

‘Can we fix it?!’: Understanding the impact of children’s hospice short breaks on parental relationships of life-limited and life-threatened children and young people.

Ashley James Eric Mitchell

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Abstract

This thesis describes a PhD study which explored the impact of short breaks provided by children's hospices on the partner relationship between parents. The specific objectives of the study were to: (1) explore parents' perceptions of parenting life-limited/ threatened children or young people on their relationships, (2) determine if frequent short breaks enhance relationship satisfaction between parental figures compared to those who receive short breaks less frequently or not at all, (3) identify effects on relationships of parents receiving home and hospice-based short breaks compared to those receiving hospice-based short breaks only or home-based care only, and (4) identify societal factors influencing romantic relationships between parents of families receiving short breaks.

A two phase exploratory sequential mixed methods design was used. In the first phase fifteen parental figures accessing a children's hospice were interviewed. Three main themes were identified, reflecting parents' perceptions of short breaks on their relationship with their partners: (1) 'Every family is different', (2) 'Short break significance' and (3) 'Short break quality'. The theme 'Every family is different' encompassed three sub-themes: (i) 'Alternative short breaks'; (ii) 'Pressure and conflict between parental figures' and (iii) 'Together but separate'. 'Short break significance' comprised (i) 'Significance to relationship' and (ii) 'Children before relationship'. 'Short break quality' encompassed: (i) 'Building trust' and (ii) 'Getting a real break'. The second phase, an online survey, further explored interview themes. Participating children's hospices distributed the survey to parents currently accessing short breaks. Results suggested hospice short breaks positively impacted relationship satisfaction and also supported interview themes.

Integration of findings from both phases revealed the impact of children's hospice short breaks on parental relationships is mediated by both external and internal influences. External influences are represented by a modified ABCX model of adjustment and adaptation (McCubbin and Patterson 1983) and the

theme 'Every family is different'. Families differ externally in terms of contributory stressors and protective resources. Couples with high contributing stressors and low protective resources benefit from short breaks, whilst those with low contributing factors and high protective resources benefit less. The theme of 'Short break quality' represented internal influences, comprising 'Building trust' and 'Getting a real break'. Building trust was strongly linked to frequency of short breaks and hospice staff knowing the child or young person. The theme 'Getting a real break' was linked to short break location. If short break quality was perceived to be poor, perceived impact on relationships between parents was lessened.

This study has significant implications for how short breaks are delivered by children's hospices, specifically the importance of recognising individual family differences, tailoring short breaks to meet these differing needs and building trust between parents and hospice staff.

1 Introduction to Thesis

1.1 Origins of the research

Julia's House, a children's hospice in Dorset, began as the Julia Perks Foundation, founded in memory of Julia Perks who worked to raise awareness locally of children with life-limiting and life-threatening conditions. After providing services in children's homes from 2003, the hospice officially opened in March 2006 and now has a team of 100 nurses and carers working both at the hospice and in people's homes. Collaboration between staff at Bournemouth University and Julia's House began when experienced, senior nurses from Julia's House started to contribute to pre-registration children's nursing programmes at the University. To further this collaboration, Julia's House expressed an interest in developing joint research with an academic, experienced in the field of children's palliative care. To this end, a matched funded project with funding provided equally between Bournemouth University and Julia's House was initiated to explore the impact of short breaks on relationships between parents.

My own involvement in the research project began as I was nearing the completion of a MSc Lifespan Neuropsychology at Bournemouth University when the position of fulltime matched funded PhD student within the (then) School of Health and Social Care was advertised. I found the research project interesting on a number of levels. Having enjoyed carrying out a research project on the MSc in Lifespan Neuropsychology, I was intent on further developing my research skills and experience. Just as importantly, in previous employment, I had worked in a short break service for parents who had children with challenging behaviour and complex health needs. I had seen first-hand the emotional and physical strain that parents experienced and how short breaks could alleviate this. Whilst children's palliative care is a different area of care to this experience, I was enthused to take part in research that could have a real impact on people's lives.

1.2 Background to the study

It is estimated that 40,000 families in the UK have palliative care requirements for their children (Norman and Fraser 2014) with UK children's hospices providing short breaks and other services to 7,638 children and 9,930 families (Devanney and Bradley 2012). Since Helen House, the first children's hospice, opened in Oxford in 1982 the UK has steered the international children's hospice movement. Since their early foundations, the number of children's hospice services has increased to 49 in the UK to meet the needs of children and young people with life-limiting or threatening illnesses and their families (Together for Short Lives 2016).

Having a child with a life-limiting or life-threatening condition can place emotional, physical and financial strain on parents, who often experience lack of time for each other, physical exhaustion, dealing with grief, financial pressures and social isolation (Glenn 2007; Contact a Family 2011). The cost to the state of family breakdown is high, with some suggesting it to be as high as £47.5 billion annually (Relationships Foundation 2015). In addition, it has been estimated that unpaid or informal caring saves the health and social care system £132 billion pounds a year in the UK (Buckner and Yeandle 2015). If a family breaks down and is unable to provide the same level of informal care as before the breakdown, additional costs are placed on state health and social care (Buckner and Yeandle 2015). With this in mind, stability in families is of great importance and the financial costs of family breakdown and ways of reducing these costs have been high on political agendas (Contact a Family 2011). Children's hospices are one potential source of short breaks for parents, providing them with relief. However, children's hospices vary in the type and frequency of short break provided. Despite it being over thirty years since the opening of the world's first children's hospice, there is a paucity of research exploring the impact of short breaks on partner relationships in relation to frequency and short break models.

The terms 'short break' and 'respite' are often used interchangeably. However, the word 'respite' has connotations of burden and parents needing a break from

their children (Miller 2002; Brown and Warr 2007; Robertson et al. 2011; Swallow et al. 2012); as such the term ‘short breaks’ will be used for the majority of the thesis as this is now the preferred terminology in literature and practice.

1.3 Aims of the study

The overall aim of this research was to explore how varying models of short breaks, in terms of type, regularity and frequency, influence partner relationships of those with life-limited or life-threatened children or young people. With this in mind there were four specific objectives:

1. Exploring parents’ perceptions of parenting life-limited/ threatened children or young people on their relationships.
2. Determining if frequent short breaks enhance relationship satisfaction between parental figures compared to those who receive short breaks less frequently or not at all.
3. Identifying effects on relationships of parents receiving home and hospice-based short breaks compared to those receiving hospice-based short breaks only or home-based care only.
4. Identifying societal factors influencing partner relationships between parents of families receiving short breaks.

1.4 Key definitions

Child: Any person under the age of eighteen (Children Act 1989). However, children over 13 may also be referred to as a ‘young person’ (Chambers 2013). Both ‘child’ and ‘young person’ are used within this thesis.

Complex needs: This term is used within this thesis interchangeably with the terms ‘life-limited’ or ‘life-threatened’, referring to children who are either

dependent on technology or require a significant amount of extra care (Hewitt-Taylor 2012).

Life-limiting conditions: Any condition where there is no reasonable hope of cure (Chambers 2013).

Life-threatening condition: Any condition where a cure exists, but has the potential to fail (Chambers 2013).

Partner relationships: The term ‘partner relationship’ is used within this thesis to describe the relationship between two parental figures and derives from the word ‘partner’. The word ‘partner’ can be defined as either member of a married couple or of an established unmarried couple (Oxford Dictionaries 2016).

Young adult: Describes any person from their 19th birthday (Chambers 2013).

Young person: The definition of a ‘young person’ conflicts somewhat with the definition of a ‘child’ as it describes a person from their 13th to 19th birthday (Chambers 2013).

1.5 An outline of the thesis

The thesis is structured as follows:

1.5.1 Chapter two: children’s hospices: setting the scene

This chapter situates the current children’s hospice network in relation to the development of the hospice and palliative care movements. Charting the development of hospices and the emergence of palliative care as a specialist field is important in understanding the philosophy and nature of contemporary children’s hospice networks. The chapter starts with an account of medieval hospices and the diverging growth of hospices and hospitals. The emergence of contemporary hospices is then considered in relation to the development of medicine and increasing medicalisation of life-threatening and life-limiting

conditions. This sets the scene for the work of Dame Cicely Saunders, the founder of the hospice movement, the opening of St. Christopher's Hospice in SE London in 1967 and the rise of palliative care as a specialism. The chapter then focuses on key milestones in children's palliative care and the foundations for the children's hospice movement. Similarities and differences between adult and children's palliative care are outlined. Finally, the chapter describes the children's hospice network and services currently provided.

1.5.2 Chapter three: short breaks and the impact of caring for children and young people with life-limiting and life-threatening conditions

The third chapter focuses on an essential service offered by children's hospices: short breaks. The chapter opens by outlining different perspectives on how short breaks should be defined with attention on why 'short breaks' is now the preferred term to 'respite'. The next section outlines the variation in short break models across a range of service providers to determine common underlying principles. To put literature exploring short break impact on families in context, the next section will first outline the effect that caring for a child or young person with complex needs can have. With the context delineated, both the positive impact and potential limitations of short breaks will be described over the subsequent two sections.

1.5.3 Chapter four: partner relationships: sociological and psychological perspectives

The fourth chapter outlines theories and research evidence concerning family units and partner relationships. The chapter opens with a broad outline of sociological perspectives on family units, highlighting how the concept of family has changed over time. Breakdown of traditional family units is a common theme within sociological research and the next section explains marriage, cohabitation and civil partnerships in the UK. This is followed by research into divorce and relationship dissolution in the UK. The second half of this chapter outlines five differing theories on marriage and partner relationships: social exchange theory, behaviourism, attachment theory, dynamic goal theory and the ABCX model of adjustment and adaptation. The

ABCX model is presented as the most suitable explanation due to benefits it holds over the other four explanations.

1.5.4 Chapter five: mixed methods research: uniting quantitative and qualitative methods

Mixed methods are widely used within social and health research. Chapter five focuses on mixed methods with the objective of presenting it as the most suitable approach for answering the research aim and objectives. The first half of this chapter is concerned with the history and development of mixed methods research. Considered in this section are the ‘paradigm wars’, the principles of quantitative and qualitative research approaches, and how mixed methods overcame criticism to be considered a sustainable research paradigm in terms of the merits it offers. The next section discusses variations in mixed method designs, emphasising the three main design typologies: sequential, concurrent and transformative. The final section of the chapter will evaluate the advantages and disadvantages of mixing methods, ultimately highlighting the suitability of mixed methods for the present research.

1.5.5 Chapter six: pragmatism: a practical way of thinking or the emergence of an alternative research paradigm?

Increasing usage of mixed methods in research has resulted in an amplified interest in pragmatism as a research philosophy, yet it is often poorly understood. This chapter presents pragmatism as a suitable research philosophy for mixed methods based on pragmatism’s key principles. The first section outlines how contributions from Peirce, James and Dewey shaped the development of pragmatic principles. This is followed by an appraisal of compatibility between pragmatism and mixed methods, based on the pragmatic principle of answering the research aim using the most suitable method. The final section concerns strengths and weaknesses of pragmatism as an underlying research philosophy, including how pragmatism is easily misunderstood as ‘just being practical’.

1.5.6 Chapter seven: methods for semi-structured interviews

Chapter seven is the first of two methods chapters, in this case focusing on the procedure and analytic process for the first phase of the study, semi-structured

interviews from a national sample. The first section of the chapter compares structured, unstructured and semi-structured interviews. This is followed by descriptions of samples and study sites included for semi-structured interviews in the current study. The next section considers ethical issues relevant to the study including: harm to participants, invasion of privacy, informed consent, deception and role conflict, and describes gaining ethical approval. The final section of the chapter outlines how data analysis was carried out using thematic analysis guidelines proposed by Braun and Clarke (2006).

1.5.7 Chapter eight: thematic exploration of partner relationships and short break significance

The aim of this study was to explore how varying models of short breaks impact the partner relationship between parents, accounting for type, regularity and frequency. This is the first of two results chapters outlining and presenting results from analysis of semi-structured interviews. Through the use of supportive extracts, this chapter presents three main themes developed from the semi-structured interview data: ‘Every family is different’, ‘Short break significance’ and ‘Short break quality’. The chapter concludes with a rationale for development of the second stage of this mixed methods research, a national online survey.

1.5.8 Chapter nine: design and methods for national online survey

Chapter nine describes the design and methods used for the national online survey. The chapter starts with an overview of surveys as a data collection method, discussing strengths and weaknesses of the method. The next sections outline the development of the online survey from planning in the pre-pilot stage to conducting the online survey. The following section describes how respondents were accessed and how the surveys were distributed. The final section of the chapter outlines the analytic process of both statistical and open question data.

1.5.9 Chapter ten: an analysis of national online survey data from parental figures accessing short breaks from children's hospices

This is the second of two chapters presenting quantitative findings from the study and reports results from the online survey. The chapter begins with a brief overview of how analysis was undertaken, outlining the reasoning for utilising both parametric and non-parametric statistical tests. This is followed by demographic data concerning parental status and geographic location of respondents. The next sections present results for those respondents who were currently in a relationship relative to a Revised Dyadic Adjustment Scale (RDAS) score, a measure of relationship satisfaction. Next, responses given by divorced and separated respondents about the breakdown of their relationship are presented. The final section of this chapter presents results from an optional open question included in the online survey. This starts with a description of how the open question data were analysed using thematic analysis before outlining two key themes developed from the data: (1) 'Relationship impact' and (2) 'Wellbeing'.

1.5.10 Chapter eleven: Drawing the threads together: a discussion of findings

This study aimed to understand the impact of varying models of short breaks provided by children's hospices on the relationship between parents. Chapter Eleven draws together findings from Chapters Eight and Ten, with literature from Chapters Two, Three and Four. A redefined ABCX model of adjustment and adaptation is discussed in relation to findings and existing literature. The chapter outlines how the impact on the relationship between parents is mediated by factors external and internal to children's hospice short breaks. External influences are represented by the theme of 'Every family is different' with each family having differing stressors and protective factors. Internal influences refer to those elements which impact 'Short break quality', influenced by the themes of 'Building trust' and 'Getting a real break'.

1.5.11 Chapter twelve: Conclusions, implications for practice and recommendations for future research

The concluding chapter of the thesis outlines implications for practice arising from findings discussed in chapter eleven. Proposals for children's hospices to improve the impact that short breaks have on the relationship between parents include recognising individual family differences, providing family-centred short breaks and building trust between parents and hospice staff. However, in order to offer flexible and family centred-short breaks, more children's hospices need to offer both home and hospice-based short breaks. Suggestions about this could be achieved are also discussed in chapter twelve. In addition to fulfilling the research aims, the present study has also created opportunities for future research. Recommendations for future research are outlined this chapter.

2 Children's Hospices: Setting the Scene

2.1 Chapter introduction

The research outlined in this thesis aimed to explore how varying models of short breaks, in terms of type, regularity and frequency, influence partner relationships of those with life-limited or life-threatened children or young people. This research explored three elements that first need to be considered: children's hospices, partner relationships and short breaks. This chapter will focus on the first, children's hospices. It commences with the origins of the word 'hospice' and draws distinction between the usage in medieval times and present days. Medicalisation of death within healthcare will be outlined, followed by the subsequent emergence of palliative care as a humanistic alternative. The foundation of Helen House and emergence of children's palliative care as a distinct speciality are outlined, before ending with a description of current children's hospice services.

2.2 Early hospices

The origins of the term 'hospice' begin with the Latin word 'hospes', meaning 'guest' (Goldin 1981; Buckingham 1996; Simms 2007). Over time and due to the influence of Christianity the word 'hospes' became associated with 'visitors' (Goldin 1981; Maruyama 1999; Simms 2007). Building on this understanding, later definition of the word 'hospes' included a 'host' who welcomed unexpected strangers (Goldin 1981; Buckingham 1996; Simms 2007). During medieval times there was no association between 'hospices' and the dying, hospices were merely places of shelter for travelling strangers or pilgrims (Goldin 1981; Buckingham 1996; Maruyama 1999). At this point in history there was no clear distinction between 'hospices' and 'hospitals'.

During the 7th or 8th century both hospices and hospitals were known as a 'hospitium' and provided shelter for pilgrims visiting the tomb of St. Peter in Rome. There was no indication that a 'hospitium' was a place for the sick and dying, or even offered any health care at all (Buckingham 1996; Maruyama 1999; Rawcliffe 1999). These shelters expanded across Europe during the

Middle Ages with hospices being established in Italy, Germany, Malta and England (Maruyama 1999). These shelters followed the principle that the soul was equally as important as the body, resulting in an emphasis on faith. At this point in time, there would have been very little difference between hospices and other types of hospitals such as those that sheltered lepers, since they all emphasised the importance of care (Maruyama 1999). Likewise, Clark (1998) warned against making too many links between contemporary hospices and those from ancient times, as they share little in common other than the word 'hospice'. To understand the evolution of traditional hospices to contemporary ones of today, the development of medicine and hospitals firstly need exploration.

2.3 The medicalisation of healthcare

Medicalisation has been defined as: *"a process by which non-medical problems become defined and treated as medical problems usually in terms of illnesses or disorders"* (Conrad 1992, p.209). Medicalisation has negative connotations regarding the impact medicine has had on some aspects of society (Clark 2002). The emergence of medicine and subsequent medicalisation of society have foundations in the development of scientific knowledge in the 16th century. Emergence of scientific medicine was influenced by the philosophical work of Descartes who argued for a mind-body dichotomy, with illness and disease viewed as a malfunction of the body (Hockey 1990).

This position was further cemented in the eighteenth century during the Enlightenment with improvements in technology and prestige of doctors (Clark and Seymour 1999; Maruyama 1999). After the Enlightenment, medical professionals increasingly followed scientific and research aspects of medicine (Clark and Seymour 1999). The twentieth century saw not only rapid medical advances but also increasing elements of life being brought under medical inquiry (Field 1994). Normal aspects of life such as birth, ageing and death increasingly came under medical control and, in parallel to these societal attitudes to death, is a change in the nature of disease with acute infectious diseases less likely to have fatal outcomes (Field 1994).

A strong focus on treatment and curing the sick (Abel 1986) meant doctors of this time viewed 'death' and 'dying' as a failure of science and consequently it was ignored or dismissed (Maruyama 1999; Clark 2002; Clark 2007). Death became viewed as a 'failure of treatment' rather than an inevitable part of life (Field 1994). Medicalisation of death is closely linked to societal changes in industrialised countries, such as changing household structures and the industrialisation of death in hospitals (Blauner 1966; Field 1994). At the start of the 20th century most deaths occurred in family homes, however by the middle of the century fifty per cent of deaths occurred in hospitals (Field 1994; Clark 1999).

Treatment of cancer in the twentieth century illustrates the impact of medicalisation. In 1902 the Imperial Cancer Research Fund (ICRF) was set up with a strong focus on research, anticipating a cure for cancer would soon be discovered (Maruyama 1999). In addition, the 1950- 60s were characterised by post-war reconstruction and implementation of the National Health Service, a socialised and all-inclusive healthcare system with changes in the nature of disease and acute infectious diseases less likely to have fatal outcomes (Clark and Seymour 1999). Subsequently cancer treatment became increasingly medicalised, with less emphasis on treating patients as individuals and increasing numbers of people dying from cancer in hospital rather than at home (Clark 1998, 1999; Clark and Seymour 1999; Maruyama 1999). The prevailing belief in the mid-twentieth century was the dying should be kept in a state of ignorance regarding diagnosis of a terminal illness, resulting in social isolation (Fitts and Ravdin 1953; Oken 1961) and feelings of anxiety or mistrust in dying individuals (Field 1994).

In response to this situation, there was an emergence of literature discussing the medicalisation of death between the 1950s and 1970s (Clark 1999; Seymour 1999; Clark 2007). One critic of medicalisation during this period was Ivan Illich who, in the mid-1970s, specifically criticised the medicalisation of death. Yet, even before Illich spoke out about the medicalisation of death, concern around the institution of death was raised by Cicely Saunders, resulting in the

emergence of the hospice movement and palliative care (Clark 1998; Seymour 1999).

2.4 Contemporary hospices and the emergence of palliative care

With an initial focus on cancer, the hospice movement emerged as the main alternative to the traditional medical model and paved the way for the rise of palliative care as a specialism (Field 1994; McNamara et al. 1994; Saunders 1996; Clark 1998, 1999; 2007). Whilst the hospice movement and palliative care would evolve to include many conditions, cancer initially received more attention and debate from the hospice movement than other terminal illnesses (Field 1994; Clark 1999; 2007). Dame Cicely Saunders is generally regarded as the founder of the hospice movement through the opening of St. Christopher's Hospice in South-East London in 1967 (Saunders 1996; Clark 2007). Saunders herself wrote:

“The development of the modern hospice movement dates from the opening of St. Christopher's Hospice in 1967 and its home care team in 1969. Since then it has spread worldwide and has shown that the basic principles derived from many sources, combined and demonstrated, can be interpreted in a wide variety of settings and cultures”.

(Saunders 1996, p.317)

One aspect of Saunders' thinking that changed over the decade was inclusion of religion within the hospice (Bradshaw 1996; Clark 1998; 2001). Saunders was motivated by her Christian faith and her early thoughts for St. Christopher's envisioned a religious community. However, religion became less central for Saunders as plans for St. Christopher's developed (Bradshaw 1996; Clark 1998; 2001). The change of focus from a religious community was a key component in the success of the hospice movement (Clark 1998; 2001), with no links to one specific religion, it allowed flexibility and could be applied to any society or culture. Hospices can, and often do, have spiritual or religious elements, but the model is not dependent upon them for success (Clark 1998).

Clark (1998, 2001) credited moving away from religion as a core principle leading to increased focus on professional development within the hospice

movement. From inception, St Christopher's Hospice had a strong focus on learning, research and developing practice, in addition to networking with professionals. These goals would have been difficult to achieve under a rigid religious doctrine (Clark 2001). By the early 1980s there were over sixty adult hospices in the UK (Price et al. 2005) but this lacked suitability for children and their families (Worswick 2000) because the needs of life-limited or life-threatened children differ significantly to those of adults (Price et al. 2005; Malcolm et al. 2008; Spathis et al. 2012). These differences are discussed in detail in section 2.7.

After the opening of St. Christopher's Hospice, growth of the hospice movement was initially quite slow, for both practical and philosophical reasons. Practically, a key element of the contemporary hospice movement was a physical building for hospices (Saunders 1959). Charitable status, usually arising through local individuals recognising the need for a hospice, drove early hospice development. Philosophically, the principles of the hospice movement opposed traditional medical views of 'death as failure' (Clark 2002; Clark 2007). The next hospices to be built were St. Luke's in Sheffield and St Anne's in Manchester, both in 1971 (Clark and Seymour 1999). However, by the 1980s there was a 'golden age' of hospice development with approximately ten new hospices being opened yearly (Clark 2007).

In addition to the expansion of the hospice movement in the 1980s, contributions to the field of palliative care included: the formation of a palliative care medical association, establishment of a scientific journal and palliative care being recognised as a specialist field by both the Nursing and Midwifery Council and British Medical Association (Clark 2007).

According to the World Health Organisation (World Health Organisation n.d.) palliative care: (1) provides pain or symptom relief, (2) treats death as a normal life process, (3) neither hastens or postpones death (4) recognises both the psychological and spiritual aspects of care, (5) helps families during patients' illnesses and during bereavement, (6) utilises a multidisciplinary approach to

patient care, and (7) emphasises quality of life all the way to death. With these principles in mind, the WHO defines palliative care as:

“...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

(World Health Organisation n.d.)

The underlying principles of palliative care, highlighted in this definition, have links with the establishment of the modern hospice movement (Clark 1998; Clark and Seymour 1999).

2.5 Helen House: the first children’s hospice

Palliative care services for children in the UK were not established until the opening of Helen House in 1982 (Burne 1982; Burne et al. 1984). Worswick (2000) outlined how the sudden illness of her daughter, Helen, was a catalyst for the first hospice specifically for children. The initial years of Helen’s illness, the challenges and the experiences of her parents prior to the development of Helen House are important because they became a key influence in shaping the philosophy of Helen House; a home away from home (Worswick 2000).

In August 1978, at the age of two and a half, Helen was admitted to hospital after falling ill (Burne 1982). During this extended period spent at hospital Mother Frances Dominica became involved in the life of Helen and her family as a potential source of emotional and spiritual support (Dominica 1987). Being involved in the life of Helen and her family made Mother Dominica realise how little support was available for families, with the physical and emotional strain of care becoming tiring for her parents. Subsequently Mother Dominica envisioned a home for dying children that would help families by offering friendship with practical and moral support (Helen and Douglas House 2015). Central to this idea would be offering short breaks for children, allowing families to have a break from caring for their terminally ill child, so they could recharge and be ready to continue caring (Burne 1982; Dominica 1987).

The aim of Helen House was to fit with existing services, rather than overlap (Burne et al. 1984; Dominica 1987). It was not intended to provide long-term residential care or to provide acute care that was already available at hospitals (Burne et al. 1984; Dominica 1987; Worswick 2000). Principle usage would be for children needing end-of-life care and for short breaks for families to provide a break. The hospice would not be medically focused, aiming to provide a home away from home. Whilst there would be no active medical treatment, the hospice would provide pain relief and symptom control (Burne et al. 1984; Dominica 1987).

Five years after the opening of Helen House, a second children's hospice, Martin House opened in 1987 in West Yorkshire. Martin House opened after three years of campaigning by local paediatricians and the Vicar of Boston Spa saw the need for a children's hospice in the north (Hill 1990). Martin House was influenced by coordination and shared experiences from Helen House and consequently shared the same philosophy of hospices being home away from home and treating families as friends (Hill 1990).

Also around this time a local West Midland charity, the Calthorpe Association for the Handicapped was involved in providing help for parents with disabled children. Whilst the staff was happy doing this on an ad-hoc basis, there was recognition that an extra, more permanent service was required (Day 1990). A registered charity, the Children's Hospice Trust, was created and the Acorns children's hospice opened in South Birmingham in 1988 (Day 1990). The founding members of Acorns Children's Hospice faced two considerations when establishing the hospice, evidencing need and cultural differences. At the time there were no statistics on the number of children with life-limiting or life-threatening conditions, so questionnaire responses from paediatricians and special needs schools were needed to demonstrate local need (Day 1990). A second important consideration was variety in culture and religion in the West Midlands. It was identified that many families in the West Midlands relied on

extended families and religious leaders. The aim was to provide a service that could be utilised alongside traditional family support (Day 1990).

2.6 Additional important milestones in children's palliative care

In parallel to the development of the children's hospice movement, were several initiatives aimed at providing improved care for children with cancer and their families, including the creation of paediatric oncology community nurse specialists (POCNS), later to become Paediatric Oncology Outreach Nurse Specialists (POONSs). Development of POCNS was a result of three main factors: government policy, research and establishment of charities dedicated to caring for children with cancer in their home settings (Hunt 1995, 1998).

Research of the time (Kohler and Radford 1985; Martinson et al. 1986) recognised home to be the place of choice for families caring for children with cancer and leukaemia (Hunt 1995). In addition, government recommendations around care of children in the community cumulated in the NHS and Community Care Act 1990 (Hunt 1995). Finally, charities were established by bereaved and highly motivated parents to provide funding for services for families with children or young people with life-limiting or life-threatening conditions. Whilst there were many charities established (Hunt 1998), the three main organisations initially associated with the funding of POCNS outside of the NHS: The Rupert Foundation, The Cancer Relief Macmillan Fund (CRMF) and The Cancer and Leukaemia in Childhood Trust (CLIC).

The Rupert Foundation was founded in 1982 and within a few years became the first charity to fund POCNS at a regional centre (Hunt 1998). The first longstanding service was created at Great Ormond Street in 1986, followed by similar services in Newcastle, Southampton and other parts of London. CRMF became involved with children's palliative care when taking over the funding of POCNS when The Rupert Foundation financially collapsed (Hunt 1998). CRMF had previously focused on adult palliative care and subsequently posts created mirrored the philosophy of adult services. CLIC was established in 1976 to provide three dimensions of childhood cancer care in the South-West: treatment, research and welfare (Woodward 1990; Hunt 1998).

The Rainbow Trust specialised in providing help at home for families with children with life-threatening illnesses. In contrast to the CLIC domiciliary team, the Rainbow Trust initially focused less on medical care, providing expertise and training enabling families to survive both emotionally and physically (Cleary 1990). The Rainbow Trust was established based on the experiences of Bernadette Cleary in supporting a mother emotionally and physically, whose 12-year old daughter was terminally ill. After the daughter died, Cleary found herself overwhelmed with requests to support other families in similar situations. A clear need for a domiciliary team led to the foundation of the Rainbow Trust in 1986 (Cleary 1990, 2016). Whilst members of the early team comprised of qualified nurses, services offered were not nursing focused. Domiciliary team workers help families with everyday activities, washing, ironing, shopping and babysitting, for sick children and their siblings (Cleary 1990, 2016). Flexibility is a crucial requirement for staff, enabling them to fit around families' individual needs. Services were extended in 1990 with the opening of Rainbow House, a holiday house enabling families to have short breaks and reduce isolation by meeting other families in similar situations (Cleary 2016).

2.7 Distinctions between adults' and children's palliative care

Children's and adults' palliative care services have evolved to share fundamental principles including holistic care, focusing on quality of life (Spathis et al. 2012; Nicholl and Tracey 2015; Peate 2015). Both children's and adults' palliative care emphasise physical, psychological and spiritual aspects of care (Himmelstein 2006). However, children's palliative care has emerged as a speciality in its own right (Price et al. 2005; Malcolm et al. 2008; Spathis et al. 2012) and a number of authors warn against overstating similarities between children's and adults' palliative care in terms of needs and practice (Malcolm et al. 2008; Spathis et al. 2012; Nicholl and Tracey 2015). Children's and adults' palliative care differ in relation to needs and day-to-day practice (Hill and Coyne 2012; Spathis et al. 2012).

Traditionally adults' palliative care focused on individuals with cancer, whereas children's palliative care concerned a broader disease-range including

neuromuscular, genetic and congenital conditions (Hynson and Sawyer 2001; Hynson et al. 2003; Malcolm et al. 2008; Spathis et al. 2012). However, adult palliative care now encompasses motor neurone disease, cardio-vascular disease and multiple sclerosis in addition to cancer (Beresford 2013). Adult hospices are increasingly caring for people with life-limiting conditions such as dementia (Hospice UK 2015). The genetic nature of some life-limiting conditions mean families may have more than one child with palliative care needs (Goldman 1998; Malcolm et al. 2008). Often children's conditions are extremely rare and specific to childhood (Goldman 1998; Price et al. 2005; Malcolm et al. 2008; Together for Short Lives 2016). Significant medical advancements have resulted in children surviving, when they would have previously died (Hynson et al. 2003; Hill and Coyne 2012). Deterioration in the disease process or late onset complications can result in increasing numbers of children and young adults with co-morbidities and disabilities, such as cognitive impairment (Hynson et al. 2003).

In adult palliative care, illness trajectory is usually clearly defined (Nicholl and Tracey 2015). By contrast children's palliative care faces challenges in providing both active treatment and palliative care simultaneously (Nicholl and Tracey 2015). Many life-limiting or life-threatening conditions associated with childhood have unpredictable trajectories (Hynson et al. 2003; Malcolm et al. 2008; Spathis et al. 2012; Nicholl and Tracey 2015), even children with the same condition will vary in their needs for palliative care (Nicholl and Tracey 2015). The number of children dying is relatively small compared to adults (Malcolm et al. 2008).

The timescale of palliative care differs between children and adults, as palliative care may be required from infancy for a number of years (Goldman 1998; Hynson and Sawyer 2001; McNamara-Goodger and Cooke 2009). It is not uncommon for a child's health to rapidly decline but then stabilise and improve with active interventions (Spathis et al. 2012). Consequently, children or young people may go through end-of-life care at several points in their life (Malcolm et al. 2008). Variable illness trajectories mean that the needs of children and

families will change over time (Hynson et al. 2003). By contrast, palliative care for adults tends to be pronounced for a comparatively short period of time (Malcolm et al. 2008).

The importance of children's continuing physical, emotional and cognitive development is a fundamental component of children's palliative care (Goldman 1998; Hynson and Sawyer 2001; McNamara-Goodger and Cooke 2009; Spathis et al. 2012). Unlike adults, children continue developing physically and cognitively throughout their illness (Malcolm et al. 2008; Spathis et al. 2012), impacting not only a child's understanding of their condition, but also treatment and prescription of medication (Goldman 1998; Himelstein 2006; Malcolm et al. 2008; Nicholl and Tracey 2015).

Periods of illness impact upon children differently depending on age: infants' development may be disrupted due to separation from attachment figures during treatment, whilst adolescents may face anxiety over body image or interruptions to socialisation with peers (Hynson and Sawyer 2001; Hynson et al. 2003). Consequently, health professionals within children's palliative care need to be aware of developmental stages as this will influence information processing, pain or symptom management, and decision making (Hynson and Sawyer 2001; Hynson et al. 2003). In addition, health professionals need to consider children's abilities to make informed decisions about their treatment and care vary depending on cognitive ability and age (Hynson et al. 2003; Malcolm et al. 2008). However, it has been suggested that children with life-limiting conditions are likely to be better positioned to give an informed decision, over older children with no medical history because of their experiences (Hynson et al. 2003).

Another distinction between children's and adult's palliative care is the extent of impact on a family (Goldman 1998; Hynson et al. 2003; Spathis et al. 2012), with children's palliative care impacting family, including parents, siblings and grandparents (Morrod 2004; Hewitt-Taylor 2005; Steele and Davis 2006; Eaton 2008; O' Brien et al. 2009; Hobson and Noyes 2011). It has been suggested the

grief of a child dying is greater than the death of a spouse or parent (Hynson et al. 2003). As a result of life limited children living longer than they would have previously, children's palliative care requirements are generally longer than those of adults (Goldman 1998; Hynson and Sawyer 2001; McNamara-Goodger and Cooke 2009), meaning that parents face the pressure of care for long periods of time (McNamara-Goodger and Cooke 2009; Spathis et al. 2012). Caring places parents under a great amount of difficulty, with exhaustion, financial difficulties, mental health issues and divorce reported (Hynson et al. 2003; Spathis et al. 2012). Parents of children with genetic conditions may also face feelings of guilt and blame (Goldman 1998; Hynson and Sawyer 2001; Hynson et al. 2003; Himmelstein 2006).

Caution must be used, however, in over exaggerating differences between children's and adult palliative care. Malcolm et al (2008), for example, suggest that children's palliative care differs from adult palliative care in that it embraces the whole family. However, the WHO contradicts this suggestion, stating palliative care, including adult palliative care: "*offers a support system to help the family cope during the patient's illness*" (World Health Organisation n.d.). There is evidence that caring for a loved one with adult palliative care needs also impacts family members financially (Aoun et al. 2005; Gardiner et al. 2014), emotionally (Brazil et al. 2003; Draper et al. 2013; Thomas et al. 2014; Morris et al. 2015) and physically (Brazil et al. 2003; Aoun et al. 2005).

2.8 The evolution of children's hospices: children's hospices today

Shortly after the first few children's hospices were established, it was predicted that no more than four children's hospices nationally would be needed (Chambers 1987). Contrary to this suggestion, since the opening of Helen House, the children's hospice movement has grown both nationally and internationally due to increasing numbers of children with life-limiting or life-threatening conditions (Fraser et al. 2014). There are now 45 children's hospice services across the UK, supporting 7,638 children and 9,930 families, inclusive of bereaved parents (Devanney and Bradley 2012) and demand is still growing. In 2011/12 the number of children and families supported increased by eight and seven per cent respectively. In addition, hospices received a 12% increase

in referrals for support (Devanney and Bradley 2012), clearly demonstrating demand for services offered by children's hospices. This increased demand placed on children's hospices is also a result in changing demands and services offered. As increasing numbers of children are surviving longer, some hospices have started to offer services for young adults (Beresford 2013). For example, Douglas House opened in February 2004 specifically for young adults (Helen and Douglas House 2015).

As demonstrated by examples such as Helen House, individual children's hospices mostly emerged due to local individuals or professionals recognising the need for a children's hospice in their area and were self-funded (Goldman 1994). Whilst children's hospices today are linked via the Together for Short Lives and regional networks, their autonomous development is reflected in the differing services each offers (Devanney and Bradley 2012). Contemporary children's hospices offer a range of services including end-of-life care, family support services, sibling support, emergency care, symptom management, play therapy, complementary therapies and psychological therapies (Devanney and Bradley 2012). A key service that is offered by the majority of hospices is short breaks (Mash and Lloyd-Williams 2006; Devanney and Bradley 2012). Children's hospices provide short breaks to allow families to take a break from caring responsibilities and to give children new opportunities for socialisation (Robertson et al. 2011).

2.9 Chapter conclusion

This chapter outlined parallel development of the contemporary hospice movement and the emergence of palliative care as a speciality both for adults and for children. Contemporary hospices have little in common with historical hospices that sheltered pilgrims and travellers. Based on Saunders' leadership, the hospice movement and palliative care emerged, caring for the dying not just physically, but also psychologically and spiritually. Prior to the opening of Helen House in 1982 there had been few specific services for children with life-limiting or life-threatening illnesses. The rise of children's palliative care as a distinct speciality was important as there are some distinct differences in the needs of children to adults, such as psychosocial and physical development and

the health conditions, which result in palliative care needs. Contemporary children's hospices offer a range of services, with short breaks being an essential service offered by most. The subsequent chapter will focus on short breaks and the impact that they potentially have.

