was not only an invaluable time to offload and voice my own perceptions, but was also a constructive challenge to my own limitations in thinking about my impact upon the research process. Bearing in mind all elements of a research study, any research design, according to McLeod (1994), throws up ethical issues which must also be considered. Consequently I will now discuss the ethical considerations that should be taken into account in any research undertaking.

3.9 Ethical Considerations

Within any research project, the onus is on the researcher to develop an ethical “mindfulness” as described by Bond (2004), which is deemed to be a continuous process where the researcher, rather than prescriptively referring to a code of guidelines, aims to be ethically minded throughout the research (Bond, 2000). Having completed, prior to carrying out the research, the necessary documentation for the University of Manchester’s Ethical Committee, ethical approval for this study was granted. This documentation, alongside the British Association for Counselling and Psychotherapy Ethical Guidelines for
Counselling and Psychotherapy Research (Bond, 2004, 2005), helped me to more fully consider the following points:

- Informed consent and of it being sought where necessary.

Consent refers to the right of participants to decide whether or not to voluntarily enter into participation in the research. Informed consent is where the participant has agreed to participate in the full knowledge of the purpose of the study, the extent of their involvement in it, what data will be collected, what will happen to that data and what potential risks could be incurred. Prior to the start of the study, two Participant Information Sheets were written for this study outlining the purpose of the survey and the purpose of the recorded interview. Only when each sheet had been read was the participant requested to sign the consent form. West and Byrne (2006) argue that informed consent in research is challenging, in that they question how people can give consent to “something they have not experienced and where the researcher themselves may only have a vague idea of which way the research is going.” Qualitative research often involves much data gathering over the research period, therefore gaining informed consent only once may be inadequate and researchers may need to consider asking for informed consent on several occasions, engaging in what Munall (1988) in West (2002) termed “process consenting.” West and Byrne (2006) suggest that the term informed consent be abandoned and replaced with the terms “initial consent, process consent and closure consent.”

Robson et al (2000:543) draw attention to whether participants can “voluntarily decide on participating free from blatant or subtle extraneous factors that may compel them to participate.” The participants in this study were all hospice counsellors and therefore may have felt some obligation to help a fellow professional in their field. I concur with Robson et al (2000) that we cannot presume our participants are free from these extraneous factors in terms of voluntariness; however, the only recourse researchers have is to ensure that the participants are fully aware and are reminded that they can opt out of the research at any time during the process right up to the point of publication.

- Security and storage of the data.
Research must be conscientious about security and storage of data. The data for this study was kept in a locked cabinet within the researcher’s home. The data will be stored for two years after confirmation of the degree result; then paper data will be shredded and audio-recordings erased.

• anonymity within the thesis and any published work resulting from the study.

Guaranteeing anonymity to participants is normal procedure, in order to rule out possible negative consequences for research participants (Bond 2004). All data was anonymised by removing all personal identifiers and in the interview transcript, each participant’s name was replaced with a random numerical tag.

• Member check of the transcript for accuracy and the opportunity to delete or amend any of the data.

Each participant was emailed a copy of the written transcript and requested to feed back on its accuracy and to amend or delete any of the data before commencement of the analysis.

• Awareness of any possible adverse effects upon participants as a result of being interviewed.

West (2002) considers the impact of any kind of research upon the participants and in particular, the use of surveys. To gather data through any particular method requires participants to consider and reveal thoughts/feelings on the research subject, and therefore no researcher can know what the impact of being interviewed or asked to complete a survey has been upon the participant. With regard to my use of a survey in this study, it asked for names and contact details, since this tool was essentially employed to recruit willing participants to interview. The fact that I did not receive many responses could have indicated a negative impact of receiving the survey; but a telephone call to the various hospices as described earlier on in this chapter suggested that some potential participants did not see the relevance of completing the survey, since they were not qualified counsellors.
In sending the transcript to each participant I invited them to feedback on the accuracy of the transcription and the interview itself. However, apart from confirming its accuracy, and one participant making slight amendments to her transcript, I did not receive any comments on the experience of being interviewed. My contact details and that of my research supervisors for this study were given to each participant, as set out in the consent forms, for them to raise with us whatever negative impact the interview or indeed any part of the research process may have had on them. Certainly there is a question for me as a researcher about incorporating as a matter of course into research findings some feedback from participants about their particular research experience, which would add another dimension to the findings. For example, as a result of carrying out this research I was left with a sense of keen interest from the participants in pursuing the subject of assessment within children’s hospices, and I feel confident that should I return to this subject matter I would find willing participants to collaborate in a piece of action research. However, here I am only stating what my own feelings were at the end of the interviewing stage – had I obtained some of the participants’ specific thoughts and feelings on being interviewed and what, if any, impact it had had upon them, it might have confirmed or refuted the feelings I was left with after the interviewing process was completed.

Power differences between the participant and the researcher can create an ethical dilemma, in that the researcher as author of final publication has control over the research study. In terms of possible future publication, West (2002) suggests that the researcher “shares the draft material” with the participants of the research, in order that “their consent and editing is built into the publication process” (2002: 265).

Having fully explored the methodological considerations, the next chapter will now present the findings of this research study.
Chapter Four – Findings of Study

This chapter presents the key findings in relation to the research questions posed within this study. The research has been conducted within a thematic analysis structure, with the emphasis on the findings being reflected in the research participants’ own words, their accounts of their experiences (Finlay and Evans, 2009:189) of assessing and implementing support within children’s hospices. Therefore direct quotes have been used throughout the chapter to endorse the themes presented.

I hope that representation of the research participants’ voices within the themes presented offers “specific applicable knowledge” (McLeod, 2011:81) in relation to the professionals who work with people who face bereavement, or who have been bereaved.

I will present the thematic map (Braun and Clarke 2006) of how the main codes from the transcripts were clustered into main themes in relation to the research questions. The codes were identified from the raw interview data regarding what participants’ spoke about most often, without myself making any interpretations of theorising (Braun and Clarke 2006:84)

The three main research questions that were under exploration were:

- How do children’s hospice counsellors’ implement a support service during the pre and post bereavement period and what, if any, are the challenges?
- How is the pre and post-bereavement assessment of needs being carried out within children’s hospices?
- What are counsellors’ thoughts/feelings about the assessment of the needs of children/young people and their families during the pre and post bereavement periods?

In order to clarify for the reader the terms pre and post bereavement periods used within this research study, the point of referral to the hospice and throughout the terminal phase of life is regarded as the pre-bereavement
period. The post-bereavement period is from the death of the child/young person up to the point families no longer access the support service.

To ensure anonymity, the participants were assigned a number and are referred to within the findings as P1 - P7, followed by the transcript page number where the participant had made a comment e.g. P5:11 would be participant 5, transcript page number 11. Prior to the main research questions being posed within semi-structured interviews, a very short survey, used basically as a recruitment tool, was employed to identify potential research participants, their level of qualifications and whether they carried out any form of assessment of needs during the pre and post bereavement periods.

4.1 First Phase of Study - Survey Information Results

The short survey was emailed to 34 children’s hospices throughout the U.K. The rationale for sending out a very basic form was to identify qualified counsellors working within children’s hospices and to gather key information on their level of counselling qualifications, and whether or not any form of assessment tool was used to determine the pre and post bereavement needs of their hospice service users and families. Nine completed forms were returned giving an overall response rate of 26.4%.

The first observation of this study was the low response rate to the survey and in order to establish why this was so, I decided to check that the form had been received by contacting, via telephone, the hospices I had had no reply from. A listing of children’s hospices throughout the U.K with the names of people responsible for providing psycho-social/bereavement care was provided for me by the organisation Children’s Hospices UK, now known as ‘Together for Short Lives.’ The follow-up telephone calls, where I was able to speak directly to the person responsible for providing psycho-social support, revealed the fact that not all children’s hospices employ qualified counsellors to deliver pre and post-bereavement support. Rather, many hospices have what are termed ‘bereavement co-ordinators’, who have a dual role within the multi-disciplinary team i.e. a senior nurse or social worker with extra responsibility to provide a
degree of emotional support and who refer to outside agencies if counselling is considered to be required.

This fact impacted upon the study’s sample size and the subsequent statements that could be made about the delivery of pre and post bereavement support within children’s hospices in the U.K. I did not choose to include other health professionals, as this study was aimed specifically at counsellors and how they work within children’s hospices. The sample represented this single group of professionals practising within a multi-disciplinary working environment, where valuable insights into the delivery of support and counselling practices have been gleaned from the generous contributions of all the research participants.

Further data from the survey revealed that all respondents were qualified at least to Diploma level, with 4 respondents having a degree or higher degree with person-centred, family-centred and integrative models of counselling being highlighted. Also, 5 respondents did not carry out any specific pre-bereavement assessment of the needs of the children/young people or their families accessing the hospice services. However, according to the Children’s Hospice Provision Survey (2010:13), the assessment process during the pre-bereavement period seeks to establish such aspects as the child’s/young person’s medical requirements, personal care/social needs, as well as emotional and spiritual needs. The Children’s Hospice Provision Survey (2010) also established that members of staff within the multi-disciplinary team carry out these co-ordinated assessments, often jointly with outside agencies (51%). This particular study’s finding, that 5 of the respondents did not carry out any form of pre-bereavement assessment, correlates to the Children’s Hospice Provision Survey (2010) finding, that pre-bereavement assessment of needs is focused upon the child/young person’s medical as well as psycho-social needs, and is conducted by other members of the multi-disciplinary team within children’s hospices.

The question of whether assessments of post-bereavement needs were being carried out within children’s hospices was also posed within the survey. The results revealed that 5 counsellors did conduct an assessment of needs of
grieving family members during the bereavement period. Therefore, it may be suggested that counsellors have a higher level of engagement with the assessment of family members’ bereavement needs and involvement during the initial bereavement period than at the pre-bereavement stage.

Of the respondents who commented on how they assessed clients’ pre and post-bereavement needs at the point of referral to the counselling service, the responses revealed several methods of informally gauging clients’ needs.

Using data from the survey and data from the semi-structured interviews, the range of assessment tools, as defined by the research participants, being used during the pre and post bereavement periods were as follows:

**Table 2: Range of assessment tools used by children’s hospice counsellors**

<table>
<thead>
<tr>
<th>Participants</th>
<th>Assessment tool used to determine pre-bereavement needs</th>
<th>Assessment tool used to determine post-bereavement needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Basic assessment form</td>
<td></td>
</tr>
<tr>
<td>P2</td>
<td>Informal discussion</td>
<td>Informal discussion/Blob Cards © (for use with children)</td>
</tr>
<tr>
<td>P3</td>
<td>Self-Assessment</td>
<td>Self-Assessment/Blob Cards © (for use with children)</td>
</tr>
<tr>
<td>P4</td>
<td></td>
<td>Genograms</td>
</tr>
<tr>
<td>P5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P6</td>
<td></td>
<td>Referral Form</td>
</tr>
<tr>
<td>P7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Informal discussion between counsellor and client, and self-assessment, were cited as means of identifying the individual’s needs for support. The emphasis placed upon this informal discussion of the client’s needs for support without looking at predefined criteria, would suggest that attention is being given to what Holland and Neimeyer (2012) proposed assessment should focus on - how the client has come to make sense of their loss, and not on clinical opinion as Payne (2001) commented. A phenomenological counselling approach, which some of the research participants’ stated was their counselling modality, would empathically focus on the client’s sensing and understanding of their loss. However, with such informality surrounding assessment, Payne and Relf (1994 cited in Agnew, 2010), raised concerns about inconsistent practice and ad hoc systems, although no such concerns were conveyed by the participants of this study.

### 4.2 Results from Semi-Structured Interviews

An overall thematic map (Figure 2) representing the main themes arising from the study is outlined below.

**Figure 2: Thematic Map of Main Themes**
In relation to Research Question 1: How do children’s hospice counsellors’ implement a support service during the pre and post bereavement period and what, if any, are the challenges, seven themes arose which were categorised under the broad headings of pre and post bereavement periods.

4.2.1 Families’ Needs during the Pre-Bereavement Period

In discussion of the pre-bereavement period, participants (P1, P2 & P4) described and perceived parents as needing other people to understand what their experiences are, to - “hear their story, their worries and concerns” (P4:3), to share time with other parents going through similar experiences (P2:4) and “for other people to understand….what it means to have their child in ITU and to be sitting up in a plastic chair for 48 hours by the bedside without a cup of tea” (P1:2). Furthermore, the parents’ concerns included practical issues, for example, obtaining equipment for the child, adaptations to their home (P1:2); how siblings are coping (P5:5); and onto deeper fears of their child “dying in pain” (P4:3).

With reference to the brothers and sisters of the ill child, the siblings within families were perceived by P2:2 to be in need of emotional support, commenting that the sibling lives “in the shadows of the ill child” and are “sometimes side-lined because of all the time that’s needed on the child” therefore providing psychological support in the format of group-work and sibling group events was considered to be very important and various forms of sibling support was being offered by all the children’s hospices within this study.

4.2.2 Composition and Delivery of Pre-Bereavement Support

Based around the particular needs of families who access a children’s hospice, pre-bereavement support, often referred to as psychosocial support within children’s hospices, has two main constituents – social and therapeutic (counselling) support. Social support consisted of: providing family fun days (P6:5; P3:6); accompanying siblings to places such as cinema/shopping trips (P3:5); bowling and theme parks (P5:5); accompanying parents to hospital appointments (P7:5) complimentary therapies (P2:4); informal social groups – drop in sessions/lunches (P7:5); grandparent days (P5:5). Also, assisting with grant applications and end of life plans/advanced care directives (P7:5);
providing help with obtaining equipment and signposting to other agencies for advice and practical support (P1:2) were all considered to be supportive measures that feature in the pre-bereavement period. Emotional support and specific counselling work at this time encompassed individual and family counselling (P1:1); working with the “sick” child, parents and medical team (P4:2); helping parents to support siblings (P2:5; P5:5); group-work with new parents and sibling group-work (P5:4). The group format for implementation of pre-bereavement support to parents and siblings was evident from the data gathered in this study.

In addition to these findings, this study found that the pre-bereavement support offered was delivered mostly by other members of the multi-disciplinary care team and hospice community outreach teams. Participants highlighted the involvement of hospice co-ordinators/nurses/healthcare assistants/family support workers (P1:1; P2:1; P6:5; P4:3), sibling support workers (P3:5).

Participants P1, P3, P4 and P5 stated that their involvement throughout the pre-bereavement period was specifically of a therapeutic nature, where counselling had been particularly requested by a family member, or when a referral had been made by another member of staff concerned about the individual (P6:6; P4:3 P5:1). In informing families of how the counsellor could help them through the passage of the child’s illness trajectory, P6 believed that this may help the families at bereavement:

“What I’m saying thinking about that is, if you can support the family earlier, right at the beginning and say this is not a pleasant journey but this is a journey, that from our experience, most families take and if you can say this is how we can help you and all of that then that will help the end part (P6:14).”

It was discovered that where counsellors would take the lead amongst the multi-disciplinary team is in pre-bereavement activities, in which where there was a therapeutic element to group-work such as sibling work (P2:5; P5:5); new parents group (P5:5); and workshops such as helping parents in supporting siblings (P5:5). As one participant (pg. 5) stated, the pre-bereavement period is “not just about death and dying, it is about living” and the needs of some parents is just to “have a chat”; therefore the involvement of all members of the
hospice multidisciplinary team in providing support during the pre-bereavement period was evident in this study’s findings.

4.2.3 Challenges for Counsellors in the Pre-Bereavement Period

The professional challenges in providing support to families in the pre-bereavement period were varied. For participants P3:6 and P6:5, the size of the hospices’ catchment area was cited as a challenge, with large distances and transport of siblings to the hospice creating difficulties in attending events on the hospice site.

The limited amount of time available to give support and having to work over one’s hours P5:5; the limited number of staff available to give emotional support P6:8; P7:5 and for P4:3 the assumption made by other staff members, that the counsellor, knowing the child and family, would be able to continue this helping relationship into the post-bereavement period were professional challenges, with P7:5 emphasising that whatever support is offered “has to be sustainable, not just to tick a box and then take it away because the box has been ticked.” For P5:5 and P6:8, hospice staff knowing when to refer to counselling and knowing when their particular input was sufficient was a professional challenge.

4.2.4 Pre-Bereavement Support Impacting upon Post-Bereavement Support

Participants were asked if pre-bereavement work provided any indicators of potential needs for support during the post-bereavement period. The participants’ responses were that the wide range of reactions to the death could not be predicted:

“…families are surprising and the families you think might struggle don’t or the other way around so I don’t know. I like to be open.” (P1:11)

Therefore pre-bereavement work with an individual was not necessarily an indication of the need for bereavement support. P4:4 described more of an “intuition...based upon experience,” which gave her a sense of whether future post-bereavement support would be needed, and that if they were distressed and seeking help in the pre-bereavement period then she would “make an assumption” that there might be a need for further support later on.
Of pre-bereavement work, P1:3 and P3:7 spoke of the established therapeutic relationship being helpful to siblings, particularly young people, in accessing post-bereavement support when they were at their most vulnerable. Sibling group-work in the pre-bereavement period may consist of bereaved children and those with a brother or sister who were continuing to access the hospice. In response to staff at her hospice being reticent about having pre and post-bereaved siblings together, P2 commented that:

“...it isn't an issue. It's actually an issue for the external people and not members of the group in my experience and this group seems to feedback that they are happy it's mixed” (P2:4)

In summary of pre-bereavement support, providing emotional support during this period was found not to be the exclusive domain of the counsellors. Members of the multi-disciplinary team were involved in delivering a range of activities and support, with referral to the counsellor made if the staff member had concerns about the individual. It was also recognised by the counsellors that there were various levels of support and that these levels of support were monitored and discussed with team members either in monthly team meetings (P1:4) or when a referral to the counsellor had been made. The needs of parents during this time were in dealing with practical issues, as well as the need to talk with other parents about their experiences; therefore social/therapeutic group sessions, together with individual support from individual members of the multi-disciplinary team such as the physiotherapist or social work team, were provided. Siblings' needs were acknowledged through the provision of therapeutic group-work and being invited to participate in fun events. Assessment at this stage was often an informal discussion with the person about their needs for support, with tools such as the genogram used to gather information about the person and his/her relationships with other family members. The challenges during the pre-bereavement period were seen as limited time/resources, and for other hospice staff members, knowing when to appropriately refer to the counsellor. It was found that the established therapeutic relationship pre-bereavement made it helpful for siblings to access support post-bereavement, but for some counsellors, the response to death and the need for support post-bereavement could not be predicted.
4.3 Implementation of Post-Bereavement Support

As in the pre-bereavement period, delivery of support after the death of a child/young person was provided by community teams and those hospice staff members who had previously been involved with the family. The length of time bereavement support would be offered ranged from up to two years (P2:4; P5:9) to “there is no limit, we’ll carry on as long as it is seen to be valuable and that the family want our support” (P3:13) with all the participants emphasising that it was important to be flexible, and as P5:9 put it, “it’s an elastic wall” on the length of time a bereaved person might need their support.

Three main themes were identified within the post-bereavement support, and they were as follows:

4.3.1 Feelings of Bereaved Parents

Three of this study’s participants spoke of parents’ despair following the death of their child. P5:3 highlighted that during the initial home visit thoughts of wanting to be with their dead child are not uncommon thoughts but are rather ‘normal’ responses during this period. For P4:5, hearing the depth of despair can be overwhelming for other members of staff, and is often the point at which the counsellor is called upon to give support. P3:9 spoke of suicidal ideation being “incredibly common for bereaved parents” and that checking out the safety of the person and involving the G.P would be her initial concern and task.

4.3.2 Composition and Delivery of Post Bereavement Support

Initial bereavement support was provided by assisting the family with funeral arrangements such as liaising with funeral directors and helping to compile memory boxes for the siblings. Further bereavement support activities included the provision of group support to the various client groups: parents, siblings and grandparents (P2:10; P3:8; P5:11; P6:11: P7:11). For P2:4, the provision of mixed groups of pre and post bereaved parents and pre and post bereaved siblings worked very well for the group members, with a few staff members being a “little reticent” about mixing the two groups. All the participants mentioned their hospices’ annual Remembrance Service or Memory Day, as an event that brings all bereaved families together to celebrate the life of their child.
4.3.3 Challenges for Counsellors in the Post-Bereavement Period

For some of the participants of this study, a professional challenge was the multi-disciplinary team’s pre-bereavement support of the family tailoring off or being passed over to the counsellor in the post-bereavement period. P2, P4 and P6 had experienced staff withdrawing or not appearing comfortable in providing bereavement support, with the reasons given as not having confidence in their own abilities (P6:4); wanting to quickly relieve and take away the pain (P2:12); or expecting the counsellor to offer more in terms of support (P4:4). It was also noted by P4:4 that the staff members’ input into post-bereavement support was not only less, but that the attitude of staff towards the counsellor was more a case of “over to you.” For P2:12 she felt that there was a greater challenge and demand to provide support in the post-bereavement period as, after the death of a child, the professionals external to hospice staff will withdraw from the family, and this withdrawal can make the sense of the child’s absence even greater, with a sense of loneliness being experienced due to the loss of the friendships family members have developed with these professionals. In P7’s experience, the bereaved families’ fear of losing contact with the hospice and its staff was a professional challenge that she has had to manage.