3 Short Breaks and the Impact of Caring for Children and Young People with Life-limiting and Life-threatening Conditions

3.1 Chapter introduction

The preceding chapter outlined the interwoven development of the contemporary hospice movement and the emergence of both adults' and children's palliative care services. It was established that modern hospices have little in common with medieval hospices which sheltered pilgrims and travellers. The formation of St. Christopher's in 1967 started the modern adult hospice movement, followed by the first children's hospice in 1982. Contemporary children's hospices offer a range of services to families of children and young people with life-limiting or life-threatening illnesses. This chapter focuses on one fundamental service offered by children's hospices key to informing this research: short breaks.

The first section of this chapter, outlines difficulties in defining short breaks and highlights why the term 'short break' is preferred to 'respite'. The next section concerns the function of short breaks, with contemporary short breaks emphasising the needs of a whole family. This is followed by a review of short break models that have been highlighted across past literature. Prior to outlining the benefits that short breaks can have for families, it is first important to understand the impact that caring for a child with complex needs can have. The next section concerns the emotional and physical impact that caring for children or young people with life-limiting or life-threatening conditions can have on both parents and the family as a whole. Following on from this section, literature concerning the impact short breaks can have for families and parents are reviewed. The final section outlines potential limitations with short breaks such as lack of availability and invasion of privacy.

3.2 Short breaks: a definition

Children's palliative care focuses not on end-of-life care but also embraces short breaks (Mash and Lloyd-Williams 2006), making short breaks a crucial aspect of children's palliative care (Horsburgh et al. 2002; Craft and Killen

2007; Lewis 2008; Ling 2012; Remedios et al. 2015). Short breaks are recognised as a method by which the voluntary and statutory sectors help parents and family units in caring for their children either separately or in partnership (Eaton 2008). Short breaks allow families time away from caring responsibilities and give affected children new social opportunities (Robertson et al. 2011). There is considerable confusion and variation regarding how 'short breaks' is defined (Ling 2012). This is an important consideration because short breaks' providers and families have differing expectations (MacDonald and Callery 2004; Ling 2012). Short breaks are also difficult to define because the term has been used to describe a wide spectrum of services from home help to hospital in-patient services (Eaton 2008).

The term respite has been used to describe short breaks and is still used in some literature. Traditional definitions of respite refer to the needs of carers, giving a complete break from the demands or burden of care (Horsburgh et al. 2002; McConkey et al. 2004). In recent years the word respite has been replaced by short breaks because of negative connotations associated with the word 'respite' (Miller 2002; Brown and Warr 2007; Robertson et al. 2011; Swallow et al. 2012). 'Respite' assumes that cared for individuals are a 'burden', however this idea of 'burden' is unpopular because it is based on the premise that caring relationships are not reciprocal and are unrewarding (Ingleton et al. 2003). The phrase short breaks can be used to describe both a service and an outcome (Ingleton et al. 2003; Ling 2012). 'Short break care' refers to the service offered, whereas 'short break' refers to the individuals' perception of receiving a break from caregiving (Neufeld et al. 2001; Eaton 2008). Short breaks or respite can also be understood in terms of their function.

Parallel to this change in language has been the development of a new model of short breaks, moving away from the traditional model of respite as relieving burden (Robertson et al. 2011). This is partly due to increasing awareness of equal opportunities, with parents feeling more empowered to seek out rewarding and stimulating breaks for their child (Staley 2008). Consequently, short break services are getting increasingly better at meeting families'

individual needs (Staley 2008). More recently there has been government recognition of the importance of short breaks in the Care Act (2014). The 2014 Care Act highlights the economic contribution informal carers make in England and Wales and recognises that families need short breaks to sustain informal caring.

New models of 'short breaks' emphasise flexibility to meet individual family needs (McConkey and Adams 2000; Corkin et al. 2006; Lewis 2008; Staley 2008; Wilkie and Barr 2008; Hunt et al. 2013). Indeed research has demonstrated that parents place great importance on flexibility (Kirk 1998; Mash and Lloyd-Williams 2006; Eaton 2008; Thomas and Price 2012) and their perceptions of available short breaks determine engagement with services (MacDonald and Callery 2004). Short breaks both at home and in a hospice are often booked several weeks in advance (Eaton 2008). However, this system of booking is inflexible and inappropriate for meeting the needs of a child that can change rapidly (Olsen and Maslin-Prothero 2001; Eaton 2008). The needs of children can vary greatly, such as invasive medical treatments, specialist equipment or needing two-to-one care (Holmes et al. 2010; McDermid et al. 2011). On the other hand, some children will have needs that are easier to meet and will be able to access universal services such as short breaks which do not require specialist knowledge of medical interventions (Holmes et al. 2010).

MacDonald and Callery (2008) also emphasise that short break needs of families and children are dynamic; therefore, services need to be flexible and responsive to this need. Flexibility is also crucial because the needs of each individual family will be different with some needing day help, others relief from the physical side of care, overnight care, or even help in accessing activities as a family (Beresford et al. 2007). Additionally, more recent models of short breaks emphasis quality of life and social integration for not only parents, but also the children and wider family (McConkey et al. 2004).

3.3 Function of short breaks

Traditionally, short breaks focused on residential care for children, young people and young adults with a disability or complex needs. Contemporary

short break models also emphasise the needs of whole family units (Lavery and Reet 2001; Staley 2008), empowering family members and maintaining their wellbeing (Lavery and Reet 2001). For example, the function of short breaks may also be to provide families with the opportunity to take a holiday (Hunt et al. 2013). New models emphasise enjoyment and positive experiences for children and young people from short breaks (Staley 2008; Swallow et al. 2012). This is important for parents, because if their child enjoys and is gaining something from short breaks, parental guilt and discomfort can be reduced (Beresford 1994; Miller 2002). Research indicates parents place emphasis on children enjoying short breaks, even at the expense of their own benefit (Welch et al. 2010). However, the old definition of short breaks purely for the function of giving parents a break is still apparent in some literature (Remedios et al. 2015).

Chambers (2013) explains short breaks in relation to their aims, namely: (1) providing children or young people opportunities to have a break and enjoy social interaction, (2) supporting families in the care of their child in either their home or at a hospice, and (3) giving siblings the chance to have fun and also be supported. Chambers continues by defining specialist short breaks as including all of the previous functions, in addition to also catering for children with highly complex needs or who have technology dependency.

3.4 Models of short breaks

Geographic variation in short break provision (MacDonald and Callery 2004; Eaton 2008) means a wide spectrum of short break models exist across the UK, ranging from informal help from family members to staying at a residential location, such as a hospice of varying durations (McConkey and Adams 2000; MacDonald and Callery 2004; McConkey et al. 2004; Merriman and Canavan 2007; Ling 2012). Available models of short breaks, including those provided by children's hospices, are often determined by availability of local services, geographical coverage and funding available (Eaton 2008; Robertson et al. 2011).

Short breaks provided vary along four dimensions: (1) location, (2) duration, (3) timing and (4) the provider (Robertson et al. 2011). Short breaks can be given in several locations including a home, foster home, a residential setting or at a hospice (Eaton 2008; Ling 2012). This may be in the form of overnight stays, days, evenings or weekends (Holmes et al. 2010). Duration of breaks vary from a few hours to several days, occurring at weekdays, weekends, evenings or overnight (Robertson et al. 2011). Finally, short breaks providers vary and may include voluntary agencies such as hospices or government initiative such as direct payments (Holmes et al. 2010; Robertson et al. 2011).

As part of the process of calculating the overall cost of short break services, Holmes et al (2010) identified a wide range of short breaks services created in response to local need across three local authorities in England. The range of services highlighted included: (1) overnight residential where overnight stays are received at a specialist residential unit, (2) family based overnight with foster families, (3) nursery day care in a specialist nursery, (4) family based day care with foster families, (5) domiciliary home visits from specialist workers providing practical support, (6) befriending whereby a worker provides two to three hours of care in the family home, (7) supported access providing short term care enabling children to access universal services, (8) play group sessions for pre-schoolers or group sessions for older children, (9) after school clubs (10) weekend clubs, (11) school holiday play schemes, (12) specialist holidays either in the form of residential holidays or support for parents on family holidays, (13) direct payments to parents to purchase their own short breaks, and (14) transport support including help with lifting and managing children.

By contrast, MacDonald and Callery (2004) found that parents routinely describe three models of short breaks: (1) short breaks provided by family, (2) short breaks of around three to four hours usually in the family home, and (3) short breaks outside of the family home. Breaks provided by families usually start when children are young, decreasing in frequency as the age and complexity of children's needs increase (MacDonald and Callery 2004). The second form of short breaks includes breaks of around three to four hours

provided by an outside agency, usually within the family home (MacDonald and Callery 2004). These models of short breaks have been used for household chores, shopping or spending time with other children. The family home is usually the location of choice for short breaks (Neufeld et al. 2001; Eaton 2008; Staley 2008; Ling 2012) because the environment is familiar to children, equipment does not have to be transported and is cost effective (Neufeld et al. 2001; Eaton 2008). However, home short breaks may still have a number of drawbacks for some families, most notably a lack of space (Kirk 1998) and the loss of privacy (Eaton 2008).

The third form of short breaks arises when children with complex needs are cared for in a residential location such as a children's hospice for anywhere from a day to a week (MacDonald and Callery 2004). This type of short break is associated with having a real break by parents, giving them a chance to be 'normal'. If short breaks are given outside the family home, parents prefer them to be local, reducing travelling time (Ling 2012).

Short breaks provided by children's hospices differ depending on varying models of care adopted. However, there are three models of short breaks across all children's hospices: (1) short breaks at the hospice only, (2) short breaks in the family home only and (3) short breaks in both at hospice and in the family home. The type of short break offered by children's hospices is strongly determined by the availability of a physical hospice building. If no such location is available, short breaks at home is the only possible option (Eaton 2008). The models of breaks available in an area also depend on local funding (Craft and Killen 2007). According to the most recent service provision evaluation (Devanney and Bradley 2012), 64% offer short breaks only in a children's hospice, 34% in both a hospice and local community and 2% only provide short break care in children's homes.

There is a wealth of literature exploring the impact of short breaks on various aspects of life. However, prior to reviewing the impact of short breaks, it is important to understand the impact that caring for children or young people

with life-limiting or life-threatening conditions can have on parents and the wider family. The next section of the chapter focuses on this.

3.5 Impact of caring for life-limited and life-threatened children on parents

Home is the preferred location for care for the NHS and social services, not because it is better for families, but because it costs significantly less than hospitalisation or residential care (Corkin et al. 2006; Davies and Carter 2013; Hunt et al. 2015). Therefore, it is in the interest of these agencies that families are well supported in order to keep children cared for in their own home environment. However, keeping children at home for as long as possible and the impact of caring for children or young people with life-limiting or life-threatening conditions has resulted in increasing psychological, physical and financial pressure on parents caring for their child at home (Miller 2002; MacDonald and Callery 2008; McCann et al. 2012). Parents increasingly carry out aspects of complex care that would have traditionally been carried out by health professionals in institutions (Horsburgh et al. 2002; Hewitt-Taylor 2005; Thurgate 2005; MacDonald and Callery 2008; 2009). In addition, children with life-limiting conditions tend to have co-morbidities alongside their primary condition, further complicating the impact of care on parents (Hunt et al. 2013).

Similarities can be drawn between the impact of care faced by parents of life-limited or life-threatened children to those parents of children with complex needs or disabilities (Corkin et al. 2006; Ling 2012). Past research has indicated that there is an overlap in short break need and provision for children with complex needs and children with life-limiting or threatening conditions (McConkey and Adams 2000). Parents face both physical and psychological stress (Chan and Sigafoos 2001; Nelson and Rushton 2001; Horsburgh et al. 2002; Ingleton et al. 2003; Hewitt-Taylor 2005; Mash and Lloyd-Williams 2006; Yantzi et al. 2007; Eaton 2008; Thomas and Price 2012; Hunt et al. 2013; Remedios et al. 2015). Physically, parents face missing sleep (McConkey and Adams 2000; Horsburgh et al. 2002) with chronic fatigue being common (Murphy 2001). Typical activities such as shopping, days out and holidays become more stressful and difficult to organise (Mash and Lloyd-Williams

2006; Yantzi et al. 2007). Siblings can become young carers themselves or experience psychological distress due to the nature of their brothers or sisters condition (Hamama et al. 2008; O' Brien et al. 2009; Gaab et al. 2014; Malcolm et al. 2014).

Whilst health needs of life-limited children are met, parents providing care routines feel frustration at the lack of psychological support available (Hunt et al. 2013). Care routines involve the use and storage of medical equipment, encumbering the home and creating a hospital-like environment (Glendinning and Kirk 2000). Parents describe the emotional impact of seeing rapid changes in their child's health and the impact it also has on their other children (Murphy 2001; Hays et al. 2003; Hewitt-Taylor 2005; Thomas and Price 2012). Mental health problems have been reported in parents who become carers of life-threatened children (Remedios et al. 2015). Importantly, in contrast to healthy children, children with complex needs will always be dependent upon care from their parents, having conditions that deteriorate over time (Corkin et al. 2006). Families frequently describe having to manage complex care routines and the uncertainty of rapidly changing health (Horsburgh et al. 2002; Eaton 2008). Parents also report a loss of normality in life (Wood et al. 2010).

Horsburgh (2002) argued that there is little evidence to suggest increased divorce rates amongst parents caring for children with complex needs. However, there have been documented increases in marital distress, due to feelings of guilt and anger (Vogel et al. 1996; Gold 1997). When asked what would help make them stronger socially, 43% of parents with children who had a disability said social time with partner or spouse away from caring would help (Contact a Family 2003). However, this is not always possible, as one parent is usually needed to care for his or her child. Compounding this are feelings of fear, uncertainty and grief due to the uncertain nature of their child's health (Steele and Davis 2006).

The impact of care on relationships between parents was explored in a survey of 2,000 parents of disabled children (Contact a Family 2003). Seventeen percent

said their relationship was variable, six percent not good and 14% had little or no contact. When children lived with both parents, 38% said it had caused some problems between them, 12% said major problems existed and two percent said this had led to separation. When a disabled child lived with only one parent responses were different; 18% said it had caused some problems, 16% major problems and 24% said it had led to separation. It is worth noting that some parents did state that having a disabled child brought them closer together as a couple.

Social isolation is a widely reported impact of caring for a child or young person with complex needs (Gold 1997; Robinson et al. 2001; Davies et al. 2004; Beresford et al. 2007; Thomas and Price 2012; Hunt et al. 2013), with parents feeling trapped in their own homes due to medical equipment or unpredictability of children's health (Brinchmann 1999; Davies et al. 2004; Yantzi et al. 2007; Eaton 2008; Wood et al. 2010). Eaton (2008) found that parents feel they become isolated from friends and families due to the care of their child. It has been reported that whilst parents may initially receive support from family members, this decreases over time as increased training and responsibility is needed (Beresford 1994; Kirk 1998).

Caring for a child with complex needs impacts financial and employment opportunities (Horsburgh et al. 2002; Corkin et al. 2006; Thomas and Price 2012; Hunt et al. 2013; Gardiner et al. 2014). One or both parents may give up full time work, not only impacting financially but also on personal development and self-esteem (Horsburgh et al. 2002). A survey carried out by Hunt et al (2013) found that 60% of parents who responded reported that they had lost income due to caring for their life-limited child. Remedios et al (2015) found that over half of parents caring for life-limited children felt considerable concern regarding finances. Financial hardship is often common due to giving up full time work and the costs involved in caring for a sick child (Gold 1997; Hunt et al. 2013).

There are frequent costs involved in caring for a child with life-limiting conditions such as specialised dietary food, clothing, travel and heating, in addition to infrequent additional costs such as housing, equipment and home adaptations (Hunt et al. 2013). As a consequence, families often forgo basic essentials such as food, heating and specialist equipment, resorting to taking out loans to pay for these essentials (Harrison and Woolley 2004; Contact a Family 2012). Consequently, financial difficulties can often lead to parents feeling pressured, anxious and stressed, potentially impacting the relationship with each other (Contact a Family 2012). Poverty has also been associated with increased risk of mental health problems in mothers of disabled children (Emerson and Llewellyn 2008).

There are currently approximately six million informal carers in the UK caring for both adults and children. It has been estimated that unpaid or informal caring saves the health and social care system £132 billion pounds a year in the UK (Buckner and Yeandle 2015), greater than the NHS budget as a whole. If a family breaks down and is unable to provide the same level of informal care, additional costs are placed on state health and social care (Relationships Foundation 2015). With this in mind, section 3.6 outlines literature relating to the impact that short breaks may have on main caregivers and families as a whole.

3.6 Impact of short breaks

Research has frequently highlighted the benefits of short breaks for caregivers, extended family members and children affected by life-limiting conditions, life-threatening conditions or disabilities (McConkey and Adams 2000; Chan and Sigafos 2001; Neufeld et al. 2001; Horsburgh et al. 2002; MacDonald and Callery 2004; Eaton 2008; Thomas and Price 2012; Remedios et al. 2015). For example, in a study exploring the impact of short breaks for families of life-limited or life-threatened children, parents stated they were unable to cope prior to receiving short breaks (Eaton 2008). Literature reviews about short breaks impact indicate benefits to both the parents and affected children in a positive way (Strunk 2010; Robertson et al. 2011) and as such are valued by parents (Craft and Killen 2007).

Crucially, one of the key benefits of short breaks is allowing parents to have a break from caring for their child (Gold 1997; Horsburgh et al. 2002; MacDonald and Callery 2004), giving parents opportunities to catch up on rest or spend time with the wider family, resulting in improved well-being (McNally et al. 1999; Corkin et al. 2006; Eaton 2008). It has been suggested that breaks from caring enable parents to continue caring for their child at home in the long term (MacDonald and Callery 2004; Eaton 2008; Wilkie and Barr 2008). Additional reported benefits include reduced carer stress, reduction in exhaustion, ability to care and opportunity for children to socialise (MacDonald and Callery 2004; Grinyer et al. 2010; Robertson et al. 2011). In a survey of 108 parents caring for a child with a life-limiting condition two-thirds of respondents stated that the main benefit of accessing hospice short breaks was getting a break from caring (Kirk and Pritchard 2012). Perceived benefits of short breaks vary between parents and children, with parents emphasising acquisition of new skills and physical development, and children focusing on activities enjoyed (Welch et al. 2014).

Another reported benefit of short breaks is that they allow families opportunities to feel normal by undertaking activities that would otherwise be impossible (MacDonald and Callery 2004; Mansell and Wilson 2009; Robertson et al. 2011). Beresford, Rabiee and Sloper (2007) found that short breaks give parents a break from focusing on one child, giving opportunities to spend time with siblings or with each other as a couple. The benefit of being able to spend time with other children has been reported elsewhere also (MacDonald and Callery 2004; Wilkie and Barr 2008).

Parents who are carers have reported being moderately fatigued and having lower mental health than the general population. Parents who have then received short breaks show significant improvements in psychological adjustment, fatigue and mental health (Remedios et al. 2015). However, no significant differences in physical health or quality of relationship with partner have been found (Remedios et al. 2015). Similarly, an Australian study into the

impact of short breaks on parents of children with Rett Syndrome, found that short breaks have no significant impact on either physical or psychological health of parents (Urbanowicz et al. 2011). These studies however, had small sample sizes and therefore it is difficult to generalise the impact of short breaks on parents (Remedios et al. 2015). Additionally, there is limited research exploring the impact of short breaks on the relationship between parents and that which does is often inconclusive (Robertson et al. 2011).

3.7 Limitations of short breaks

Lack of availability of short breaks for families has been frequently highlighted as a service limitation (Beresford 1994; MacDonald and Callery 2004; McConkey et al. 2004; 2008; Wilkie and Barr 2008; Welch et al. 2010; McDermid et al. 2011; Thomas and Price 2012). Demand for short breaks is high (Hunt et al. 2013) and service availability varies depending on the area families live in (Holmes et al. 2010; Hunt et al. 2013). Campaigning for funding for short breaks from statutory services has also been an issue for parents (Kirk 1998; Craft and Killen 2007).

Tailoring short breaks to individual circumstances of a child and family is difficult for two reasons (McConkey et al. 2004). Firstly, families may accept whatever short breaks they are offered, even if it is poor quality or does not meet their needs (McConkey et al. 2004) due to shortage of short break availability (Beresford 1994). Therefore, parents may have to learn complex procedures to care for their child (Glendinning and Kirk 2000) and alongside this issue, the competency and quality of staff has been demonstrated as a potential concern for parents (Kirk 1998; Eaton 2008; MacDonald and Callery 2008). For parents to feel confident in relinquishing care of their child, they need to trust staff providing short breaks services will carry out their child's care to a high level (Eaton 2008; MacDonald and Callery 2008).

Cost effectiveness of a short break service depends on several factors; the provider, type of staff, number of staff, length of break and the needs of children (Holmes et al. 2010). Due to the high cost of educating staff, specialist equipment and the rigorous levels of interaction needed, short break services

can be costly (Ward et al. 2008). Whilst there is still limited research, what evidence there is suggests that short break services offer value for money by keeping life-limited or life-threatened children out of hospital or full time care whilst also providing a high quality service (Beresford 1994; Chan and Sigafos 2001; Staley 2008; Holmes et al. 2010).

Parents have stated short breaks are only a 'real' break when children stay away from home overnight (Mansell and Wilson 2009). The length of short breaks away from the home, however, can be an issue. If parents consider the break offered to be too short, packing equipment and travelling can be considered disproportionate to the break received (Grinyer et al. 2010). Ingleton (2003) suggested that parents will weigh up the benefits and costs of accessing a short break service. If the service is of poor quality or does not meet their needs, they are less likely to access it. Lack of choice or flexibility has been raised as an issue with short breaks (Thurgate 2005), especially during holidays (Wilkie and Barr 2008) or emergencies (Eaton 2008). The changing nature of a child's life-limiting or life-threatening condition means booking short breaks weeks in advance is not always possible (Eaton 2008). It has been suggested that for some families, short breaks end up being used for relatively dull activities, such as catching up on sleep (MacDonald and Callery 2004; Eaton 2008).

Short breaks can result in anxiety for parents over relinquishing care of their child and quality of care (Neufeld et al. 2001; McConkey 2008; 2011). Some children with learning disabilities have exhibited distress and homesickness when accessing short breaks (Radcliffe and Turk 2008; Robertson et al. 2011). Some parents may find it difficult to accept their child has a life-limiting condition and this lack of acceptance may prevent them from utilising short breaks (Eaton 2008). There may be underlying power disadvantages between parents and staff, with parents being thankful for the short break they receive and not wanting to question or raise concerns with the provider (Eaton 2008; Grinyer et al. 2010). Short breaks at home can involve issues surrounding privacy (Kirk 1998; Eaton 2008), with some parents feeling they cannot sleep

with carers in their house or let siblings wonder around in little clothing (Eaton 2008).

3.8 Chapter conclusion

Short breaks are a fundamental service offered by children's hospices, aiming to give families a break from caring responsibilities and giving children opportunities for socialising. Whilst the term 'respite' was often used instead of 'short breaks', it has fallen out of favour due to the negative connotations associated with it. Short break models vary between organisations, however the notion that it involves an outside agency taking over care from the main caregiver is universal. Children's hospices offer short breaks at three locations; either at home only, a hospice only or in both the home and the hospice. A range of literature has explored the effect of caring for a child or young person on their main caregivers, usually the parents. Short breaks can have a positive impact by giving caregivers a pause from caring. Literature has explored the benefits this has to the physical and mental health of individual caregivers. However, there has been little research exploring the impact that short breaks may have on relationship between parents.

4 Partner Relationships: Sociological and Psychological Perspectives

4.1 Chapter overview

Chapter Three outlined short breaks, a key service offered by children's hospices and the impact that they have for children with complex needs' life threatening and life-limiting conditions and their caregivers. However, there is a paucity of literature investigating how short breaks affect partner relationships between caregivers. This chapter reviews literature relating to partner relationships, commencing with an overview on sociological perspectives on family units to set the scene. This is followed by an outline of marriage, cohabitation and civil partnerships in the United Kingdom, before discussing divorce and relationship dissolution. The last part of this chapter outlines and appraises five dominant perspectives of partner relationships including: social exchange theory, behaviourism, attachment theory, dynamic goal theory and the ABCX model of adjustment and adaptation.

4.2 Sociological perspectives on family units

In the nineteenth century, the field of anthropology influenced early sociological concepts of families with partner relationships serving a biological function, reproduction and raising of children (Bernardes 1997; Newman and Grauerholz 2002; Chambers 2015). This sociobiological perspective suggests that biology interacts with culture to influence family structures and continues to influence how families are viewed (Newman and Grauerholz 2002; Chambers 2015). Additionally, other family forms such as polygamy (having more than one partner) or matriarchies (where women are the head of the family) were dismissed in favour of the patriarchal monogamous partner relationship and nuclear family (Bernardes 1997; Newman and Grauerholz 2002). Parallels were drawn with evolutionary theories, giving support for the nuclear family as the most effective family unit for survival, with men remaining with women and children to protect them (Newman and Grauerholz 2002). There was little factual evidence to support these claims, yet the idea of a

nuclear family became accepted amongst academics and wider communities (Bernardes 1997; Newman and Grauerholz 2002; Chambers 2015). The impact that this has was outlined by Muncie:

“[The] idea of the nuclear family clearly retains a potency such that all other forms tend to be defined in reference to it”.

(Muncie 1997, p.10)

In the twentieth century sociologists focused their attention on the impact of industrialisation and economic factors on family units through, for example, the functionalist approach (Bernardes 1997; Dozier and Schwartz 2001). Parsons and Bale (1956) argued that by necessity family units were transformed from large extended units to smaller, mobile ones. Furthermore, industrialisation required that families had geographical and social mobility, resulting in two parent and two children units (Bernardes 1997). Functionalism is also characterised by the state taking over roles traditionally fulfilled within families such as education and healthcare (Bernardes 1997; Chambers 2015). The role of families therefore became educational, teaching children cultural norms and supporting their emotional needs with a husband and wife taking on the respective roles of breadwinner and housekeeper (Parsons and Bales 1956; Wilson 1985; Bernardes 1997; Dozier and Schwartz 2001).

The functionalist explanation of families has been criticised on a number of levels before being discredited (Wilson 1985; Andersen and Taylor 2012; Chambers 2015). In practice, socialisation is not the sole responsibility of families, but also external establishments including the government, education and media (Andersen and Taylor 2012). The functionalist explanation was also criticised by feminists for emphasising and validating imbalanced division of domestic labour (Marsh 2006; Chambers 2015). Finally, functionalism failed to explain and account for family units that differed from the traditional nuclear family model with such alternatives being viewed as deviant (Andersen and Taylor 2012; Chambers 2015). However, the functional explanation of families was influential until the 1970s and continues to impact on both wider societies

and policy makers' perceptions on what constitutes a family today (Marsh 2006; Chambers 2015).

Consequently, concerns over family decline continue to influence social theory and policy. Modern family forms, including same-sex couples, single-parent families and post-separation families (also referred to as reconstituted families), are said to be part of a society in decline (Chambers 2015). Work by Giddens (1992) and Bauman (2002) attempted to explain this increase in family variation through the individualisation thesis. The individualisation thesis highlights the erosion of traditional family customs to be replaced with individual agency and choice (Smart and Shipman 2004; Chambers 2015). Individualism reconsidered concepts such as 'gender' and 'sexuality', which had previously been considered biological in nature; this gave individuals the autonomy and freedom from traditional roles, including gender specific roles such as 'housewife'.

This has led some to argue that individualism is risky because it encourages transient relationships, with increased divorce rates supporting this claim (Chambers 2015). People have increased individual choice regarding their life, but as a result relationships have become more temporary (Beck-Gernsheim 2002). Giddens (1992), however, argued that relationships between men and women are changing in a positive way, becoming more democratic compared to traditional marriages. The individualisation thesis fails to represent more complicated family lives and does not truly represent families found in contemporary everyday life. The thesis also exaggerates the personal choice individuals have (Williams 2008) and therefore fails to account for gender and class limitations that endure within family life (Chambers 2015).

Morgan (2011) rejected the emphasis on ideological sociological theory, providing an alternative way of viewing families and the concept of 'family practices'. Family practice arose from dissatisfaction with the ideologically driven notion of nuclear families that conflicted with family units in reality. Family practice focuses on how people practically 'do' relationships in reality,

rather than focusing on defining family structures or debating whether families are in decline (Morgan 2011; Chambers 2015). Family practice focuses on families as a set of social practices, rather than a longstanding institution in decline (Morgan 2011; Chambers 2015). The concept of family practice has important implications for the present research for two reasons. Firstly, it highlights that not all families are the same and meet the ideologically driven nuclear family. Secondly it takes a pragmatic attitude towards family research, advocating researching the reality of relationships. This has links with pragmatism which will be outlined in Chapter Six.

4.3 Marriage, cohabitation and civil partnerships in the UK

Marriage is *“a legally accepted relationship between two people in which they live together, or the official ceremony that results in this”* (Cambridge Dictionary 2016a). The most recent figures on the number of marriages that occurred in England and Wales in 2013 was 240,854, a decrease of 8.6% on 2012 (Office for National Statistics 2016a). The mean age for marriage in 2012 was 36.7 years for men and 34.3 years for women, an increase of ten years for both men and women since 1972, which is as far back as the ONS compares (Office for National Statistics 2016a).

Cohabitation is defined as: *“two people, especially a man and woman who are not married, cohabit, they live together and have a sexual relationship”* (Cambridge Dictionary 2016b). More recently, the ONS outlined cohabitation as individuals living with a partner without being married or in a civil partnership (Office for National Statistics 2014). Both definitions of cohabitation are similar in referring to living together without marriage. However, the most recent definition demonstrates the changing nature of social institutions like cohabitation by also including same-sex partnerships, which were absent from the earlier definition.

Between 1996 and 2016, numbers of people cohabiting doubled to 3.3 million, cohabitation being the fastest growing family type in the UK (Office for National Statistics 2016b). Earlier data suggests those most likely to cohabit are aged 25 to 34 years with 27% of this age group cohabiting (Office for National

Statistics 2012). The ONS suggests that the increase in cohabitation in this age group may be linked with the increase in age of marriage; more people are cohabiting before getting married. This seems to be supported by the fact that 96% of this age group have never been married (Office for National Statistics 2012).

Recent figures suggest that the percentage of children living in cohabiting couple families was 15% in 2016, compared to 63% for children living in married couple family (Office for National Statistics 2016b). The percentage of births outside of marriage or civil partnership rose from 47.5% in 2014 to 47.7% in 2015 (Office for National Statistics 2016c). This can be explained by increasing disconnection between the institution of marriage and childbearing (Kjeldstad and Lappegård 2014). With the increase in childbearing within cohabiting couples, marriage has become increasingly less important in forming family units (Kjeldstad and Lappegård 2014). Traditional family models present childbearing as a stage that occurs post-marriage (Berrington et al. 2015). However, marriage is now viewed as not necessary by society in Western Europe for childbearing, with parenthood being more of a statement of commitment than marriage (Holland 2013; Berrington et al. 2015; Perelli-Harris and Bernardi 2015).

Numbers of cohabiting same sex couples increased by 345% between 1996 and 2012 (Office for National Statistics 2012), significantly more than the 98% growth for heterosexual couples over the same period. In 2012, it was estimated that there were 2.9 million opposite sex couples and 69,000 same-sex couples cohabiting in the UK (Office for National Statistics 2012). The Civil Partnership Act (2004), implemented in December 2005, allowed same-sex couples to register their relationship for the first time (Ross et al. 2011). A civil partnership is formed when both civil partners sign the relevant documents in comparison to marriage that is formed when couples speak their vows (Civil Partnership Act 2004). Civil partnerships allow same-sex partners similar rights to those who are married including property rights, pension benefits and parental responsibility. Between December 2005 and December 2010 there

were 42,787 ceremonies in England and Wales which means there were 85,556 civil partners at that time (Ross et al. 2011).

4.4 Divorce and separation of partnerships in the UK

Divorce is the legal ending of a marriage (Cambridge Dictionary 2016c). The ONS provides analysis of divorce rates from 1973 to 2013. In 1973, 22% of marriages ended within fifteen years (Office for National Statistics 2014). By 1997 the number of divorces before the fifteenth year of marriage rose by a third (Office for National Statistics 2014). However, more recent data suggests a drop of 3.1% in the rate of divorce from 114,720 in 2013 to 111,169 in 2014 (Office for National Statistics 2016d). A possible explanation for this increase could be the start of the recession in 2008/9, with increased financial pressure resulting in higher divorce rates (Vaitilingam 2011). Conversely, other theorists (Wilcox and Marquardt 2011; Chowdhury 2013) have argued couples may not divorce because of economic reasons during a recession. The increased acceptance of cohabitation as an alternative to marriage may also explain this decrease in divorce as less couples are marrying and consequently not divorcing (Holland 2013; Kjeldstad and Lappegård 2014). Data for 2014 was unavailable, but just under half (48%) who divorced in 2013 had at least one child under the age of 16 (Office for National Statistics 2015). The average duration of marriage prior to divorce in 2014 was 11.7 years (Office for National Statistics 2016d).

Civil partnerships cannot be ended through divorce; instead dissolution of civil partnerships can occur if they are irretrievably broken down (Ross et al. 2011). There were no dissolutions of civil partnerships in 2006, but there were 40 in 2007. By 2010 there were 1,007 civil partnership dissolutions (Ross et al. 2011). There is a gender difference in dissolutions, with women more likely to end a civil partnership than men. By the end of 2010, 62 per cent of dissolutions were female couples, despite comprising only 44 per cent of civil partnerships (Ross et al. 2011).

There has been a long standing belief that cohabiting relationships are more likely to end in separation compared to married couples (Berrington and Stone

2015); past research has found that the percentage of cohabitating partnerships which ended in separation within five years was on the increase (Beaujouan and Bhrolcháin 2011). However, more recent research suggests it is not cohabitation itself which makes partner relationships more unstable than marriage, it is the socio-economic circumstances of those of cohabiting (Crawford et al. 2012; Berrington and Stone 2015). Cohabiting couples tend to be younger and have lower income, both of which are associated with relationship instability (Crawford et al. 2012; Berrington and Stone 2015).

4.5 Social exchange theoretical explanation of partner relationships

Social exchange theory was established by four key figures: Homans (1958, 1974), Thibaut and Kelley (1959) and Blau (1964). Social exchange theory presents a broad framework for explaining all types of relationship, both romantic and non-romantic (Gross 2010). In essence, social exchange has three core principles. First, the assumption that individuals are generally rational and calculate the costs of benefits when engaging in social exchange. Second, following on from this, the theory assumes that individuals seek to maximise their benefit from exchanges. Third, beneficial exchanges will shape patterns of behaviour for individuals. Social systems consist of multiple individuals all seeking to maximise their benefits. Therefore, power differences exist depending on resources available to achieve beneficial exchanges (Gross 2010).

Social exchange theory was first presented in “Social Behaviour as Exchange” (Homans 1958), outlining social exchange as the exchange of activity between two individuals. Exchanges can be tangible or intangible and can be rewarding, less rewarding or costly. Social exchange consists of three components: success proposition, stimulus proposition and deprivation-satiation proposition (Homans 1958). Success proposition relates to the tendency to repeat an action if rewarded. Stimulus proposition refers to the number of times a stimulus has resulted in a reward in the past (Homans 1958). The greater the number, the more likely the person is to respond to the stimulus. Finally, the reward will lose its value the more times it is received within a short time period.

Social exchange theory is the most frequently used theoretical explanation for partner relationship quality and stability (Karney and Bradbury 1995). Levinger (1976) was one of the first theorists to apply the concept of social exchange to relationships, arguing that the stability or breakdown of partner relationships is dependent on three aspects; reward, barriers and alternatives. Rewarding aspects of a relationship could be emotional security, social status or sexual fulfilment (Levinger 1976). Social and religious expectations or limited finances would be examples of barriers to ending a relationship. Alternatives refer to other options outside the relationship, such as the presence of preferred partners (Levinger 1976). If attractions within a partner relationship and barriers to ending a relationship are few then alternatives to the current relationship become more appealing.

Lewis and Spanier (Lewis and Spanier 1979; Thompson and Spanier 1983) used social exchange theory and the work of Levinger (1976) to develop typical marital typologies with satisfaction and stability as two core components. According to their typologies marriages could be: stable and satisfied, stable but unsatisfied, satisfied but unstable and unsatisfied and unstable. With this in mind, partner relationships with low satisfaction but high barriers to leaving would be classified as unsatisfied but stable. By contrast, happy but unstable relationships would have adequate satisfaction but may have no barriers to leaving, such as financial dependency (Karney and Bradbury 1995).

The social exchange theory explanation of partner relationships has two main strengths; flexibility and distinction between relationship satisfaction and relationship stability (Karney and Bradbury 1995). The flexibility of social exchange theory means not only that several variables can be included but also that they combine to influence satisfaction (Karney and Bradbury 1995). For example, barriers could include high-level variables such cultural attitudes towards divorce or separation, whilst lower level variables could include individual attitudes towards the relationship (Karney and Bradbury 1995). Secondly, distinguishing between relationship satisfaction and stability means

that the theory can allow for multiple relationship types including those where unhappy couples stay together (Lewis and Spanier 1979).

However, the social exchange theory of partner relationships does not explain the process of how an originally partner relationship becomes unstable over time and also lacks temporal perspective in terms of rewards and barriers (Karney and Bradbury 1995). In other words, the theory gives no explanation to how perceptions around reward and barriers develop over time. Ultimately, the theory does not explain the processes of how couples reach the point of dissolution in their relationship. Social exchange theory has also been criticised for viewing people as essentially selfish and seeking their own self-interests in social exchanges (Rubin 1973). Despite these criticisms, social exchange theory continues to be utilised in explaining close relationships (Nakonezny and Denton 2008; Hand and Furman 2009; Luke et al. 2011; Paat 2013).