For P6:15, the protracted death of a baby, its impact on herself and the staff and the support staff needed in such cases was a professional and personal challenge. The need for higher management to give recognition and acknowledgment of such difficulties was highlighted as a measure that would go some way in helping staff cope with such a challenge.

With regard to personal challenges of working within a hospice environment P7:14 stated that it made her “look at life very differently”, with the priorities of her life having changed, giving her a heightened sense of how fragile life can be “seeing children in the car without a seatbelt, I want to get out and scream.” P7:14 also described the challenge of saying goodbye to the family after being with them and sharing the intimacy of the child’s death.
4.3.4 Dealing with the Challenges

With staff within the hospice often passing the concerns of the bereaved families on to the counsellor, the participants spoke of educating and training the staff to enable them to feel more confident in providing bereavement support. P2:12 spoke of staff already having knowledge of the grieving process; but for her it was important to get across the message that staff members could “walk alongside these people and support them adequately, you don’t need me for every case.”

P5:2 spoke of empowering staff, supporting them when helping bereaved families, and commented on staff not often recognising that in “off-loading a lot of worries,” the person may be sufficiently supported by simply being listened to, and that often the client may not require more help than what the staff member was already providing.

4.4 Assessment of Families’ Needs during the Pre and Post-Bereavement Periods

Having identified how counsellors implement support throughout the pre and post bereavement periods, I would now like to turn to the subject of assessment of pre and post-bereavement needs, and to present the themes that were developed from engagement with the data and which correlate to the research questions 2 and 3 - how is the pre and post-bereavement assessment of needs being carried out within children’s hospices and what are counsellors thoughts/feelings about the assessment of the needs of children/young people and their families during the pre and post bereavement periods?

This study found that the needs of families during the pre-bereavement period are diverse, including the need for practical help and support as well as emotional support; and therefore the type and levels of support delivered by members of the hospice and community teams are just as diverse - ranging from fun social events and practical help to specific counselling/therapeutic support provided in individual and group formats. Participant (4:3) spoke of the “varying levels” (of support) families have when they first come to the hospice; and Participant (1:4) spoke of monitoring the level of support each family requires, having regular monthly multi-disciplinary meetings in which information
about families was shared and discussed, enabling the counsellor to keep a check on families’ needs and to “share my concerns with other people; see if they have similar concerns.” The rationale for sharing information with the team about families was the fact that support may be required in the form of extra respite visits, or home visits by the social worker or physiotherapist; therefore depending on a family’s concern, a supportive intervention may include the involvement of a member of the team other than the counsellor. Also as pre-bereavement support was delivered by members of the hospice and community teams, informal discussions with team members allowed the counsellor to identify the specific need for counselling (P1:3; P3:4; P5:2; P6:2).

When asked if pre-bereavement needs were assessed, the research participants spoke of an informal gathering of information through discussion with other members of the Care Team about their concerns for the family member (P3:4; P5:2; P6:2); followed by an arranged meeting with the family member to decide whether counselling was needed or not (P1:3; P2:2; P3:4; P6:3).

No pre-existing formal assessment tool to identify the level of support required pre or post bereavement was disclosed by any of the participants in this study. However, individual tools such as the use of genograms (P4:4) genograms particularly used with adolescents (P5:3); Blob Cards to judge a child’s current experiencing (P3:3) and a document displaying various degrees of happiness and sadness on faces used with young children (P2:1) were all mentioned in order to assist the counsellor to gather information and to help the individual highlight the impact their situation was having on them, as well as helping them to identify their feelings and current experiencing.

It was discovered in this study that the assessment of bereavement needs was deemed to be carried out not only by the counsellor but also by other professionals involved with family, often prior to referral to the counselling service.

For P4:2 it was the community team who carried out formal assessments through asking questions and gathering factual information. Therefore, at referral to the counsellor, the level of need (for counselling) had been pre-
determined by other health professionals and this counsellor’s particular way of working was to “hear their story” allowing the person to tell their story, however they wished to tell it, rather than asking questions to establish their needs. Within P6:11’s practice, the assessment of the individual’s need for counselling support was carried out by the G.P or district nurses, with those they identified as being “at risk” of a poorer bereavement outcome being discussed at the weekly multi-disciplinary team meeting, and/or a bereavement referral form completed and sent to the hospice counsellor.

For P1:5 post-bereavement assessment of families’ needs within the community was carried out, but for those already accessing the hospice prior to the child’s death, assessment was not considered necessary as the family would already know of the post bereavement support available to them, assessment therefore being perceived as an information exchange between what supportive strategies were available and the family choosing whether or not to access such support. However, P1:6 at the time of the research interview, was in the process of compiling a bereavement assessment form which listed indicators of the client’s experience such as eating/sleeping patterns, although she was aware of her resistance to a scoring scheme: as: “I guess I don’t like formalising something that is so delicate and er it’s such an intimate and vulnerable time for people.”

Other participants within this study spoke of their own involvement with assessment. For P7:12 the assessment was a constant “visual and verbal assessment” of the bereaved person’s experience, with the counsellor’s awareness of how grieving can affect the individual physically informing that assessment. P3 spoke of assessment being more of a cognitive activity for the counsellor, a process in which she determined the level of support required, whether the level of support could be provided, and whether a referral to another source was needed for the bereaved person.

4.5 Counsellors Feelings and Thoughts on Assessment

When the participants were invited to comment on their immediate thoughts and feelings of assessment, there were divided reactions between negative and positive feelings and thoughts. For participants P1 and P3 their negativity
centred around their own internal feelings, and for P6, how she would feel and be perceived by families:

“…well negative images and thoughts. I suppose that goes back to thinking of being assessed myself so it makes me feel nervous and em, and something like people being put into boxes, that’s another thought I had” (P1:1).

“…reluctance is the word that springs to mind if I’m really honest. The feeling that I may have to funnel people through some sort of process that I may feel is not appropriate – everybody is seen through a process that may not feel that comfortable with me and I guess that is because I am very person-centred (P3:1).

“Right, the word assessment straight off is a sort of clinical, ticky boxy image…coming straight from my mind, it could be a negative thing, it depends who’s doing it and how they are doing it….If I’m honest what comes to mind is if I said I was to sit doing an assessment with someone you know, with a board and pen kind of thing, I would feel more like social workery right, if I’m being honest which, for the majority of clients we have from more difficult backgrounds, dysfunctional families, that’s like a no-no. That would be a barrier before you started.” (P6:1).

For P7 and P4 the counsellor is there firstly to listen to the client’s concerns rather than immediately launching into a series of questions:

“For me and to how we work here, we don’t actually use a written assessment tool at this current time……but when I first meet a family, the first thing I do is sit and let them talk to me.” (P7:2).

“Hearing the family tell their story informs the counsellor rather than questions on a form” (P4:2).

For participants P2; P4 and P5 their immediate reaction to the word assessment was a more positive one:

“Immediately when I think about assessment I think of self-assessment because I am a person-centred counsellor I always start from the position that the client is the expert and so they self-assess...” (P2:1).

“It was part of the structure of working in CAMHS and clinical psychology where there would be educational psychologists and psychologists and psychiatric nurses and psychiatrists and counsellors so I could really see the purpose of it” (P4:1).

“I think it’s building a picture of that person and how the person is presenting and what their perceived needs are” (P5:1).
4.5.1 Informal Assessment

So what form does assessment currently take? Informal assessment by counsellors was described by the participants as a form of measuring progress and being alert to the client’s emotional state. P3:3 expressed a “constant assessing for whether the client is an emotionally safe place” but that assessment was a process going on within her head just as P2 also described assessment as:

“… something through experience that I would do and that’s why I probably didn’t mention it. I do it automatic in my mind (P2:9)

For P7:4 assessment is not a series of questions written down but more of an informal gauging of “emotional states and family dynamics”, whilst also looking out for certain indicators of clients’ distress requiring more specialist help. A report and referral to the counsellor from another member of the nursing team was considered by P6:2 to be an informal assessment of the client’s needs although the participant commented that she did not like too much information about the person or their needs since it can be the “needs of the member of staff to fix it” rather than the person’s actual need.

4.5.2 Formal Assessment

P4:1 described formal assessment as “something very formal and very structured” which was used to match the level of professional skills and expertise with the person’s needs. Formal assessment was regarded by P2:1 as a starting point, a more formal way of working with a particular assessment tool for young children being used at different times. This participant also saw the use of an assessment tool as being not only useful to the counsellor but also an educative instrument which shows the child the impact their situation is having on them and also teaching them how emotions are “free-flowing, not static.” With regard to working with adults, this participant felt that only for those who had difficulty verbalising their feelings would she talk of scales which might indicate the client’s depth of feelings and would not necessarily show them any paper or activity sheet. Participant P4 spoke of community nurses carrying out formal assessments which encompassed the gathering of factual information.
4.5.3 Counsellors Concerns about Assessment

Amongst the participants there were worries about assessing the needs of families. Assessment was perceived as perhaps not capturing the clients’ true feelings (P6:1); and P7:3 speculated on whether the counsellor carrying out an assessment with a series of questions on a sheet of paper would intimidate the individual and compel them to answer the questions rather than freely speak of their own thoughts and feelings. Also P7, whilst acknowledging it as a possible guiding tool, was also concerned about how assessment would be perceived by parents. P2 spoke of children’s hospices’ desire to create a home from home environment for the families as much as possible; and a formal, clinical assessment would be likely to change that environment to one of a hospital setting and perhaps diminish the counselling role:

“A hospice has got to be spontaneous, it has to be fluid, it’s got to meet such complex needs and I think it would be more difficult to have a rigid assessment framework here and it could appear too clinical as well. It could make it medicalised and that may detract from the aims and objectives are as a counsellor (P2:13).

P5 commented that she would not want any assessment tool to be the determinant of the number of counselling sessions a client was offered:

“I wouldn’t want one that said right, tick all the boxes and now add up the score, this score indicates this person will need six sessions or this person will need ten sessions em I wouldn’t want to work in that framework. I don’t think that would be helpful (P5:12).

Assessment carried out by one counsellor and the client being referred to another for counselling within the same service, also posed a dilemma for P5. How much prior information should pass between the assessor and counsellor? For P5:1, client self-disclosure was seen as a potential problem and likely to “skewer the counselling session if you have some information about the person which they then don’t disclose to the counsellor.” In addition, comparing the National Institute for Health & Clinical Excellence guidelines (2004:12) in identifying the various levels of support needed, P5 thought that any bereaved parent could automatically be put into a “high risk” category and therefore in need of level 3 support. However, although P1 and P5 saw assessment within adult hospices as being needed due to the high volume of deaths which occur within them, they did not perceive their particular children’s hospice as needing
an assessment tool for such “gate-keeping” purposes, since not all families were referred to their actual counselling services (P5:12; P1:6).

P3 did not like the idea of the focus of her work being changed in the initial session, from concentrating on the person to looking at some form and ticking the boxes; whilst P1 spoke of assessment setting her up as a person “..with the power”, and felt that assessment would require the counsellor to give to the person being assessed an explanation of its purpose.

4.6 How Assessment could be conducted within Children’s Hospices

This study found that children’s hospice counsellors would want to share their theoretical and practical knowledge with other children’s hospice counsellors and have some input into the introduction of an assessment tool if a more formal assessment tool was to be considered for implementation in their hospice. P5:12 spoke of returning to “grass roots and sharing what they do now,” perceiving any development of an assessment tool that helped match the client’s needs with the resources available, as having a positive purpose. P4 also commented on sharing a dialogue on assessment:

“…with like-minded, not with people with different views but with people working in the area of work rather than being a pure academic exercise that erm ticks the boxes but doesn’t open up the opportunity for debate of how we’ve come to get to that” (P4:9).

P4:9 also highlighted the considerable amount of theoretical knowledge and skills involved in working with children in grief and loss and that an assessment tool that was designed with “…all the collective knowledge of others working in the same field would be wonderful.”

Whatever form the assessment took, participants’ spoke of it needing to be consistent with the professional’s counselling approach. For P3:2, the way to conduct assessment would be in a very person-centred way with the consideration of the wording being, in P7:5’s viewpoint, “imperative…and the questions non-threatening” in a standardized survey used “across the board of children’s hospices and not everybody doing their own thing.”

Clearly, if the existing ways of assessment within children’s hospices were to change and a new model of bereavement assessment introduced to children’s
hospices then the participants of this study, it was discovered, wanted to be part of discussions about potential introduction of any assessment tool to practice across children’s hospices.

Having presented the findings of this study in this chapter I would now like to present the discussion chapter which places the findings within the context of the literature.
Chapter Five – Discussion of Findings

This chapter presents the key themes in relation to the research questions posed within this study. The purpose of this study was to examine children’s hospice counsellors’ practice of the assessment and implementation of pre and post bereavement support within children’s hospices throughout the U.K. This involved looking at the counsellors’ practice within a multi-disciplinary team that delivers medical care and psycho-social support to children/young people with life-limiting/life-threatening conditions and their families, in their own homes and within the palliative care setting of a children’s hospice.

The research has been conducted within a thematic analysis structure, appreciating research participants’ first-hand accounts of the research phenomena, and enabling the findings to reflect their experiences in their own words (Finlay and Evans, 2009:189).

The themes presented and the transparency of the data hopefully offers “specific applicable knowledge” (McLeod, 2011:81) to counsellors within children’s hospices and to those working within the bereavement field.

Within this chapter, the findings from this study will be discussed in relation to the literature review; the study’s limitations will be outlined and possible areas highlighted for further development and research.

5.1. Second phase of study – Semi-structured Interviewing

The second phase of the research study consisted of semi-structured interviews where the three main questions were addressed. With reference to question one, I posed the question - how do children’s hospice counsellors implement a support service during the pre and post bereavement periods and what, if any, are the challenges?

5.1.1 Implementation of Pre-Bereavement Period

One finding of this study was that during the pre-bereavement period, families’ concerns were based not only on the ill child (P4:3) and parents’ needs to share their experiences with others (P2:4), but also involved practical concerns about obtaining equipment, considering adaptations to the house, and concern for the siblings within the family (P1:2; P5:5). Such a range of emotional and practical
issues often requires a combination of supportive interventions, not only from a psychological and counselling perspective, but also interventions from other professionals who make up the multi-disciplinary team, such as the social worker, physiotherapist etc. This finding disputes Randall and Downie’s (1999, 2006) doubts that there is any need for psychological and social intervention as part of specialist palliative and end of life care, and supports Reith & Payne’s (2009) viewpoint that family life can be chaotic during the period leading up to bereavement, which for many families accessing a children’s hospice, may extend over many years. This study also discovered that the delivery of pre-bereavement support involved hospice co-ordinators, nurses, healthcare assistants, family support workers (P1:1; P2:1; P6:5; P4:3) and sibling support workers (P3:5). This extensive combination of medical, social and therapeutic support, this study found, requires all members of the multi-disciplinary team to be actively involved during the pre-bereavement period, with counsellors taking the lead in working with siblings (P2:5; P5:5); parent groups and workshops for parents (P5:5); all of which, according to P6:14, contributes to assisting the family at the end of life stage and through to bereavement care.

This study’s findings of counsellors’ concerns about staff referring perhaps inappropriately or prematurely to the counselling service (P5:5; P6:8) reinforces Relf’s (2008) concern over nursing staff having the time, skills and knowledge needed to conduct assessments. This strongly highlights a case for assessment skills training and for hospice counsellors to become more involved with staff training, where they may need, during the pre-bereavement period, to inform staff as to the nature of counselling and provide training in basic counselling skills, anticipatory grief theory and self-awareness, in order to help staff become more confident in handling issues on death and dying. Emotional support, especially during end of life care, has been stated by Main (2002:795 & 799) to be a “key component” in the subsequent period of grieving, yet if the professionals supporting families “often feel unequipped to deal with issues around death and dying”, then staff referring to the counselling service due to feelings of inadequacy in supporting those about to be bereaved, would, in my opinion, eventually lead to an over-stretching of the counselling service and/or an ad hoc system of support such as Relf (1994) described. Although P2:12
spoke of staff members “walking alongside and supporting adequately” bereaved people, it could equally apply to the pre-bereavement period, with the counsellor having a supportive role in empowering the multi-disciplinary team through education and training and supervision, to support families through the pre-bereavement period and particularly through end of life care. P5:5 spoke of conferring with the staff member prior to accepting the referral in order to determine the reason for referral. This highlights the supportive element of the counsellor’s role within the multi-disciplinary team, whilst also highlighting the danger of colluding with a ‘patching up’ mentality by accepting referrals to the counselling service without determining what is needed and who may be the more appropriate staff member to give support. Also, if the counsellor carries out this assessment that would perhaps go some way towards addressing the concerns of P5:1 over how much information passed between the assessor and counsellor could “skewer the counselling session” if self-disclosure by the client to the assessor was passed to the counsellor and then not raised by the client with the counsellor.

Some further challenges of the pre-bereavement period were identified in this study as counsellors having limited time to give support (P5:5) and not enough staff to give support (P6:8). Although P4:3 spoke of “varying levels of support” and P1:4 spoke of “monitoring the level of support each family requires” by sharing information with other members of the team, these levels of support were not clearly defined. In addition to providing social and fun events for families, assessing more formally the pre-bereavement support needs of families and giving support to those most in need of counselling would conceivably resolve to a degree, the issue of limited time and staff to give support.

The evidence contained within the study’s findings of pre-bereavement support comprising social events as well as counselling support highlights the fact that the rationale for providing pre-bereavement support, certainly within a children’s hospice, is to assist families in providing happy occasions as well as practical and emotional support. This period is not solely about focusing on helping families prepare for the death of their loved one, but as P5:5 commented, it is “about living” and I would further add, finding the joy contained within that living.
To confirm or refute Payne’s (2001) assertion that there is no evidence to suggest the efficacy of pre-bereavement support in preparing people for grief, certainly within children’s hospices, would require an examination of existing longitudinal studies into the impact of pre-bereavement support upon post bereavement functioning, with some measurement being evident of the impact the various social and therapeutic activities have had on the person’s perceived needs and the fulfilment of those needs. I have not been able to identify such research, and therefore an opening for further research into this area can be suggested.

The need of parents to share their experiences with others, as identified by P1:2; P2:4 and P4:3, and the needs of siblings to be recognised as they “live in the shadows of the ill child” (P2:2), would indicate that groups of both a therapeutic and social nature are opportunities to help family members explore and communicate their experiences amongst those whose lives are also affected by disability and illness within the pre-bereavement period. Hence, I would say that knowledge of group dynamics and group facilitation skills are a necessary element of the experienced hospice counsellors’ practice, as is the ability to determine the suitability and readiness of the potential group member to undertake therapeutic group-work.

Additional challenges for counsellors within the pre-bereavement period were varied, ranging from limited time and resources to give support (P4:3; P5:5; P6:8; P7:5) suggesting already over-stretched resources, to the hospices’ catchment size and the distances families had to travel to the hospice for support (P3:6: P6:5). The flexibility of the hospice counsellor to take their supportive role into the home is one way in which the challenge of distance is to an extent met; however, the need to consider supporting clients in more innovative ways such as parents/adolescent forums through the hospice’s website is today, I feel, becoming a more obvious way of meeting the supportive needs of families.

Further challenges for P4:3 P6:8, P7:5 were the assumptions made by staff that previous input by the counsellor during pre-bereavement indicated the availability of support by the counsellor in the post-bereavement period. P1: 11
was of the opinion that a family's response to death could not be predicted and therefore no assumptions about their need for support during bereavement could be made and yet obviously assumptions by staff are being made within some hospices as indicated by the comments of the above participants. P4:4 spoke of her “intuition based upon experience” as a gauge of whether bereavement support was likely to be needed in the future and if counsellors were more proactive in assessing emotional needs during the pre-bereavement period, this would, to some degree I believe, indicate those likely to be in need of general bereavement support and those who may want the additional and specific support of the counsellor. This would aid at least one of the counselling manager’s tasks in meeting the service providers’ demands for evidence of the current and predictive need for the counselling service and making a possible case for increasing its staffing levels.