4.6 Behavioural explanations of partner relationships

Behaviourism was the dominant paradigm within psychology between the 1920s and 1950s and is associated with figures such as Skinner (1948, 1953), Thorndike (Thorndike 1905) and Pavlov (Pavlov and Thompson 1910). Behaviourism was founded on several key assumptions. Firstly, that psychology should obey the scientific paradigm with theories being supported by empirical data collected through observation and measurement (Bouton 2009; Gross 2010; Brown and Gillard 2015; Rachman 2015). Therefore, behaviourists are only concerned with observable phenomena that can be objectively measured. Unobservable internal thoughts are considered irrelevant. Secondly, behaviourists reason that there is no such thing as free will; individual behaviours are shaped in response to their environment (Bouton 2009; Gross 2010; Brown and Gillard 2015). Lastly, no matter how complex, all behaviour is the result of an association between stimulus and response (Bouton 2009; Gross 2010; Brown and Gillard 2015).

The social exchange theory of relationships focused on the concepts of rewards and barriers, with rewarding aspects such as emotional and sexual fulfilment promoting stable relationships (Karney and Bradbury 1995). Behavioural

approaches to relationships also consider reward and barriers, albeit to a lesser extent. Instead, the core focus is the exchange of key behaviours between individuals in a relationship (John et al. 1976; Karney and Bradbury 1995). More specifically, behavioural research has focused on behaviours during problem solving and is founded on the principle that positive behaviours enhance relationship evaluations, whilst negative or punishing behaviours harm relationships (Stuart 1969; Wills et al. 1974; Markman 1981).

The behavioural approach to relationships provides a process that proposes how couples' feelings about relationships can change over time, a weakness of social exchange theory. As Bradbury and Fincham (1991, p.134) stated: "*spouses learn on the basis of their interactions and the appraisals that follow from them whether or not they are in a rewarding relationship*". When a couple has a positive interaction, this leads to further positive interactions and subsequently results in a satisfied relationship or marriage. By contrast, unsatisfied partner relationships are characterised by negative interactions and difficulties in dealing with conflict from within and outside the relationship (Karney and Bradbury 1995). This process was further developed through coercion theory (Karney and Bradbury 1995) describing how partners unconsciously reward negative behaviours. For example, if constant shouting by one partner results in a desired behaviour by the other partner, the negative behaviour (shouting) has been reinforced and is more likely to occur again.

However, emphasis on interactions is also a weakness of the behaviourist approach to relationships (Karney and Bradbury 1995). Focusing purely on behavioural interactions between partners in a relationship, leads to macro-level factors such as personality, education or life events, being negated (Karney and Bradbury 1995). A second disadvantage of behavioural theory is that it explains a limited number of relationship outcomes. According to Karney and Bradbury (1995), behavioural theory would be able to explain between couple variation in relationship satisfaction, but only in one direction. Some unsatisfied couples separate within a few years, whilst other unsatisfied couples may continue to be

together for an extended period of time. Behavioural theory cannot explain this variation in outcome in relationships.

4.7 Attachment theory and partner relationships

The roots of attachment theory lay in the influential work of John Bowlby (1958, 1969). Other notable contributors to attachment theory include Mary Ainsworth (1979; 1991), Rudolph Schaefer (1960) and Mary Main (Main and Solomon 1986; Main and Hesse 1990). Attachment theory suggests the nature of a child's first close relationship lay the foundations for conceptualisation of relationships throughout life (Bowlby 1969). There are three main attachment styles: secure, anxious-ambivalent and anxious-avoidant (Ainsworth 1979). Children who feel safe to explore their world develop secure attachment styles (Bowlby 1969; Ainsworth 1979; Ainsworth and Bowlby 1991). Parents who are inconsistent in how they respond to their child, may result in a child with an anxious-ambivalent attachment style where they both seek and resent their caregivers. By contrast, anxious-avoidant children avoid contact with their caregivers without showing any signs of distress (Bowlby 1969; Ainsworth 1979; Ainsworth and Bowlby 1991). In the mid-eighties Main and Solomon (1986) added a fourth attachment type, insecure-disorganised attachment. Children with insecure-disorganised attachment style only present as disorganised for short periods of time and as such are also given a secondary attachment type from the original Ainsworth three (Main et al. 2011).

Consequently, those who apply attachment theory to adult relationships (Hollist and Miller 2005; Millwood and Waltz 2008; Merz and Jak 2013; Hall 2015) believe that childhood attachments, usually with caregivers, will shape adult relationships and in particular, partner relationships. Researchers (Hazan and Shaver 1987; Hazan and Shaver 1994; Hazan and Diamond 2000; Mikulincer and Shaver 2005; Brassard et al. 2007; Butner et al. 2007; Hicks and Diamond 2011; Brassard et al. 2012) have suggested that early attachment styles developed in childhood could be used to explain close relationships in adulthood. Hence, attachment theory has been used to explain partner relationships and other close adult relationships (Hazan and Shaver 1994; Hazan and Diamond 2000; Hollist and Miller 2005; Millwood and Waltz 2008;

Merz and Jak 2013; Hall 2015). According to attachment theory, relationship satisfaction is determined by whether the basic needs of comfort, care and sexual gratification are met (Hazan and Shaver 1994; Hazan and Diamond 2000).

Consideration of each partner's early attachment and family history prior to the relationship is a strength of attachment theory (Karney and Bradbury 1995). However, this is based on an assumption that individuals maintain the same attachment style throughout the lifespan, with no scope for sources of change (Karney and Bradbury 1995; Fraley and Shaver 2000). Additionally, although attachment theory does accept that the priority of individual needs change when in a partner relationship (Hazan and Shaver 1994; Fraley and Shaver 2000; Hazan and Diamond 2000), it does not explain the source of this change, how change occurs and how the relationship is impacted upon when two people with different attachment styles come together.

Attachment theory also fails to explain two types of variability. Firstly, it fails to explain why some with a secure attachment style have short adult relationships and conversely why some with anxious-avoidant attachment styles have longstanding adult relationships (Karney and Bradbury 1995; Fraley and Shaver 2000). Secondly, the variability in relationship satisfaction between couples who share the same attachment style has yet to be explained (Karney and Bradbury 1995; Fraley and Shaver 2000).

4.8 Dynamic goal theory and partner relationships

One possible theory to explain relationship satisfaction is dynamic goal theory (Li and Fung 2011). Human goals can be defined as internal representations that individuals hold on desired outcomes, events or processes (Austin and Vancouver 1996). Dynamic goal theory has four specific elements underpinning it: (1) that all people have multiple desired goals to achieve in partner relationships, (2) prioritisation of these goals will change across the lifespan, (3) relationship satisfaction will be determined by whether these prioritised goals are met at the right point, and (4) other factors impact relationship satisfaction by influencing prioritisation or achievement of relationship goals.

Using previous research into goal theory as a foundation (Austin and Vancouver 1996), Li and Fung (2011) suggested that relationship goals could be divided into three categories: (1) personal growth goals, (2) instrumental goals and (3) companionship goals. Personal growth goals encompass an individual's aim to improve themselves within a partner relationship, with good relationships enabling people to achieve personal goals (Li and Fung 2011). Instrumental goals relate to practical tasks in partner relationships such as division of labour, managing family finances and child rearing. Relationships where division of labour is viewed as unequal will have higher levels of marital conflict (Li and Fung 2011). Companionship goals include two fundamental psychological needs; the desire for a feeling of belonging and relatedness in marriage (Li and Fung 2011).

Building on the lifespan theory of control (Heckhausen and Schulz 1995), Li and Fung argued that relationship goals and their importance change over the lifespan, with personal growth goals taking priority in the early years (Li and Fung 2011). Li and Fung (2011) predicted that instrumental goals peak during middle adulthood by arguing that middle adulthood is a time when individuals face greatest pressure from both family and work life. Increased pressures consume valuable mental and physical resources, resulting in lower life satisfaction. Hence, there is greater need for support with instrumental goals during this period of life. Finally, companionship goals become more important as people age with increasing focus on seeking out meaningful social relationships (Li and Fung 2011).

Dynamic goal theory suggests individuals have expectations when entering a partner relationship and relationship satisfaction is mediated by prioritised goals being met at the appropriate developmental stage (Li and Fung 2011). Past research has found relationship satisfaction is influenced by whether expectations were met (Campbell et al. 2001). However, developmental stages and associated prioritised relationship goals are linked to age rather than length of the relationship between a couple. For those who marry later in life,

companionship goals will be prioritised immediately rather than personal growth goals (Li and Fung 2011).

Finally, dynamic goal theory considers interaction between relationship goals and other influencing factors which influence relationship satisfaction (Li and Fung 2011). Factors include: individual personality, communication between a couple, personality similarities, presence of children and a couple's social network (Bradbury et al. 2000). Additional influencing factors can be divided into micro and macro factors. Culture would be an example of a macro factor influencing the dynamic of relationship goals (Li and Fung 2011); for example, instrumental goals are emphasised in prearranged marriages. Having children exemplifies micro factors (Li and Fung 2011). Having a child takes up time and attention. As a consequence, instrumental goals will increase and take priority over personal growth goals.

Dynamic goal theory was developed from two existing theories; goal construct theory (Austin and Vancouver 1996) and life-span theory of control (Heckhausen and Schulz 1995), both of which are widely cited and utilised to explain a range of goal or motivation-based phenomena within psychological research and theory (Kanfer et al. 2013; Rodkin et al. 2013; Rapp et al. 2014; Rand et al. 2016). By contrast, dynamic goal theory as proposed by Li and Fung has been cited in very few articles and there has been no additional supportive evidence for the theory since it was published five years ago.

4.9 The ABCX model of adjustment and adaptation

All of the previous explanations of partner relationships or marriage have failed to explain relationships fully. An alternative theory that could be modified to explain partner relationships is the ABCX model of adjustment and adaptation (McCubbin and Patterson 1983). The ABCX model of adjustment and adaptation developed from the work of Hill (1949), explored family reactions to stress and, specifically, why some families respond better than others to hostile or stressful situations, resulting in the ABCX model. The ABCX model incorporates four key aspects: (A) adaptation to stressful situations is required by families, (B) families have variable quantities of concrete resources and (C)

families may perceive stressful events differently, modifying the impact of these events. The type of crisis and whether a family will overcome it (X) is therefore determined by ability to adapt (A), resource availability (B) and (C) perception of the crisis.

This model was further developed by McCubbin and Patterson (1983) who believed that the original model was limited in focusing only on variables that existed before a stressful event. They expanded the model in two ways. Firstly, they argued that reactions to an event may develop over time. Secondly, following on from this, they also argued that how future events are perceived will be shaped by reactions to past events. These two expansions to the original model resulted in the double ABCX model (Figure 4.1), where each of the original components has a primary meaning and a secondary meaning that later emerges. Put into practice this means: (aA) the initial effort to cope with an event can lead to additional stressors, a process known as *pileup*, (bB) an initial level of adaptive resources which can be enhanced in response to an event and (cC), an initial perception of an event, which can influence future event perceptions. The resulting response to the stressful event (xX) can be either adaptive or maladaptive.

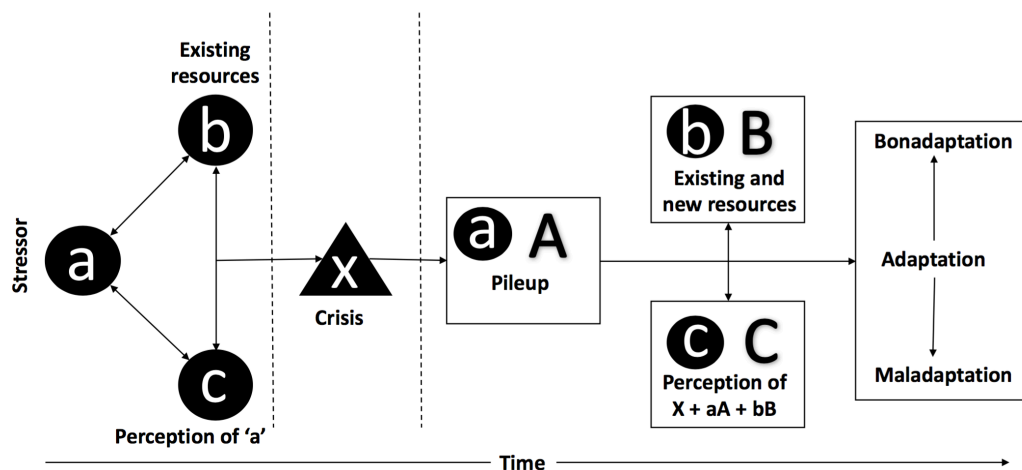


Figure 4.1: The Double ABCX model of adjustment and adaptation

Whilst the model was initially developed to explain family functioning and adaptation during stressful events, it has been suggested the ABCX model could

be used to explain marital or partner relationship outcomes, with reduced relationship satisfaction and separation or divorce resulting from ineffective stress management (Karney and Bradbury 1995; Williams 1995; Lavee 2005). Therefore, couples who experience more stressful events are more likely to have poor relationship outcomes, but these outcomes will also be mediated by resources available and how events are perceived (Lavee et al. 1985; Karney and Bradbury 1995; Williams 1995). For example, the ABCX model has been used to explain the impact of having children with autism on partner relationships (Stuart and McGrew 2009; Manning et al. 2011; Ramisch 2012; Paynter et al. 2013).

Whilst there are studies that use the ABCX model to explain the impact of other conditions, such as autism on partner relationships, to date there are few that use the model to explain the impact of parenting life-threatened or life-limited children or young people on partner relationships. Lavee (2005) applied the ABCX model as a framework to explain both positive and negative change in the marital relationship among parents of children with cancer. Lavee and Mey-Dan (2003) used the ABCX model as one possible explanation for patterns of change in marital relationships among parents of children with cancer. However, it was one of many explanations given and the ABCX model was not fully integrated with the study from the start.

The main benefits of the ABCX model include simplicity, ease of use and the ability to explain a wide range of situations (Lavee 2013). Lavee (2013) contended this is why the model is widely used and has remained unchanged for the last thirty years. An additional benefit of using the ABCX model to explain partner relationships is the focus on interactions between couples and the external world (Karney and Bradbury 1995; Lavee 2013). Previous theories explained relationships in terms of variables from within or between partners (Levinger 1976; Lewis and Spanier 1979); there is little focus on the external world. Attachment theory, for example, focuses on the relationship styles in explaining adult relationships (Hazan and Shaver 1987; Hazan and Shaver 1994; Hazan and Diamond 2000; Mikulincer and Shaver 2005; Brassard et al.

2007; Butner et al. 2007; Hicks and Diamond 2011; Brassard et al. 2012) but does not consider external influences.

By contrast, the ABCX model has the flexibility to consider both the impact of external events on the processes within and between couples (adaptation) (Karney and Bradbury 1995; Lavee 2013). This means it explains relationship outcomes that other perspectives fail to address (Karney and Bradbury 1995). Failure to adapt to stressful events results in an increased likelihood of problems in partner relationships and families (McCubbin and Patterson 1983; Karney and Bradbury 1995; Lavee 2013). Until stressful events occur, even vulnerable relationships may remain intact. The inclusion of external stressors on relationships, adds an extra dimension that other perspectives fail to address (Karney and Bradbury 1995; Lavee 2013). The most prominent limitation of using the ABCX model to explain partner relationships is the lack of explanation regarding the process of adapting to stressful events, with few researchers outlining the specific coping mechanisms that lead couples to either be adaptive or maladaptive (Karney and Bradbury 1995; Lavee 2013).

4.10 Chapter conclusion

Sociological perspectives on families and the role of marriage have evolved from early theoretical perspectives of the ‘nuclear family’ to the contemporary concept of ‘family practices’. With this shift in theory, attention has moved away from debating family structures and relationships in decline, to how relationships actually function in practice. The move away from viewing families under traditional sociological perspectives has occurred alongside increasing acceptance of alternatives of marriage: cohabitation and civil partnerships. Several psychological theories have attempted to explain relationships and the breakdown of relationships, including social exchange theory, behavioural explanations, attachment theory and dynamic goal theory. Whilst all of these explanations of partner relationships had some merit, they also failed to explain all aspects of partner relationships.

The ABCX model of adjustment and adaptation was presented as an alternative way of explaining partner relationships (Karney and Bradbury 1995; Williams

1995; Lavee 2005). Building on the work of Hill (1949) the model consists of four components: (aA) initial efforts to cope with an event can lead to additional stressors, a process known as ‘pile-up’, (bB) initial levels of resources which can be enhanced in response to an event and (cC) initial perceptions of an event, which can influence future event perceptions (McCubbin and Patterson 1983). The subsequent response to the crisis (xX) can either be adaptive or maladaptive. Whilst there is little application of the ABCX model to partner relationships of those with life-limited or life-threatened children (Lavee and Mey-Dan 2003; Lavee 2005), the model has been effectively used to explore the relationships of parents of children with other conditions, such as autism (Stuart and McGrew 2009; Manning et al. 2011; Ramisch 2012; Paynter et al. 2013).

The preceding three Chapters considered three key topics essential to the research aim and objectives: children’s hospices (Chapter Two), short breaks (Chapter Three) and partner relationships (Chapter Four). The next two chapters consider how the research aim and objectives are best answered in terms of methods used and the overall philosophical underpinning for the research. This begins with Chapter Five, which concerns mixed methods research and will be followed by Chapter Six, which outlines pragmatism as a research philosophy.

5 Mixed Methods Research: Uniting Quantitative and Qualitative Methods

5.1 Chapter introduction

The preceding chapters set the scene for this research through the symbiotic development of children's hospices and palliative care, the impact of short breaks and psychosocial theories of partner relationships. There is an absence of research investigating the impact of short breaks provided by children's hospices on the relationship satisfaction between parents. This research project explored the impact that short breaks have on partner relationships with four specific objectives. To: (1) explore parents' perceptions of parenting life-limited or life-threatened children or young people on their relationships, (2) determine if frequent short breaks enhance partner relationships compared to those who receive short breaks less frequently or not at all, (3) identify effects on relationships of parents receiving home and hospice-based short breaks compared to those receiving hospice-based short breaks only or home-based care only, and (4) identify societal factors influencing partner relationships in families receiving short breaks.

This chapter concentrates on mixed methods, justifying it as the most appropriate approach to answering the research aim and objectives. Mixed methods research can be defined as research that utilises both quantitative and qualitative approaches in one project (Bryman 2012; Bishop 2015). The term mixed methods is now the prevalent term used, but it has also been referred to as multi-method or multi-strategy in earlier literature (Bryman 2012). The mixture of qualitative and quantitative data within one study however, is not a new concept (Johnson et al. 2007).

Mixed methods is becoming increasingly popular (Creswell and Clark 2011; Pluye and Hong 2014), especially within health (Crocker et al. 2015; Mason et al. 2015; Pesut et al. 2015; Bergenholtz et al. 2016; Ingham-Broomfield 2016) and psychological research (Abdul - Razzak et al. 2016; Elliott et al. 2016; Louick et al. 2016; Olson et al. 2016). The chapter begins with an historical

overview of mixed methods. The ‘paradigm wars’ is then outlined, a period of debate about the compatibility of qualitative and quantitative methodologies. This leads to an account of six contemporary issues on mixed methods as highlighted by Teddlie and Tashakkori (2009). The final sections examine the advantages and disadvantages of mixed methods research, before identifying mixed methods as the best approach for this research.

5.2 Mixed methods research history

The foundations for current day mixed research methods are often attributed to the work of Campbell and Fiske (1959) when they used ‘multi-methods’ to investigate the validity of psychological traits (Creswell and Clark 2011). In their paper ‘Convergent and Discriminant Validation by the Multitrait-multimethod Matrix’ they used both qualitative and quantitative data to evaluate the validity of psychometric scales. Their justification for this was that weaknesses of one method could be counter-balanced by the strengths of the other. This paved the way for the development of mixed methods as an alternative to mono-method approaches to research.

It has taken a number of years for mixed methods to become accepted as a legitimate approach to research, with five phases in the historical development and subsequent acceptance of it (Creswell and Clark 2011). Following the work of Campbell and Fiske (1959) a formative phase occurred until the early 1980s with researchers exploring and developing the possibility of mixing methods. This phase overlapped with a period during the 1970s and 80s where there was great debate over the philosophical, epistemological and ontological differences between qualitative and quantitative approaches. This phase has been referred to as the ‘paradigm wars’ (Bryman 2006b) and is discussed in more detail below.

From the late 1980s onwards researchers began focusing on how mixed methods research should be and designed and conducted. Following this developmental stage, there was a period of great expansion in the acceptance and use of mixed methods, characterised by advocacy of mixed method as a distinctive approach and reflected by the publication of a separate handbook for

mixed methods research (Bryman 2006b; Creswell and Clark 2011). Finally, a period of reflection began in 2005 where many researchers took stock of where mixed methods were, concluding that mixed methods were a distinct and legitimate method (Creswell and Clark 2011).

5.3 Defining ‘paradigm’

The term paradigm has its foundations in Kuhn’s (1962) work on revolutionising scientific knowledge. There are variations in how the word paradigm is used, but Morgan (2007) summarises it as worldviews, epistemological stances, shared beliefs or as model examples of research. Paradigms, at the broadest level, are seen as worldviews, ways of thinking and experiencing the world such as morals and values for example (Morgan 2007). Whilst this was not the version of paradigms that Kuhn suggested, who saw the term paradigm as being exclusive to the natural sciences; it has nonetheless become common within social sciences. However, paradigms as a worldview give little insight into why mixing methods has become both popular and contentious (Morgan 2007).

At the next level, a paradigm can be viewed as an epistemological stance, such as positivism or constructivism, following a unique belief system impacting the way researchers approach and answer research questions (Morgan 2007). This view of paradigms characteristically involves asking questions about the nature of knowledge, highlighting differing views that social researchers may have about what knowledge is. However, this definition of paradigm is broad and whilst giving some insight into the underlying assumptions of researchers, it tells us little about decisions regarding what to study and how to do so (Morgan 2007). There has been a great deal of discussion around the combination of methods at this level, mainly around the compatibility of differing epistemological stances. This will be outlined in more detail in the next section.

Kuhn’s (Kuhn 1962; 1970) favoured definition of paradigms was shared beliefs within a community of researchers about which questions are meaningful and which procedures are the most suitable for asking meaningful questions (Morgan 2007). In regards to the mixing of qualitative and quantitative

methods, this level of paradigm, as shared beliefs, has received less focus than the epistemological level (Morgan 2007). However, Morgan goes on to argue that it makes sense to examine changes in beliefs and how to conduct research. For example, beliefs within research communities changed and researchers began to accept qualitative research as a valid and meaningful way of answering questions. In more recent years, beliefs about questions and how they should be answered have taken a pragmatic shift towards mixing of methods (Bryman 2006a; Morgan 2007; Tebes 2012; Bishop 2015). The final and narrowest definition of paradigms is that of model examples of research of how to carry out particular studies (Morgan 2007). Morgan highlights that whilst, in general, little focus has been given to paradigms in this sense, it is relevant to the concept of mixing methods because many articles and books provide set examples of possible mixed method designs.

Morgan (2007) proposes that none of these versions of paradigms is right or wrong, and each is interlinked. Model examples of research reflect the beliefs of research communities, which in turn are influenced by epistemological stances. The assumptions of a researcher regarding the nature of knowledge are then important components of the worldview of researchers. The two views of paradigms that are most relevant to the argument of mixing methods are that of paradigms as an epistemological stance and as shared beliefs within a community. These will be discussed in relation to the next section, where the debate regarding mixing of methods is outlined.

5.4 The paradigm wars

The foundation of a long-standing philosophical debate, often referred to as the ‘paradigm wars’ (Johnson and Onwuegbuzie 2004; Teddlie and Tashakkori 2009; Lincoln 2010), is based on the ‘incompatibility thesis’, the belief that qualitative and quantitative paradigms are and should remain separate (Howe 1988). Advocates of the incompatibility thesis argue that the epistemological, ontological and methodological differences between qualitative and quantitative approaches are so large they cannot be combined (Sale et al. 2002). The basis of the philosophical argument against mixed methods lies in the belief that quantitative methods are typically associated with a positivist or post-positivist

epistemology, whilst qualitative approaches on the other hand are associated with interpretive or constructionist epistemologies (Bishop 2015). Teddlie and Tashakkori (2009) provide a useful summary of the properties of ‘pure’ quantitative and qualitative approaches as presented in Table 5.1.

Table 5.1: Properties of qualitative and quantitative approaches from Teddlie and Tashakkori (2009)

| Dimension of contrast | Qualitative | Quantitative |
|-----------------------------------|---|--|
| Paradigms | Constructivist and other variants | Post-positivism and positivism |
| Research questions | Qualitative research questions | Quantitative research questions; hypotheses |
| Form of data | Typically narrative | Typically numeric |
| Purpose of research | Often exploratory but also confirmatory | Often confirmatory but also exploratory |
| Role of theory; logic | Grounded theory; inductive logic | Rooted in a conceptual framework or theory; hypothetic-deductive model |
| Typical studies or designs | Ethnographic research designs and others such as case studies | Correlational; survey; experimental; quasi-experimental |
| Sampling | Mostly purposive | Mostly probability |
| Data analysis | Thematic strategies; categorical and contextualising | Statistical analyses; descriptive and inferential |
| Validity/ trust worthiness issues | Trustworthiness; credibility and transferability | Internal validity; external validity |

There are four major differences between qualitative and quantitative approaches to research (Firestone 1987; Bryman 2012). Firstly, the approaches differ in their epistemological assumptions, such as positivist versus constructivist. Secondly, the perceived purpose of the research differs, with those taking a quantitative approach focusing on explaining facts or causation, and those following a qualitative approach focus on exploring social phenomena (Firestone 1987; Bryman 2012). The third difference is the role of the researcher, experimental for quantitative and observational for qualitative (Firestone 1987; Bryman 2012). Lastly, researchers are either detached for quantitative research or immersed for qualitative approaches (Firestone 1987; Bryman 2012).

Detractors of mixed methods argue that methods cannot be mixed for two reasons. First, methods used by researchers are not isolated, but also carry certain epistemological and ontological assumptions (Smith and Heshusius 1986). Semi-structured interviews, for example, are not only a method of data collection but also philosophically a rejection of an empirical or positivist approach to research (Bryman 2012). Second, following this argument, is the paradigm argument suggesting that qualitative and quantitative research have separate paradigms that are incompatible (Morgan 2007). As a consequence, mixed method projects are not really combining methods and integration is purely superficial.

It has been argued that the differences between qualitative and quantitative research approaches have been exaggerated and in fact there are a number of shared principles suggesting they are not incompatible (Johnson and Onwuegbuzie 2004). To varying degrees, both qualitative and quantitative approaches to research use empirical observation to address research questions or aims, both involving safeguards to reduce the chance of bias (Johnson and Onwuegbuzie 2004). In both cases, researchers seek to collect and describe data, use this data to develop explanations and speculate why the outcomes occurred like they did (Sechrest and Sidani 1995).

Thus, the late 1980s saw a counter-offensive against the incompatibility thesis, with researchers arguing the combination of methods is not only possible but also advantageous (Howe 1988). Johnson and Onwuegbuzie (2004) went as far as to argue that mixed methods could be considered a third paradigm to qualitative and quantitative paradigms. However, despite increasing support for the compatibility of mixing methods, there is still great debate around paradigmatic issues. Teddlie and Tashakkori (2009) outlined six issues regarding paradigm use in mixed methods research. These are outlined below.

(1) The a-paradigmatic stance

Researchers and scholars who see the debate regarding epistemology as distracting or unwarranted take the a-paradigmatic stance, using whichever method is the most appropriate to answer the research question or aim (Teddlie

and Tashakkori 2009). This stance is often associated with pragmatism (Morgan 2007) which advocates a practical approach to answering research questions and aims, emphasising shared meanings and joint action among researchers, whilst circumventing epistemological and philosophical debates.

(2) The incompatibility thesis

As previously outlined above, this approach is based on the principle that quantitative and qualitative research approaches are incompatible due to their conflicting epistemological principles and related methods. However, Teddlie and Tashakkori (2009) argue that the incompatibility thesis has been largely discredited since many researchers have now demonstrated it is possible and beneficial to mix methods.

(3) The complementary strengths thesis

It has been proposed that mixed method studies should have a principal methodological focus, whether that be quantitative or qualitative in nature (Morse 2003). Building on the proposal, the complementary strengths thesis is based on an argument that mixed methods research is possible but the quantitative and qualitative elements must remain separate (Teddlie and Tashakkori 2009).

(4) The single paradigm thesis

In a similar manner to quantitative research being linked to positivism and qualitative to constructivism, campaigners for mixed methods have sought a single paradigm for mixed methods research. Typically, the most frequently cited paradigm is pragmatism (Tashakkori and Teddlie 2003; Johnson and Onwuegbuzie 2004; Morgan 2007; Pearce 2012; Hall 2013; Morgan 2014). Pragmatism as a suitable paradigm for mixed methods is the focus of Chapter Six.

(5) The multiple paradigms thesis

Researchers such as Creswell (2003) have argued for the use of multiple paradigms as the foundation for mixed methods research, dependent upon the design being implemented (Teddlie and Tashakkori 2009). The multiple paradigm thesis links differing paradigms with specific research designs, rather

than specific methods as with the traditional epistemological-methods partnership. Therefore, under this approach to mixed methods, one study with a quantitative focus may utilise post-positivism, whilst another with a qualitative focus will employ interpretivism.

(6) The dialectical thesis

The basis for the dialectical thesis is that all paradigms have benefits and that the use of multiple paradigms provides a greater understanding of a phenomenon under study (Teddlie and Tashakkori 2009). The most active champions of the dialectical thesis are Greene and Caracelli (2003) who discarded pursuit for a specific overall paradigm as a remnant of the paradigm wars. Multiple research perspectives are beneficial in exploring the complexity of contemporary society (Greene and Caracelli 2003). A crucial element of this view is the ability to consider opposing viewpoints and the subsequent tensions that may arise.

5.5 Mixed methods designs

Qualitative and quantitative methods can be combined at any stage of research from designing a research aim, to data collection and analysis or interpretation (Johnson and Onwuegbuzie 2004). However, many argue mixed methods designs fully integrate quantitative and qualitative findings (Johnson et al. 2007). Studies using both quantitative and qualitative research methods, but failing to integrate these two elements at any level would not be considered mixed methods (Leech and Onwuegbuzie 2009).

Order and emphasis to qualitative and quantitative components of mixed methods research design require consideration (Morse 1991; Bryman 2006a, 2012). Order concerns sequencing of qualitative and quantitative components of research design, either sequentially or simultaneously. Emphasis concerns weighting of individual components within a design, with emphasis placed on either qualitative or quantitative elements, or equally balanced. Researchers also need to consider the purpose of integrating qualitative and quantitative methods (Creswell et al. 2013). Integration of mixed methods could be for triangulation, exploration or explanation.

Three main design typologies exist for mixed methods: (1) sequential - where data collection method follows another, (2) concurrent - where data are collected from two methods at the same time and (3) transformative - whereby discoveries or ideas radically change the way we view an existing topic (Creswell and Clark 2011). These descriptions of sequential design typologies only take order into account and not timing. If qualitative elements occur before quantitative ones it is more accurately described as an exploratory sequential mixed methods design, an exploratory qualitative phase that informs or is supported by a quantitative stage. If the quantitative stage occurs first, then it is an explanatory mixed methods design. For example, a researcher may follow up answers given in a questionnaire with interviews, to give more depth to the quantitative data.

5.6 The advantages and challenges of mixed methods

There has been a substantial rise in the use of mixed methods research (Bryman 2006a; O'Cathain et al. 2009; Creswell and Clark 2011; Pluye and Hong 2014; Bishop 2015) because it has a number of advantages (Johnson and Onwuegbuzie 2004). The main advantage of mixed methods is that combining qualitative and quantitative methods can overcome their individual weaknesses (Bryman 2006a; Creswell and Clark 2011). Numbers from quantitative methods such as surveys or questionnaires can give precision and generalisability to narratives or small numbers of interviews. Qualitative data such as that acquired from interview transcripts can give meaning to numbers achieved from quantitative methods (Johnson and Onwuegbuzie 2004). This, in turn, can result in a much stronger and comprehensive research project overall, with potentially more insight being gained on a phenomenon (Creswell and Clark 2011). It has been argued that mixing methods also gives 'completeness'; the idea that a more comprehensive account of an area of study can be achieved (Bryman 2006a). Mixing of methods also allows for a diversity of views, looking at a phenomenon through both a qualitative and quantitative lens (Bryman 2006a). Teddlie and Tashakkori (2003) give one of the simplest and clearest advantages of mixed methods research:

“Mixed methods research can answer research questions that the other methodologies cannot”.

(Tashakkori and Teddlie 2003, p.14)

Mixed methods research is no different to mono-methods research in that a poorly planned and implemented project will yield poor results (Bryman 2012). The research question and/ or aims should be the starting point for any planning. One of the first issues to overcome when conducting mixed methods research is the philosophical challenges (Farquhar et al. 2011). Whilst arguments against mixed methods due to philosophical or technical difficulties have mostly been rejected now (Creswell and Clark 2011; Bryman 2012), researchers need to justify usage of mixed methods and address issues of integration. This can be especially difficult when considering the diverse debate surrounding mixed methods (Teddlie and Tashakkori 2012) and this can be confusing for new researchers.

Farquhar et al. (2011) also argued that there are practical issues in regards to data collection, data integration, costs and dissemination. Data collection in a mixed methods design can be challenging for students, as novice researchers need to be skilled in more than one method of data collection. Researchers carrying out an exploratory sequential mixed methods project will need an understanding of how to conduct and analyse both semi-structured interviews and surveys. It has been suggested that, as a consequence, mixed methods research may end up being low in quality (Teddlie and Tashakkori 2012). However, this issue can be overcome if a supervisory team with experience and knowledge supports the student (Teddlie and Tashakkori 2012). It can offer experience and training for researchers unfamiliar with particular methods, but only if novice researchers are working with someone who is an expert in the method (Teddlie and Tashakkori 2012).

Data integration is one of the biggest challenges for researchers undertaking mixed methods research (Ivankova et al. 2006; Anne et al. 2007; Bryman 2012) because there is a tendency for researchers to present qualitative and quantitative elements of their research separately (Farquhar et al. 2011). The

strength of mixed methods research comes from the integration of qualitative and quantitative methods, overcoming their individual weaknesses. If integration does not occur or is merely superficial, it could be argued that the project is not mixed methods (O’Cathain et al. 2010).

Researchers conducting mixed methods research also need to be aware that this approach takes up more resources both financially and in regards to time compared with mono methods research (Farquhar et al. 2011). Financially, there are implications with using more than one method. For example, if interviews and a survey are being conducted under a mixed methods design costs will include travelling for interviews or reimbursing participants, recording equipment, transcription, analysis software; costs for surveys will include designing, distribution and statistical analysis software (Farquhar et al. 2011). It takes researchers longer to collect and analyse data compared to mono method research (Tashakkori and Teddlie 2003; Farquhar et al. 2011). This issue can be overcome if there is a team of researchers working on a mixed methods project, but is more of an issue if it is a project with one researcher, such as a PhD student.

Dissemination of results from mixed methods studies has been difficult in the past due to a lack of guidance and standardisation, however this became less of an issue since the publication of dedicated mixed methods journals (Farquhar et al. 2011). Another pitfall with dissemination of mixed methods research is the tendency to focus on either the qualitative or quantitative element to the detriment of the other (Bryman 2012). In recent years, some mixed methods’ advocates have worked towards consistency and uniformity. However, Freshwater (2007, 2013) is concerned this could limit the flexibility found within mixed methods, forcing researchers to be unoriginal with their designs. An alternative approach to standardising mixed methods studies is identifying core characteristics (Teddlie and Tashakkori 2012) giving consistency without restricting flexibility.

5.7 Chapter conclusion

At a basic level, mixed methods research can be defined as a study that incorporates both qualitative and quantitative elements. Research studies are increasingly utilising mixed methods (Creswell and Clark 2011; Pluye and Hong 2014), particularly within the social and health sciences. Prior to this there was a great deal of opposition to mixed methods in the form of the ‘incompatibility thesis’. This opposition has now been largely discredited and mixed methods has been accepted as a legitimate approach that can potentially answer research questions and aims that other methodological approaches cannot, making it the most suitable method for the present research.

In place of the ‘incompatibility thesis’ debate, discussion has moved towards the design and philosophy of mixed methods. In terms of design there are two elements that need to be considered; order and emphasis of the qualitative and quantitative components. The sequential mixed methods design of the present research has been informed by the research aim, objectives and this discussion. There has also been a great deal of debate about the philosophical underpinnings for mixed methods research. Pragmatism has received by far the most attention and is outlined in the following chapter.

6 Pragmatism: A Practical Way of Thinking or the Emergence of an Alternative Research Paradigm?

6.1 Chapter introduction

The preceding chapter concerned the history and development of mixed research methods, emphasising the suitability of the approach for answering the research aim and objectives. A crucial historical debate within mixed methods is the compatibility of the quantitative and qualitative components, often referred to as the ‘paradigm wars’ (Johnson and Onwuegbuzie 2004; Teddlie and Tashakkori 2009; Lincoln 2010). Pragmatism has been proposed as a suitable philosophy to overcome the perceived divide within mixed methods research (Tashakkori and Teddlie 2003; Johnson and Onwuegbuzie 2004; Morgan 2007; Pearce 2012; Hall 2013; Morgan 2014).