P1:3 and P3:7’s remarks of previous pre-bereavement work with siblings pointed to the established therapeutic relationship “being helpful” to young people in accessing post-bereavement support, and this supports the rationale for its provision. This may be an indication that where young people may have more difficulties than adults in seeking and asking for help, knowing the counsellor and the service they provide prior to bereavement may make access to counselling support easier during the initial bereavement stage.

5.1.2 Implementation of Post-Bereavement Period

The types of bereavement support ascertained within the Children's Hospices Provision Report (2010) corresponded to the findings within this study. Funeral planning; memorial days; bereavement work with siblings; group-work for parents, grandparents and siblings were all identified as supportive interventions which the counsellor was involved with.

The participants of this study revealed that one of the professional challenges was the staff withdrawal of support after the death of a child/young person and that an attitude of “now over to you” (P4:4) prevailed with the counsellor being perceived as having more to offer in terms of emotional support. The reasons for this withdrawal of support was not only staff not having the confidence in their abilities (P6:4,) but also the need to quickly relieve and take away the pain
Therefore the hospice counsellor could provide some skill training to staff members in ‘staying with’ powerful emotions, empowering them in the support they give during end of life and initial bereavement support. Also, P2 thought that the greater demand on counsellors for support from families was due to the withdrawal of all professionals that had previously been involved in their lives and this, they believed, led to a "greater sense of the child’s absence and loneliness" (P2:12).

Another finding of this study was that the length of time for bereavement support being offered varied between two years (P2:4; P5:9) to there being “no limit” as long as it was of value to the family (P3:13). That there can be a limit to the amount of support being offered in one hospice and no time limit in another, highlights the variation in the amount of bereavement care being offered within children’s hospices and yet as Relf, Machin and Archer (2010:6) pointed out, only support for those who are “at risk” or finding their grief challenging seems to be beneficial.

Having had the opportunity to examine the aspects of pre and post bereavement support provided within children’s hospices, the major finding which gripped my attention, was the challenge around assessment of this support - the counsellors’ perceptions of assessment, their views and concerns about the format and delivery of assessment and its place in practice within children's hospices. I will focus upon these specific findings.

5.2 Assessment of Needs

The further two research questions related to assessing pre and post bereavement needs were posed within this study:

- How is the assessment of needs being carried out within children’s hospices?
- How do counsellors feel about assessing needs during the pre and post bereavement periods?

5.2.1 How Assessment of Pre-Bereavement Needs is Conducted

No formal model of assessment was indicated in the participants’ responses, although Relf et al (2008) proposed the use of Machin’s (2009) Range of
Response to Loss Model as an assessment framework, which Agnew et al (2010) referred to as a possible means to:

“...inform the development of documentation for continuous assessment from the point of admission into early bereavement.”

(Agnew et al 2010, p.6)

Continuous assessment is not possible within children’s hospices. The difference between an adult and children’s hospice is that the period between admission to the hospice’s services and bereavement can extend over many years in a children’s hospice. The children's hospice service provides, in addition to end of life care, regular respite visits where the child/young person and their family can stay and use all of the hospice’s facilities, with medical staff providing one to one nursing care for the child/young person. Hence, the pre-bereavement assessment of a child/young person’s support needs within a children's hospice is unlike that of an adult hospice, where death is expected within a relatively short space of time. The majority of assessments within children's hospices capture any changes to the child/young person's medical/social/emotional needs at the particular point of admission to the hospice for respite, so the child/young person may be far from the end of life stage.

That pre-bereavement assessment of the child/young person’s needs is carried out on admission by medical staff raises the question of the competence of staff to assess needs other than medical needs. Jeffrey (2003) refers not only to the physical needs of the person but also the psychological, social and spiritual needs, and the need to work within the limits of the multi-disciplinary team’s areas of professional competence. This would suggest that more professionals within their own spheres of expertise should be involved with assessment of the various needs. Therefore, is there an opportunity for counsellors to become more involved in the pre-bereavement assessment of emotional needs during the individual's stay at the hospice? Perhaps incorporating the family's support needs into the assessment or carrying out an additional assessment of families’ needs may lead to a more responsive shaping and delivery of pre-bereavement support. Also, sharing the carrying out of assessments, with the counsellor
focusing upon the emotional needs, might address the issue that centres around informed consent, of Relf & Payne's (2009:6) concern of relatives’ “unawareness of being assessed and staff's hesitancy in asking intrusive questions.”

5.2.2 How Assessment of Post-Bereavement Needs is Conducted

With the delivery of support being shared amongst the hospice and community teams, the assessment of bereavement needs was being carried out by professionals other than the counsellor. On further exploration of the nature of these assessments, it was discovered that they consisted mainly of community teams gathering basic factual information and then referring to the counsellor; but little information was put forward by the participants as to what, if any, assessment model was being used by the community teams to determine the individual’s level of need for support. It was revealed that doctors and district nurses were identifying individuals as being “at risk” of a poorer bereavement outcome and referring to the counsellor (P6:11), suggesting that Parkes and Weiss’s (1983) Bereavement Risk Index, which looks at assessing the vulnerability and probability of poor bereavement outcome, might be being referred to. It was revealed within the literature review that a risk factor approach does not, according to Stroebe et al (2006:2441), take into account the “processes that impede or facilitate adjustment”; and “faulty conclusions” can be drawn from a failure to recognise the interaction between factors or “coping variables” (Wijngaards-de Meij et al 2005 cited in Stroebe et al 2006:2448). The National Institute for Health & Clinical Excellence guidelines (2004) also suggest that “risk assessment tools cannot be relied upon as a predictor of outcome” (p.169). However, Stroebe et al (2006:2449) proposed the use of an “integrative risk factor framework”, which incorporates not only the intra and interpersonal factors in bereavement adjustment, but also appraisal and the coping processes that contribute to bereavement outcome. The framework, the authors added, would be “difficult to test as a whole simply because it is so comprehensive” (p, 2449).

For P1:5, only assessment of bereavement needs within the community was being carried out, since it was deemed that those families already known to the
hospice would already know of the hospice’s bereavement support and how to access it if it was required. However, P1:6 was, at the time of the interview, in the process of compiling a more detailed bereavement assessment form which would highlight the client’s current experiencing of grief and its impact upon them. The findings of this study indicate that very basic bereavement assessments are being carried out by an array of professionals; yet it remains unclear as to what the assessments are being based upon and this supports Payne’s (2001:108) view that “judgements about potential need for support is being based upon clinical opinions rather than predefined criteria” (p.108).” In addition to this, these findings reflect the ambiguity that exists in carrying out bereavement assessments, since Agnew et al (2010:3) could not, after searching through UK policy guidance documents, find any approaches for conducting bereavement risk assessment.

That it remains unclear as to how other professionals determine what constitutes a referral to the hospice counselling service post-bereavement during the initial stages of grieving poses a challenge for counsellors providing support. This study revealed that some counsellors found that it was not uncommon for parents to feel like they wanted to be with their child after death and it could be that the expression of such feelings by the family member may initiate concern by other members of the team and immediate referral to the counsellor. Again, this indicates the possibility of the need for further training and supervision of staff members within the hospice on the grieving process as experienced by bereaved parents, in order that staff are able to feel more competent in identifying grief reactions and staying with a bereaved person and their initial and sometimes overwhelming feelings and thoughts surrounding death and dying rather than feeling “unequipped” as Main (2002:799) suggests they feel and referring them, perhaps inappropriately, on to the counsellor. Furthermore, it is my opinion that if an assessment tool that reflects a theoretical understanding of the parental grieving process was implemented across children’s hospices, then this could provide clarity to hospice staff members and other health professionals sharing the delivery of post-bereavement support, making referral to the counselling service more accurate in matching level of need to the level of professional support available.
5.3 Counsellors’ Thoughts/Feelings on Assessment

The remaining research question was explored within this study - how do counsellors feel about assessing needs during the pre and post bereavement periods?

5.3.1 Initial Reactions to the Term “Assessment”

It was discovered during the research interviews that the participants’ immediate thoughts on assessment were a blend of negative and positive deliberations. Negative views of the process of assessment centred on how counsellors themselves felt about being assessed and secondly, how they as counsellors, would be perceived by families. P1:1 could relate assessment to her own feelings of nervousness at being assessed and how it felt like it was “putting people into boxes” whilst the image of “funnelling people through a process”, did not feel congruent with P3’s theoretical orientation (P3:1). Thinking that assessment was a very “clinical, ticky boxy image and social workery thing to do” P6 thought that conducting more structured assessments would not be perceived by clients as being helpful, a definite “no-no” (P6:1).

Obviously, where a large number of deaths occur annually, such as within an adult hospice, the demand for support is greater than within a children’s hospice, which on average, within my own hospice, sees approximately 20 deaths a year. So where there are large numbers of bereaved people wanting various levels of support, some system surely has to be instigated whereby those levels of support are matched to the most appropriate person that can provide the level of support required. I concur with Relf, Machin & Archer (2008:2) that making “best use of our bereavement services” means “offer(ing) the right help to the right people.”

It is my opinion that children’s hospices, due to the lower level of demand for bereavement support, compared to that of an adult hospice, have had the luxury of being able to respond to all those who have wanted support, whether that has been in the form of bereavement support or counselling. However, the danger of accepting all referrals to the counselling service without discerning what level of support is needed could potentially be viewed as perhaps collusion with the pathologising of grief. Just as the inclusion of prolonged grief as a
disorder in the American Diagnostic and Statistical Manuel of Mental Disorders, Granek and O'Rourke (2012) suggest, will promote fears that more people’s grief will be diagnosed as abnormal or extreme, so too the offer of counselling to those who are not in need of the skills of a counsellor could be seen as dis-empowering to the individual’s own coping abilities.

Another entry from my personal journal revealed my own thoughts on assessment:

“As counsellors, do we sit rather too comfortably between the medic and the cleric, giving out our own brand of support without questioning and discerning more fully what level of support is required and whom amongst the multi-disciplinary team, is the most suitable staff member to provide comfort and reassurance to those bereft of their loved ones? Are we as practitioners, in not examining the ways in which we and other members of our team assess the needs of those who access a children’s hospice (as part of our overall evaluation), guilty of making assumptions as Payne (2001) suggests and going on what we think is needed rather than on providing what is actually required? Could we in some way perhaps, be diluting our service in under-playing our professional expertise or not being proactive enough in leading on the training and supervising of health professionals who are with families at the traumatic time of loss?”

(Personal Journal, January 2012)

On a more positive note, informal assessment was viewed by other participants as a two-way process whereby the counsellor is “building a picture” of what the client perceives as needing (P5:1) and the person themselves defining what they need (P2:1). For P7 and P4, allowing the client to talk and for the counsellor to hear “their story”, rather than being directed by a series of questions (P4:2), was the focus of the initial session.