This chapter focuses on pragmatism, links to mixed methods and provides application to this research. It opens with an account of the history and development of pragmatism as a philosophy, emphasising key pragmatic principles established over time via three main contributors: Peirce, James and Dewey. This is followed by an outline of the key principles of contemporary pragmatism. The links between pragmatism and mixed methods are explored, underlining the suitability of pragmatism as an underlying philosophy for mixed methods research. This chapter ends with an appraisal of pragmatism as a research paradigm for mixed methods research.

6.2 Pragmatism

Pragmatism was founded on the work of Peirce and the concept of the practical impacts of knowledge; it was then further developed by James and Dewey (Cherryholmes 1992; Johnson and Onwuegbuzie 2004). Pragmatism has been written about by more contemporary authors including Rorty (1982), Patton (2002) and Morgan (2007; 2014). Pragmatism’s history extends over a hundred years, resulting in difficulties pinpointing one specific form of pragmatism (Ormerod 2006; Feilzer 2010). Ormerod (2006, p.892) defined pragmatism as:

“a philosophical doctrine that can be traced back to the academic sceptics of classical antiquity who denied the possibility of achieving authentic knowledge regarding the real truth”.

In other words, pragmatic researchers should reject fixed principles and only deal with the current problem at hand. This is not to say that researchers are not rigorous or systematic, but following one rigid paradigm is not beneficial to human development (Florczak 2014). Before outlining the characteristics of pragmatism, benefits and links with mixed methods, understanding the history and development of pragmatism as a philosophy is crucial.

6.3 Charles Peirce: the foundations of pragmatism

Charles Peirce is considered to be the founder of pragmatism, but Peirce did not initially refer to his ideas using this terminology. As a chemist, Peirce saw empiricism as the approach that should be used both by researchers and philosophers. Peirce’s pragmatism is conservative and can be outlined in relation to three criticisms he had with traditional scientific thinking based upon the work of Descartes (Peirce 1877).

Descartes’ philosophical writings arose in the context of the emergence of scientific method. The scientific approach radically changed the worldview of many intellectual thinkers, including Descartes. Descartes’ contribution to philosophy was to suggest that the mind was separate from the external world (Sorell 2000). Knowledge was seen by Descartes to be our internal representation of the external world within the private sphere of the mind. However, this mind-world dichotomy has caused philosophers to argue that humankind is not in direct contact with objects in the world, only mental representations of them. Therefore, Descartes reasoned we should always be unsure whether our representations of the world are accurate and only when we are completely free from doubt can we be sure that knowledge is accurate (Sorell 2000). Descartes also argued for the concept of knowledge before experience, with knowledge formed from basic perception before experience.

Whilst Peirce accepted Descartes' philosophy as an improvement from reliance on religion, he believed Descartes approach to knowledge was incorrect.

Peirce's criticism led to the development of four key components of contemporary pragmatism: (1) knowledge deriving from interaction with the external world, (2) knowledge through collective exploration, (3) inquiry as settlement of doubt and (4) practical consequences of inquiry.

6.3.1 Knowledge deriving from interaction

Peirce (1868a) defined 'cognition' as an object of thought, such as a concept of judgement and 'intuitions' as objects of thought that have been arrived at independently of any previous knowledge. Peirce understood people to believe they have intuitions but rejected the idea of immediate awareness of cognitions, arguing there is sparse evidence supporting intuitions or that intuitions cannot be linked to previous knowledge. All knowledge is a result of an individual interacting with the external world, rather than being immediate:

"our whole knowledge of the internal world is derived from the observation of external facts".

(Peirce 1868b, p.110).

Followers of Descartes argue that all humans appear to have an innate self-awareness from a young age. Peirce again argued there is no evidence to support this notion, as young children initially do not demonstrate self-awareness, self-awareness developing through interaction with the world. Proponents of Descartes present colours as an example of knowledge immediately available to the mind. Peirce answered this by providing one of the most important distinctions in twentieth-century philosophy: the difference between knowledge and sensory awareness (Bacon 2012). The knowledge of the concept of red is different from the sensory perception of red (Bacon 2012). This paved the way for a key pragmatic concept; all knowledge derives from interaction with the external world.

6.3.2 Knowledge through collective exploration

Peirce's next contribution to pragmatism emerged from criticism of the Cartesian view that everything should be doubted and only those beliefs which

survive doubt can be true. Peirce argued that this was artificial in nature and we cannot doubt everything. Peirce conceded truth could be revised or renounced, based on further evidence, but only when a belief genuinely needs revising. In contrast to Descartes, Peirce also believed that knowledge is arrived at through collective exploration of a topic rather than individuals as final evaluators of truth (Bacon 2012). The development of knowledge involved a compendium of mutually supporting beliefs rather than linear as with Descartes (Bacon 2012). Peirce used the metaphor of knowledge as being like a cable, with different strands of investigation together forming a whole. Upon further investigation, a strand within a cable may be found to be incorrect, but this will not affect the entire structure of knowledge (Bacon 2012).

6.3.3 Inquiry as settlement of doubt

Peirce (1877) defined ‘belief’ as something that someone would be prepared to act upon and ‘doubt’ as the uneasy feeling one gets if the belief does not result in the desired outcome. Therefore, investigation occurs to obtain knowledge or beliefs that do not result in doubt, with the sole purpose of inquiry being the settlement of doubt rather than seeking absolute truth. This is an important foundation for pragmatism, for pragmatists there is no absolute truth, only what is true at the time. This raises the question of how one might bring an end to doubt.

Peirce (1877) suggested four methods for ending doubt and establishing a belief. The first, where individuals strongly maintain beliefs regardless of evidence against it by avoiding situations where beliefs may get questioned is known as the ‘method of tenacity’. The second method, ‘method of authority’ refers to those where an organisation such as the government or religion claim to have authority. This method is similar to tenacity because it also protects beliefs from revision by reason and evidence. However, both methods are unsuccessful in the long term; individuals following the tenacity and authority method will doubt their beliefs when they encounter others who disagree with them. The third method is ‘the *a priori* method’ by which belief is based on what appears to be ‘agreeable to reason’. Peirce believed this method to be an improvement on the previous two, but finds fault in the method for focusing on

individual inquirers and relying initially on intuition. The underlying fault that all three of these methods has is reliance on personal attitudes alone to establish beliefs. With this in mind, Peirce stated:

“It is necessary that a method should be found by which our beliefs may be caused by nothing human, but by some external permanency – by something that our thinking has no effect”.

(Peirce 1877, p.9)

Peirce believed the answer was the ‘method of science’ whereby there is an external real world, which is independent of our opinions. This external world can be investigated by observers to gather evidence, support or revise a belief. The scientific method incorporates combined investigation of many inquirers to reach a belief. Knowledge is based on previous findings of researchers, which is then developed by further scientific research. Therefore, scientific inquiry that is performed correctly leads to a consensus (Peirce 1878). This gives an important insight into Peirce’s understanding of truth. Truth for Peirce arises when individuals within a community follow true investigative science and are willing to revise currently existing truths (Peirce 1878).

6.3.4 Practical consequences of inquiry

For an idea to be true Descartes argued it had to be clear. Peirce argued for a distinct difference between an idea seeming clear and actually being clear. When outlining his definition of what makes an idea clear, Peirce created a key concept of pragmatism, practical consequence, whereby clarity in truth is defined by practical consequences that follow. This principle became known as the ‘pragmatic maxim’ (Bacon 2012). In Peirce’s own words:

“Consider what effects, which might conceivably have practical bearings, we conceive the object to have. Then, our conception of these effects in the whole of our conception of the object”.

(Peirce 1905, p.110)

6.4 William James

Although Peirce laid the foundations for pragmatism, James built upon them and first used the term (De Waal 2006; Bacon 2012). James was a psychologist

who introduced pragmatism as a philosophy in 1898. James attributed pragmatism to Peirce, but also went on to develop his own unique views on what pragmatism stood for, differing from Peirce's original vision (De Waal 2006; Bacon 2012). James provided a number of contributions to pragmatism including incorporating psychological consequences and social or cultural influences, outlined below.

6.4.1 Psychological consequences and belief in pragmatism

Peirce emphasised the importance of science and as such observable practical consequences, with belief being meaningless without tangible consequences (Peirce 1877). Conversely, James argued that belief can have meaning if it provides psychological consequences. For James, pragmatism was a means of addressing psychological elements other philosophies neglected. Pragmatism therefore should address questions no matter how abstract, in order of their practical impact and to explore lived experiences. James' view is slightly more complex than this, however, conceding that in the case of natural science beliefs cannot be established without objective evidence observed from tangible objects (James 1896). Yet, James believed other considerations such as ones hopes, dreams and passions also play a part in deciding belief and it is possible to believe even without satisfactory objective evidence (James 1896).

James' argument that people have the right to believe in something even without sufficient evidence proved to be unpopular. James's emphasis on psychological consequences of belief has been criticised for opening the way to subjectivism in knowledge (Bacon 2012). In response James clarified that he was only referring to those beliefs that could not be settled by scientific methods, such as morals or ethics. The importance of James's argument about the will to believe, or as he later amended it to, the right to believe, is highlighting the importance for him of psychological belief in pragmatism (Bacon 2012).

6.4.2 Fluid truth and cultural or social influences

James saw pragmatism as an improvement on empiricism and rationalism; despite their apparent differences, both committed to 'intellectualism'. James defined intellectualism as defined as:

“the belief that our mind comes upon a world complete in itself, and has a duty of ascertaining its contents; but has no power of re-determining its character, for that is already given”.

(James 1977, p.735)

James did not subscribe to this view; he believed that humankind does not simply observe a world complete as passive observers from a ‘God-like’ perspective, but that people are part of an observed world and, as a consequence, change it. This view reflects in James’s version of pragmatism and his idea of truth, it is not static and fixed; it is fluid and ever changing (Bacon 2012). Like Peirce, James believed inquiry should build on previous knowledge and that experience was the basic element of knowledge. However, he thought positivist researchers did not fully appreciate the significance of experience because of the emphasis on being passive observers of the world (Bacon 2012). We are fully integrated into the world that we study and view it in context to our lives. As such James believed that we confront the world directly (James 1977).

James (1977) described a journey he took to rural North Carolina where he came across a landscape that was completely devoid of wildlife and plants. James was initially appalled at the destroyed landscape but after speaking to local residents, discovered that they had done so to cultivate the land and they were immensely proud of the hard work they had done. This example illustrates an important element of pragmatism: pluralism, the idea that cultures, societies and people think differently and do not experience the world in the same way (Bacon 2012). James believed that investigators should be open to pluralism, so that they do not miss genuine differences. In relation to truth, James hoped this was demonstrating that there is no one truth and that multiple perspectives need to be embraced.

6.5 John Dewey

Alongside Peirce and James, John Dewey was one of the biggest influences on pragmatism (Bacon 2012). John Dewey was influenced by Charles Darwin’s ‘On the Origin of Species’ in 1859. The idea of evolution and an ever changing

world can be found through Dewey's contributions to pragmatism and philosophy in general such as in *Reconstruction in Philosophy* (1920) and *The Quest for Certainty* (1929) where Dewey argued the purpose of philosophy was to aid understanding of survival for humans. Early humans had no explanation for natural disasters, famine or disease, and as such relied on religion and myth for some kind of explanation. This, according to Dewey (1929), gave rise to moral codes that were instigated by religious beliefs. Eventually this approach could not solve all of society's problems and the scientific method provided an alternative. Humans will always aim for knowledge that is fixed and certain (Dewey 1929).

The science that Dewey advocated was influenced by the work of Charles Darwin. Traditional Newtonian science aimed to find concrete physical laws that could be used to explain all areas of life. Darwinism, by contrast, recognises the importance of the temporary and contingent (Bacon 2012). Darwin demonstrated humans are, despite our complexity, still animals who need to adapt to our environment to survive. With this in mind, beliefs or ways of thinking should be judged on their utility by the consequences they have (Dewey 1929). In some respects, this is in line with both Peirce and James who both argue that truth is fluid and open to change.

6.5.1 Transactional theory

One of the main contributions that Dewey's version of pragmatism made was overcoming long standing epistemological questions, not by directly answering them, but by questioning and changing the assumptions on which these questions were based (Biesta 2009). Traditional epistemology centres on how individuals can acquire knowledge of the outside world (Biesta 2009) based on the Cartesian mind-world divide (Bacon 2012).

Dewey's pragmatism offers an alternative epistemology, circumventing the dualistic mind-world schema. Dewey's new way of thinking was based on transactions, referring to interactions occurring in nature more generally (Dewey 1920). Within transactions, a key component is experience. Within transactional analysis, experience refers to the transactions of living organisms

and their environment. Experience is a two-way relationship between the organism and their environment, with knowledge being the connection between our actions and their consequences (Dewey 1920). Therefore, knowledge enables greater control over our actions than simple trial and error. This did not mean that Dewey believed we would have complete control, but it would allow us to plan and direct our actions (Biesta 2009). For Dewey the world is not viewed passively but built of interactions between humans and objects.

Dewey's transactional theory of experience has important consequences for our understanding of knowledge and reality (Biesta 2009). All experience is important because it is a result of transactions between an organism and its environment. This has important implications for research because it means that all perspectives and experience are of equal importance. An important consequence of Dewey's transactional approach is rejection of 'spectator theory of knowledge', the idea that knowledge reflects how the world is (Biesta 2009).

In contrast to traditional philosophy, Dewey's transactional approach is not automatically sceptical (Biesta 2009). However, under transactional theory, knowledge is never certain, it only offers possibilities (Biesta 2009).

Knowledge can sometimes be used effectively in other similar situations, but sometimes situations change or the knowledge is ineffective for new situations. Dewey avoided using the word 'truth' and preferred 'warranted assertions', because assertions made about actions and consequences are always open to change (Biesta 2009).

6.5.2 Warranted assertions

The nature of inquiry is the process where beliefs that have become problematic are examined and resolved through action (Morgan 2014). Dewey made no distinction between everyday inquiry and research; the only difference is research inquiry is conducted more consciously and systematically (Morgan 2014). Research is still a form of inquiry that is formed by experience.

However, inquiry is not a purely rational or logical process, mediated by emotions at all stages. As James (2010, p.49) stated, "*The trail of the human serpent is thus over everything*". Dewey's pragmatism revolves around carrying

out an action and experiencing the outcome, leading to the development of ‘warranted assertions’ (Morgan 2014).

6.5.3 Role of emotions and social justice

Dewey’s pragmatism emphasised emotions, arguing experiences are always emotionally embodied and feelings provide links between beliefs and actions (Morgan 2014). Emotions are both the source and outcome for experiences. For Dewey discussions about life should be contextual, emotional and social. Talking about inquiry in terms of emotions gives the indication that it is individual in nature. However, Dewey also argued that the process of inquiry at any level, everyday inquiry or research, is social in nature (Morgan 2014). For example, within research, individuals work within teams, submit for peer review and follow guidelines set by social bodies.

Dewey was active in the progressive politics of his day with his pragmatism strongly advocates social justice. Central to Dewey’s pragmatism is freedom of inquiry for all, unrestricted by either force or economic domination. Individuals and social communities should be able to determine important issues and investigate them in a way that was meaningful to them. Therefore, pragmatism has strong links with promoting social justice because of the emphasis on openness, fairness and freedom of expression (Morgan 2014).

6.6 General characteristics of pragmatism

Given the varied history of pragmatism, it is not unexpected that the definition of pragmatism for research can differ between researchers (Cherryholmes 1992; Bishop 2015). On one hand, pragmatism is linked to research that combines qualitative and quantitative elements and on the other, pragmatism is a duty to conduct research that will answer a specific research question or aim (Bryman 2006a). There are several broad themes that run across all variations of pragmatism.

Pragmatism in all its forms rejects dualisms, whether it be objective-subjective or mind-world (Feilzer 2010; Bishop 2015). Scientific truths are always provisional (Dures et al. 2010; Creswell and Clark 2011) and can be established through not only traditional experimentation, but also various types of

experience (Creswell and Clark 2011; Bishop 2015). Practical consequences of action are the core focus of pragmatism. In other words, pragmatists do not ask “*does this accurately reflect the underlying reality?*”, but instead ask: “*does this knowledge serve our purpose?*” (Cornish and Gillespie 2009, p.802). As such pragmatists consider research questions or aims to be more important than either the method used or the paradigm that underlies the method, the best methods or techniques to answer the question at hand (Tashakkori and Teddlie 2003; Creswell and Clark 2011). With this in mind, pragmatic researchers have freedom of choice in regards to their method (Creswell and Clark 2011). The emphasis on truth being provisional means pragmatism recognises research is historically, socially and culturally situated (Creswell and Clark 2011).

6.7 Pragmatism and mixed methods research

Increasing numbers of researchers follow pragmatism either explicitly or implicitly; some use pragmatic principles either without realising it or without stating it explicitly (Bryman 2006a). The resurgence in pragmatism as a paradigm in recent years can be attributed to the difficulties that mixed methods has had in overcoming the epistemological and ontological differences between quantitative and qualitative approaches (Bryman 2006a; Dures et al. 2010; Morgan 2014). Pragmatism’s appeal lies in its practical answer to this problem and as such is a good match for mixed methods (Feilzer 2010). Pragmatism acknowledges epistemological differences between qualitative and quantitative research approaches, but views them as two different perspectives on issues to be solved (Bishop 2015).

Pragmatism is often associated with mixed methods research due to the centrality given to the research question or aim. The most suitable method should be chosen to address the research in hand and in doing so, long-standing arguments about epistemology and ontology become less important (Bryman 2006b). Researchers using a pragmatic approach will place the research aim at the centre of the research, making it more important than either methods utilised or the paradigm that underlies the method (Tashakkori and Teddlie 2003).

Placing emphasis on the research question or aim not only supports mixed methods, it makes it desirable or essential to answer certain research aims (Bryman 2006b). Pearce (2012) goes so far as to call pragmatism a ‘third paradigm’ in addition to post-positivism and constructivism. Creswell (2011) suggested three ways in which pragmatism supports mixed methods: (1) pragmatism is not dedicated to any one traditional paradigm, (2) individual researchers are free to choose the methods, procedures and techniques that best serve the research question, and (3) truth is fluid, is what works at the time and is not based on a strict mind-world dualism.

6.8 Strengths and weaknesses of pragmatism as a research paradigm

Pragmatism is a new research paradigm (Pearce 2012; Hall 2013; Morgan 2014) which resolves traditional paradigm divisions, such as qualitative versus quantitative methodologies or realism against constructivism, towards seeing these differences as distinctive approaches to social action (Johnson and Onwuegbuzie 2004; Cornish and Gillespie 2009; Morgan 2014). In turn, pragmatism refocuses attention towards a productive approach to knowledge development (Cornish and Gillespie 2009) and improves coordination between those who have different research backgrounds (Johnson and Onwuegbuzie 2004).

Pragmatism enables positive social action by emphasising the purpose and consequences of knowledge (Cornish and Gillespie 2009). The centrality of the research aim and emphasis on practicality means that the aim and objectives should be addressed in the best possible way and is therefore not only practically beneficial for mixed methods, but research methodology as a whole (Morgan 2014). Morgan also believes that pragmatism is well suited to the study of human experience.

Whilst being advocated by mixed methods researchers as a practical solution to overcoming the differences between quantitative and qualitative approaches (Denscombe 2008; Dures et al. 2010; Feilzer 2010) has led to increased interest in pragmatism, it has also led to over-simplification and misunderstanding of

pragmatism in two ways (Morgan 2014). Firstly, pragmatism is a paradigm just for mixed methods research. This is similar to longstanding misconceptions that certain methods are linked to certain paradigms, such as qualitative methods to constructivism and quantitative to post-positivism (Morgan 2014).

Secondly, pragmatism is often misperceived as ‘just being practical’ or utilitarian in nature (Cornish and Gillespie 2009; Morgan 2014), a misunderstanding shared by both critics and those sympathetic to pragmatism (Biesta 2009; Morgan 2014). Pragmatism is often construed as a practical solution to overcoming epistemological debates by many researchers or ‘what works practically’ with no references to philosophical positions (Bryman 2006b). A narrow focus on pragmatism being ‘what works’ or utilitarian is not enough, as it would ignore choices about goals to be pursued and how to meet those goals (Denscombe 2008; Cornish and Gillespie 2009; Morgan 2014; Bishop 2015).

Consequently, pragmatism has been under-valued as an alternative research paradigm and is mostly underdeveloped when it is used (Morgan 2014). Morgan believes *“the time has come for social research to dig more deeply into pragmatism as a philosophy”* (Morgan 2014, p.1051). Morgan (2007) outlines pragmatism’s potential to be a new paradigm that overcomes the traditional issues in sociological research. Morgan believes there are three key issues with research methodology: (1) connection of theory and data, (2) relationship to research process and (3) inference from data. These are outlined in Table 6.1:

Table 6.1: Comparison of qualitative, quantitative and pragmatic approaches

| | Qualitative Approach | Quantitative Approach | Pragmatic Approach |
|----------------------------------|----------------------|-----------------------|--------------------|
| Connection of theory and data | Induction | Deduction | Abduction |
| Relationship to research process | Subjectivity | Objectivity | Inter-subjectivity |
| Inference from data | Context | Generality | Transferability |

Where qualitative and quantitative approaches are inductive and deductive respectively, pragmatism by contrast is abductive (Morgan 2007). Abduction

refers to moving between both induction and deduction; so inductive semi-structured interviews could then inform a deductive survey. Morgan also highlighted the forced dualism between subjectivity and objectivity. Pragmatism is inter-subjective, where both a 'real world' and individual or social constructions exist (Morgan 2014). Likewise, qualitative and quantitative approaches are based on a dichotomy of context and generality. Pragmatism focuses on transferability, focusing on finding the best kind of knowledge to answer the research question or aim. The crucial argument is that pragmatism is a well-suited paradigm for social or health research utilising either qualitative, quantitative or mixed methods (Pearce 2012; Morgan 2014).

Whilst some advocate pragmatism as a source of social change (Cornish and Gillespie 2009), others criticise its vague methods for social change (Mills 1964). One of the key benefits of pragmatism is it does not dictate any particular method and is not linked to a specific form of social transformation. Pragmatism should not be viewed as an easy approach to research, as pragmatism requires familiarity with both quantitative and qualitative methods (Feilzer 2010). A challenge posed by both pragmatism and mixed methods are learning many different methods, increasing workload, especially for students (Pearce 2012). However, this may be less of an issue in more recent years, where collaboration across disciplines is more prevalent (Pearce 2012).

Lincoln (2010) expressed concerns that some who do not fully understand pragmatism may believe it is acceptable to simply not declare any philosophical research belief under the pretence of being 'pragmatic'. Lincoln takes this argument further by citing Pierre and Roulston (2006) who argued that all research has a theory or philosophy driving it. With this in mind, Lincoln believed it is naïve just to declare oneself a 'pragmatist' without providing adequate detail about the theoretical underpinning for research.

Lincoln (2010) also argued that the incompatibility issue, the problem of mixing differing methods, has still not been overcome. When carrying out research, researchers pretending to have no assumptions or underlying paradigms or choosing not to declare them, are no better than those who thought it possible to

be completely objective, an idea that is largely discredited (Lincoln 2010). However, Lincoln (2010) does not object to pragmatism or the mixing of methods, but to those mixed methods researchers who use pragmatism at a rudimentary level, without discussing epistemology, ontology or axiology. It is fundamental for a mixed methods or pragmatic researcher to include this information because it outlines a researcher's viewpoint and where they stand in relation to the phenomenon being studied.

6.9 Chapter conclusion

Pragmatism has had a long and varied history, with contributions from various philosophers who have contributed to the principles of contemporary pragmatism. Peirce laid the foundations for pragmatism with the establishment of four key pragmatic principles: (1) knowledge derives from interaction with the external world, (2) knowledge through collective exploration, (3) inquiry as a settlement of doubt, and (4) practical consequences of inquiry. James and Dewey developed pragmatism further with their own contributions: psychological consequences, fluid truth and social influences by James, and transactional theory and social justice by Dewey. As a result of these contributions, contemporary pragmatism has four universal principles: (1) rejection of dualisms, (2) truth is always provisional, (3) practical consequences of research, and (4) all research is historically, socially and culturally situated. The emphasis on practical consequences means that pragmatism advocates using the most suitable methods for answering the research aim and objectives at hand, making pragmatism a suitable paradigm for mixed methods and hence for this research.

7 Semi-Structured Interviews: The Methods

7.1 Introduction

Chapters Five and Six outlined the suitability of a mixed methods design and an underlying pragmatic philosophy respectively. As part of a mixed methods design, this chapter concerns semi-structured interviews, commencing by describing the study design, population and inclusion criteria. Ethical approval processes are outlined. Sites where semi-structured interviews were undertaken are profiled and rationales for their selection are outlined in relation to addressing the aims and objectives posed within this research. The interview procedure and how semi-structured interviews were conducted are also described. The final section describes analytic processes for semi-structured interviews.

7.2 Study design

This project utilised an exploratory sequential mixed methods two-stage design (Morse 1991; Bryman 2006a; Creswell and Clark 2011). The first phase concerned semi-structured interviews conducted with parents at three different locations across the UK. The results from this phase were used to develop the second phase, a national online survey, outlined in Chapter Nine.

7.3 Method overview: interviewing

Interviewing is a common method of data collection within health care research (DiCicco-Bloom and Crabtree 2006; Hewitt 2007; Ryan et al. 2009). The defining characteristic of an interview is a direct interaction between researchers and participants (Smith et al. 2012). This interaction is usually face-to-face, but other media such as telephone interviews or with the advance of technology, online video conferencing can be used (Creswell and Clark 2011; Bryman 2012; Smith et al. 2012). Interviews are typically voice based with data being recorded via a digital recorder or dictation machine (Gillham 2005). However, they also occur through written mediums such as email or social media platforms (Gillham 2005; Smith et al. 2012). Interviews are not tied to any particular philosophical point of view and are flexible in both design and function (Gillham 2005).

There are considered to be three major types of interview: structured, semi-structured and unstructured (Gillham 2005; DiCicco-Bloom and Crabtree 2006; Bryman 2012). Structured interviews involve researchers following strict schedules or sets of questions in exactly the same context and order with all participants, aiming to ensure reliability and validity between respondents. This type of interviewing is very similar to the questionnaire or survey method, with researchers reading questions in exactly the same order and manner, using pre-designed briefs and prompts. Consequently, structured interviews are associated with quantitative research paradigms (Gillham 2005; Bryman 2012).

Unlike semi-structured or unstructured interviews, standardised questions and answers within structured interviews are pre-coded and do not need to be analysed qualitatively, promoting accuracy, easy data processing, and coding (Gillham 2005; Bryman 2012). This saves time and prevents an interviewer misreporting responses. Structured interviews work on the assumption that a researcher is asking questions that need to be asked and that all possible responses are included (Bryman 2012). Building rapport with an interviewee in interviews, including sensitive topics, can be an important step in putting participants at ease (Lee and Renzetti 1990; Dickson-Swift et al. 2007; Dempsey et al. 2016). The rigid structure of structured interviews reduces chances to build rapport with interviewees (Dickson-Swift et al. 2007; Bryman 2012; Dempsey et al. 2016). With this in mind, structured interviews would be unsuitable in this research as sensitive subjects were involved. Additionally, this research is exploratory in nature because there is little research exploring the impact of varying models of short breaks on the relationship between parents. For the research outlined in this thesis, it was important that participants were able to raise topics that may not have been highlighted in previous literature.

Structured interviews are also associated with power imbalances between researchers and participants (Gillham 2005; Bryman 2012). Structured interviews assume researchers who have constructed the questions posed are experts on the topic over participant experiences. Following on from this point is the assumption that researchers understand participants' worldviews, when

often this is not the case. As questions tend to be closed in nature rather than open, respondents may feel forced to choose a particular answer that does not represent their true answer (Gillham 2005; Bryman 2012).

By contrast, to guide unstructured interviews, researchers have an interview guide or aide-mémoire, a general list of topics to be included, without a formal structure (Gillham 2005). Interviews in this context tend to be relaxed and informal, with question ordering varying between interviews. Interviews may open with a single question, with interviewers following up on respondents' answers (Gillham 2005). In this regard unstructured interviewing is often described as being similar in character to a conversation (Bryman 2012). Interviews akin to a conversation were appealing as a method for this research, reducing perceived power imbalances between interviewer and interviewees. This in turn could help participants relax and talk freely about sensitive topics (Lee and Renzetti 1990). However, gaining ethical approval for this approach made it unsuitable. To grant ethical approval many ethics boards want a clear interview schedule of questions or topics to be included, especially if the participants interviewed are considered vulnerable or if the topic is potentially sensitive. Ethical approval was granted (Appendix C) for final interview guide developed (Appendix E).

Semi-structured interviews lie between structured and unstructured interviews, with interviewers having a list of topics in a general interview schedule, but unlike structured interviews interviewers have flexibility to change the order of questions and follow up on interesting replies with further questions. As such, semi-structured interviews emphasise initial generation of research ideas or information gathering on under researched areas (Bryman 2012). There is also a much greater interest in participants' points of view, interviewers are interested in their perspective on the topics rather than collecting quantifiable data. Semi-structured interviews are often chosen for sensitive topics in health research (Liamputtong 2006; Elmir et al. 2011).

7.4 Study sites

Study sites were three children's hospices located across England. There were three criteria in the selection of study sites for the research. The first criteria necessitated one hospice being purposively selected from each of the three short breaks care models identified in Chapter Three: 'hospice and home short breaks', 'hospice short breaks only' and 'home short breaks only'. A useful and unpublished map was produced by one of the participating hospices, outlining the geographic locations and model of short breaks provided for all children's hospices in the UK. No hospices in northern England offered 'hospice and home' or 'home only' short breaks, so those shortlisted in northern England (see criteria 2 in Table 7.1 below) provided 'hospice only' short breaks.

Secondly, in order to address the fourth objective of the research, identifying societal factors influencing partner relationships of families receiving short breaks, sampling needed to represent socio-economic divisions that exist between northern and southern England (Gardiner et al. 2013). It was thus important that at least one of the three hospices be in Northern England.

Thirdly, culture, ethnicity and religion are important societal factors (Durà-Vilà and Hodes 2009; Cowan 2014) and so one of the hospices needed to provide services to an ethnically diverse population.

7.4.1 Profile of study sites

Hospice A

Hospice A is a children's hospice located in South-West England, following the hospice and home model of short breaks care (Table 7.1). Ethnicity in the area is predominately white (97.9%), covering a geographic area of 2,542 square kilometres¹. Hospice A currently provides short breaks to around 100 children and young people, offering overnight short breaks within the hospice building for up to four children at any one time. Hospice A offers short breaks to children at the hospice during the day and one or two overnight stays. Short breaks in families' homes are offered on a weekly basis for two to three hours.

¹ Demographic details obtained from most recent Office for National Statistics data. Reference not included to prevent hospices from being identified.

In addition to offering short breaks for children and young people with life-threatening illness and life-limiting conditions, the hospice also offers wider family support through parent and sibling groups.

Hospice B

Hospice B is located in the Midlands, providing hospice only short breaks (Table 7.1) within a geographic area of 902 square kilometres. Ethnicity in this area is diverse as 70.1% of the population are white, 18.9% are Asian, 6% are black, 3.4% are of mixed race and 1.6% are of other ethnicities. The hospice currently provides short breaks and other services such as end-of-life care and emergency care to over 600 children and 900 families including those who are bereaved. At the time of data collection, Hospice B was trialling home short breaks in specific areas of the Midlands and provided emergency hospice short breaks to families twenty-four hours a day, seven days a week.

Hospice C

Hospice C is representative of the home only model of short breaks (Table 7.1). Like Hospice A, Hospice C is located in South-West England and provides services to over 100 families. The hospice provides short breaks to families in their home or in a hospital setting but not in a hospice building. The population of the catchment area of Hospice C is 110 square kilometres, comprising white British people (78%) but also small numbers of families from ethnic minorities such as Asian (5.5%), black (6%) and 0.3% Arab. According to the hospice's annual report, on average, families receive 60 hours of short breaks a year, taking place in people's homes.

Table 7.1: Hospice selection criteria

| Criteria | Hospice & Home | Hospice Only | Home Only |
|--------------------|----------------|--------------|-----------|
| Non-Southern | | Hospice B | |
| Culturally Diverse | | Hospice B | Hospice C |
| Rural Geography | Hospice A | | Hospice C |

7.5 Interview population

The study population included parents or parental figures of children and young people with life-limiting conditions or life-threatening illnesses, who currently access a children's hospice in the UK, for short breaks. According to most current data, there are 6,754 families who currently access children's hospices (Devanney and Bradley 2012). Participants currently access short breaks from a children's hospice providing one of the three models of short breaks identified in Chapter Three; either at home, at a hospice, or both. Inclusion criteria for participation: parents were not required to be the biological parent of a child or children receiving short break care, rather the participant was required to undertake a parenting role with a life-limited or life-threatened child as demonstrated in research where strong parental bonds are formed between adopted children and their same-sex parents (Goldberg et al. 2013).

Exclusion criteria for participation: foster parents. Becoming a foster parent is increasingly being recognised as a paid occupation (Francis 2012; Foster Care Associates n.d.). Secondly, the length of time that a child is fostered can vary from emergency, overnight care to long-term (Francis 2012). Therefore, partner relationships may not be impacted by the care of the fostered child or young person with a life-limiting or life-threatening condition.

A convenience, purposive sample was employed for the semi-structured interviews. The sample was purposive because three participating hospices were chosen on the criteria highlighted in section 7.4. It was also convenience based because participants responded to invitations sent out by the participating hospices. The aim of the semi-structured interviews was to gain rich and meaningful data. As a result, the sample size for the interviews was kept to a manageable size.

There is a great deal of debate about how many qualitative interviews are 'enough', with no consensus on a quantifiable amount (Baker et al. 2012; Walker 2012; O'reilly and Parker 2013; Fusch and Ness 2015). Regarding this

research, a 'manageable sample size' was determined by two factors: data saturation and practicality.

Within qualitative interview based studies, the number of participants required is often justified through 'data saturation'. Data saturation was first introduced by Glaser and Strauss (1967), referring to the point in data collection where no new additional data are found which help to further develop conceptual theory. Researchers agree that data saturation is reached when no new coding, themes or concepts are evident in the data (Guest et al. 2006; Francis et al. 2010; Walker 2012; O'reilly and Parker 2013).

In relation to practicality, time and resources available should be considered when deciding on interview sample sizes (Baker et al. 2012). Collecting and analysing qualitative data is labour intensive, so collecting large sample sizes is impractical (Ritchie and Elam 2003). Transcribing interviews is a time-consuming process. Whilst it is important to conduct enough interviews to get meaningful data, this should be balanced against the time taken to carry out, transcribe and analyse the interviews.

7.6 Access procedure

Participants of semi-structured interviews were accessed via staff at participating hospices who acted as gatekeepers and distributed invitation letters to parents meeting inclusion criteria currently accessing that hospice. Invitation letters (Appendix A) and participant information sheets (Appendix B) outlined why the research was being conducted, inviting parents to email or telephone the research student if they wished to participate. Once participants made initial contact, a date and time for an interview was arranged via phone and/or email. Having to recruit participants through gatekeepers can present difficulties (Ewing et al. 2004; Steinhäuser et al. 2006). One issue presented by gatekeepers is the additional time required to negotiate access, which is disproportionate to the number of participants recruited (Ewing et al. 2004). Secondly, gatekeepers may be conflicted, recognising the importance of research but also needing to protect participants (Ewing et al. 2004). These difficulties were overcome by

clearly explaining the research objectives to potential gatekeepers and what would be required of participants.

7.7 Interview schedule development

The interview schedule was developed from the literature reviewed, the research aim, objectives and supervisor expertise. As such, interviews needed to include parents' contribution to care, their perceptions of parenting a life-limited or life-threatened child and impact on their partner relationships, differences in short breaks and societal factors that might impact upon partner relationships.

Structuring the interview was guided by three factors: building rapport, the need for flexibility and the need for sensitivity (Renzetti and Lee 1993; DiCicco-Bloom and Crabtree 2006). Building on the guidance suggested by Spradley (1979), DiCicco-Bloom and Crabtree (2006) suggest the first step of interviews should be putting the interviewee at ease and encouraging them to talk. They suggest doing this by asking a broad, open and non-threatening question, which relates to the research aim as a whole (DiCicco-Bloom and Crabtree 2006). As such, the first few topics of the interview were factual to help 'ease' the participant into the interview, allowing rapport to be built. Reading through the information sheet and signing the consent form was important for informed consent, but also as a stage in building rapport with the researcher. Asking participants about their child also provided a factual topic to ease them into the main body of the interview.

Following the initial stages, interviews were relatively flexible giving participants the chance to 'tell their story'. Giving participants opportunities to tell their story has the benefit of potentially being therapeutic for them (Abma 1998; Banks-Wallace 1998) and gives opportunities for new relevant data to emerge that might be ignored in more structured interviews.

7.8 Interview locations

Participants who lived in the South-West of England were offered the option of being interviewed at three locations: their home, their children's hospice or at the university hosting this research. Non-local parents were offered two options for practical reasons: their home or their hospice.

There were main two considerations in determining interview locations: convenience and avoidance of invasion of privacy (Lee and Renzetti 1990; Gagnon et al. 2015). Participants being interviewed often have little free time as most of it is spent caring for their children (Mash and Lloyd-Williams 2006; Yantzi et al. 2007; Wood et al. 2010; Hunt et al. 2013), so they were offered an interview location and time that was convenient for their needs (Gagnon et al. 2015). It was also acknowledged that parents frequently contend with multiple visits from health professionals and carers (Hunt et al. 2013), and may wish to avoid another visitor coming into their home. Interviews conducted at the hosting university or hospices were carried out in a quiet, distraction free location. Interviews conducted at parents' homes were mostly distraction free, but the occasional distraction such as a home phone ringing was unavoidable, meaning that interviews had to be paused on occasion.

7.9 Ethical approval

The Nuremburg Code (1947) was developed in response to unethical research conducted by the Nazis during the 1930 -40s and underpins research ethics (Shuster 1997; Weindling 2001; Thieren and Mauron 2007). The Nuremburg Code serves as the foundation of rights of participants taking part in research (Shuster 1997) and consequently researchers are obligated to ensure research is ethically sound (Holloway and Wheeler 2013). Ethical considerations can be divided into four main domains (Diener and Crandall 1978): (1) preventing harm to participants, (2) ensuring informed consent is provided, (3) reducing invasion of privacy and (4) avoiding deception. The four categories have potential relevance to this research such as potential sensitivity and informed consent. However, other ethical issues such as harm to researchers (Bahn 2012; Barr and Welch 2012) and role conflict (Lee and Renzetti 1990; Seymour and

Ingleton 2005) are not considered by Diener and Crandall, but also need to be considered.

Lee and Renzetti (1993) defined sensitive research topics as being potentially threatening to those involved, both to participants and researchers, during data collection, storage and dissemination of research findings. An alternative definition of sensitive research related to health is any reference to specifically sensitive topics such as HIV/AIDS, palliative care, mental health and bereavement (Elmir et al. 2011). Planning sensitive research can be difficult because the phrase 'sensitive' is often used in research with the assumption there is a universal definition giving the same meaning to everyone (Renzetti and Lee 1993). Discussion of finance or sexual matters, are often considered highly sensitive as they involve entering individuals' personal and private spheres (Renzetti and Lee 1993).

Seeking ethical approval from a National Health Service research ethics committee was deemed good practice for three reasons: (1) the potentially sensitive nature of this research (Renzetti and Lee 1993), (2) debate within the palliative care research community about research participation (Bentley and O'Connor 2015; Kars et al. 2016), and (3) some potential participating parents were recipients of NHS healthcare. Ethical approval was sought and granted from Oxford B NHS Regional Ethics Committee (Appendix C). Ethical approval was granted for the interviews after addressing amendments. Approval was granted once Bournemouth University Ethics Committee had received a copy of the NHS REC approval.

7.9.1 Informed consent and deception

Participation in research may be influenced by altruism, a desire to help others (Wulf et al. 2012; Hein et al. 2015). Participating in research may give participants some degree of comfort and sense of worth if their participation could potentially help others in a similar situation (Nordentoft and Kappel 2011; Wulf et al. 2012; Hein et al. 2015). If researchers suggested to potential participants that research could help others or their own family, this could be akin to coercion (Seymour and Ingleton 2005). Additionally, potential

participants may feel a debt of gratitude to service providers and staff for providing services feeling obligated to take part (Seymour and Ingleton 2005; Agar et al. 2013). Therefore, informed consent may not be black and white; rather there are degrees of consent depending on circumstances (Seymour and Ingleton 2005; Agar et al. 2013).

Presentation of research to participants is also an important consideration in relation to deception and informed consent. There are two forms of deception that can occur in research (Schwab 2013). The first, occurs when potential participants are lied to during the consent process. Milgram's (1963) study into obedience is one of the best known examples of deception in research. Potential participants were told the study was about learning, when it was actually researching obedience to authority. The second form of deception concerns omission (Schwab 2013), when researchers fail to disclose information to participants during the consent phase. Researchers need to decide if the topic of an interview should be outlined in detail to participants, as this could influence both informed consent and the answers given by the participant (Renzetti and Lee 1993). Without transparency informed consent may not be fully informed and participants may be deceived by omission (Renzetti and Lee 1993; Schwab 2013).

Reflecting these considerations, participants were sent a standardised Participant Information Sheet (PIS) (Appendix B) at least two weeks in advance of interviews giving them reasonable time to make an informed choice as to whether to participate or not (National Research Authority 2014). The PIS outlined the aims and purpose of the research, participant involvement, participant rights and contacts to ask questions in advance. Reassurance was given that participation in the research, or not, would not affect the care received from their hospice in any way. On the day of interviews participants were again given an opportunity to ask questions before signing the consent form.

7.9.2 Role conflict

Within healthcare research, conflict and confusion can arise regarding boundaries between researchers and participants (Lee and Renzetti 1990; Seymour and Ingleton 2005). Previous literature has highlighted potential for conflict of those who have a dual-role as a nurse and a researcher (Allmark et al. 2009; Blythe et al. 2013; Judkins-Cohn et al. 2014). Potential for confusion and role conflict has been demonstrated in research into end-of-life care (Seymour and Ingleton 2005). When carrying out their research Seymour and Ingleton found it difficult to separate their role as researchers from that of being nurses. Vulnerability of participants in healthcare research may be a source of role conflict for those with dual roles as there is an obligation to help those in need (Holloway and Wheeler 1995).

The sensitive nature of some healthcare related research may also lead to potential confusion between researcher role, particularly when using semi-structured interviews. The role of a researcher is one of investigation rather than a councillor or therapist (Smith 1992). However, when participants talk about sensitive or difficult topics a dependent relationship between researcher and participant can form (Holloway and Wheeler 1995; Nordentoft and Kappel 2011). This is especially true as building rapport with participants is important to increasing disclosure during semi-structured interviews (Renzetti and Lee 1993). Finding the balance between establishing trust and rapport with the participant against not crossing professional boundaries causes conflict. Smith (2012) advocates actively listening to the participant, whilst avoiding offering advice as the best approach to take.

Whilst I am not a nurse or a counsellor, I volunteered for a national charity where I was trained to offer emotional support to individuals who were suicidal or struggling to cope with life events. Drawing on the training provided by the charity was beneficial to interviews, especially the skill of ‘active listening’, whereby the listener fully concentrates on what is being said by the speaker (Roberston 2005). Whilst utilising this skill I was aware that my role was that of a researcher and was not to offer emotional support or offer advice.

7.10 Interview procedure

The interview procedure began prior to the interview date with participants emailed a participant information sheet (Appendix B). Participants should be given time to consider taking part in research (National Research Authority 2014). There is no explicit length of time for how long participants should be given to consider taking part in research, however the NRA (2014) suggests some considerations: (1) complexity of the research, (2) the desire to avoid coercion, (3) the participants level of understanding and (4) the setting of the research. With this in mind participant information sheets (PIS) were sent to parents two weeks before the arranged interview, ensuring participating parents time for understanding the research purpose, asking questions and giving informed consent. The interviews began with introductions, reading through the PIS, their rights to withdrawal and giving parents an opportunity to ask questions (Whiting 2008). Participants were reminded that the interview would be recorded for transcription purposes and what would happen with the data. Participants were then asked to sign a written consent form (Appendix D).

Once participants had signed a consent form, the digital recorder (Stockdale 2002) was turned on; digital recorders are commonly used within interviews to capture data (Stockdale 2002; Fernandez and Griffiths 2007; Al-Yateem 2012). The initial aim of the structure of interviews was to put participants at ease, building rapport, so that participants would feel more comfortable answering sensitive questions (Lee and Renzetti 1990). Therefore, the first question was designed to be open, asking participants about their child or young person currently accessing a children's hospice and their day-to-day needs. Whilst there was an interview guide (Appendix E) with a list of topics and questions that all interviews followed, sufficient flexibility allowed these to be approached differently depending on interviewees. This flexibility allowed the interviewer to follow up on interesting topics or points relevant to the research aim which had not been covered in the interview guide (Dearnley 2005).

This open approach to the semi-structured interviews had both advantages and disadvantages (McCann and Clark 2005). Often topics or relevant points arose,

which had not previously been contemplated prior to interviews but related to the research aim and objectives. However, the open nature of the interviews meant some topics that were not completely relevant were also discussed, meaning a degree of guidance was needed from the interviewer to keep the interviewee on topic. Interviews lasted between 45- 240 minutes depending on how much the participant wanted to talk.

In most interviews, participants responded individually but due to their time restrictions, some parents were interviewed together. In practice, the dynamic often worked well with partners being open and frank about the impact of caring for children and young people with complex needs on their relationship, in addition to the impact of hospice short breaks. One couple commented that the interview was the first time they had the opportunity to discuss their relationship and that they had found it therapeutic (Abma 1998; Banks-Wallace 1998).

When each interview had finished parents were thanked for their time and asked if they had any final questions about the research. The digital dictation machine was not turned off immediately because I learnt in the first few interviews that often parents continue to talk about relevant topics long after an interview has concluded.

7.11 Semi-structured interviews: data analysis

Data from the semi-structured interviews were analysed through thematic analysis. Thematic analysis is widely used within health research, yet there is little guidance on implementing it (Arrington 2015; Christensen and Probst 2015; Yildiran and Holt 2015; Pettigrew et al. 2016; Thompson-Janes et al. 2016). Numerous research articles published using thematic analysis do not detail the analytic procedure, making it hard to judge the quality of the research (Braun and Clarke 2006; Howitt and Cramer 2014). Novice researchers often choose thematic analysis because it requires less knowledge of epistemological and ontological assumptions than other qualitative analysis methods such as content analysis or discourse analysis (Howitt and Cramer 2014). Yet, Howitt and Cramer also argue that researchers need to be clear about their

philosophical underpinnings whether it be pragmatic, feminist or phenomenological, for example. Lack of formal guidance on utilising thematic analysis can also be a barrier to novice researchers (Clarke and Braun 2013). Despite these issues, thematic analysis has potential to be as robust a method of analysis as others such as discourse or content analysis, both of which are techniques for systematically describing written, spoken or visual communication (Braun and Clarke 2006; Howitt and Cramer 2014).

A number of authors have made contributions to thematic analysis in an effort to improve robustness (Braun and Clarke 2006; Joffe 2012; Clarke and Braun 2013; Howitt and Cramer 2014). The concept of analytic effort was proposed by Howitt and Cramer (2014), with analytic effort referring to the amount of work researchers apply to analysing text when generating themes. Analytic effort is mediated by five factors: (1) the amount of time spent familiarising oneself with the data, (2) whether data are analysed line-by-line or skim-read, (3) how many times data are processed and reprocessed, (4) the number of difficulties experienced by a researcher during analysis and (5) researcher willingness to check and recheck final themes against the original data (Howitt and Cramer 2014).

Joffe (2012) also made an important contribution to guidance on thematic analysis, creating a coding framework, defining a coding framework as a conceptual tool used for classifying datasets and guiding thematic analysis. The coding framework is developed from both inductive codes grounded in the data and theoretically developed codes based on previous research in the area. Essentially, it is a full list of codes that could be applied to the data. The coding framework should consist of three columns: the code name, code description and an example of the code (Joffe 2012).

Braun and Clarke (2006) recognised that while widely used, there is little formal guidance on how to carry out thematic analysis in a thorough and detailed way. They proposed a six-step procedure to carrying out thematic analysis: (1) familiarisation with data, (2) initial coding generation, (3) searching for themes based on the initial coding, (4) reviewing the themes, (5)

theme definition and labelling, and (6) report writing. A modified version of this approach which incorporated coding frameworks as proposed by Joffe (2012) was utilised to analyse data in my study and is outlined in detail in the next two sections.

7.12 Transcription and data familiarisation

The first step in analysing data from the semi-structured interviews was transcription of the interview recordings verbatim. Transcription is the transformation of verbal language into written language (Lapadat 2000). Transcription is time-consuming (Alcock and Iphofen 2007), taking approximately six to seven hours per hour of interview recording (Britten 1995). Professional transcription was considered, but this idea was decided against because interviews involved discussing topics that some may consider sensitive and as such protecting the identity of interviewees is important (MacLean et al. 2004). Secondly, familiarisation with data is a crucial step in Braun and Clarke's thematic analysis and transcription. Whilst transcription is time consuming, it allowed me to become familiar with the data (Lapadat 2000).

There is no one recognised transcription format, instead transcription depends on the research purpose (Ochs 1979; Lapadat 2000). Interviews were transcribed including utterances such as 'umm' and 'err' and pauses using Microsoft Word®. Occurrences not relevant to the research aim and objectives, such as participants having to answer the phone or go for a toilet break were excluded from transcription. Initially speech recognition software was used in the transcription process. However, the accuracy of the software was poor and this method of transcription proved to be more time consuming than manual transcription; difficulties with speech recognition software have been noted in previous research (Johnson et al. 2014; Hodgson and Coiera 2015). Completed transcriptions were checked against the audio recordings for accuracy and any changes were made. During this accuracy check process, participants and their families were given pseudonyms to protect their identity. A transcript extract can be found in Appendix F.

7.13 Analysis

Step 1 (familiarisation with data): Following familiarisation with data, the first stage of analysis involved generating initial codes from the semi-structured interview transcripts. This began when transcriptions were checked for accuracy, with initial patterns being noted. Transcripts were read through systematically with equal attention given to all data. Data relevant to the research aim and objectives were identified with three criteria in mind: (1) codes must relate to the research aim and objectives at hand, (2) sentences can be coded more than once and (3) there was to be no interpretation of what participants were saying, what they said is what they meant. Coding was initially descriptive.

NVivo, a computer software package, was chosen to aid analysis because it was freely available and I had already received NVivo training. A new ‘project’ was created in NVivo and transcripts were exported from Microsoft Word into a PDF file, as it was found PDFs are more compatible with NVivo. Data coded reflected a distinct element of the research aim and objectives (Braun and Clarke 2006). Passages of text were not considered to be exclusive, and were coded multiple times. For example, text from the paragraph in Figure 7.1, from participant 5, was coded as ‘Worrying about finances’.

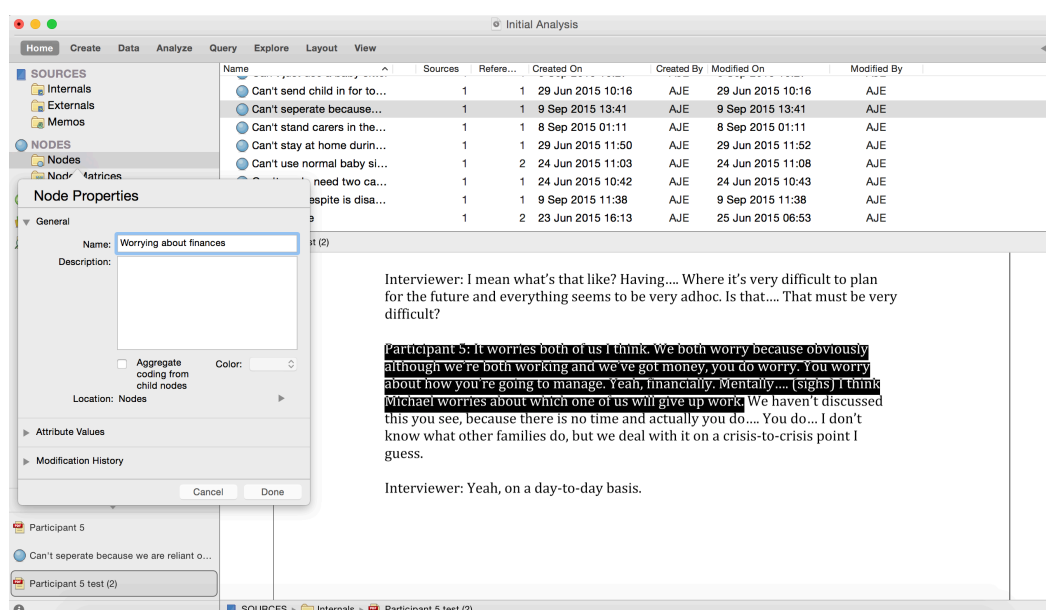


Figure 7.1: First example of coding

However, a selection of text from the same paragraph was also coded as ‘Communication between partners’ (Figure 7.2).

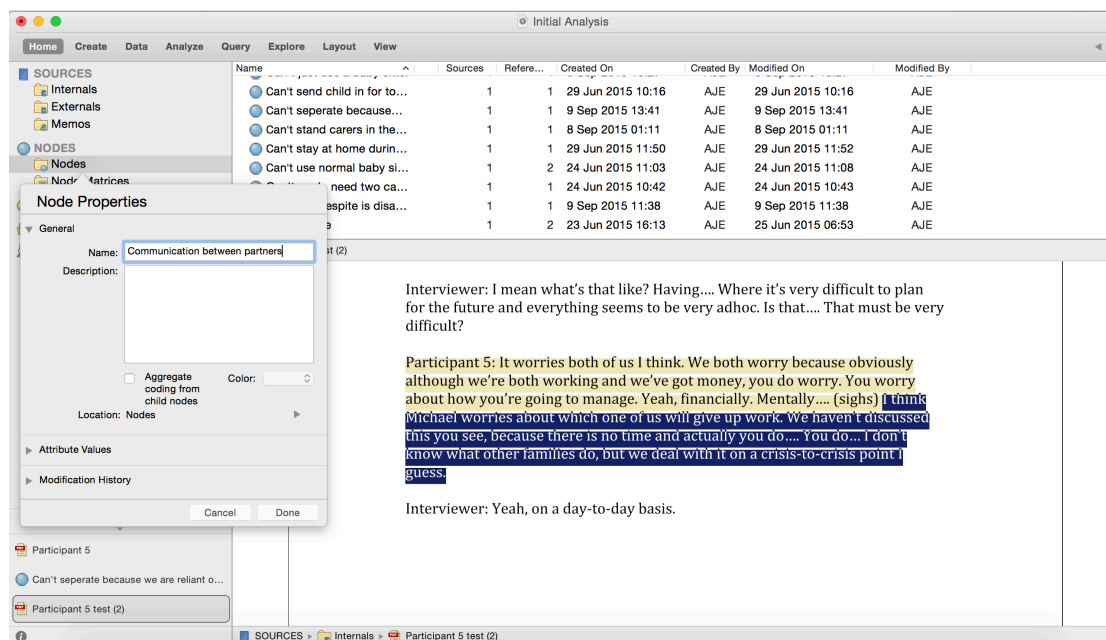


Figure 7.2: Second example of coding

The initial coding phase resulted in a list of codes (Figure 7.3).

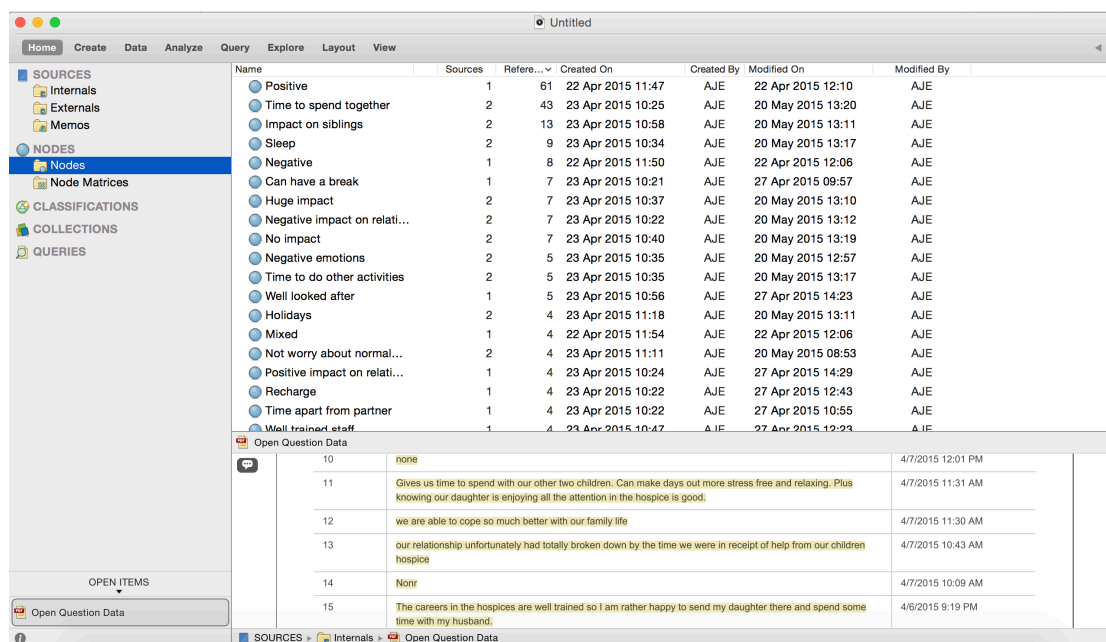


Figure 7.3: Example of initial list of codes for open question

Step 2 (initial coding generation): This step modified preliminary themes (Braun and Clarke 2006) by creating a coding framework (Joffe 2012), aiming to move analysis towards a broader level by sorting the initial list of codes into similar patterns or themes. The code lists (Figure 7.3) were exported from NVivo into a Word document. Consolidation of codes, considered replications or characterising comparable data was an important process. For example, the code ‘Lack of respite’ was merged with ‘A shortage of respite’, as they referred to the same phenomenon. Consolidation was ongoing throughout the step two of initial analysis as per Braun and Clarke (2006).

Consolidating codes into potential themes and developing descriptions for them were two additional important procedures. Braun and Clarke (2006) suggest using tables or mind-maps to aid the sorting process. In line with this suggestion, codes covering similar data were collated under potential theme headings by copying and pasting within Microsoft Word[®]. Some codes combined to become main themes, whilst others became sub-themes. No codes were disposed of at this point, even if they did not fit in with a theme. Instead they were placed into a ‘miscellaneous’ theme, for potential use at a later point. Justifications, decision processes and formative descriptions were recorded to ensure auditability. Figures 7.4 and 7.5 demonstrate the development of themes.

Benefits of respite

Social isolation → Reducing social isolation, not feeling alone, being able to talk to the hospice or others in the same situation.

We're not alone → Realised that we're not alone.

Any reference to reducing the effects of social isolation.

Break from caring role → Having a break from the routine of being a carer.

Can have a break → Same as above. Merge into one. Reference to having a real break. Time away from caring. Time to catch up on sleep, chores or being together.

Caring taking up a huge amount of time → Merge with above

Housework → Having more time to catch up on chores.

Not being a carer → Again seems to fit with the codes above.

Not worry about normal routine → Not having to worry about normal caring routine, includes meds, illness, etc.

Less Pressure → Fit in with above.

Reduces Stress → Reduces the stress of daily life

Switch off → Mentally switch off.

Time to relax → As above.

Figure 7.4: Early organisation from thematic analysis

Benefits of respite

~~Social isolation~~ → ~~Reducing social isolation, not feeling alone, being able to talk to the hospice or others in the same situation.~~

~~We're not alone~~ → ~~Realised that we're not alone.~~ Social isolation and we're not alone can be merged into one. A better title for code might be 'Reduction of social isolation'.

Reduction of Social Isolation → Parents often feel socially isolated. Data will make reference to receiving respite or hospice support reducing social isolation and not feeling alone. Being able to talk to the hospice or others in the same situation.

~~Any reference to reducing the effects of social isolation.~~

Break from caring role → Having a break from the routine of being a carer.

~~Can have a break~~ → Same as above. Merge into one. Reference to having a real break. Time away from caring. Time to catch up on sleep, chores or being together.

Caring taking up a huge amount of time → Merge with above

~~Not being a carer~~ → Again seems to fit with the codes above.

~~Not worry about normal routine~~ → ~~Not having to worry about normal caring routine, includes meds, illness, etc.~~ all of the above could be combined under one code such as 'break from caring routine'.

Night routine → Break from night routine, which can be exhausting. Night routine could also be included here.

Break from caring routine → Having a break from the normal routine of being a carer, having more free time and not having to worry about normal routine including meds and illness. This also includes having a break from night routines which can be especially tiring.

Figure 7.5: Further analysis development demonstrating consolidation, justifications and early descriptions

The organisation and development of themes were incorporated into a coding framework (Joffe 2012). This consisted of themes, related codes, code descriptions and code examples. In the example in Figure 7.7 the overall theme is ‘Impact of caring role prior to short breaks’. One code that informed this theme was ‘Physical impact of care’. The description for this code was developed in the stages discussed earlier.

| Impact of caring role prior to short breaks | | |
|--|--|--|
| Code Name | Description | Example |
| Physical impact of care | Physical impact will be any reference to exhaustion or tiredness due to care routine. The impact of night care will also fall under this code. | “When away we are really tired due to the constant strain of caring for our son, including often being up during the night. So although we enjoy are time away we always need to catch up on sleep and so never manage to go away anywhere exciting” |

Figure 7.6: Example of coding framework

Step 3 (searching for themes): Following preliminary coding framework construction, overarching themes, related codes and code descriptions were entered into a new NVivo project. Figure 7.8 demonstrates the code ‘Physical impact of care’ being entered into NVivo with the relevant description.

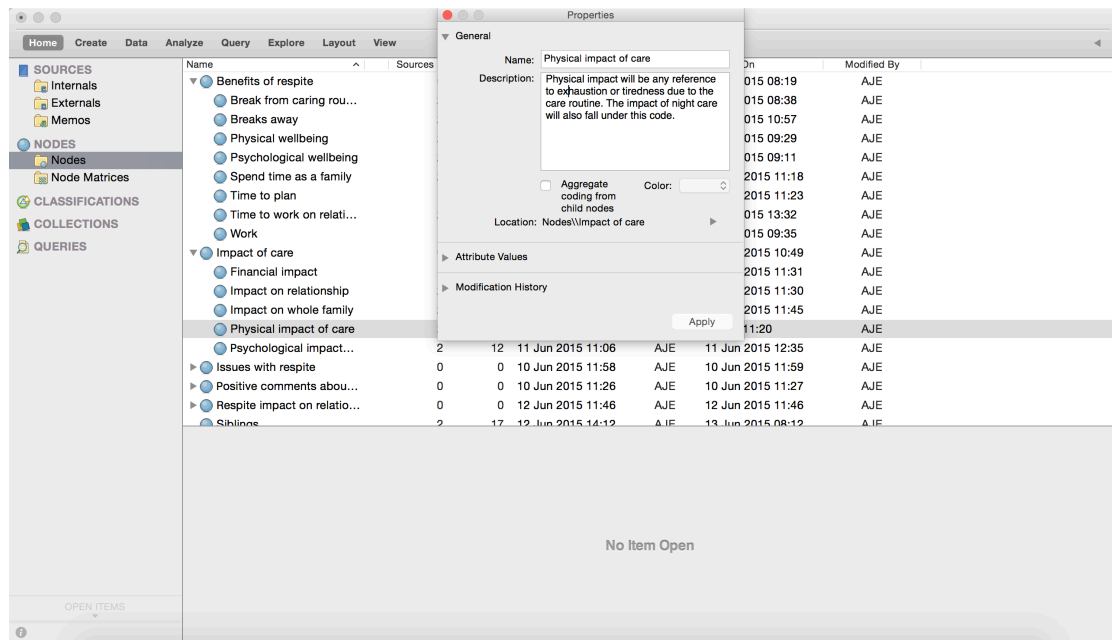


Figure 7.7: Preliminary coding framework entered into NVivo

Utilising the preliminary coding framework as a guide, the entire dataset was analysed line-by-line and recoded, constituting phase four of Braun and Clarke's (2006) thematic analysis; reviewing themes. Sections of the dataset related to research objectives that did fit existing framework themes were added as new codes. Two questions were considered during this stage: a) "*what is this theme trying to say?*" b) "*how does it fit in with other themes and the research as a whole?*" (Braun and Clarke 2006). The aim was to end with a clear and logical narrative for each theme, clearly defining what the theme includes.

Step 4 (reviewing the themes): Once line-by-line coding of the dataset was completed, the preliminary coding framework and themes were re-examined as per **Step 2**, resulting in a revised coding framework and themes.

Step 5 (theme definition and labelling): The revised coding framework, themes and code descriptions were re-entered into a new NVivo project. The dataset was re-analysed using the revised coding framework. When the coding framework, corresponding themes and descriptions represented the dataset, the final coding framework had been developed. The analysis cycle is shown in Figure 7.9.

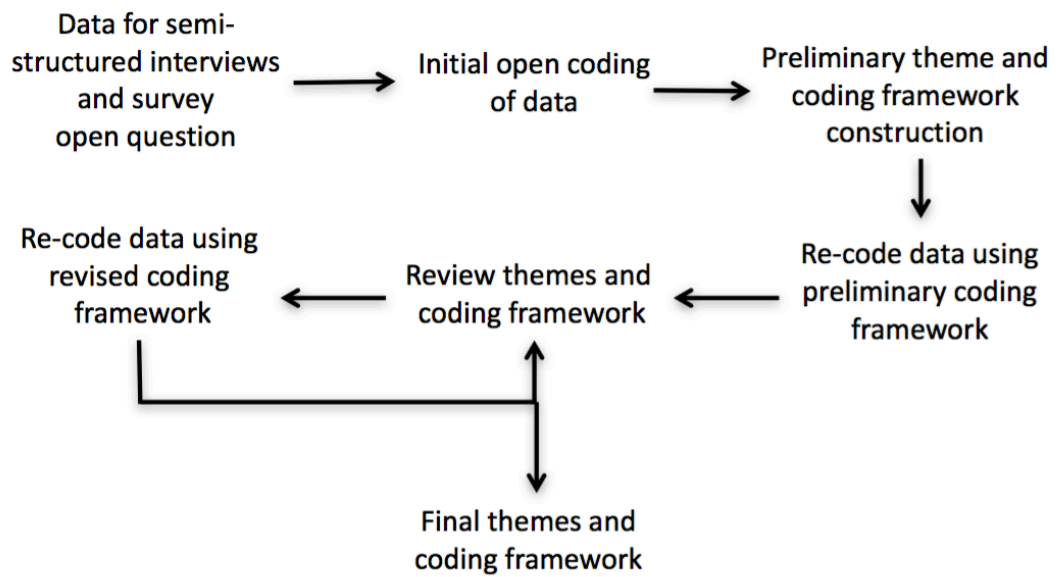


Figure 7.8: Analysis process

7.14 Chapter conclusion

This chapter outlined the methods and analytic procedure for the first of two phases of this sequential mixed methods study. The merits of interviewing as a method, in addition to the advantages and disadvantages of the three main interview types were presented and a rationale for semi-structured interviews provided. Justification for study site selection was then outlined, followed by descriptive profiles of the selected sites, three children's hospices in the UK. This was followed by an outline of the research population and sample for the present study, parental figures currently accessing short break services at a children's hospice. The next section described the process of gaining ethical approval and considered ethical issues relevant to the study including: harm to participants, invasion of privacy, informed consent, deception and role conflict. The final half of the chapter concerned the analysis of semi-structured interview data, utilising Braun and Clarke's (2006) thematic analysis which was modified to incorporate coding frameworks as proposed by Joffe (2012).

8 Thematic Exploration of Partner Relationships and Short Break Significance

8.1 Introduction

Chapters Two and Three set the scene for this research and identified an absence of understanding about the impact of various models of children's hospice short breaks on partner relationships between parents, in relation to frequency. This chapter presents findings from the first of two phases of this study, semi-structured interviews conducted with parents currently accessing a children's hospice in the UK. The first half of this chapter provides an overview of the interview and analysis procedure, before profiling participating parents. The second half of the chapter presents the main themes developed: short break significance, every family is different and short break quality. External ('Every family is different') and internal ('Short break quality') influences mediated the perceived significance of children's hospice short breaks to the relationship between parental figures. The implications of these findings for the development of the second phase, a national online survey, are then outlined.

8.2 Semi-structured interview procedure and analysis

The first phase of this research involved interviewing parental figures who had either a child or young person currently accessing at least one children's hospice in the UK. Participating children's hospices distributed invitation letters to parents meeting inclusion criteria and currently accessing the hospice. Once participants made initial contact, a date and time for an interview was arranged via phone and/or email. Semi-structured interviews were conducted with fifteen parents, nine mothers and six fathers, at the three identified study sites (see Chapter Seven). Most participants were interviewed individually, however four were interviewed together.

8.3 Interviewee profiles²

8.3.1 Hospice A- South-West

Interviewee one- Carol

Carol is the biological mother of Bella (age ten) and is Bella's full time carer, whilst her husband, David, works long hours. Bella is their only child. Hospice A offers 210 hours per year of short breaks to families either at home or at the hospice, but Carol and David currently only have short breaks at home because Bella finds hospice short breaks distressing. Some help is received from their family members, but they find caring for Bella's medical needs intimidating. No other forms of short breaks are received.

Interviewees two and three- Debbie and Mark

Debbie and Mark are Alice's (age eleven) biological parents. Debbie is Alice's main carer during the day, but Mark helps in the evening after work. They have one other child, Harry. They currently use only half their short breaks allowance provided by their hospice as they also privately pay an au pair for short breaks at home. When they do access Hospice A for short breaks, it is only for a day, rather than overnight. Alice's grandparents provide moral support, but due to their age are not able to provide short breaks. A close friend has provided short breaks in the past, but this has stopped due Alice's increased health needs. Debbie and Mark are aware that they will need to use more of their children's hospice short breaks as Alice reaches the end of her life.

Interviewee four- Mary

Mary is Kit's (age eleven) biological mother and full time carer, whilst her husband, Eric, works long hours. They have two other children, Daniel (age thirteen) and Lauren (age nine). They currently receive two hours a week of short breaks at home from their children's hospice and choose not to use hospice-based short breaks as they perceive them to be too infrequent to be useful. There is no practical support from family or friends. Social care fund

² All participants and their families have been given a pseudonym to protect identities.

overnight short breaks for Kit away from their home every weekend at a private short break organisation. In addition, NHS funding provides one overnight short break per week in the home.

Interviewee five- Eva

Eva is Andrew's (age seventeen) biological mother and full-time carer. Whilst her husband John works full-time, he also helps with Andrew's care when possible. They have two other children, Carl (age seventeen) and Jessie (age seven). They currently receive short breaks at home from Hospice A once a week for two hours. They are offered an overnight weekend short break once a year, but do not use it. They receive three weekend short breaks a month at a private short break organisation, funded by social care, which they feel comfortable using as the staff know their son well. Eva's family provide a great deal of support, but John's do not and this is often a source of conflict.

Interviewee six- Amy

Amy is Frankie's (aged ten) biological mother and is currently accessing two children's hospices in the South-West. Both Amy and her husband Michael work, whilst also caring for Frankie. They have two other children, Sam (aged twelve) and Erica (aged eight). They receive six hours a month of home short breaks and one full weekend a year at Hospice A. In addition, they receive up to 16 days of short breaks at a second hospice. Amy's mother has provided short breaks in the past, but as Frankie has grown, this has become less manageable. No other sources of short breaks are received.

Interviewee seven- John

John, Eva's husband (Interview five), was interviewed separately. John works full-time and will help with care in evenings after work. John feels his family lack understanding about Andrew's needs and how they impact the family and his relationship with Eva. Andrew can often display aggressive behaviour towards all family members, but especially Eva. This has caused tension in the past because John believes a firmer approach should be taken towards James when he displays challenging behaviour, something Eva disagrees with.

8.3.2 Hospice B- Midlands

Interviewee eight- Aaesha

Aaesha is Piruz's (aged seventeen) biological mother and is the main carer for both Piruz and a grandparent who lives with them. Her husband Rashid, works full time but also cares for Piruz in the evening. They have one other son, who has now left the family home. They receive a weekend short break every 10 to 12 weeks. Ten hours per week of home short breaks are also received from a local charity and social care provide a 'small' amount of unspecified short breaks. Aaesha receives no practical support from family, who do not live locally but her husband's family provides emotional support.

Interviewee nine- Sarina

Sarina and her husband Fahad have one son, Jayesh (aged eighteen) and two daughters, Sara (aged fifteen) and Aleena (aged sixteen). Both Sarina and Fahad gave up full time work to care for Jayesh, with Fahad doing most of the physical work required in caring for Jayesh. They receive one weekend short break a month at the hospice and one week during the school holidays from Hospice B. In addition, they receive four hours per week of short breaks at home with a registered nurse, but the local council funds this. Sarina receives no support from family or friends.

Interviewee ten- Sam

Sam is Jasmine's (aged twelve) biological father. Both Sam and his wife Gillian, care for Jasmine and their two other daughters, Bella (aged fourteen) and Michelle (aged sixteen). However, it is Bella's health concerns and related challenging behaviour that is causing the most anxiety and conflict for Sam and Gillian, rather than Jasmine's health needs. They receive a weekend short break at the hospice every 12- 16 weeks and short breaks at home- although the length and frequency of these short breaks was not specified. Private carers also come into the house to provide short breaks. Family members also provide breaks, but Sam was conscious of overburdening their family members. Gillian was not interviewed.

Interviewee eleven- Steve

Steve is Bruce's (aged nine) biological father. Both Steve and his wife Lisa have given up work to care for Bruce full-time. They also have an older daughter, Amanda (age eleven). They receive both short breaks in the home and at the hospice, although the frequency was not stated.

Interviewees twelve and thirteen- Fiona and Liam

Fiona and Liam were Anna's biological parents, who had died six months prior to the interview. Bereaved parents were excluded from the study, but staff at Hospice B, acting as a gatekeeper, had still forwarded the details of the research to Fiona and Liam. Both parents were still happy to participate, gave informed consent and reflected that they had found the interview to be a useful experience. Fiona and Liam have two other daughters, Sarah (aged seven) and Kelly (aged five). It was unclear how many hours of short breaks Fiona and Liam were receiving.