In conducting the research I found that counsellors viewed informal assessment as something they did “automatic in my mind” (P2:9); a “process going on in my head” (P3:3); a “gauging of emotional states and family dynamics” (P7:4). A more formal, pictorial assessment that in some way identified and measured feelings was viewed by P2:1 as an “educative instrument” for children and helpful for those adults who found verbalising feelings difficult. It might be said then, that the format of the assessment and how assessments are carried out are important aspects of practice for counsellors.
5.3.2 Concerns about Assessment within Children’s Hospices

The majority of concerns about assessment were that a battery of questions could intimidate and force answers that did not capture the individual’s true feelings (P6:1) or could curtail the individual’s freedom to directly speak of their own thoughts and feelings (P7:3). The uniqueness of a children’s hospice, where staff endeavour to recreate a home from home relaxed atmosphere, produced fears that any assessment framework would be rigid and appear too clinical (P2:14). However, I would argue that children’s hospice counsellors already work in a setting that is staffed by highly qualified medical staff, and whilst we all strive to create informality that families perceive as homely, our practice need not dismiss assessment as being incongruent within a children’s hospice.

The managing of a professional service is a demanding task, in meeting the requirements of the service user whilst taking into account the demands from service providers to deliver an efficient and effective service through targeting resources. Assessment of pre and post bereavement needs, I believe, would aid that process, so that those in most need would be able to get the right kind of help when they needed it. Furthermore, it has been established within this study that informal assessment already takes place. I believe we can incorporate a more structured assessment framework that would aid us as practitioners to more readily identify the needs of the diverse client groups - children, young people, parents - and make the delivery of pre and post bereavement support more efficient in providing a tiered system of support matching the level of need required with the most appropriately skilled staff member.

In support of assessment, it was identified in this study’s literature review that the National Institute for Health & Clinical Excellence guidelines (2004) suggest all bereavement services should have assessment methods in place (Agnew et al 2010:3). However, it is my opinion that any implementation of an assessment model for practitioners requires prior consideration and consultation with members of any bereavement service and, particularly in the case of children’s hospices, the multi-disciplinary team. Also, the question of who would be the most appropriate professional to carry out the assessment of families’
emotional/bereavement needs, and how well and harmoniously the particular assessment model would sit within the counsellor’s approach and practice, would require further deliberation. Pilot studies of an assessment model in practice may help inform practitioners and further develop new ways of practice in the assessment of bereavement needs.

5.3.3 The Transferability of a Bereavement Needs Assessment Tool to a Children’s Hospice

One of this study’s findings was that children’ hospice counsellors were more involved in assessing bereavement needs than in assessing needs during the pre-bereavement period, although doctors, district nurses and community teams were making decisions and referring individuals to the hospices’ counselling service after some assessment of the bereaved person’s need for professional support. This study did not look into how these particular professionals carried out assessment and what tools were being employed. However, the assessments carried out by counsellors within children’s hospices were described as “a constant visual and verbal assessment” (P7:12); perceived as the gathering of information using genograms (P4:4; P5:3) and assessment sheets recording eating and sleeping patterns (P1:6) and Blob Cards for children (P3:3). Also for P3, assessment was a cognitive process for the counsellor, whereby in her mind she determined whether she could help the client or not.

According to The National Institute for Health & Clinical Excellence guidelines (2004:169), the prediction of bereavement outcome cannot be relied upon where that assessment has only taken into account risk factors. There has been an expansion of bereavement literature in focusing not only on the vulnerability in bereavement and risk factors, such as those contained within Parkes and Weiss’ (1983) Bereavement Risk Index, assessing the probability of poor bereavement outcome, but also upon the factors promoting resilience and which facilitate adjustment to loss (Stroebe, Schut and Stroebe 2007). Since, as Stroebe, Schut and Stroebe (2007:1968) comment, “many risk factors have been under researched” and how they relate to outcome “remains to be seen”, predicting bereavement outcome is difficult. However, in promoting our
understanding of a person’s journey through their grief, a new model has emerged for practitioners working in the bereavement field - Machin’s (2009) Range of Response to Loss Model, which was developed from the views of bereaved people (Machin, 1980) and counselling practice (Machin, 2009). I believe it is a flexible and relatable model that counsellors working within children’s hospices could apply within their own practice. By ‘relatable’, I mean in terms of it being understandable to both practitioners and clients. Practitioners can relate this model to other theories of grief such as Stroebe and Schut’s (1999) Dual Process Model of Grief which, for myself working with bereaved parents, has aided my own and my clients’ understanding of grief, and how it is manifest within the individual’s experience.

The Response to Loss Model is also a model which has emerged from the descriptions of other bereaved individuals and therefore the three broad reactions of grief, that of being overwhelmed, balanced/resilient or controlled, are ones which clients, on their journey through grief, can easily identify with. If, as the National Institute for Health & Clinical Excellence (2004:169) guidelines state, “clinical judgement is currently the most effective way of identifying those at risk” or maybe that should read, most in need of support, then I personally need my judgements about other people’s grief to come not only from listening to the client but also having the confidence that the theoretical knowledge and models I refer to, stem from the actual findings of research with bereaved individuals.

My overall findings on the subject of assessment within children’s hospices were that counsellors do informally assess the pre and post bereavement needs of their clients through self-assessment and informal discussion. However, my conclusion is that we, as children’s hospice counsellors, and I include myself here, in the area of assessment, have the challenge of assessing needs that not only fit with our counselling approach but also fit into a children’s hospice environment, where families expect a professional service within a homely environment. There is much a children’s hospice counsellor can offer in terms of educating and training nursing staff in becoming more confident in supporting children/young people and adults during both the pre and post bereavement periods. However, before we can offer support to other professionals in
assessing needs, we first have to grapple with assessment frameworks that, like certain grief models, are appropriate to working with bereaved parents, bereaved children and bereaved adolescents.

In addition, exploration within this research study of how counsellors assess, brought with it discussion of the challenges such as the particular format and delivery of assessment within the setting of a children’s hospice. Whilst I noted during the interviews the participants’ various reactions to the hypothetical scenario I put to them - of the implementation of a more formal assessment tool within a children’s hospice, the research participants did not dismiss outright the concept of a more formal assessment tool being used. Rather, what I discovered by the end of each research interview was that the participants became interested and keen to look at and become engaged in a dialogue about how an assessment tool could work within a children’s hospice, an assessment tool that was designed with “...all the collective knowledge of others working in the same field would be wonderful (P4:9), consistent with the practitioner’s counselling approach (P3:2), an assessment tool that was used “across the board of children’s hospices and not everybody doing their own thing .”

In line with the National Institute for Health & Clinical Excellence (2004) guidance that all bereavement services should have assessment methods in place; and taking into account that current bereavement literature has highlighted resilience as well as risk factors being an important factor in bereavement outcome and that new models for understanding how people cope with loss, such as Machin’s (2009) Range of Response to Loss Model have been developed, I believe this study has highlighted that there is possible further scope to develop counselling practice in assessing bereavement needs that meets the challenge of finite resources being directed at those most in need of support.

Drapeau (2002) drew attention to any research project being influenced by the internal motivations of the researcher and Chew-Graham et al (2002:288) also warned of creating within the research relationship, “a case of shared conceptual blindness allowing the interviewer’s own feelings and opinions about
the field to govern the dialogue and interpretation.” The researcher’s own positivity on the subject of assessment could have influenced the participants’ responses; however, being an experienced counsellor myself, and being familiar with suspending my own thoughts and feelings within counselling sessions, I think I was able to do the same within the interviews. Also, in recording my own thoughts, feelings and biases about the subject within a personal journal, I believe the interview was centrally focused upon the participants’ perspectives and that their positivity towards the use of an assessment tool were genuine responses to the subject of assessment and how they felt about it within their own practice.

5.4 Study’s Limitations

This study has not addressed the efficacy or efficiency of counselling support services within children’s hospices – only its methods of assessment and implementation. In undertaking this exploration of counsellors’ practice, I was taken by surprise by the fact that counsellors are not more widely employed to deliver a support service. My assumption, based upon my professional connections with local children’s hospices, was that I would obtain a good number of counsellors/participants for my study. That other professionals such as social workers and senior nurses are employed to deliver emotional support impacted upon my sample size, reducing it considerably. Therefore, no generalisations can be made in this study regarding the overall delivery of pre and post bereavement support within children’s hospices throughout the U.K. Had this study been opened up to include all professionals having a responsibility for delivery of pre and post-bereavement support, a more encompassing perspective and in-depth report may have been provided. Also, had it been realised sooner that bereavement needs assessment was being carried out by community teams as well as other professionals, not just the hospice counsellor, introducing another group of professionals into the study might have expanded the current picture of how assessment of bereavement needs are being conducted. However, the initial focus of the study was on the implementation of pre and post-bereavement support by counsellors alone, with assessment being a significant part of, but not the entire focal point of the research enquiry. This study used purposive sampling in order to gain insight
and deeper understanding of how children’s hospice counsellors assess needs and implement a support service. This sample consisted of all white, British female counsellors, which could be considered a limitation of the study since culturally, the research study represents only their perceptions and does not reflect the rich, diverse world-views of counsellors from other ethnic backgrounds, which might have expanded this study’s findings. However, the sample criteria was designed to be inclusive of all qualified counsellors from any ethnic background, female and male, aged between 18-65 and working within the U.K as a children’s hospice counsellor. The findings of this study, I believe, have been kept in context and reflect the voices and world-views of the participants and their professional practice.

Also, regrettably, in the current economic climate financial and time constraints did not enable me to expand my sample criteria to include all professionals who deliver pre and post bereavement support within children’s hospices, and such constraints will always influence the scale and scope of any research a single independent researcher can pursue. I believe therefore, the way to push practitioner-researcher studies forward is to progress one’s findings through the auspices of the organisation the researcher is employed by, and/or to approach for funding the larger professional bodies that collectively and nationally represent the researcher’s organisation.