A note on unexpected ethical dilemmas

The ethical dilemma raised by the participation of bereaved parents, Fiona and Liam, highlights the unpredictable nature of qualitative research in practice (Oeye et al. 2007; Houghton et al. 2010; Greeff and Rennie 2016). There is a distinct difference between the static or theory driven nature of ethical guidelines and the reality of data collection in qualitative research; qualitative research should be considered relational, situational and emerging (Shaw 2008; McAreavey and Muir 2011; McAreavey and Das 2013; Øye et al. 2016). Researchers should be prepared to make critical ethical decisions based on specific situations or scenarios (McAreavey and Das 2013). Therefore, the main issue for qualitative researchers is ensuring they can handle ethical dilemmas when they arise in such a way to protect participant's health, dignity and integrity (Øye et al. 2016).

One solution that has been suggested is phronesis as a crucial decision-making skill within the context of qualitative research (McAreavey and Das 2013; Greeff and Rennie 2016). Phronesis has been presented as a solution to ethical issues that researchers may face while collecting data (McAreavey and Das

2013; Greeff and Rennie 2016). The core principle of phronesis is consideration of what is morally good and doing the right thing at the right time for the right reason (Sellman 2009; Surprenant 2012; Lacey 2013). The researchers should learn to judge the situation and mindfully respond to it (Greeff and Rennie 2016). Taking a phronetic approach to ethic means the researcher actively reflects on benefits and harm to participants (Greeff and Rennie 2016). Research has found that whilst the term ‘phronesis’ is not familiar with most researchers, it formed an integral part of their everyday existence and decision making during research (Greeff and Rennie 2016).

Whilst I was not aware of phronesis at the time, I was certainly following phronetic principles when faced with the unexpected dilemma of Fiona and Liam participating. The main ethical principle that guided my decision to continue with the interview was ‘protecting participants from harm’; I felt it would be harmful to end an interview that had already started, implicitly suggesting the difficult narrative Fiona and Liam chose to share had no value or merit to the research. In addition, Fiona and Liam had received the Participant Information Sheet and Consent Form in advance of the interview, had time to read through them and had consented to take part in the interview. Ending the interview upon learning they were bereaved parents would have their choice to participate in the interviews away from them. When the interviews had concluded, I again asked both parents if they consented for the data to be used. Both parents still consented to taking part in the research, commenting that the interview had been the first time they had talked about Anna since her death and they had found taking part to be hugely beneficial.

8.3.3 Hospice C- South-West

Interviewees fourteen and fifteen- Lillian and Richard

Lillian and Richard are Sally’s (aged seventeen) adoptive parents. Lillian is Sally’s main carer, whilst Richard works full time. Lillian and Richard have their own biological children, but they are older and have left the family home.

They receive home short breaks for three hours every week. In addition, they receive longer weekend stays from a second hospice every three months.

8.4 Semi-structured interview themes

Thematic analysis of the semi-structured interview transcripts found that parent's 'Perception' of short break impact on their partner relationship was mediated by 'External influences' and 'Internal influences', each reflected by a theme. The first, 'Every family is different' entails two sub-themes, 'Alternative short breaks' and 'Pressure and conflict between parental figures', as presented in Figure 8.1. 'Every family is different' conveys influences external to children's hospice short breaks and recognises differences in the support families receive from their family, friends or social care, and conflict arising between parents in relation to changing health needs, finances, leading separate lives and challenging behaviour. External differences between families are important as the potential strain on relationships between parents varies depending on support they receive conflicts that arise.

The second main theme 'Impact of short breaks on partner relationship' concerns parents 'Perception' of short breaks, shaped by 'External' and 'Internal influences' as presented in Figure 8.1. The focus of the theme is the perceived impact that short breaks had on relationships between parents, recognising that those parents with other children would rather utilise short breaks for the benefit of their other children over their relationship; represented by two sub-themes: 'Short breaks and relationships' and 'Children before relationship'.

The third theme: 'Short break quality' comprises two sub-themes: 'Building trust' and 'Getting a real break'. The focus of this theme concerns the importance of 'Internal influences' such as building trust between parents and hospice staff in encouraging parents to utilise short breaks and the differences between home and hospice short breaks.

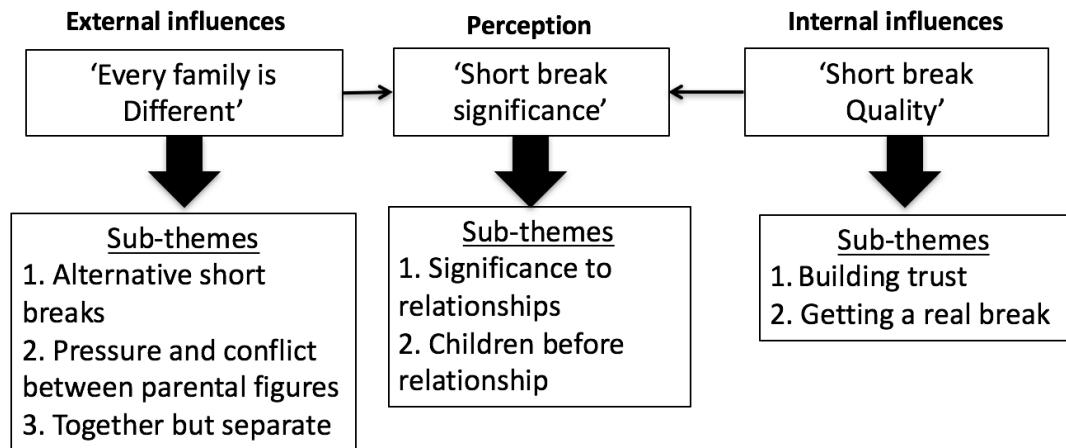


Figure 8.1: Themes and sub-themes developed from semi-structured interview data

8.5 External influences: every family is different

The data indicates that every family caring for a life-threatened or life-limited child is different in their family dynamic, the nature of the life-limiting or life-threatening condition of their child, accessing a children's hospice for short breaks, the model of short break provided, level of support from family or friends and the financial situation of the family. Therefore, external individual circumstances influence the perceived impact of short breaks on partner relationships. This is depicted by one father who said:

"I mean every family you will go to will have specific problems for their child and they will have specific things that they will have to had to argue and fight for".

[Steve, Midlands]

and by a mother who commented:

"It is hard because everybody has different needs and everybody has a different perspective on things and everybody will, you know, have a different dynamic in their family and, you know, so there is no black and white case..."

[Carol, South-West].

8.5.1 Alternative short breaks

Families differed in their use of alternative sources of short breaks to those provided by children's hospices. This was both due to availability of alternative sources of short breaks and whether or not parents chose to utilise it in addition to short breaks provided by hospices. A number of parents received short breaks from family members:

"My mum was really good; we went out because she would baby sit. She can't baby sit him anymore but we've always gone out, she's always made sure that we're able to go out on a Friday or Saturday night and she's baby-sitted the three children".

[Amy, South-West].

A frequent source of short breaks for parents comes from family members, usually grandparents. However, it was clear from the data that the age of grandparents was a crucial factor in whether it was possible to receive short breaks from them or not. Parents with older parents themselves were unable to rely on them for short breaks. This is depicted by Carol [South-West] who felt that her husband's elderly parents were: *"way too beyond looking after a special, you know, a special little person"*.

Carol suggested that *"...the only time that David and I get proper respite"* is when her parents looked after her daughter. Whether parents received short breaks from family or friends influenced perceptions of the impact of children's hospice short breaks. For a few parents like Mark in the South-West, it was friends rather than family who provided the most support: *"[We have] reasonable support from... reasonable understanding from our family but I think it's more our friends who provide support"*. Whilst some parents received either short breaks from family members or friends, others received no such support. Often this was for one of three reasons: the age of grandparents, geographical proximity of family or friends and family members or friends not feeling comfortable providing the complex care their child required.

Proximity of family and friends was also an issue for a few parents. Not having family living locally or who were spread out was also reflected on by Aesha:

“I’ve got family in Leicester and then London and places like that..... So I don’t have anyone in [local main city] as family for myself.” If parents had moved to a new area before the birth of their child, they were unable to rely on family or friends for a break from care because they lived too distantly:

“Our difficulties a lot... Because we moved down here with my husband's work about a year before we had our eldest daughter. So about... we moved down here about 14 years ago but our family... Well Eric’s family are down here now”.

[Mary, South-West]

The health of children or young people with life-limiting or life-threatening conditions can often change rapidly. Parents reported that this rapid change in health was one issue that could prevent family from providing short breaks such as with Steve from the Midlands and his son Bruce: *“None of our family that will look after Bruce and the reason behind that is that they have all seen how quickly Bruce can become unwell”*. Alongside rapidly changing health, the needs of children or young people may decline as their condition progresses. Debbie commented that a friend who had previously provided short breaks was now finding the increased responsibility too much:

“She’s [friend] done a certain amount of respite for us but she’s finding it too much. She’s finding the responsibility too much”.

[Debbie, South-West]

However, even if family members were unable to provide practical help in terms of short breaks, they would often provide emotional support:

“I mean they mean well family, but obviously they then don’t feel comfortable looking after Piruz, so we don’t get that respite through family. But they are there, you know for us to talk to and stuff...”.

[Aaesha, Midlands].

However, not all parents had family members for short breaks or emotional support. For some parents family members were an additional source of

pressure or conflict to their relationship. This was demonstrated by Fiona from the Midlands: “...*I just think that she let me down big style. And I think your mum did as well [talking about mother to husband]*”. A belief that family members had a lack of understanding about the strain parents were under was common, as exhibited by Carol:

“...but she [husband’s sister] doesn’t seem to have any understanding of sort of where we are and yet she’s... she’s you know, presumably our family”.

[Carol, South-West].

For some families, cultural differences were a factor in the support offered by family. In the case of Sarina, she believed cultural issues meant that family did not offer short breaks:

“Umm neither one of our families were supportive of us. In our culture it’s a little bit different. They just thought ‘ooh God, they’ve got a sick child’ and we just found everybody, people just backing off from us”.

[Sarina, Midlands]

For some parents, the negativity experienced or lack of practical help with short breaks from family members meant they had little contact with them at all: “*We have a very, very limited contact with my family now because they are... they are against us, rather than with us*” [Debbie, South-West]. For some parents, friends can also be a potential source of support, practically or emotionally. However, parents also reported losing contact with friends as demonstrated by Eva from the South West: “*They didn’t know what to say and they literally withdrew from our lives*”.

For many parents, family or friends are a potential source of short breaks from caring. However, some parents are unable to receive short breaks from family or friends and therefore short breaks from children’s hospices are more likely to have a substantial impact. Sarina demonstrated the importance of short breaks from children’s hospices when family are unable or unwilling to help:

“Umm we kind of met it but didn’t because his condition wasn’t... it was life- threatening if he had a seizure that’s... but then again it’s not diagnosed a life-threatening condition. So that was the problem we had, but because the consultant said ‘look this family has got nowhere to go. They’ve got no help from other family...’, none of our families were willing to take us on for a couple of hours or a day, just because they were scared of the risk in case something happens”.

[Sarina, Midlands].

In addition to receiving short breaks from family members or friends, some parents received short breaks from other sources such as social care or charities. The most common source of short breaks other than those provided by children’s hospices were from social care, in the form of direct payments:

“We have one weekend a month at [social services respite], which is run by [local care company] and then we have direct payments where we pay... we’ve got two families that have Andrew one weekend a month as well”.

[Eva, South-West]

In addition to short breaks provided by social care, some parents like Mary also received funding for short breaks from the NHS depending on their child’s health needs: *“He stays there twice a week, once paid for by the PCT because of his medical needs and once by social services”* [Mary, South-West]. Children’s hospices are independent organisations with their own catchment areas and as a consequence, some parents received short breaks from more than one children’s hospice dependent on geographic location:

“We... He also goes to [2nd children’s hospice]. So we can, we can go away for about a fortnight but saying that we usually do about four or five days”.

[Mary, South-West]

8.5.2 Pressure and conflict between parental figures

Depending on individual family circumstances, parents interviewed faced varying pressures related to having children or young people with a life-limiting

or life-threatening condition and these pressures created conflict between parents. The main sources of pressure were financial difficulties, individual needs of their life-limited or life-threatened children and challenging behaviour of their children, leading to conflict between parental figures.

Families' financial pressures are contributory factors to conflict between parents, in addition to reliance on and significance of hospice short breaks on partner relationships. Parents spoke of increased financial pressures due to at least one parent having to give up work, in addition to associated costs of care. Steve, for example, said:

"I was in a good job with good money, so life was good. And along comes Bruce and the first eight months of his life he was in hospital.... We were spending probably a hundred and fifty to two hundred pound a week commuting backwards and forwards to [the hospital] and car parking..."

[Steve, Midlands]

Conversely, parents in a stable financial position, like Amy in the South-West stated they felt less financial pressure: *"...well the financial of 'are we going to keep the roof over our head?', well we don't have that"*. This consequently meant there was less financial pressure on the partner relationship between the two parents. However, a number of parents recognised that children who are life-limited or life-threatened may go through extended periods of decline in health, resulting in one or both parents giving up work.

Parents were always aware that financial pressures might increase if the health of their child declined and required one or both parents to leave full-time work to provide care, demonstrating that financial pressure is interlinked with the health of a child or young person. As illustrated by Amy: *"You worry about how you're going to manage.... I think Michael worries about which one of us will give up work"*. The few parents interviewed who were in sound financial

situations were less reliant on short breaks from children's hospices. In the case of Mark and Debbie:

"... We're in a very, very fortunate situation relatively to a lot of other families because financially we can afford to... afford to have some help at home".

[Mark and Debbie, South-West]

The sub-theme of 'pressure and conflict between parental figures' encompassed individual needs of children or young people. Children's needs varied, putting more or less of a strain on parents, their relationship and increasing the perceived impact of hospice short breaks on relationships between them. Specific health needs, age or physicality and presence of challenging behaviour were factors that could increase pressure on parents, leading to conflict in their relationship. Most parents interviewed emphasised that no one child will have the same health needs. This was exemplified by Carol [South-West] who stated even children who have the same condition will have variable health needs: *"So although there is another little girl at school that apparently has got the same syndrome but they are so different"*.

It was clear from interviews that every child or young person with life-limiting or life-threatening conditions varied in ability and manifestation of symptomology. Some children's or young people's health remains stable over long periods of time, reducing care pressures on parents. Often the nature of children's conditions means that health can decline quickly or require twenty-four-hour care, as illustrated by Sarina from the Midlands: *"...his epilepsy's unpredictable so he can go to bed perfectly well and then the next few hours that's it... and we'll end up in hospital..."*.

Complex and unpredictable health needs can place additional pressures on partner relationships, increasing the significance of short breaks. Complex unpredictable health needs links to the theme of 'building trust', with parents finding it difficult to accept help from children hospices if trust has not been developed. This was the case for Mary who did not feel assured about letting her son Kit stay at their local children's hospice: *"... because of all his medical*

needs. He needs people who really know him". The negative impact that inconstant health can have on partner relationships between parental figures, through increasing pressure and instigating conflict, was also reflected on by Mary: *"When Kit is well it doesn't have a major impact on us. When Kit is unwell, then tempers get frayed everything and it does have more of an impact"*. The impact of pressure and conflict arising from unpredictable children's health on partner relationships was also demonstrated by Eva when she recounted going on a family holiday when her son Andrew was ill:

"He [husband, John] was cross with me because I wasn't concentrating on the family holiday and I was just worried about Andrew all the time and checking flight times and so we didn't have a great holiday because it was full of friction and you know...".

[Eva, South-West]

The age of children or young people was linked to physicality, with older children being physically heavier and more difficult to manage. Physicality of children or young people often determines the main caregiver, as demonstrated by Amy and her husband Michael: *"In the early years it was me who did all the care for all three of them because I could manage it. Because of the size of him now, I'm quite hands off really"*. The age and size of children increases pressure and physical strain on parents, with most parents reporting health problems resulting from manual handling, as outlined by Sarina: *"Umm my husband has actually now because of all the care, he has actually damaged all his whole back, just because of the lifting and stuff"*. Increased physical needs of older children complicate care routines, reducing opportunities for parents to have a break and increasing pressure on parents:

"So when he was younger and easier to lift the handle, one of us could each night could go to bed each night early... to get an early night, because he's up a lot in the night and one could stay with him. But now we both have to stay up with up with him so we never get into bed early. So we're... we're both tired all the time...".

[Eva, South-West]

In addition to erratic health needs and the physicality of the child, parents also highlighted additional complications of having a child or young adult with

challenging behaviour. Challenging behaviour often manifested as violence towards the parents. Sarina described both the consequences of challenging behaviour and the importance of short breaks in relieving stress:

“Respite is also for... cos we used to go through a phase where he was having a bit of challenging behaviour.... But it used to be stressful, pull our hair and kick us and you know, he’d get up in the night and he’d like be confused and he’d be banging his head on the wall and stuff like that”.

[Sarina, Midlands]

In addition to physical injuries and mental strain, challenging or violent behaviour from children or young people can cause direct conflict in the partner relationship reflecting parents differing approaches to the problem:

“Whereas my husband will raise his voice, you know and then it just produces tension between me and my husband because I get cross with my husband and.... So we end up then having a full blown argument...”.

[Eva, South-West]

8.5.3 Together but separate

‘Together but separate’ recognises that parents may be together, as parents, working to care for their child, but are separate romantically. Amy from the South-West, felt that her relationship with her husband was *“not even vaguely in the equation”*, exemplifying this sub-theme. Amy expanded on this by saying separation was not possible because: *“we all need each other and we’re a team that can’t separate”*. Amy epitomises how parents may be together practically, but separate emotionally and romantically. In essence, parents may be leading separate lives despite being a couple in the same household.

It became apparent from the data that there were two main causes for leading separate lives: long care routines and working long hours to compensate financially for one parent not working. When talking about the extended evening care routine for her daughter, Debbie [South-West] reflected: *“That’s a real, potentially a really defining moment in a relationship because we are now leading separate lives in the evenings”*. Likewise, Aaesha highlighted that

either she or her husband spent most of their time with their son *“caring for him, feeding him, giving him meds, making sure he’s comfortable”* and, as a consequence, she felt: *“she had no time for anything else”*.

Being separated romantically due to the nature of the care routine for and needs of their daughter was mirrored by Sam in the Midlands who stated, *“we’re kind of separate I would say for a lot of the evening”*. Sam went on to say *“trying to spend a bit more time together which everybody kind of knows is the answer to building a relationship, but it’s easier said than done”*. Debbie and Mark [South-West] further reflected on the impact of their daughter’s care routine on leading separate lives:

Debbie: *“Well I do the majority of the day care, but you seem to burden with most of the night care.”*

Mark: *“Yeah I mean we probably... we alternate on kind of doing the midnight shift in the evening but I tend to be awake in the morning so I do the six o’clock shift most mornings. Umm and...”*

Debbie: *“But again that’s... that’s a real... that’s a real, potentially a really defining moment in a relationship because we are now leading separate lives in the evenings”*.

In addition to extensive care routines, parents also discussed the impact of working long hours on leading separate lives. For some families, one parent working additional hours is required to support the family financially. Mary said that her husband *“works very long hours”* and that *“it’s more because of his job to be honest that we don’t tend to see each other”* [Mary, South-West] rather than the care of their son. Carol’s husband David works *“every hour God sends bless him... and therefore our time is really restricted...”* [Carol, South-West]. Sam summarised the impact that long working hours can have on leading separate lives, the relationship between parents and cause of conflict:

“I still worked kind of doubly hard to pay for everything while Gill was looking after Bell and all the needs that she had. Then Jasmine came along. I was still at work and then the care was pretty much split between day and night. It was quite difficult because I think we both felt we were getting the sharp end of the stick”.

[Sam, Midlands]

The practical impact of ‘Together but separate’ was reflected in two key areas for parents: spending time together and communication. Due to the impact of care or working long hours, most parents highlighted that they often found it difficult to spend time together, further supporting the practicality of being together as a caring team, but separate as a couple. Mark and Debbie spoke about how *“two or three years ago we would maybe go away for a weekend together on our own”* and now this was less possible and *“the challenge for us is that those bonds may start to loosen so much that something breaks over time”* [Debbie and Mark, South-West]. When asked if they still managed to get time out to themselves Mark stated that they rarely did. Similarly, Eva spoke about the implications of caring for their son Andrew and how this meant *“We do everything very separately”* [Eva, South-West]. Eva spoke of how one parent would stay with Andrew, whilst the other would take the siblings out and as a result she felt *“we’re very much a split family”* [Eva, South-West].

The theme of ‘Together but separate’ also includes reference to communication between parental figures. As a result of the routines required to care for their children and long working hours, parents often find little time to talk with each other. This is demonstrated by Eva who felt that: *“Mornings are just a rush, it’s not a matter of wake up and having a quick chat about day”* [Eva, South-West] and Mark felt *“We’re not having as much time as we were”* [Mark, South-West] to communicate. It was clear from the data that parents communicated about practical issues out of necessity because as Fiona stated *“you’ve got a child like Isla you had to have these talks”* [Fiona, Midlands]. Emphasis on communication around practical issues is supported by Amy who said: *“So we have made practical changes but emotional we’re not good at”* [Amy, South-West]. The impact that not being able to communicate as a couple can have was best illustrated by Lillian who said:

"I think we've never really talked about our two relationships before and it is really hurtful (sobs). For me I need to be cuddled when she's very ill... and I think Richard finds comfort from going away from it... so he just leaves me to cope and I... I sort of don't feel I can say 'please can you cuddle me; I need it'. I do sometimes. I know it's a bit silly really".

[Lillian, South-West]

8.6 Perception: short break significance

Parental 'Perception' of the significance of children's hospice short breaks is shaped by both external influences outlined in section 8.5 and internal influences outlined in section 8.7. The related theme, 'Short break significance' is primarily concerned with the significance of short breaks across two domains: partner relationships and siblings. These two domains are represented by two sub-themes: 'Significance to parental relationships' and 'Children before relationship'.

8.6.1 Significance to partner relationship

The perceived impact of short breaks on partner relationships varied between parents because 'Every family is different'. Some parents were explicit that short breaks had kept them together as a couple. This is depicted by Steve in the Midlands, who stated: "...if it weren't for them [children's hospice] you'd be speaking to me in a bedsit somewhere and Sarah would be here with the kids". Short breaks were also perceived as positively impacting on partner relationships by allowing parents to spend time together as a couple. This was the case for Aesha and her husband: "Yeah when we have the respite. What we try to do, we try and get away or do things together like go out for a meal or something". Such responses highlight the impact that short breaks can potentially have on a relationship by allowing parents to spend time together as a couple. This appears to be particularly important when pressures of care have caused conflict in a relationship:

“It’s like I said to you that’s what respite meant though, actually having a normal time. And it gave us time to sort of build... rebuild the fences and repair the bridges and plaster over the cracks in our marriage you know.... you... you’ve got some time to actually spend time with one another, you know”.

[Steve, Midlands]

However not all parents were able to use short breaks to benefit their relationship by spending more time together, with some using the time to pursue individual activities. As Eva commented: *“What we find we do and it’s become normal for us.... I go out once a week with friends and my husband goes out once a week with friends”*. Most parents interviewed stated that they often had little time to do household tasks and consequently parents often used the time provided by short breaks to catch up on household tasks. For those parents who had other children, short breaks are opportunities to spend time with them rather than their partner. When discussing whether short breaks provided time to spend with her husband, Amy stated: *“That’s not why I have it. I do have it to help Erica with her homework”*.

Most parents talked about physical exhaustion due to caring for a child or young person with a life-limiting or life-threatening condition. Accordingly, some parents suggested short breaks were used for physical needs, including catching up on sleep. This was the case for Sarina: *“Umm so like respite definitely... the main thing I think about respite is sleep”*. Short breaks in this way can have an indirect benefit on relationships by reducing pressure of care and reducing conflict between parents. Using short breaks to recuperate was apparent for most parents, including Steve: *“You can drop him off, come home, shut the front door and it’s all one for a couple of days and that is the thing... it’s just... it’s having that break”*. Consequently, aside from directly providing an opportunity to spend time together, short breaks can have an indirect impact on relationships by reducing pressure:

“I would say that most impact that it’s had, it’s just taken a little bit of the strain off, as opposed to us being able to kind of spend a bit more time together...”

[Sam, Midlands]

A few parents were clear that they did not believe short breaks had significance on their partner relationship. This is depicted by Carol who commented: *“We are fortunate that we have changed and stayed together... but I don’t think that’s as a result of having respite”*. For Carol, staying together had resulted from her personally changing and becoming stronger. The nature or quality of a short break appears to influence the perceived significance it has on partner relationships. The length of a short break however, may not be long enough to have an impact on relationships. When discussing the impact of short breaks on the relationship with her husband Amy stated: *“Does that help our relationship? Well no... it’s not enough time to give you, you know, any significant changes to your lifestyle”*. Aside from the length of short breaks, the type of short break influenced the perceived impact. Home short breaks are often seen to be intrusive and this may have an undesired impact on partner relationships. This is depicted by Eva [South-West] who stated:

“...you can’t have a bicker or an argument. You can’t, you know, well you can’t do anything. You, you can’t be a bit affectionate”.

8.6.2 Children before relationship

The impact that caring has on other children within a family, and provision of ‘normality’, is viewed by parents as more important than their partner relationship. The impact of isolation, arising from caring for children or young people with life-limiting or life-threatening conditions on both parents and siblings, was described by Mary who stated: *“Life was horrendous. There’s no doubt about it. At the beginning of the six-week holiday, we just used to be just stuck in for days or weeks”*. It was apparent that some parents felt they were ignoring the needs of their other children, as exemplified by Fiona: *“That’s been the hardest thing, hasn’t it? We’ve dropped everything. The girls have been passed from pillar to post”*.

The belief that siblings had suffered as a result of parents focusing on caring for the life-limited or life-threatened child is demonstrated by Eva, who felt: *“The children are the ones who suffer the most, because from a very early age they*

come down and get their own breakfast". A handful of parents detailed the consequences on parental bonds with their children due to not being able to dedicate time them. This was the case for Amy's husband Michael and their son: "You know (sighs) (pause) Michael's relationship with his eldest son is dreadful because he spends so much time with Frank".

In response to the concerns parents had about the impact of caring for their life-limited or life-threatened child on siblings, it was clear that parents felt their children should be the main beneficiary of short breaks. This was especially true for home short breaks, which are generally shorter in length than hospice short breaks. Indeed, when discussing home short breaks Mary stated: *"But they're sort of in for mainlymy girls for after-school clubs"*. Subsequently home short are often a busy time for parents who utilise the time for their other children, rather than being relaxing or a chance to spend time as a couple:

"It's not respite for us because I'm dashing around doing... If anything, that's a busy two hours. But without that, you know they would suffer".

[Eva, South-West]

The decision by parents to utilise short breaks to benefit their other children consequently has an impact on the benefit that short breaks could have on their partner relationship, as highlighted by Sam: *"... I think the relationship between me and Gill has kind of taken you know, very much a back seat to trying to keep the kids you know, on some sort of course"*. Amy's statement exemplifies how the partner relationship between parents was less of a priority in comparison to their children's needs: *"...the common goal we both have and the biggest objective for us both is that our three kids live as good a life as possible"*. Parents often spoke about putting their relationship on hold until their children were older. This is depicted by Sam who commented: *"I think our time will come as a couple, hopefully once the... once you know, Bell's kind of sorted"*.

The importance of this concern and its relevance to partner relationships was best explained by Steve who felt that people failed to recognise: *"It's not just the parents.... it's the siblings... [and the] impact on siblings then has a knock*

on impact on parental relationships". Conversely, the few parents interviewed who already had older children felt less need to use short breaks for their children and were able to reinvest in their relationship, as with Aaesha [Midlands]:

Interviewer: *"When your elder son was younger, did you use the respite more for spending time with him as a family?"*

Aaesha: *"Yes, yes. Yeah we did things like go bowling, go to the cinema and things like that with him."*

Interviewer: *"And now obviously he's gone off to university you can spend a bit more time as a couple?"*

Aaesha: *"Yeah as a couple, exactly and just have a chill out time really"*.

8.7 Internal influences: short break quality

As highlighted in Section 8.5, every family is different and therefore the perceived impact of short breaks differs depending on 'External influences' and individual circumstances. However, the perceived relationship impact of children's hospice short breaks is also predisposed by 'Internal influences', represented by the main theme 'Short break quality'. This theme was characterised by the two sub-themes of 'Building trust' and 'Getting a real break', representing frequency and type of short breaks respectively.

8.7.1 Building trust

Short breaks were undoubtedly important to parents, but their importance is mediated by internal influences such as level of trust built with staff within children's hospices. This was the case for Carol: *"The respite... the respite without a doubt gives you a chance to be individual again, but it is building that trust"*. In order for short breaks to have an impact on their relationship, short break quality is determined by a level of trust which needs to be built:

“It’s building that trust between ourselves and them and once you get that trust. I mean you know, there’s nothing better than having that respite care because without it you’re tired all the time”.

[Aaesha, Midlands]

The foundation for the need to build trust was a difficulty in handing over care to staff at children’s hospices. Relinquishing care of children or young people to hospice short break staff was repeatedly reported as being difficult for parents, as epitomised by Steve: *“Quite literally I’d be sobbing because I didn’t want to leave him there”*. The guilt that Steve felt concerning handing over care of his son Bruce, was often apparent in interviewed parents when talking about accessing short breaks:

“...we started respite at two and a half and so you’re almost like sending your baby away, you know, so... it is really really difficult”.

[Eva, South-West]

For some parents, like Debbie, the reluctance to hand over care to staff at their hospice arose from not having built the relationship with hospice staff and understanding the services offered, believing they only offered end-of-life care: *“I just like couldn’t understand the whole thing about it and why it was going to be a good solution”*. For other parents the difficulty in accepting short breaks from children’s hospices is a conviction that only they know their child best:

“But of all the respite services he has and he uses different... various different ones, none of them do it as well as I would do it”.

[Eva, South-West]

An important aspect of building trust for parents was the hospice short break staff knowing their child and his or her needs. Parents were less inclined to use a short break service from a hospice if they felt that staff did not know their child and needs well enough. This was true for Mary: *“We don’t stay at the hospice. I think mainly because... because of all his medical needs. He needs people who really know him”*. The importance that parents place on this is

demonstrated by some choosing to use a short break service that is intrusive and unbeneficial simply because children's needs are well known:

"That's why the sits at home like even though I say they're not great for us, they work well 'cos the carers really get to know him".

[Eva, South-West]

This highlights the importance of staff at hospices providing short breaks knowing children and building trust to put the parents at ease. Knowing children and their needs were linked to 'Building trust' through the frequency of short breaks, how often they were provided by children's hospices. If the short breaks were provided too infrequently then parents did not feel confident that hospice staff would know and meet children's needs, not affording opportunities to build trust:

"I think the problem with [our local hospice] is that because you would only access that probably once or twice a year and it's not enough to know him well".

[Mary, South-West]

Infrequent short breaks are a particular barrier for building trust for parents utilising short breaks when they perceive their child as having complex needs, as exemplified by Carol: *"They're so far apart that even if I were to take every respite day they offered me, it would still sort of be six weeks apart And for a child like Bella that is a long time."* Infrequency also impacts upon the perceived quality of relationship and trust-building between parents and hospice short break staff. This was the case for Amy, who felt she had a poor relationship with hospice staff: *"I do think some people have special relationships with their carer. That's never happened to us because... well we've not had it long enough"*. By contrast, if short breaks were offered more frequently then parents had opportunities to build trust with staff at children's hospices and therefore short breaks would potentially have a greater impact on partner relationships:

“Whereas [social care] respite because he is there every week... They know him and also because it’s usually the same ladies who look after him in [social care] respite who come out to do the sits at home. So they’re often looking after him twice... twice a week, three times a week sometimes. So they know him really well”.

[Mary, South-West]

Other internal influences that were important in building trust with hospice staff were consistency, capability and children’s enjoyment of their short break provided. Consistency was important in building trust for parents and ultimately in creating comfort in utilising short breaks: *“They do try, very hard to keep a similar pattern. The thing is it’s essential because, you know, Bella is different to every other child that they look after...”* [Carol]. As a result, introducing new staff can be difficult for parents and lessen the quality of short breaks, reducing the impact on partner relationships. This circumstance was familiar to Aesha: *“Sort of having to adjust to new people and sometimes that’s quite difficult. So having a few regulars is quite helpful”.* In addition to consistency, the capability of staff looking after children is also important for parents to feel relaxed during short breaks:

“Yeah and because of his communication we were a bit worried.... but to be honest I think we never had that problem with him with the [hospice] because they’re all trained nurses”.

[Sarina, Midlands]

However, capability for parents not only refers to being suitably trained, but also having a caring attitude:

Mark: *"You're not having to do, it's not having to do... it's not injecting with a needle or anything, so you're not having to do any of those kind of things. So it's you know, fitting the tube in the PEG is fairly straight forward..."*

Debbie: *"But it's having the confidence to do it and yep, just yeah..."*

Interviewer: *"And actually finding somebody with that caring attitude is probably more difficult than the medical training..."*

Debbie: *"Yeah, oh yeah".*

Mark: *"Yes".*

[Debbie and Mark, South-West]

Children or young person's enjoying their hospice short break is also very important to parents. A few felt they could only benefit from short breaks if they knew that their child enjoyed going to the hospice:

"It's a complete highlight for her when she goes and it gives her the chance to do something special in an environment where she, you know, she'll talk about it for the week before she's going about how she's going to [the hospice]".

[Mark, South-West]

8.7.2 Getting a real break

The sub-theme, 'Getting a real break' concerned parents' perceptions of whether short breaks provided by children's hospices gave an actual break. This sub-theme developed from two key assumptions held by most parents. First, parents were aware of disparity between how they actually used short breaks (siblings or catching up on house hold tasks) and how they could be used (recuperation or spending more time together as a couple). Secondly, 'Getting a real break' was also defined by the location and length of short breaks. For most parents, short breaks at home were mainly used as a break from their daily care routines. As Carol illustrated:

"I mean ultimately if she's having respite for an evening sit, that... that... that's a really nice change of scene for me because I don't have to bath her and put her to bed".

[Carol, South-West]

This benefitted parents by saving them time from carrying out the usual care: *"So they're quite good at doing those jobs to save me time"* [Mary, South-West]. Ultimately, home short breaks provided by children's hospices can have a positive impact by giving parents a real break from caring routines. This is the case for Sarina: *"Umm that's why home help will make a difference because it will give us less duties to do on a weekly basis"*. However, not all parents considered home short breaks as a real break:

"...respite in the home I class as personal care rather than respite.... they come in and bath him and that saves me bathing him for the night which is fine. But it's not a respite at all...".

[Eva, South-West]

In addition, some parents commented that home short breaks were not a real break for three main reasons. First, most parents stated that they used home short breaks as an opportunity to catch up on household tasks that they were unable to do normally, rather than utilise it to relax or spend time with their partner. This was demonstrated by Aeesha: *"Community care I use more for things like... so I can go and do shopping and stuff"*. Second, linked to the sub-theme 'Children before relationship', most parents stated short breaks at home were used for their other children rather than having a break or to focus on their relationship:

"...therefore it's just people who know him coming to the house and to cover mainly from me for me to take my other children out and that's why [1st hospice] come into the house".

[Mary, South-West]

However, the third and most common reason given by parents for home short breaks not being a real break or finding it difficult to relax was having carers in the home. This is described by Eva: *"I mean, I'm sure my husband will tell you, even to this day, he likes the carers and he gets on with them, but he can't stand*

them in the home". Many parents such as Steve felt home short breaks are an invasion of privacy: *"I've always found it an invasion. I don't like it (laughs).... that's my personal feeling"*. Steve went on to say that because home short breaks feel like an invasion of privacy, he did not always see them as beneficial: *"There have been times when we both looked at it and thought it's more hassle than beneficial"*. Linked to the notion of invasion of privacy, Amy discussed home short breaks creating more work:

"So I do like the sits outside the home. I find it more intrusive when they come in because I feel I have to offer them coffee and I know that sounds really anal, it's only really three hours but I do feel like I have to and then I have more washing up to do...."

[Amy, South-West]

For a few parents the intrusion of home short breaks has a negative impact on their partner relationship with parents feeling unable to show affection in front of carers. Eva described how she felt most couples would act: *"you know the husband comes in from work, he comes to give his wife a hug and a cuddle and a kiss or whatever"*. However, Eva went on to say that she did not feel able to do this if she was receiving short breaks in the home: *"...but I'll often be the kitchen talking to a carer when my husband comes in. So my husband comes in says 'oh hi' and walks [out]"*. Not being able to express emotions as a couple when carers were in the house for home short breaks was also emphasised by Aaesha:

"It is very difficult. And I mean, you know when we get people come to the house. There are times when we end up getting tearful because those emotions are still there at the back but you know, we're not able to bring them to the forefront at times".

[Aaesha, Midlands]

Some parents stated that eventually they got used to having people in their house during home short breaks. Steve stated: *"I think it comes to a point where you have to realise that... you have to accept it"*. Linked to the theme of 'Short break quality', building trust with regular carers was an important factor in overcoming the intrusion that parents felt during home short breaks: *"I think*

because I've known the carers for years then it helps" [Mary, South-West].

In contrast to the difficulties parents experience with home short breaks, short breaks at the hospice were often considered to be a real break by parents. This was the case for Eva: *"So that's why respite away from home is so crucial and that's when we have our downtime, that's our relaxation time"*. Short breaks at a hospice tended to be associated with a chance to fully recuperate both physically and mentally, allowing parents to continue caring:

"Umm and so I've started really when we do book the respite, book it so we've got a slightly longer stay and then we can get that proper respite. We can recover and then we've got the energy to take better care of him afterwards".

[Aaesha, Midlands]

The length of a short break, was one of the main internal influences that guided the perceived impact on partner relationships between home and hospice short breaks. Eva commented that her family were often split due to the care of her son Andrew and the only spent time together when they didn't have him, but *"...having care in the home doesn't really help that, because it's such a short period of time"*. The desired length of stay at the hospice varied between parents depending on their circumstances. Sam talked about wanting short breaks more frequently, but for shorter lengths of time:

"Umm and as I say we only stop for the two nights. It would be nicer to have that more frequently, the stay over. I wouldn't do it for too long, I wouldn't do it for even longer".

[Sam, Midlands]

The length of short breaks as a crucial internal factor is demonstrated in some parents perceiving shorter stays at a hospice as less beneficial if they have to travel, as they are not getting a real break. In the case of Steve: *"It must... because if you're going for day care and you need to spend an hour driving up there and an hour driving back out here... It's just not worth it"*. As a consequence, Steve arranged longer stays at the hospice to ensure they are beneficial: *"Yeah we just have... because we're so far away from it we have...."*

We normally have a week". Opportunities to get a real break from hospice short breaks was limited by length and time travelling across the West Midlands, which Fiona and Liam reflected on:

Liam: *"It's quite a good way to get there. It takes two hours"*.

Fiona: *"Especially when you're bringing something over this way, you know..."*

Liam: *"...and it starts at ten in the morning so, you know, sometimes it's your only...your only day for a lie-in and you've got to get up really early, get them up and it's a never-ending journey. We have to wait around two hours, don't we...?"*

Fiona: *"... 'cause there's no point coming back to travel then an hour. So yeah, we keep saying, 'When are you going to come closer?' but again it's funding"*.

8.8 Implications for survey development

Findings from the semi-structured interviews have resulted in further questions to be explored, evolving in the second phase of the research being developed: a national online survey. It was clear that some parents received short breaks from sources other than a children's hospice, such as family, friends, social care or charities, which were beneficial to some families. This raised a number of questions relating to the research aim and objectives: (1) How many parents receive short breaks from another source? (2) How many hours of short breaks do they receive? (3) What impact do these other sources of short breaks have on the partner relationship between parents?

The theme 'Pressure and conflict between parental figures' concerned families facing different pressures in relation to finances, leading separate lives and challenging behaviour from their child or young person. Both these external influences appear to have an impact on partner relationships and the potential benefits of short breaks for parents. This therefore also raises a number of questions for the national online survey such as: (1) How many parents experience challenging behaviour/ financial disagreements/ leading separate lives? (2) What impact does experiencing challenging behaviour / financial

disagreements/ leading separate lives have on the partner relationship between parents? The implication for the national online survey development is that a measure of relationship satisfaction will need to be included. Responses of all of the above questions, in addition to questions about the model and number of hours of short breaks received from children's hospices will be measured against the chosen measure of relationship satisfaction.

8.9 Chapter conclusion

Semi-structured interviews were conducted with parents currently accessing one of three children's hospices in the UK. Semi-structured interview transcripts were analysed using thematic analysis. Findings demonstrated parental that parental 'Perception' of short break impact was mediated by 'External' and 'Internal influences', which were interlinked with three main themes: 'Short breaks and parental relationships', 'Every family is different' and 'Short break quality'. The theme: 'Short breaks and parental relationships' covered the perceived impact of short breaks on the relationship between parents and intertwined with the other two themes. The theme 'Every family is different', associated with 'External influences', demonstrated that each family had differing levels of support from other sources and unique pressures to face, resulting in conflict. Parents receiving less support from other sources and facing increased conflict were more reliant on short breaks provided by children's hospices. The third theme established quality of short breaks as an important 'Internal influence' in the perceived impact of short breaks on relationships. Building trust is crucial for parents to feel relaxed enough to utilise short breaks provided by children's hospices. Inflexibility and paperwork were often perceived as barriers to accessing short breaks. With these findings in mind, the development of a national online survey necessitated delving further into: sources of support, financial difficulties, leading separate lives and managing challenging behaviours of their children.

9 Chapter Nine: Developing a National Online Survey

9.1 Chapter introduction

The preceding two chapters outlined the methods for and results of the first phase of this sequential mixed methods study, semi-structured interviews with parents currently accessing a children's hospice within the UK. This chapter will outline the methods for the second phase of the research, a national online survey. The chapter commences with an overview of surveys as a method within research, with a focus on both strengths and weaknesses. The advent of the internet led to an opportunity to distribute surveys online. Online surveys share similarities to traditional paper surveys, but also have their own distinct strengths and weaknesses; these will be outlined in the next section. The remainder of the chapter describes the development, distribution and analysis of the online survey. The section concerning development outlines the pre-pilot planning, piloting the draft survey and the finalised survey. The section of the chapter concerning distribution summarises access procedure and how informed consent was gained. The final section of the chapter describes the analytic process and statistical tests used to analyse the online survey data.

9.2 Method overview: surveys

Surveys are widely used within healthcare research (Rattray and Jones 2007). The word 'survey' is often used interchangeably with the word 'questionnaire' and can be best described as a method of collecting data or information (Sue and Ritter 2012). The purpose of a survey can be to understand attitudes, knowledge and practice, across time points or at one point in time (Rattray and Jones 2007; Duffett et al. 2012). Surveys are widely used within research as they have a number of advantages. Surveys often cost less and are less time-consuming than some other methods of data collection (Gillham 2008; Breakwell et al. 2012; Cummings et al. 2013; Cope 2014). For example, carrying out face-to-face interviews with respondents involve significant travelling costs for researchers and time costs for both researchers and the respondents (Gillham 2008; Cummings et al. 2013).

Surveys also allow researchers to collect data from respondents relatively quickly in comparison to interview methods (Umbach 2004; Rattray and Jones 2007; Couper and Miller 2008; Gillham 2008; Cummings et al. 2013; Cope 2014). Self-completion surveys involve less pressure for respondents to reply and as such can be completed at their own pace, with time to think questions over (Gillham 2008; Cummings et al. 2013). However, this increases the risk of rehearsed answers rather than immediate answers and non-responses (Gillham 2008). Surveys also provide respondents with a greater confidence that they will receive anonymity in comparison to phone or face-to-face interviews (Gillham 2008). Consequently, surveys are often considered a good method for sensitive research (Gillham 2008; Cummings et al. 2013).

Surveys can overcome issues of interviewer bias, whereby questions may be read aloud to respondents because all questions are standardised (Cummings et al. 2013). However, this is not to say that respondents will interpret questions in the same way. Dependent on survey layout, respondents may see all the questions on one page and answer questions out of order reducing standardisation (Gillham 2008). Surveys are widely used because of their advantages. However, unless the topic is of interest to potential respondents, response rates to surveys are typically quite low (Gillham 2008; Sinclair et al. 2012). Sinclair et al. (2012) found internet surveys had the lowest response rate (5%) in comparison to postal surveys (11%) and telephone surveys (30%). Motivating respondents is also difficult due to surveys oversaturation. However, these will have less of an impact in the present study because respondents who feel they have a vested interest in a survey, are likely to complete it (Gillham 2008).

Surveys that include closed questions assume those constructing the survey have all the potential answers respondents would want to give (Rattray and Jones 2007; Gillham 2008). Likewise, they also assume respondents have an answer to questions being asked. This is unlikely to be an issue for factual questions, unless they involve recall, however, it can be an issue when asking for opinions (Gillham 2008; Sue and Ritter 2012). The respondent may have not considered their opinion on the question at hand, may think the answers do not

include their opinion or may not have an opinion on the matter at all. According to Gillham (2008) this could lead to participants ending the survey if they get frustrated with lack of choice. It has also been argued it is impossible to check the honesty of answers with surveys (Gillham 2008; Sue and Ritter 2012). It could be argued that this is not specific to surveys, there is no guarantee a participant will give honest answers in face-to-face interview, although there may be more obvious facial or bodily cues.

9.3 Online surveys

The advent of the internet has led to the option of online surveys, via either email or websites for researchers (Cope 2014; Cummings et al. 2013). Online surveys are increasingly used in place of traditional postal or telephone surveys for a number of reasons (Cummings et al. 2013). Online surveys are notable for reducing the costs associated with printing and posting traditional surveys (Cope 2014; Cummings et al. 2013; Van Gelder and Pijpe 2013). Links to the survey can be emailed to participants, giving them instant access to the questionnaire. Additionally, human error can be reduced in two ways with online surveys. Firstly, with traditional surveys, even if clear instructions and guidance have been offered respondents will answer questions they do not need to and this will result in errors. By contrast online surveys have automatic question skip logic avoiding respondents answering non-relevant questions, reducing errors (Cummings et al. 2013; Van Gelder and Pijpe 2013).

A second advantage that online surveys has over traditional surveys is automatic data entry (Cummings et al. 2013; Cope 2014). Data has to be entered manually with paper surveys, which is both time-consuming (Cope 2014; Cummings et al. 2013; Van Gelder and Pijpe 2013) and prone to human error (Cummings et al 2013; Van Gelder and Pijpe 2013). Data are returned more quickly than with traditional paper surveys (Van Gelder and Pijpe 2013). In relation to the present study this is beneficial for a PhD project with limited time and resources to carry out data analysis. However, it was worth noting that a badly designed and implemented survey will still return poor data regardless of automatic data entry (Van Gelder and Pijpe 2013).

Past research has suggested that online surveys have lower response rates than traditional paper surveys (Manfreda et al. 2008; Sinclair et al. 2012). Research by Sinclair suggested that online survey response rates can be as low as 5% compared to 11% for postal surveys. However, research by Van Gelder and Pijpe (2013) suggested that this figure is inaccurate. Van Gelder and Pijpe combined several studies which compared responses rates between postal and online surveys, finding a response rate of 50% for postal surveys and 56% for online surveys. It is often stated that a drawback of online surveys is that they can only be sent to those participants who have internet access (Cummings et al. 2013). Whilst this may have been a disadvantage when access to the internet was limited, internet access has increased in recent years; in 2016, for example, 89% of households in Great Britain had internet access (Office for National Statistics 2016e).

There are multiple commercial software programmes and web-based services for conducting online surveys (Sue and Ritter 2012). Sue and Ritter highlight several considerations when choosing a service: expense, ease of use, question formatting, presence of skip logic, distribution options, analysis options. Two online survey tools considered were SurveyMonkey[©] and the Bristol Online Survey[©] (BOS). SurveyMonkey[©] was used as it fulfilled all of the criteria outlined by Sue and Ritter (2012) and experience had already been gained in using SurveyMonkey[©].

9.4 Online survey population

The online survey population was identical to that identified for the semi-structured interviews outlined in Chapter Seven. The online survey was aimed at parents or parental figures of children and young people with life-limiting conditions or life-threatening illnesses, who currently access a children's hospice in the UK, for short breaks. Respondents accessed short breaks from a children's hospice delivering one of the three models of short breaks presented in Chapter Three; either at home, at a hospice, or both.

Inclusion criteria for survey participation: respondents did not need to be the biological parent of children receiving short break care, rather respondents were

required to assume a parenting role with a life-limited or life-threatened child as strong parental bonds can form between adopted children and non-biological parents (Goldberg et al. 2013). Exclusion criteria for survey participation included foster parents, because: a) being a foster parent can be a paid occupation (Francis 2012; Foster Care Associates n.d.) and the length of time a child is fostered for can vary from emergency, overnight care to long-term (Francis 2012).

9.5 Online survey design

Surveys are often perceived as being easy to construct, hence their popularity as a method, but in reality, survey development is challenging (Gillham 2008; Breakwell et al. 2012). Consequently, this perception can lead to poor survey development and planning, resulting in underdeveloped questions and a survey that does not measure what it intends (Gillham 2008; Breakwell et al. 2012).

The principles of online survey development are the same as those for traditional survey development (Cummings et al. 2013). Rattray and Jones (2007) suggest the development process should be outlined in sufficient detail by researchers. With this in mind, notes and drafts were kept throughout the development of the survey. The next sections of this thesis outline the development of the online survey, providing justification for questions asked and the final survey structure, starting with the pre-pilot stage.

9.5.1 Pre-Pilot Stage

This stage of survey design involves initial planning, including drafting of questions, anticipating potential answers and planning structure (Gillham 2008). The risk of respondent misinterpretation can be reduced by developing questions through pre-piloting and piloting (Sue and Ritter 2012). Unlike interviews, misunderstandings cannot be corrected in surveys (Gillham 2008). Initial planning occurred during supervision, starting with the research aim and objectives; survey questions and answers must represent these and include key concepts for target respondents (Rattray and Jones 2007; Sue and Ritter 2012). The core dependent variable of the survey was a 'relationship satisfaction' measure against several independent variables including 'length of short break', 'frequency of short break', 'model of short break' and 'societal factors'.

At this stage, the necessity of including the health conditions of children or young people in the survey was considered; they were not included for two reasons. Firstly, a survey should only include questions that needed to answer the research (Rattray and Jones 2007; Sue and Ritter 2012); Questions regarding the child or young person's condition was not relevant. Secondly, a number of the conditions are genetic or extremely rare and could potentially identify respondents.

Types of demographic data to be collected were also considered with two important definitions being clarified. First, a 'parental relationship' did not have to relate to a biological parental figure, it could be a respondent who had taken on parental responsibility for a child or young person who was currently accessing a children's hospice (Education Act 1996; Children Act 1989). Second, data on the geographic area of the respondent was also considered to be important to capture, but without potentially identifying respondents. As postcodes could potentially identify respondents, counties were used. Notes from this planning stage are presented in Figure 9.1.

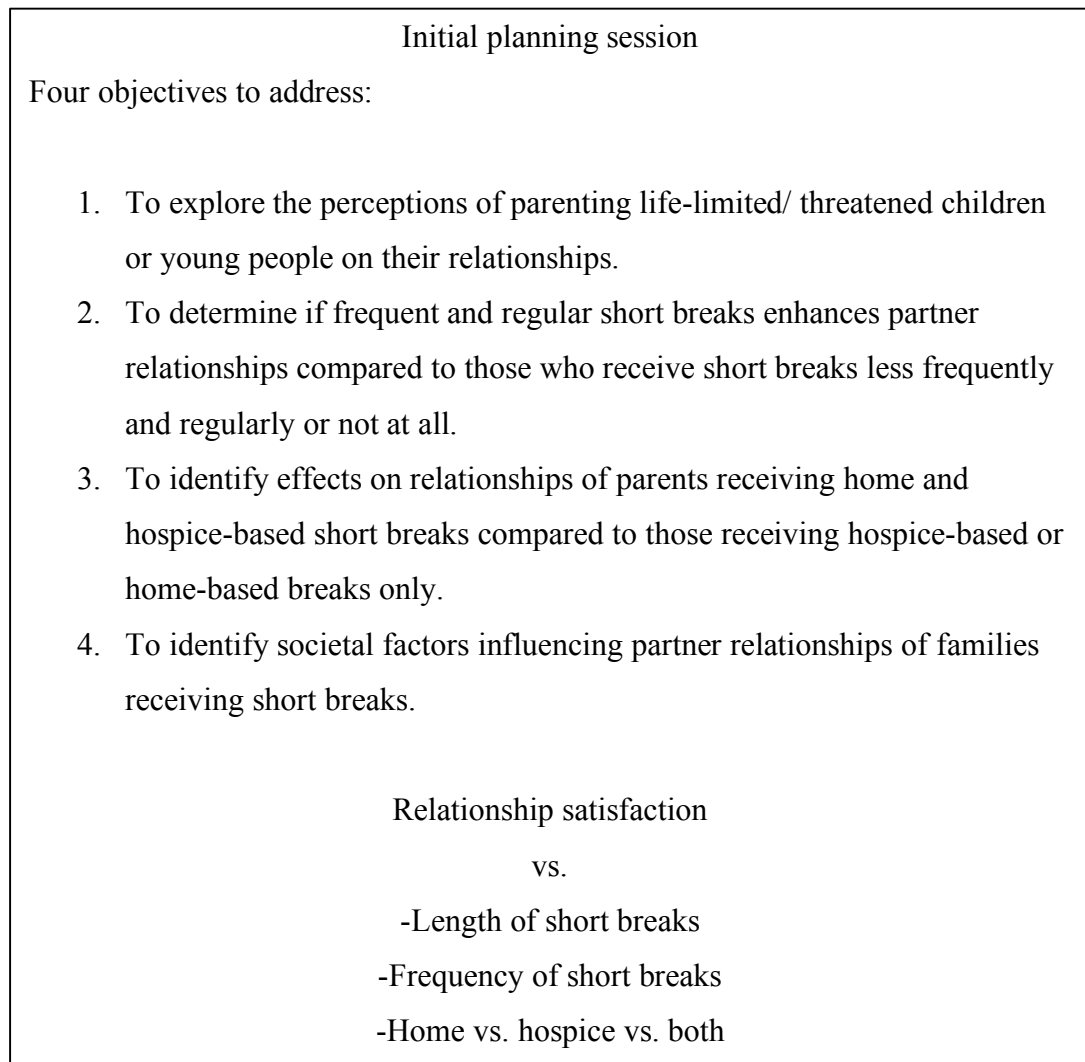


Figure 9.1: Thoughts from initial planning stage

Following the initial planning session, a more detailed plan for the survey was written. Possible questions and answers were drafted, informed by both themes that emerged from interviews and literature (Rattray and Jones 2007). Related topics or questions were grouped together into distinct sections (Cummings et al. 2013). At this stage it was determined that the survey would consist of five distinct sections: (1) Introduction and consent, (2) Demographical questions, (3) Relationship satisfaction, (4) Model of short break received and (5) Perceptions and social factors. Each of these will be outlined in the following sections.

9.5.2 Introduction and consent

Researchers must ensure that informed consent is gained from participants taking part in research (National Research Authority 2014). An introduction

page is crucial in online surveys for securing informed consent (Brace 2008). From an ethical standpoint the introduction page should include: the name of the organisation conducting the research, the survey topic, whether the survey will be confidential and how long it will take to complete (Brace 2008). Brace argues that this gives respondents' information to facilitate informed consent.

9.5.3 Demographical questions

As outlined in the planning stage, it was important to ask participants the type of parental relationship, number of children accessing a hospice, the age of the child or children, relationship status and geographic location by county.

Additionally, an initial filter question was drafted to ensure the respondent was accessing a children's hospice currently and filter out respondents who did not meet these criteria.

9.5.4 Relationship satisfaction

When a survey measures a dependent variable against several independent variables, the main measurement is the most important part of a survey. Cummings et al. (2013) advocate utilising a pre-validated and established measure wherever possible. The Revised Dyadic Adjustment Scale (RDAS; Busby et al. 1995) was chosen as the main measure of relationship satisfaction (Appendix G). The RDAS built on the strengths of the original Dyadic Adjustment Scale (DAS; Spanier 1976) which was validated and brief in length. The RDAS is described by Busby et al. (1995) as 'an improved' version of the DAS which also determines if dyadic relationships are distressed or non-distressed. The RDAS comprises of three subscales; the Dyadic Consensus Subscale, the Dyadic Satisfaction Subscale and the Dyadic Cohesion Subscale (Busby et al. 1995). Scores in the RDAS range from 0 to 69 (Busby et al. 1995), with a cut-off score of 48 (Crane et al. 2000).

The RDAS retains the benefits of the DAS, whilst gaining three main benefits over the DAS; (1) conciseness, the original DAS contained 32 items, the RDAS contains only 14, (2) satisfactory levels of construct validity and (3) acceptable internal consistency, with Cronbach's Alpha coefficient of .90 and Spearman-Brown split-half reliability coefficient of .95 (Busby et al. 1995). The RDAS has been used for hundreds of relationship studies (Harper et al. 2013; Turliuc

and Muraru 2013; Pace et al. 2015; Kreutzer et al. 2016) and works with multiple relationship types including married, cohabiting and same-sex couples (Crane et al. 2000; Lewis et al. 2014; Kelley et al. 2015). In summary, the RDAS is much shorter than the original DAS but still with the same accuracy. In relation to the present study, this allowed the survey to be shorter in length which is a factor in respondents being more likely to complete surveys (Gillham 2008).

9.5.5 Model of short break received

This section asked questions about the type of short break received by families whether at home, at a hospice or both. Semi-structured interviews with parents demonstrated that both ‘respite’ and ‘short breaks’ are used by parents interchangeably. With this in mind, both terms were used within questions to cater for all parents. Another important consideration that came from the semi-structured interviews was that dependent on geographic location some children were accessing more than one children’s hospice.

9.5.6 Additional questions informed by first phase

Data from the semi-structured interviews suggested that two important themes were ‘pressure and conflict between parental figures’ and ‘alternative short breaks’. The theme of ‘pressure and conflict between parental figures’ that emerged from the first phase of research suggested that financial disagreements, having a child with challenging behaviour and leading separate lives impacted on relationships between parents. A second important theme, ‘alternative short breaks’ suggested that other sources of support outside of children’s hospices such as social care, family and friends.

An open question was also drafted to be included at the end of the survey; open questions have the benefits of capturing data not considered in closed questions, making respondents feel their experiences are valued (Cummings et al. 2013). Open questions are more time consuming to analyse than closed questions (Cummings et al. 2013). However, obtaining deeper data and giving respondents opportunities to give more detail about the impact of short breaks on their relationship outweighed any additional analysis time (Cummings et al. 2013).

The structure and flow of the survey was also considered in the planning stage. Ordering of questions within distinct sections is important with surveys. For example, potentially sensitive questions should follow factual questions, giving respondents an opportunity to get used to the survey (Cummings et al. 2013). With this in mind, the survey opened with ‘demographics’, followed by ‘DAS’, ‘model of care’ and finally ‘societal factors’. Two possible structures for the survey were designed, shown in Figure 9.2. Design 1 would allow the data for both parents to be compared and contrasted. However, this design was not used as it was complicated and comparing data between parents would not address the research objectives directly. Design 2 was used for the survey.

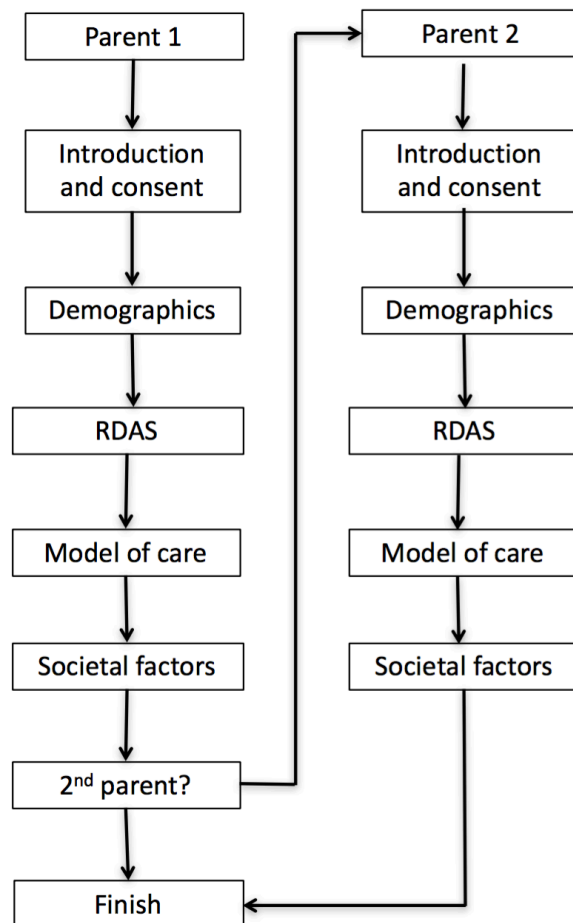


Figure 9.2: Survey designs considered

9.5.7 Supervisor Consultation

Once a draft survey was constructed using SurveyMonkey[®], it was reviewed with supervisors to get feedback on language, structure and content (Gillham

2008; Sue and Ritter 2012; Cummings et al. 2013). A test link was emailed to supervisors. To improve ease of feedback the pilot survey, feedback boxes were included for each question (Figure 9.3).

| | |
|--|-------------------|
| Q11: What is your parental relationship to the child or young person? | Biological mother |
| Q12: What county do you live in? | Hampshire |
| Q13: Feedback section | |
| You may need to consider this for each child within a family as relationships between parents and children may vary e.g. birth parent to one child, step parent to another | |

Figure 9.3: Example of feedback section in draft survey

Feedback from supervisors led to several improvements in the survey design. For example in Figure 9.3, supervisors suggested that for those respondents who had multiple children accessing a children's hospice there was the possibility that there could be differing parental relationships for each child. The original draft question is presented in Figure 9.4 and the amended version in Figure 9.5. The revised question allows for different parental relationships for each child or young person.

| Q9: What are the ages of your children or young persons currently accessing respite? Complete as necessary. | | |
|--|--------------|---------------|
| | Years | Months |
| 1st child or young person | 4 | 1 |
| 2nd child or young person | 1 | 1 |
| 3rd child or young person | 0 | 0 |
| 4th child or young person | 0 | 0 |

Figure 9.4: Draft parental relationship question

5. What are the ages of your children or young persons currently accessing respite and your relationship to them? Complete as necessary.

| | Years | Months | Parental Relationship |
|---------------------------|----------------------|----------------------|-----------------------|
| 1st child or young person | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 2nd child or young person | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 3rd child or young person | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| 4th child or young person | <input type="text"/> | <input type="text"/> | <input type="text"/> |
| Other (please specify) | <input type="text"/> | | |

Figure 9.5: Amended parental relationship question

9.5.8 Piloting with target population

Following amendments, the modified online survey was piloted with a small number of parents currently accessing a children's hospice. One participating hospice emailed parents the link to the draft survey and instructions (Appendix H) for reviewing the survey. The aim of piloting the survey with the target population was to check two main areas: (1) language and questions, and (2) structure and layout (Gillham 2008). 'Language and questions' specifically referred to whether there were any errors or mistakes, whether the questions made sense, if there were any jargon words which were not understood, whether respondents felt all possible answers had been considered and whether information sections clearly explained the survey (Gillham 2008; Cummings et al. 2013). With 'structure and layout' respondents were asked to consider whether the survey followed a logical order, see if there were any broken links, whether presentation was clear, establish if the survey was easy to navigate and how long it took to complete (Gillham 2008; and Cummings et al. 2013).

Feedback from respondents highlighted that there was a missing link in the question skip logic which meant that respondents who answered a particular way were unable to complete the survey. This was fixed and rechecked. The layout of the consent page was stressed as being unclear due to a lack of distinct headings. Cummings et al. (2013) also suggested that each section of an online survey should have a clear heading. Implementing the changes resulted in the final survey structure presented in Figure 9.6.

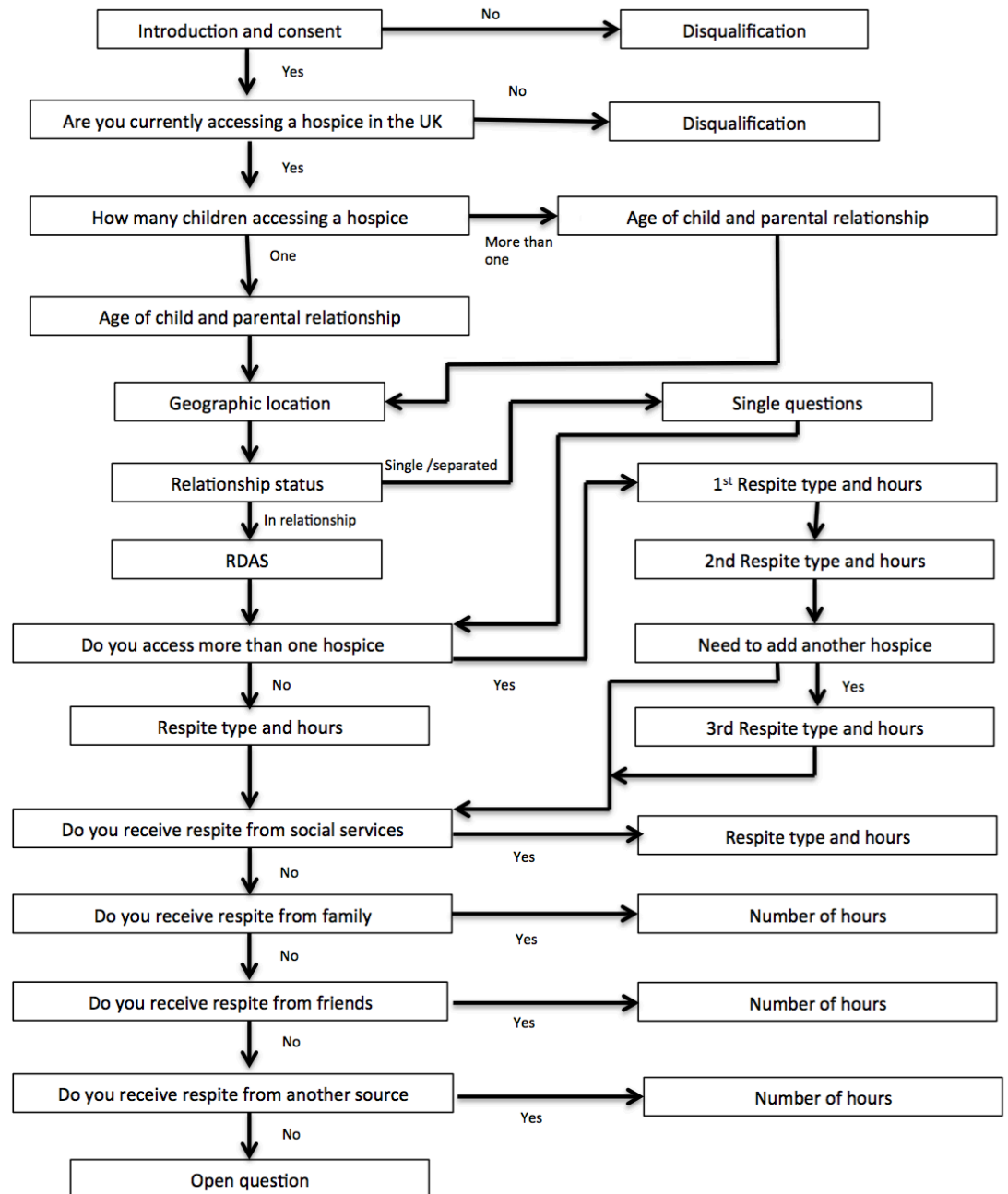


Figure 9.6: Final online survey structure

9.6 Access procedure and gaining informed consent

Prior to distribution of the online survey, hospices were contacted via email and telephone, and staff asked if they would be willing to distribute email invitations to parents currently accessing the hospice. Staff at seventeen hospices agreed to distribute invitations to parents. The email sent to parents outlined the research and provided a link to the online survey (Appendix I). The first page of the online survey (Appendix J) outlined the purpose of the research, why the parent had been invited to take part, how long the survey would take and who to contact if they had any questions (Brace 2008). By clicking 'Yes' on this page, the participant was considered to have given informed consent to take part. This is commonly accepted with online surveys or questionnaires (Dillman and Smyth 2007; Brace 2008; Sue and Ritter 2012).

9.7 Online survey data analysis

Before analysis could happen, data needed to be exported from SurveyMonkey[®] into Microsoft Excel and organised. The export from SurveyMonkey[®] contained extraneous data that were not relevant to the research, such as date and time of survey completion and these were deleted. Data from the survey were then organised by having a separate 'tab' for each question in Excel. A new tab was created, 'Question 2' for example, and the corresponding data were copied and pasted. Responses to the RDAS were scored and totalled using the Excel spreadsheet and the RDAS scoring criteria.

When asked about the number of hours of respite or short breaks received respondents were given the option of entering hours per week, month or year. Consequently some of the responses given needed to be converted to give a 'hours per year' figure. Single or separated parents were highlighted on the Excel spreadsheet in yellow. The single parent questions were different to other respondents and were analysed separately. Non-responses, incomplete responses were identified. A separate spreadsheet was created for those respondents who had completed the RDAS, this did not include single parent respondents or non-respondents. Data were then imported into SPSS[™] (Statistical Package for Social Scientists) version 22.00 for Mac. As there was a

large volume of data to be tested individual SPSS™ files were created for each independent variable.

The same procedure for analysis was followed for all the data tested. Data were tested for normal distribution using Shapiro-Wilk (SW) if the number of respondents in a group were below 50 and Kolmogorov-Smirnov (KS) was used for numbers of 50 or more (Field 2013; Mayers 2013). If the SW or KS outcome was non-significant then data were considered to be normally distributed. Non-parametric data were explored for outliers and these were adjusted if possible. The data were then retested for normal distribution, if the data were still not normally distributed then non-parametric tests were used (Field 2013; Mayers 2013).

The statistical test used to analyse data depended on two factors; whether the data were normally distributed and the number of groups within the data. If the data were normally distributed and there were only two groups, such as 'distressed' and 'non-distressed', then an independent t-test was used. The non-parametric of this test was the Mann-Whitney U. If the data was normally distributed and had more than two groups, such as 'short breaks at home', 'short breaks at hospice' and 'short breaks at both', then a one-way Independent ANOVA was used (Field 2013; Mayers 2013). The non-parametric equivalent of this was the Kruskal-Wallis H. This procedure is presented in Figure 9.7.

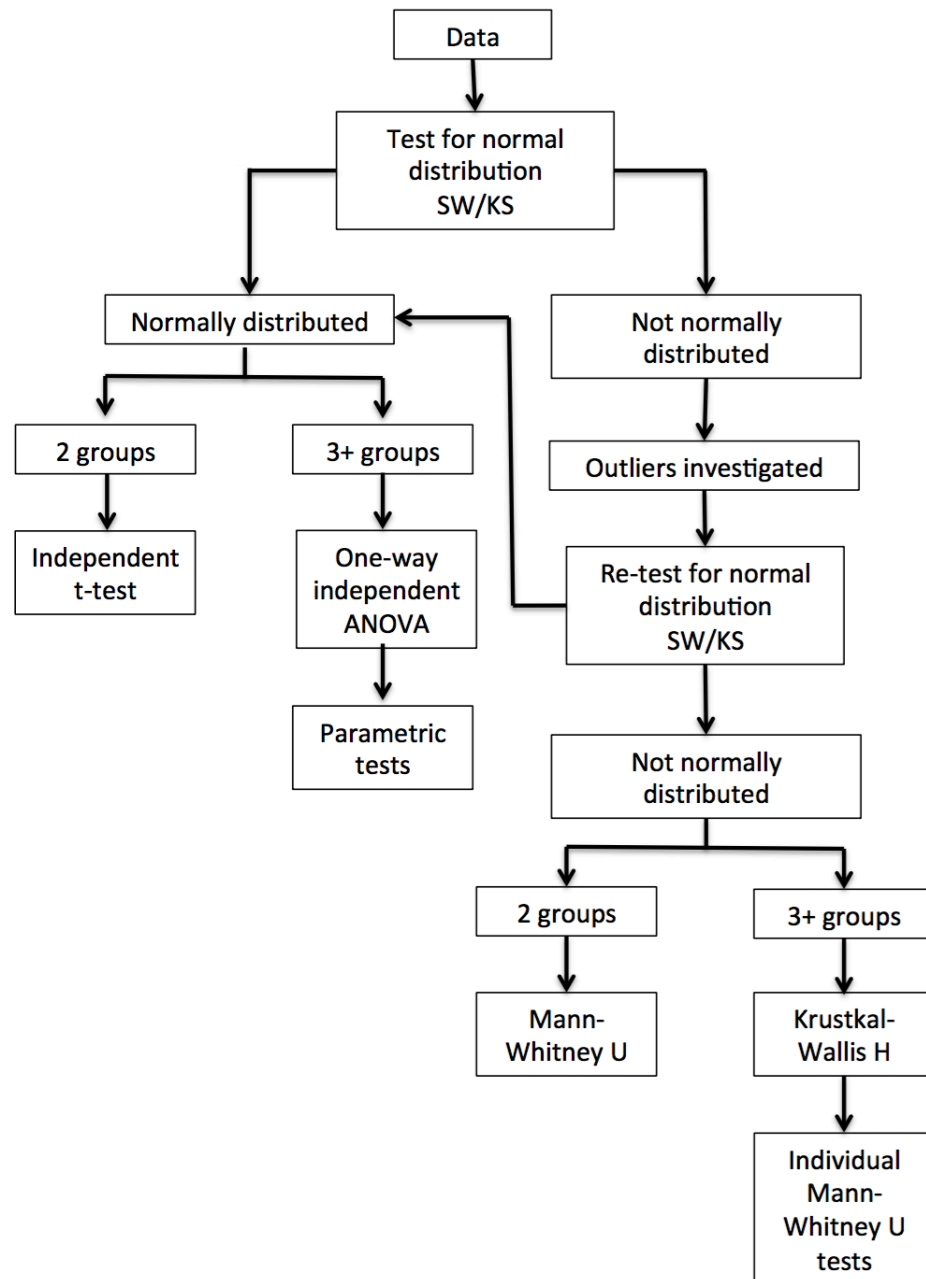


Figure 9.7: Procedure for online survey data analysis

9.8 Chapter conclusion

This chapter outlined the development of the online survey and data analysis. The online survey went through multiple stages of development beginning with initial planning. In line with the pragmatic philosophy outlined in Chapter Six the foundations for this initial planning were the research aim and objectives. Initial survey planning was also informed by findings from semi-structured

interviews outlined in Chapter Eight, following a sequential exploratory mixed methods design outlined in Chapter Five.

The survey comprised of four sections: demographics, relationship measure, model of care and societal factors. Questions were drafted around these areas and a draft survey was constructed. This draft survey was piloted with supervisors and amendments were made. The finished survey was distributed via participating hospices. Data gathered from the online survey were exported from SurveyMonkey[®] into Microsoft Excel where it was 'tidied up'. Data were then imported into SPSS where both parametric and non-parametric tests were utilised. The next chapter presents findings analysed from data collected from the online survey.