In hindsight, conducting the interviews where each participant worked, i.e. the children’s hospice, was, in the context of collecting the data, not perhaps the ideal place, since two of the hospices on the day of the actual interviews had experienced the death of a child, and I was very conscious of the fact that the counsellor/research participant, could have been called to attend to the bereaved families. As a hospice counsellor myself, and being familiar with the dynamics of a hospice working environment, I was fully aware of the particular involvement and demands made upon the counsellor at such times, and I was fully prepared to re-schedule the interviews had the need arose. However, I owe a debt of gratitude to all the participants, as they did all they could to ensure that there were no interruptions during the interviews. I think that for many people unfamiliar with visiting hospices, it can be a very daunting prospect to enter such a building, and I was at an advantage as an interviewer
in that I felt more relaxed conducting the interviews within the participants’ workplace. However, I should perhaps have given my participants the option of being interviewed in their own home, where they might have felt more comfortable, rather than the workplace.

Personally, there was a slight feeling of discomfort with my status as a researcher interviewing people who were fellow professionals within the same field as myself, some of whom were part of my professional network. It was sometimes difficult to stay focused on the fact that the interview was specifically research focused and not slip into a more casual dialogue between colleagues; but the time boundary of 90 minutes per interview helped with this. I was also very conscious of the fact that as a practitioner/researcher, bias could have crept into the interviews; but the fact that I was alert to my own issues relating to working in this area and writing of them within a personal journal, reduced to a certain extent, I think, their impact on the research process. Also, I attempted to minimise the potential for bias through verifying my understanding during the interviews and ensuring that the participants were satisfied with the accuracy of their transcription. During the analysis of the data I referred to a colleague who did not work within the counselling or bereavement sphere, in order to check out my interpretation of the data.

Initially in the role of researcher, I did not like the feeling of being the instigator of a process which called upon me to proactively seek out others and to ask them for their time. As a counsellor, I am more familiar and comfortable with people approaching me for help, and whilst it is in another context, the task of asking people to help me made me feel slightly anxious and uncomfortable. As the research study progressed, I felt I became more confident in my approach and I did not have any difficulties in asking all participants to verify the accuracy of the transcripts before I undertook data analysis and requested they look over the findings chapter of this study. My initial hesitancy may have impacted to a degree upon the interview and perhaps a more assured approach would have resulted in more engagement and extracted more data from the participants.

Data analysis proved sometimes difficult in terms of ensuring I had a sufficient stretch of uninterrupted time to fully immerse myself in the data, although one of
the strengths I will profess to own is the ability to identify and group together common themes amongst huge amounts of data. The interview schedule and the questions posed, I think, proved useful in providing some structure and a starting point in the analysis, allowing me to focus on the research participants’ responses and subsequently grouping the similarities together to form themes. I remember thinking at the time of transcribing the interviews that I missed several opportunities to more fully open up the discussions, but I asked each participant, when requesting them to verify the accuracy of the transcript, whether they wished me to amend, add or delete anything they were not happy with. I believe this gave them a certain degree of control over their contribution to this study.

Carrying out this research has had both a positive and negative impact upon me. It has highlighted to my hospice’s board of trustees how committed I am to developing the counselling service within the hospice, and I believe it has raised their awareness of the support that is being delivered. The negative impact has been the virtual overthrow of the work/life balance since my research has centred on my full-time work and studying has taken up a considerable amount of personal time and annual leave to reach this stage. The result of this is a tiredness that will require some months of rest before I consider further progression of my study. However, I would not have changed this experience and the benefits of working as a researcher in exploring counsellors’ experiences of practice within children’s hospices and producing a piece of work which I believe is unique and makes a contribution to knowledge in practice has outweighed the challenges.

5.5 Strengths of the Research Study

This study set out to establish what McLeod (1999:205) described as “knowledge in context” rather than a “universal truth”; therefore I believe the strength of this research study lies in the fact that it is grounded in the experiences and practice of counsellors who have the responsibility of implementing a support service and assessing the needs of children/young people and their families who access a children’s hospice during the pre and post-bereavement periods. This knowledge may help to inform and have
implications for practice for those already working within this specific environment and for those counsellors working with individuals in generic settings and private practice, who are facing bereavement, or who have been bereaved.

Whilst the sample size was small, it can claim to be a country-wide study, and since many who deliver bereavement support within children’s hospices have dual roles, the sample represented a high proportion of counsellors that are employed within the hospices’ multi-disciplinary teams. I believe I was perceived as trustworthy and that I created a safe environment which allowed the participants to talk freely about their practice without any defensiveness. I hope that this research study will evolve into further action research being undertaken into the assessment of pre and post-bereavement needs carried out by other professionals within a children’s hospice multi-disciplinary team and other settings which provide such support. Moreover, I would like to think that in the not too far distant future, publishing some research findings will promote critical discussion amongst practitioners as to what constitutes best practice within the area of assessment of pre and post bereavement needs.

Having discussed this study’s findings in relation to the literature review, I would now like to summarise the main conclusions drawn and highlight certain areas that could be developed through training and further research in the bereavement field.
Chapter Six: Conclusion and Implications

This study set out to examine children’s hospice counsellors’ practice of assessing the needs of families and implementing pre and post bereavement support within children’s hospices throughout the U.K. It was discovered that the identification of the emotional needs during the pre-bereavement stage, of the child/young person accessing a hospice service, is encompassed within a much larger holistic assessment of the individual’s medical, social and spiritual needs, and was carried out by staff members of the multi-disciplinary team other than the counsellor.

What resulted from conducting this research was the raising of more questions about those who currently carry out pre-bereavement assessment of the child’s/young person’s needs. Are hospice staff sufficiently equipped and trained to identify the level of psychological support the child/young person may require? How do staff members determine the level of support required and how do they know when it is appropriate to refer to the counselling service?

6.1. Implications from the Findings of Pre-Bereavement Support

Is there a case for the assessment of psycho-social/spiritual needs being separated from the existing hospice assessment carried out by medical staff and conducted by the professional who has the responsibility for providing their particular branch of support within the hospice? Furthermore, should this assessment include defining the family members’ needs, since the term holistic could not only be interpreted as encompassing all of the child’s/young person’s psycho-social needs but also the needs of his/her family who are also invited to involve themselves in the activities offered by the hospices’ support services. Should there be two separate assessments – one for the child/young person and the other for the family members’ needs?

If a proactive approach were to be adopted by counsellors in carrying out a separate assessment of psychological/emotional needs, it could benefit the support service twofold. Firstly, counsellors would be able to meet with and introduce the families to the type and levels of support available - this would serve to distinguish counselling activities from other forms of support offered by hospice staff. Secondly, in carrying out pre-bereavement assessment of the
psychological needs, this would perhaps more clearly target and match the level of need with the level of support required during the pre-bereavement period. I recommend that these questions should, perhaps through publication within a relevant professional journal, be opened up for debate amongst staff working within children’s hospices.

Opening up such discussions may encourage further deliberation upon and further research into an appropriate assessment framework that would be feasible to use in the pre-bereavement stage. This framework would need to aid the practitioner’s understanding of the coping mechanisms employed by children/young people and adults in the face of such pre-bereavement issues as anticipatory grief and managing gradual loss of functioning, of well-being, of a “normal” life etc.

Also, from this study’s findings arose the question of the transferability of a bereavement needs assessment tool to a children’s hospice, and within this study’s literature review, Machin’s (2009) Range of Response to Loss Model and Adult Attitude to Grief Scale was identified as a model and tool that could possibly sit very well within children’s hospices. Furthermore, Machin’s (2009) model could possibly be useful not only at the bereavement stage but also in the pre-bereavement period. Further action research involving children’s hospice staff piloting this particular model and engaging the staff in evaluating its usefulness within practice through perhaps staff focus groups, could be the next step in progressing the findings of this particular study. Without a more formal method of assessing pre-bereavement needs, the existing practice of staff referring without reference to a common assessment framework, inevitably means the challenges of inappropriate referral to counselling and the demands made upon the counsellors’ time which the participants of this study identified, will unfortunately continue.

Several findings of this study strongly indicated a case for hospice counsellors becoming more involved with supporting hospice staff through supervision and providing training where they may need, during the pre-bereavement period, to raise an awareness of and training in basic counselling skills, anticipatory grief theory and self-awareness, in order to assist staff to become more confident in
handling issues on death and dying and subsequently providing a more clearly defined tiered system of pre-bereavement support within the hospice.

Initial counsellor training courses could be expanded to raise future counsellors’ awareness of the particular models of grief which attempt to aid understanding of how grief can be experienced by client groups such as bereaved parents, children, adolescents etc., thereby increasing their capacity to enter working environments where the counsellor is available to give support during end of life care, and support nurses supporting families through the loss of their loved one.

6.2 Implications from the Findings of Post-Bereavement Support

It was established in this study that during the bereavement stage, assessment of bereavement needs was being carried out by an assortment of professionals and since this study did not include professionals other than counsellors, it remains unclear as to what criteria are being used to determine the potential need for bereavement support. Therefore the study’s findings would suggest that there may be a call for further training in assessment of bereavement needs for professionals such as hospital staff and community health teams giving advice and initial bereavement support to families. In addition to this, training in grief theory, communication skills and the provision of supervision for hospice staff is indicated in order that staff develop their skills, feel more proficient and feel less isolated in supporting grieving families when a loved one is dying or has died.

The implications from this research study would suggest that our hospice support services may well benefit from a more robust system of assessment of the pre and post bereavement needs of those children/young people and families who access a children’s hospice. If a common needs assessment framework for identifying the need for pre and post bereavement support was piloted within children’s hospices, this potentially would not only prove to service providers that resources were being used efficiently but more importantly, would ensure, in the words of Relf, Machin and Archer (2008:2) that “the right people get the right help” and at the right time for them.
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Appendices

Appendix I – Participant Information Sheet 1

Appendix II – Consent Form I

Appendix III – Survey

Appendix IV – Participant Information Sheet II

Appendix V – Consent Form II

Appendix VI – Interview Schedule

Appendix VII – Data Analysis Process
Appendix I

Participant Information Sheet I
You are being invited to take part in a research study as part of a Doctorate in Counselling Course. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Who will conduct the research?

Christine Buscombe, School of Education, University of Manchester, Oxford Road, Manchester

Title of the Research

“How do counsellors assess and implement pre and post bereavement support to children/young people and their families within a children’s hospice service?”

What is the aim of the research?

The overall aim of the research is to capture counsellors’ experiences of practice within a children’s hospice and how they assess and deliver support to all those who access the hospice during the pre and post bereavement periods. For the first phase of the study the aim is to obtain a broad picture of what support services are available, who provides the support and what methods of assessment, if any, are used.
Why have I been chosen?

The on-line survey which you have been asked to complete has been sent to all Heads of Care within children’s hospices throughout the U.K with the request that they direct the survey to those within their organisation who currently provide pre and post bereavement support to children/young people and their families who access your hospice.

What would I be asked to do if I took part?

You will be asked to complete a short on-line survey which should take no longer than 15 minutes to fill in.

What happens to the data collected?

The data will used to provide a broad picture of the pre and post bereavement support services available and the level of training/counselling background of the professionals delivering this support within children’s hospices throughout the U.K This information will be presented within a written thesis.

How is confidentiality maintained?

Confidentiality will be maintained throughout the course of this research. The use of pseudonyms will be used as a means of breaking the link between data and identifiable individuals. The data will be stored within a locked cabinet at the researcher’s home. All data will be held for two years after confirmation of the degree result. All paper data will be shredded and audio recordings deleted.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

Will I be paid for participating in the research?

No - your participation is entirely voluntary
What is the duration of this part of the research?

The short survey should take no longer than 15-20 minutes to complete.

Will the outcomes of the research be published?

The outcome of this research may be published at a later date within relevant professional healthcare journals.

Criminal Records Check (if applicable)

I work full-time as a children’s hospice counsellor and therefore undergo a mandatory enhanced criminal records check every three years.

Contact for further information

Should you require further information I may be contacted at work: 0151-334-4626, email: chris@claire-house.org.uk

What if something goes wrong?

If you wish to discuss any problem arising from participation in the research study you may contact myself or my research supervisors Dr Clare Lennie or Dr William West at any time

Chris Buscombe (Researcher) Work Tel: 0151 334 4626

Dr Clare Lennie (Research Supervisor) Tel: 0161-275-8627

Dr William West (Research Supervisor) Tel: 0161-275-3397

If you wish to make a formal complaint about the conduct of this research please contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.
Appendix II

Consent Form I

If you are happy to participate please complete and sign the consent form below

I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to any treatment/service.

I agree that data collected from the survey may be presented in the written thesis.

I agree to take part in the above project

Name of Participant                            Date                 Signature

.............................................................................................................................

Name of Researcher                          Date                  Signature
Appendix III

Research Survey
Please complete this survey by XXXXXX and return to:
chris@claire-house.org.uk

Please click in the shaded areas to type your answers.

Title

First Name

Surname

Address Line 1

Address Line 2

Address Line 3

Postcode

Telephone:

Mobile:

Email:

Professional role within the hospice:

☐ Counsellor
☐ Social Worker
☒ Senior Nurse

☐ Other

If a counsellor, what is your model of counselling?

Qualification Level

☐ PhD
☐ Masters
☐ Degree

☐ Diploma
Assessment of clients’ needs

Do you carry out assessment of pre-bereavement needs? □Yes □No

If yes, with which client group?
☐ Children ☐ Young People ☐ Parents ☐ Other

Do you carry out assessment of post-bereavement needs?
☐ Yes ☐ No

If yes, with which client group?
☐ Children ☐ Young People ☐ Parents ☐ Other

If you carry out assessment of pre and post bereavement needs, what assessment tools/frameworks do you use?

Do you give your permission for the above information to be used as data in this study?
Yes ☐ No ☐

Of the surveys returned, ten will be chosen for phase two. Should your surveys be selected, would you be willing to participate in a research interview? Yes ☐ No ☐
Appendix IV

Participant Information Sheet II
Thank you for participating in phase one of my research study by completing the on-line survey. You are now being invited to take part in phase two of a research study. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take further part in the study. Thank you for reading this.

Who will conduct the research?
Christine Buscombe, School of Education, University of Manchester, Oxford Road, Manchester

Title of the Research
“How do counsellors assess and implement pre and post bereavement support to children/young people and their families within a children’s hospice service?”

What is the aim of the research?
The aim of the research is to capture counsellors’ experiences of practice within a children’s hospice and how they assess and implement support to all those who access the hospice during the pre and post bereavement periods.

Why have I been chosen?
You have been chosen as you are currently highlighted within the Association of Children’s Hospices UK’s address list as a healthcare professional working
within a children’s hospice. Nine other participants, all experienced children’s hospice professionals, will be involved in this the second phase of the research study.

What would I be asked to do if I took part?

I will telephone you to arrange a mutually convenient time and date for an audio-taped interview of approx. 90 minutes to take place in your own hospice if this is acceptable to you and the hospice management. After the interview I will provide you with a transcript for your perusal and verification of its accuracy. No analysis of the data will take place until I receive confirmation of your satisfaction with the data gathered.

What happens to the data collected?

The data will be analysed using Thematic Analysis in which the data is initially coded and then grouped into themes. These themes will then be presented within a written thesis.

How is confidentiality maintained?

Confidentiality will be maintained throughout the course of this research. The use of pseudonyms will be used as a means of breaking the link between data and identifiable individuals. The data will be stored within a locked cabinet at the researcher’s home. All data will be held for two years after confirmation of the degree result. All paper data will be shredded and audio recordings deleted.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

Will I be paid for participating in the research?

No - your participation is entirely voluntary.

What is the duration of the research interview?
The interview will be a maximum of 90 minutes.

What if I become upset during the interview?

During the interview, if you, for any reason, you wish to stop the discussion, the audio recording will turned off. If you become distressed my priority will be your well-being and sufficient time will be given to debrief. I feel confident in dealing with high emotions given my experience in bereavement work and my training as a counsellor.

Where will the research be conducted?

Within your hospice setting.

Will the outcomes of the research be published?

The outcome of this research may be published at a later date within relevant professional healthcare journals.

Criminal Records Check (if applicable)

I work full-time as a children’s hospice counsellor and therefore undergo a mandatory enhanced criminal records check every three years.

Contact for further information

Should you require further information I may be contacted at work: 0151-334-4626, email: chris@claire-house.org.uk

What if something goes wrong?

If you wish to discuss any problem arising from participation in the research study you may contact myself or my research supervisors Dr Clare Lennie or Dr William West at any time

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If you wish to make a formal complaint about the conduct of this research please contact the Head of the Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL.
Appendix V

Consent Form II

If you are happy to participate please complete and sign the consent form below

I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.

I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to any treatment/service.

I understand that the interviews will be audio-recorded

I agree to the use of anonymous quotes
I agree to take part in the above project

<table>
<thead>
<tr>
<th>Name of participant</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of person taking consent</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>
Appendix VI

Interview Schedule
1. Given that assessment may be formal and informal, what is your experience of/how do you assess the emotional needs of children/young people and adults accessing your hospice during the pre-bereavement period?
2. How do you implement the levels of support offered to the various client groups during the pre-bereavement period?
3. What is your experience of/how do you assess the emotional needs of children/young people and adults during the post bereavement period?
4. How do you implement the levels of support offered to the various client groups based upon your assessment of their post bereavement needs?
5. Are there any particular factors you believe any formal assessment framework should include if being applied within a children’s hospice?
6. Are there any particular challenges to assessing the needs of the diverse client groups that access a children’s hospice?
7. Are there any particular challenges to implementing the support you offer?
8. How do you think these challenges may be addressed?
9. Do you have anything more you wish to add?
Appendix VII

Data Analysis Process

Step 1 – Transcribing of the recorded data and emailing each participant a copy of the transcript. Analysis of the data did not begin until all participants were satisfied with the accuracy of the transcript. Transcriptions were printed onto various coloured A4 sheets of paper so that each individual transcript (data item) was easily identifiable by colour.

Step 2 – Repeated reading of each data item and across the entire data set (all transcripts), searching for patterns and noting down potential ideas for a coding structure.

Step 3 - Generating initial codes and matching data extracts that demonstrate each code.

Table 3: Example of Initial Coding

Select sample of initial coding – abbreviated codes were written in the left-hand margins of the research transcriptions and a card index system kept with the definitions of each code.

<table>
<thead>
<tr>
<th>Initial Coding</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code: A (Pr)</td>
<td>Assessment during pre-bereavement period</td>
</tr>
<tr>
<td>Code: A (Po)</td>
<td>Assessment during post-bereavement period</td>
</tr>
<tr>
<td>Code: Co Pr (P)</td>
<td>Composition of pre-bereavement support for parents</td>
</tr>
<tr>
<td>Code: Co Pr (S)</td>
<td>Composition of pre-bereavement support for siblings</td>
</tr>
<tr>
<td>Code: Co Pr (C)</td>
<td>Composition of pre-bereavement support for hospice child/young person</td>
</tr>
</tbody>
</table>
Step 4 – Collating codes into potential themes and pasting all relevant data to each potential theme onto large sheets of A1 paper.

Figure 3: Picture of Coded Extracts for Theme of Pre-bereavement Support

Table 4: Samples of coded extracts

<table>
<thead>
<tr>
<th>Subtheme</th>
<th>Code</th>
<th>Extract/Quote</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support for parents</td>
<td>Co Pr (P)</td>
<td>“We run a parent group once a month that parents come to. We do an Asian mum’s lunch, we do a drop-in for parents. The drs do now...”</td>
</tr>
</tbody>
</table>
Consulting for symptom/pain management and that's a really, really good package that can be offered in the way of pre-bereavement support.” 

<table>
<thead>
<tr>
<th>Support for siblings</th>
<th>Co Pr (S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>“..we run a siblings group, well we have two sibling groups. We have SOCKS which is Siblings of Chase Kids and that's for 5-14 yrs old. We do a whole weekend day and in the morning it is very much about therapeutic activities….in the afternoon it’s a fun thing so for example two weeks ago they went rock climbing in the afternoon and in the morning they all made journals about their life as a sibling. “ P5:5-6</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Support for hospice child/young person</th>
<th>CO Pr (C)</th>
</tr>
</thead>
<tbody>
<tr>
<td>“..it’s not unusual to hear that they worry about their mum and dad and then I ascertain if they would like me to spend time talking to mum and dad where we can then all get together and share the worries and the concerns. It can be behavioural problems that I am asked to help out with. It can be sleep issues for the child, it can be nightmares, it can be phobias, there is a range of things that I’m called upon to help with.” P4:4</td>
<td></td>
</tr>
</tbody>
</table>
Step 5 – Broad themes were identified using a semantic approach, the emphasis being placed on the explicit meanings of the data and which did not go beyond what a participant had spoken.

Step 6 – Refining each identified theme – checking all coded extracts for each theme represent a logical pattern and ensuring a clear naming and delineation of each theme.

Step 7 – Refining all identified themes - Considering whether all the themes accurately reflect the meanings evident across the data set by re-reading the data set.

Step 8 – Selecting extract examples to present in final thesis report, highlighting the findings of study and setting them in context of the research question and current literature.