10 An Analysis of National Online Survey Data from Parental Figures Accessing Children's Hospice Short Breaks

10.1 Chapter introduction

Chapter Eight presented findings from the first phase of this sequential mixed methods study, semi-structured interviews with parents about the impact of children's hospice short breaks on their partner relationships. This chapter presents findings from the second phase of the study, an online survey with 142 parental figures currently accessing a children's hospice for their life-limited or life-threatened child or young person. The first section of this chapter outlines the analytic process, including the relationship scale and survey software used. This is followed by the presentation of findings, beginning with demographics of respondents. Survey results for married and cohabiting couples are then presented, including the amount and type of hospice short breaks received, contributing factors to relationship distress and other sources of short breaks. This is followed by a brief outline of results for divorced or separated parents, around reasons for relationship breakdown and whether short breaks were being received prior to breakdown. Finally, the last main section of the chapter outlines findings from the thematic analysis of data from the online survey open question.

10.2 Survey analysis overview

As outlined in Chapter Nine, the main measure of the survey was relationship satisfaction. Relationship satisfaction was measured using a pre-validated scale, the Revised Dyadic Adjustment Scale (RDAS) (Busby et al. 1995). The RDAS was developed as an improvement on the Dyadic Adjustment Scale (DAS) (Spanier 1976) which measured relationship satisfaction across four sub-scales: consensus, satisfaction, cohesion and affection expression. The DAS was widely used within marital research because of its brevity and strength in predicting distressed and non-distressed couples (Crane et al. 1990). By contrast the RDAS comprises of three subscales: The dyadic consensus subscale, the dyadic satisfaction subscale and the dyadic cohesion subscale. Scores in the RDAS range from 0 to 69 with a cut-off score of 48. Scores of 47 or below

indicates distress, while scores of 48 and above are considered non-distressed (Busby et al. 1995). Busby et al. (1995) argue that the RDAS retains the benefits of the DAS, whilst gaining three main benefits over the DAS: (1) conciseness, the original DAS contained 32 items, the RDAS contains only 14, (2) satisfactory levels of construct validity and (3) acceptable internal consistency, with Cronbach's Alpha coefficient of .90 and Spearman-Brown split-half reliability coefficient of .95.

Data were collected using SurveyMonkey[®], an online survey platform. SurveyMonkey[®] collated all data received from respondents and these were exported to a Microsoft Excel[™] spreadsheet. However, a number of steps were taken to organise raw data in the Excel spreadsheet. Firstly, SurveyMonkey[®] automatically includes information that may not be relevant to the analysis such as the date and time the online survey was completed. This information was removed to reduce confusion during analysis.

Organised data were imported into SPSS[™] version 22.00 for Mac. Statistical tests implemented were dependent upon whether data were normally distributed and representative of the general population (Field 2013; Mayers 2013). Normally distributed data are also referred to as parametric. Data were tested for normal distribution using Kolmogorov-Smirnov (KS) for larger samples greater than and equal to 50 ($n \geq 50$) and Shapiro-Wilk (SW) for smaller ones (< 50). In within-group studies this would refer to the total sample size, with between-group studies each group are independent and so the cut-off applies to the group size (Field 2013; Mayers 2013). When reporting normal distribution test outcomes Kolmogorov-Smirnov is represented by (D) and Shapiro-Wilk by (W) (Field 2013; Mayers 2013).

The parametric tests utilised for normally distributed data depended on the number of groups; an independent t-test for two groups and a one-way ANOVA for three or more groups. Tests for non-parametric distributed data depended on the number of groups. Mann-Whitney U for two groups and Kruskal-Wallis H for three or more. Parametric tests use the mean scores, whilst non-parametric tests use the median scores. The level of significance was set at $p < .05$, the

universally accepted level of significance for the majority of social research (Dancey and Reidy 2004; Field 2013; Mayers 2013).

Both parametric and non-parametric tests determine whether differences or relationships between variables are statistically significant (Mayers 2013). However, neither gives information about the actual size of difference in relation to the number of cases used to measure the difference. Effect size is a measure of the actual differences between two variables, in relation to the sample mean and sample standard deviation (Mayers 2013). In other words, the effect size is the measure of the degree to which differences in a dependent variable can be attributed to the independent variable (Dancey and Reidy 2004).

Effect size can be measured using either Pearson's r or Cohen's d , both differing in how they measure effect size (Dancey and Reidy 2004; Mayers 2013). Cohen's d was chosen as G*PowerTM, a commercially free effect size calculation programme, uses this measure of effect size (Mayers 2013). The following effect size (d) guidelines were used: <0.25 is a small effect size, 0.25-0.4 is a medium effect size, and above 0.4 is a large effect size (Mayers 2013; Cohen 2016). G*PowerTM was used to calculate effect size by entering the sample size, mean score and standard deviation for each group.

G* PowerTM and Cohen's d cannot be used to calculate effect size for non-parametric tests (Mayers 2013) as it uses the mean. However, Pearson's r can be used to calculate effect size for non-parametric tests as it utilises the median. Pearson's effect size (r) can be manually calculated by dividing the z -score (Z) by the square root of the sample size (n):

$$r = \frac{Z}{\sqrt{n}}$$

10.3 Demographics

One hundred and forty-two parents responded to the national online survey. However, eight responses had to be excluded for non-completion and an additional eight were excluded for not meeting inclusion criteria outlined in

Chapter Nine. Figure 10.1 presents the relationship status of those who responded. Of the 126 respondents included in the analysis, two-thirds were married, a fifth were divorced or separated, and small proportion were cohabiting with a partner (Table 10.1).

Table 10.1: Relationship status of respondents

| | No of responses | Percentage |
|--------------------------|-----------------|------------|
| Married | 84 | 67.0 |
| Cohabiting with partner | 13 | 10.0 |
| Separated but cohabiting | 2 | 1.5 |
| Divorced or separated | 25 | 20.0 |
| Widowed | 2 | 1.5 |
| Response total | 126 | |

Twenty (16%) respondents were biological fathers to children accessing hospices for short breaks, four-fifths (82%) were biological mothers, one (1%) adoptive mother and one other (1%) who described themselves as a ‘special guardian’. The survey had no responses from adoptive fathers. Three respondents chose not to answer this question. Parental figures were asked if they received short breaks at one or more children’s hospice. Four parents chose not to answer this question. Of 122 respondents, 105 (86%) received short breaks from only one hospice, whilst 17 (14%) accessed more than one hospice for short breaks.

10.4 Geographic location

The highest number of respondents came from Dorset (19.4%), Leicestershire (13.8%), Suffolk (12.2%) and South Yorkshire (9%). Other counties and their response rates are presented below in. Six parents did not respond to this question.

Table 10.2: Responses by geographic location

| | No of responses | % of responses |
|-----------------------|-----------------|----------------|
| Avon | 6 | 4.8 |
| Berkshire | 7 | 5.6 |
| Cambridgeshire | 4 | 3.2 |
| Central London | 1 | 0.8 |
| Derbyshire | 7 | 5.6 |
| Dorset | 23 | 19.4 |
| Fife | 1 | 0.8 |
| Grampian | 3 | 2.4 |
| Hampshire | 2 | 1.6 |
| Herefordshire | 1 | 0.8 |
| Highlands and Islands | 1 | 0.8 |
| Kent | 4 | 3.2 |
| Lancashire | 1 | 0.8 |
| Leicestershire | 16 | 13.8 |
| Lothian | 3 | 2.4 |
| Norfolk | 5 | 4.0 |
| Nottinghamshire | 3 | 2.4 |
| Somerset | 1 | 0.8 |
| South Yorkshire | 10 | 9.0 |
| Strathclyde | 2 | 1.6 |
| Suffolk | 14 | 12.2 |
| Tayside | 1 | 0.8 |
| Warwickshire | 1 | 0.8 |
| West Midlands | 2 | 1.6 |
| Wiltshire | 1 | 0.8 |
| Response total | 120 | |

10.5 Relationship satisfaction in married and cohabiting parental figures

This section presents results for married and cohabiting respondents only. Results for divorced or separated respondents are outlined in section 10.14. None of the respondents were in a civil partnership, hence there are no data relating to civil partnership.

10.5.1 Relationship satisfaction score (RDAS)

Of 126 respondents, 97 (77%) were married or cohabiting and completed questions relating to the RDAS. According to the cut-off score of 48 reasoned by Busby et al (1995), of the 97, 50 (52%) of respondents were considered to be *non-distressed* with a mean score of 53. By contrast, the remaining 47 (48%)

were considered to be *distressed* with a mean score of 39.

As the non-distressed group of participants numbered 50, data were tested for normal distribution using Kolmogorov-Smirnov and were found to be non-parametric, $D(50) = .155$, $p = 0.004$. The distressed group had a sample size below 50, so Shapiro-Wilk was used. Data were also non-parametric, $W(47) = .875$, $p < .001$. As data were non-parametric a Mann-Whitney U statistical test was employed.

Table 10.3: Mann-Whitney U outcome for distressed versus non-distressed RDAS score

| | No of responses | Median | 95% CI |
|----------------|-----------------|--------|--------------|
| Distressed | 47 | 42.00 | 37.26- 41.55 |
| Non-distressed | 50 | 53.00 | 52.29- 54.43 |
| Response total | 97 | | |

As presented in Table 10.3, the Mann-Whitney U indicated respondents who were classified as being distressed had significantly poorer relationship satisfaction scores than those who were considered to be non-distressed, ($U=0.00$; $N1= 47$; $N2 = 50$; $p<.001$); there was a large effect size, $r = .86$.

10.5.2 Model of short breaks received and relationship satisfaction scores

Eight (8.5%) respondents of 94 received short breaks *only at home*, 47 (50%) received short breaks *only at a hospice* and 39 (41.5%) received short breaks at *both home and at a hospice*. Three respondents did not complete this question. The mean RDAS relationship satisfaction scores for each model of short break are presented in Table 10.4 below:

Table 10.4: RDAS Score by short break model

| | No of responses | Mean RDAS Score |
|------------------------------------|-----------------|-----------------|
| Home short breaks only | 8 | 47 |
| Hospice short breaks only | 47 | 48 |
| Both home and hospice short breaks | 39 | 46 |
| Response total | 94 | |

Data for impact of short break model on relationship satisfaction scores were tested for normal distribution. All three groups had under 50 respondents and were tested using Shapiro-Wilk. The *home short breaks only* $W(8) = .964$, $p = .850$ and *both home and hospice short breaks* $W(39) = .974$, $p = .486$ were normally distributed. However, *hospice short breaks only* $W(47) = .912$, $p = .002$ were non-parametric. A Kruskal-Wallis H statistical test was employed to be cautious.

Table 10.5: Kruskal-Wallis H outcome for RDAS score by short breaks model

| | No of responses | Median | 95% CI |
|------------------------------------|-----------------|--------|--------------|
| Home short breaks only | 8 | 47 | 42.96- 50.54 |
| Hospice short breaks only | 47 | 50 | 48.08- 50.52 |
| Both home and hospice short breaks | 39 | 47 | 43.47- 48.78 |
| Response total | 94 | | |

Kruskal-Wallis H indicated there were little differences in RDAS score between those who receive short breaks at home or at both locations, as presented in Table 10.6. There was a slight difference in relationship satisfaction score for respondents receiving hospice short breaks only with a median of 50. The Kruskal-Wallis H test revealed that there was no significant difference $H(2) = 1.929$, $p = .381$.

10.5.3 Hours of children's hospice short breaks received and relationship satisfaction

Scores for short breaks hours received at home and at a hospice were combined to an overall figure for hours of short breaks received. The mean number of hours of short breaks received from a children's hospice annually for respondents was 328 hours. Non-distressed couples received an average of 388 hours per year from children's hospices, compared to 263 hours for distressed couples.

Data for yearly children's hospice hours were tested for normal distribution using Shapiro-Wilk and were found to be non-parametric for *distressed couples*, $W(49) = .737$, $p < .001$, and *non-distressed couples*, $W(48) = .671$, $p < .001$. As data were non-parametric a Mann-Whitney U statistical test was employed.

Table 10.6: Mann-Whitney U outcome for hours of hospice short breaks received annually

| | No of responses | Median | 95% CI |
|----------------|-----------------|--------|----------------|
| Distressed | 49 | 216.00 | 192.89- 333.52 |
| Non-distressed | 48 | 288.50 | 277.10- 498.61 |
| Response total | 97 | | |

As presented in Table 10.6, the Mann-Whitney U found respondents who were classified as being distressed received significantly less children's hospice short breaks than those who were considered not to be distressed ($U=875.50$; $N1= 48$; $N2 = 49$; $p=.030$); there was a small effect size, $r = .20$.

10.6 Relationship satisfaction in married and cohabiting parental figures: summary

This section outlined findings from the online survey for married and cohabiting parents who completed the Revised Dyadic Adjustment Scale (RDAS). Of the 97 who completed the RDAS, 50 were categorised as non-distressed with a mean RDAS score of 53, and 47 were categorised as distressed with a mean RDAS score of 39. There was a significant difference ($p < .001$) in RDAS score between the two groups with a strong effect size. Those who were

considered to be distressed, received significantly fewer hours of short breaks hours from a children's hospice than those who were non-distressed ($p = .030$). However, the effect size was smaller for this result. Finally, RDAS score was measured against the model of short breaks received; either home only, hospice only or both. There was no significant difference in RDAS score based on short break model.

10.7 Impact of a child's challenging behaviour on relationship satisfaction

The preceding section outlined the findings for amount and model of short break received for married and cohabiting couples. The next four sections will present findings concerning impact of contributory stressors on relationship between married and cohabiting parents, starting here with challenging behaviour. Ninety-six (76%) parental figures reported on the impact of challenging or violent behaviour from their child or young person on relationships with their partner. Of 96, 59 parental figures (61.5%) stated that their child was not violent, 17 (18.00%) said their child was violent but it did not impact on their relationship and 20 (20.5%) felt that violent behaviour from their child had impacted on their relationship. One participant did not answer this question.

Table 10.7: Impact of challenging behaviour on relationship satisfaction

| | No of responses | Percentage | Mean RDAS score |
|--|-----------------|------------|-----------------|
| Our child is not violent | 59 | 61.5% | 48.00 |
| Our child is violent but it has not impacted on our relationship | 17 | 18% | 48.00 |
| Our child is violent and it has impacted our relationship | 20 | 20.5% | 41.00 |
| Response total | 96 | | |

As demonstrated in Table 10.7 the mean RDAS relationship satisfaction score for those who both considered their child not to possess violent behaviour and

those who did consider their child to have violent behaviour, but with no impact on their relationship was 48, being non-distressed. The mean RDAS score for parents who stated that their relationship had been impacted due to violent behaviour from their child was 41, which would be distressed.

As the group stating their child was non-violent had a sample size larger than 50, Kolmogorov-Smirnov was employed with data found to be non-parametric $D(59) = .125$, $p = .022$. The group that said their child was violent but which had no impact on their relationship $W(17) = .968$, $p = .785$ and the group that said their child's violence had impacted their relationship $W(20) = .938$, $p = .221$ were tested with Shapiro-Wilk due to smaller group sizes and were found to be parametric. However, as data for the first group were non-parametric a Kruskal-Wallis H statistical test was employed. The Kruskal-Wallis H test indicated that there was a significant difference across the 3 groups $H(2) = 9.610$, $p = .008$.

Three individual Mann-Whitney U tests were run across pairs of groups to determine where the significance lay (Table 10.8). There was no significant difference in relationship satisfaction score between those who stated their child was not violent and those who had experienced violence, but stated it had not impact their relationship, ($U = 452.50$; $N1 = 59$; $N2 = 17$; $p = .541$).

Respondents who stated that violence from their child had impacted on their relationship had significantly poorer relationship satisfaction scores than those who had not experienced violence from their child, ($U = 325.00$; $N1 = 59$; $N2 = 20$; $p = .003$); there was a medium effect size, $r = .35$. Respondents who stated that they had experienced violence from their child but which had impacted on their relationship, had significantly lower relationship satisfaction scores than those who had experienced violence, but stated it had not impact their relationship, ($U = 96.50$; $N1 = 17$; $N2 = 20$; $p = .024$); there was a medium effect size $r = .38$.

Table 10.8: Mann-Whitney U outcome for challenging behaviour

| | No of responses | Median | 95% CI |
|--|-----------------|--------|-------------|
| Our child is not violent | 59 | 50 | 46.19-50.29 |
| Our child is violent but it has not impacted on our relationship | 17 | 47 | 45.38-50.62 |
| Our child is violent and it has impacted on our lives | 20 | 41 | 35.92-45.18 |
| Response total | 96 | | |

10.8 Impact of leading separate lives on relationship satisfaction

Ninety-six married or cohabiting parental figures reported the impact of leading separate lives on their relationship. As presented in Table 10.9 of the 96, 40 respondents (42%) found time together, 15 (16%) felt they led separate lives but this had not impacted their relationship and 41 (42%) stated that they led separate lives and it had impacted their relationship.

Table 10.9: Mean RDAS score for leading separate lives

| | No of responses | Percentage | Mean RDAS score |
|--|-----------------|------------|-----------------|
| Still find time together | 40 | 41.5 | 52 |
| Lead separate lives but it has not impacted on relationships | 15 | 16 | 47 |
| Lead separate lives and it has impacted on relationships | 41 | 42.5 | 41 |
| Response total | 96 | | |

The mean RDAS for those who found time together as a couple is 52 which would be considered *non-distressed*. Those who led separate lives but felt it had not impacted their relationship had a mean score of 47 which with a cut-off

score of 48, would be considered *distressed*. Finally, those who stated that their relationship had been effected by leading separate lives had mean RDAS score of 41, which would be considered *distressed*.

Data for impact of leading separate lives on relationship satisfaction were tested for normal distribution using Shapiro-Wilk and were found to be normally distributed for those who found time together, $W(40) = .983$, $p = .791$, those who led separate lives without impacting their relationship, $W(15) = .961$, $p = .716$ and those who led separate lives and felt it had impacted their relationship, $W(41) = .950$, $p = .068$. As data were normally distributed a one-way independent ANOVA statistical test was employed as presented in Table 10.10. This statistical test indicated that there was a significant difference across the groups. Assumption of homogeneity of variance was not met for this data, Welch's adjusted F ratio (21.17) was used, Welch's $F(2, 36.89) = 21.17$, $p < .001$.

A post hoc Games-Howell revealed that there was no significant difference between those who still had time together and those who led separate lives, but where the separation had not impacted their relationship ($p = .079$). Those respondents who could still find time to spend together, had significantly higher relationship satisfaction scores than those who led separate lives which impacted on their partner relationship ($< .001$). Respondents who led separate lives which impacted on their partner relationship, had significantly lower relationship satisfaction scores than those led separate lives, but which had not impacted their partner relationship ($p = .038$). This was represented by a large effect, $d = .56$.

Table 10.10: One-way ANOVA outcome for leading separate lives

| | No of responses | Mean RDAS | S.D. | S.E. | 95% CI |
|---|-----------------|-----------|-------|-------|-------------|
| Still find time together | 40 | 52 | 5.021 | 0.794 | 50.04-53.26 |
| Lead separate lives but no impact on relationship | 15 | 47 | 6.837 | 1.765 | 43.41-50.99 |
| Lead separate lives and it has impacted on relationship | 41 | 41 | 8.695 | 1.358 | 38.69-44.18 |
| Response total | 96 | | | | |

10.9 Impact of finances on relationship satisfaction

Thirty-six (36.5%) of 96 married or cohabiting respondents never had disagreements about finances, 50 (51%) had disagreements about finances occasionally and 12 (12.5%) had disagreements about finances all the time (Table 10.11).

Table 10.11: Mean RDAS score for financial disagreements

| | No of responses | Percentage | Mean RDAS score |
|--|-----------------|------------|-----------------|
| Never have disagreements about financial difficulties | 35 | 36 | 51 |
| Have disagreements about financial difficulties occasionally | 49 | 51 | 45 |
| Have disagreements about financial difficulties all the time | 12 | 13 | 39 |
| Response total | 96 | | |

The mean RDAS for those respondents who never had financial disagreements with their partner is 51 indicating them to be not distressed. Those who occasionally had disagreements about finances had a mean score of 45 denoting

them to be distressed. Finally those had financial disagreements all the time had a mean RDAS score of 39, making them distressed.

Data for impact of financial difficulties on relationship satisfaction were tested for normal distribution using Shapiro-Wilk and found to be normally distributed for no financial disagreements, $W(35) = .969$, $p = .422$, occasional financial disagreements, $W(49) = .960$, $p = .096$ and financial disagreements all the time, $W(12) = .934$, $p = .425$. As data were normally distributed a one-way independent ANOVA statistical test was employed. This (Table 10.12) statistical test indicated that there was a significant difference across the groups. However, since the assumption of homogeneity of variance was not met for this data ($p = .022$), Welch's adjusted F ratio (12.80) was used, Welch's $F(2, 28.661) = 12.80$, $p < .001$.

Table 10.12: One-way independent ANOVA outcome for financial disagreements

| | No of responses | Mean RDAS | S.D. | S.E. | 95% CI |
|--|-----------------|-----------|------|-------|-------------|
| Never have disagreements about financial difficulties | 35 | 51 | 5.67 | 0.958 | 49.05-52.95 |
| Have disagreements about financial difficulties occasionally | 49 | 45 | 8.13 | 1.162 | 43.05-47.72 |
| Have disagreements about financial difficulties all the time | 12 | 39 | 9.57 | 2.762 | 32.59-44.74 |
| Response total | 96 | | | | |

A *post hoc* Games-Howell revealed those who had disagreements about financial difficulties occasionally had significantly lower satisfaction scores than those who never had disagreements about finances ($p = .001$). There was a large effect size, $d = 0.86$. Those respondents, never had disagreements about financial difficulties had significantly higher satisfaction scores than those who had disagreements all the time ($p = .002$). There was a large effect size, $d = 1.52$. Respondents who had disagreements about finances all the time had lower satisfaction scores than those who only had disagreements occasionally,

however this was not significant ($p = .096$), with a large effect size, $d = 0.68$.

10.10 Impact of multiple contributing stressors on relationship satisfaction

Data from the survey indicates that a child with violent or challenging behaviour, disagreements about finances and leading separate lives can significantly contribute to lower relationship satisfaction. Using an Excel spreadsheet, respondents' responses were categorised by numbers of contributing stressors to determine the overall impact on relationship satisfaction. The mean RDAS score for each is presented in Table 10.13.

Table 10.13: Impact of multiple contributing stressors on mean RDAS score

| | No of responses | Percentage | Mean RDAS Score |
|------------------------------|-----------------|------------|-----------------|
| No contributing stressors | 43 | 45 | 52 |
| One contributing stressor | 35 | 36 | 45 |
| Two contributing stressors | 15 | 16 | 39 |
| Three contributing stressors | 3 | 3 | 30 |
| Response total | 96 | | |

Data for impact of financial difficulties on relationship satisfaction were tested for normal distribution using Shapiro-Wilk and were found to be normally distributed for no contributing stressors $W(43) = .974$, $p = .426$, one contributing stressor $W(35) = .961$, $p = .251$, two contributing stressors $W(15) = .932$, $p = .297$ and three contributing stressors, $W(3) = .923$, $p = .463$. As data were normally distributed an independent one-way ANOVA statistical test was employed. The ANOVA (Table 10.14) indicated that there was a significant difference across the groups. However, since the assumption of homogeneity of variance was not met ($p = .012$), Welch's $F(3, 9.717) = 28.77$, $p < .001$ and suggests the number of contributing stressors significantly impacts relationship

satisfaction.

A *post hoc* Games-Howell similarly revealed that those who had three contributing stressors had a significantly lower RDAS score than those who had no contributing stressors ($p = .017$) and one contributing stressor ($p = .028$). There was no significant difference between three and two contributing stressors ($p = 0.92$). Those who had two contributing stressors had significantly lower satisfaction than those who had no contributing stressors ($p < .001$) but not those who had one contributing stressor ($p = .165$). There was a large effect size, $d = .63$.

Table 10.14: ANOVA outcome for multiple contributory stressors

| | No of responses | Mean RDAS | S.D. | S.E. | 95% CI |
|---------------------------------|--------------------|--------------|------|-------|-----------------|
| No contributing stressors | 43 | 52 | 5.42 | 0.826 | 50.22- 53.55 |
| One contributing stressor | 35 | 45 | 7.14 | 1.207 | 42.75- 47.65 |
| Two contributing stressors | 15 | 39 | 9.39 | 2.423 | 34.14- 44.53 |
| Three contributing stressors | 3 | 30 | 4.16 | 2.404 | 19.32- 40.01 |
| Response total | 96 | | | | |

10.11 Contributing factors: summary

Analysis of semi-structured interviews revealed three contributing stressors that can place additional stress on relationships. These were; the child or young person presenting violent or challenging behaviour, leading separate lives and disagreements over finances. It was found that those who had a child or young person who presented with violent behaviour had significantly lower relationship satisfaction than those who did not ($p = .008$). It was also found that those who led separate lives and felt that it had impacted on their relationship had significantly lower satisfaction scores than those who still managed to find time together ($p < .001$). Disagreements about finances were

also found to be a significant contributing factor to relationship dissatisfaction with those who have disagreements about finances all the time having significantly lower satisfaction than those who never disagree about finances ($p = .002$).

The impact of the number of contributing stressors (violence or challenging behaviour, leading separate lives and finances) on relationships was then explored. The number of contributing stressors significantly impacts relationship satisfaction ($p < .001$) with more contributing factors resulting in lower satisfaction. Those participants who had three contributing stressors had significantly lower relationship satisfaction than those who had none ($p = 0.17$) or one ($p = .028$) contributing stressor. However, this difference was not found for those who had two contributing stressors.

10.12 Short breaks from social care, family, friends and other sources

The previous section outlined the results for contributing stressors that significantly reduce relationship satisfaction. This section will present the results for married or cohabiting parental figures in regards to whether short breaks are received from social care, family, friends, other sources and what potential impact this had on relationship satisfaction scores.

10.12.1 Social care support

As presented in Table 10.15 38 parental figures (40%) received short breaks from social care and 58 (60%) did not receive short breaks from social care. The response group that received short breaks from social care were tested for normal distribution with Shapiro-Wilk and was normally distributed $W(38) = .943$, $p = .053$. The second group, who did not receive short breaks from social care had a sample size above 50 and was tested for normal distribution using Kolmogorov-Smirnov. Data were not normally distributed $D(58) = .161$, $p < .001$. As data for one group was non-parametric a Mann Whitney-U was implemented. There was no significant difference in RDAS score between those who did and did not receive social care support ($U=1062.50$; $N1= 58$; $N2 = 38$; $p=.077$); there was a small effect size, $r = .20$.

Table 10.15: Mean RDAS score for short breaks from social care

| | No of responses | Percentage | Mean RDAS score |
|--|-----------------|------------|-----------------|
| Receive short breaks from social care | 38 | 40% | 47 |
| Do not receive short breaks from social care | 58 | 60% | 46 |
| Response total | 96 | | |

The 38 parental figures who answered they received short breaks from social care were then asked at what location they received these short breaks. Fourteen (36%) received short breaks at home, 14 (36%) at a location away from home and 10 (28%) both at home and at a location away from home (Table 10.16).

Table 10.16: Location of social care short break by mean RDAS score

| | No of responses | Percentage | RDAS score |
|---|-----------------|------------|------------|
| At home | 14 | 36% | 48 |
| At location away from home | 14 | 36% | 46 |
| Both at home and at a location away from home | 10 | 28% | 45 |
| Response total | 38 | | |

Data for location of social care short breaks on RDAS score were tested for normal distribution using Shapiro-Wilk and found to be normally distributed for those who received home only short breaks $W(14) = .939$, $p = .400$, those who received at a location away from home, $W(14) = .894$, $p = .092$ and those respondents who received short breaks both at home and away from home, $W(10) = .906$, $p = .258$. As data were normally distributed an independent one-way ANOVA statistical test was employed. Test for homogeneity of variance (Levine statistic) suggested homogeneity of variance was not violated. The independent one-way ANOVA indicated that there was no significant

difference across the groups, $F(2,37) = .234$, $p = .792$ (Table 10.19).

Table 10.17: ANOVA outcome for location of social care short break

| | No of responses | Mean RDAS | S.D. | S.E. | 95% CI |
|--|-----------------|-----------|--------|-------|-------------|
| Home only | 14 | 48 | 11.144 | 2.978 | 41.35-54.22 |
| At location away from home | 14 | 46 | 10.127 | 2.707 | 40.51-52.20 |
| At both home and a location away from home | 10 | 45 | 8.913 | 2.818 | 38.52-51.28 |
| Response total | 38 | | | | |

10.12.2 Short breaks from family members, friends and other sources

The majority of parental figures did not receive short breaks from a family member and just over one in ten specified that they did receive such short breaks (Table 10.18). Those who did have short breaks from a family member received on average 338 hours a year, mostly from grandparents.

Table 10.18: Mean RDAS score for short breaks from family members

| | No of responses | Percentage | Mean RDAS score |
|--|-----------------|------------|-----------------|
| Receive short breaks from a family member | 11 | 11% | 51 |
| Do not receive short breaks from a family member | 78 | 89% | 47 |
| Response total | 89 | | |

Those who did not receive short breaks from a family member had a mean RDAS score of 47, rendering them distressed. Respondents did receive short breaks from a family member had a mean score of 51 making them not distressed.

Data of respondents receiving short breaks from family members were tested for normal distribution using Kolmogorov-Smirnov (D) and Shapiro-Wilk (W) and were found to be normally distributed for those respondents who received short breaks from a family member $W(11) = .923$, $p = .342$ and those who stated they did not receive short breaks from a family member, $D(78) = .121$, $p = .007$. As data for the second group were non-parametric a Mann Whitney-U was employed.

Table 10.19: Mann Whitney-U outcome for short breaks from family

| | No of responses | Median | 95% CI |
|--|--------------------|--------|--------------|
| Do not receive short breaks from a family member | 78 | 48 | 44.71- 48.37 |
| Receive short breaks from a family member | 11 | 53 | 46.07- 56.66 |
| Response total | 89 | | |

Mann Whitney-U outcome (Table 10.19) indicated respondents who received short breaks from a family member had significantly higher relationship satisfaction scores than those who did not receive short breaks from a family member, ($U = 270.50$; $N1 = 78$; $N2 = 11$; $p = .024$). There was a small effect size $r = .21$.

When asked whether they received short breaks from friends, the majority of parents said that they did not receive short breaks from friends, whilst three responded did (Table 10.20). As the number of respondents who did receive short breaks from friends was so small, no statistical tests were run.

Table 10.20: Number of respondents who received short breaks from friends

| | No of responses | Percentage | Mean RDAS score |
|--|-----------------|------------|-----------------|
| Receive short breaks from friends | 3 | 4% | - |
| Do not receive short breaks from friends | 85 | 96% | - |
| Response total | 88 | | |

Sixty (69%) of respondents did not receive short breaks from another source and 27 (31.00%) did receive short breaks from another source.

Table 10.21: The mean RDAS score for respondents who receive short breaks from other source

| | No of responses | Percentage | Mean RDAS score |
|---|-----------------|------------|-----------------|
| Receive short breaks from another source | 27 | 31 | 45 |
| Do not receive short breaks from another source | 60 | 69 | 48 |
| Response total | 87 | | |

Data were tested for normal distribution using both Kolmogorov-Smirnov and Shapiro-Wilk, and were found to be non-parametric for both those respondents who did not receive short breaks from another source $D(60) = .120$, $p = .031$ and for those who did, $W(27) = .886$, $p = .006$. As data were non-parametric a Mann-Whitney U was utilised (Table 10.22) and with no significant difference in RDAS score between those who receive short breaks from another source and those who did not ($U=698.50$; $N1= 60$; $N2 = 27$; $p=.153$).

Table 10.22: Mann-Whitney U outcome for short breaks from another source

| | No of responses | Median | 95% CI |
|---|-----------------|--------|-------------|
| Receive short breaks from another source | 27 | 48 | 45.59-49.74 |
| Do not receive short breaks from another source | 60 | 49 | 42.01-48.73 |
| Response total | 87 | | |

10.13 Short breaks from social care, family, friends and other sources: summary

Data from semi-structured interviews suggested that sources of short breaks other than those provided by children's hospices also need to be considered, including: social care, family and friends. It was found that 40% of respondents to the online survey received short breaks from social care. However, receiving short breaks from social care appears not to impact on relationship satisfaction. Similarly, to children's hospice short breaks, the location of social service short breaks whether it be at home, away from home or both, has no impact on relationship satisfaction.

Receiving short breaks from a family member positively impacted upon relationship satisfaction ($p = .034$). The 11.40% of respondents who stated they received short breaks or short breaks from a family member, had significantly higher satisfaction relationship scores. Only 3% of respondents stated they received short breaks from a friend, which meant statistical analysis could not be carried out. Other sources of short breaks are received by 31% of respondents, but this had no significant impact on relationship satisfaction.

10.14 Divorced and separated respondents

The preceding section presented findings for parental figures who were currently in a relationship. This section outlines findings for respondents who were divorced or separated from the partner of their child. Of 126 respondents, 25 (20%) were divorced or separated. Divorced and separated parental figures

were first asked whether they thought having a child or young person with life-limiting or life-threatening condition contributed to the breakdown of their relationship. Nine parents believed that this did not contribute to the breakdown of their relationship, almost half felt that it was one of many reasons which contributed and four parents felt that it was the main reason for the breakdown of their relationship (Table 10.23).

Table 10.23: Contribution of having a child with a life-limiting or life-threatening condition to relationship breakdown

| | No of responses | Percentage |
|--|-----------------|------------|
| Did not contribute to the relationship breakdown | 9 | 36 |
| One of many reasons for relationship breakdown | 12 | 48 |
| Main reason for the relationship breakdown | 4 | 16 |
| Response total | 25 | |

Those parental figures who said that having a child or young person with life-limiting or life-threatening conditions were one of many reasons or the main reason for the relationship breakdown were then given the opportunity to expand on how this contributed to the breakdown. The 16 responses were sorted into one of three themes; ‘Separate lives and not enough time for each other’, ‘Partner not accepting diagnosis’ and ‘Other’(Table 10.24).

Table 10.24: Reasons given by single parents for relationship breakdown

| Theme | Example |
|---|--|
| Separate lives and not enough time for each other | <p>“We stopped having time for each other. He became the breadwinner and I became the carer”.</p> <p>“It meant that as a family we had to re-evaluate how we spent our time. I was a stay at home mum to be able to cope with all the appointments that come hand in hand with parenting a child with a life-limiting condition. My ex took our other children on holidays and days out as travelling with our youngest was difficult. Care was hard to come by so we took it in turns to go out in the evenings”.</p> |
| Partner not accepting diagnosis | <p>“Partner could not deal with the news very well.”</p> <p>“The child's father could not get to a place of acceptance and after 6 years still isn't.”</p> |
| Other | <p>“Lack of sleep.”</p> <p>“We also had builders doing renovations and adaptations on and off for a year which took its toll and added strain.”</p> <p>“No help at the start and no support in understand her condition.”</p> |

When considering if other factors contributed to the breakdown of the relationship one-fifth (20%) of parental figures said there were no other factors and four-fifths (80%) stated that there were other contributing factors. One respondent did not to answer this question.

Nineteen provided additional factors contributing to the breakdown of their relationship with their partner. Provided reasons varied and were difficult to categorise, ranging from mental health issues: “*My wife had a mixed personality disorder and was difficult to live with*”, to lack of privacy due to carers in the house: “*We had carers in overnight which brought lack of privacy*”. However, the most common reason (n=5) given was infidelity: “*My partner had an affair*”, “*His choice to get involved in a new relationship*”.

A quarter of divorced or separated parental figures had been receiving short breaks when their relationship broke down, whilst the remaining three quarters stated that they had not been receiving short breaks when their relationship broke down. One respondent did not to answer this question.

10.15 Divorced and single parents: summary

Fewer respondents were single or divorced, leading to a smaller group size (n=25) than married and cohabiting respondents (n=126). However, there were still relevant data. Half said the child and their complex needs was one of many reasons, whilst one-fifth said it was the main reason for the relationship breakdown. Two main themes emerged; *'Separate lives or not having enough time for each other'* and *'Partner not accepting the diagnosis of child'*. For 39% of single parental figures other factors also contributed to the breakdown of the relationship. The most commonly cited reason was infidelity. It was found that 75% of respondents were not receiving short breaks when their relationship broke down.

10.16 Exploring the impact of short breaks on relationships

Ninety-eight parents commented in an open question on the impact that short breaks from children's hospices had on the relationship with their partner. Open question data were collected through Survey Monkey© and exported as a Microsoft Excel™ spreadsheet. This spreadsheet was converted into a PDF format before being imported into NVivo™. Data from the open question were analysed using thematic analysis as proposed by Braun and Clarke (2006). As outlined in Chapter Seven thematic analysis involved data familiarisation, generating initial codes, searching for themes, reviewing themes, defining themes and the on-going write-up of the analysis.

Two main themes were identified concerning the impact of short breaks from children's hospices on partner relationships with their partner: (1) 'Relationship impact' and (2) 'Wellbeing'. The theme of 'Relationship impact' incorporated any references to the relationship with their partner in terms of burden of care and the impact that children's hospice short breaks might have. By contrast, the theme of 'Wellbeing' related to the impact that the burden of caring for their

life-limited or threatened child and children's hospice short breaks had on both psychological and physical wellbeing. Data also suggested that wellbeing, in turn, impacts on relationships between parental figures. The relationship between the two main themes and sub-themes is presented in the thematic map below (Figure 10.1).

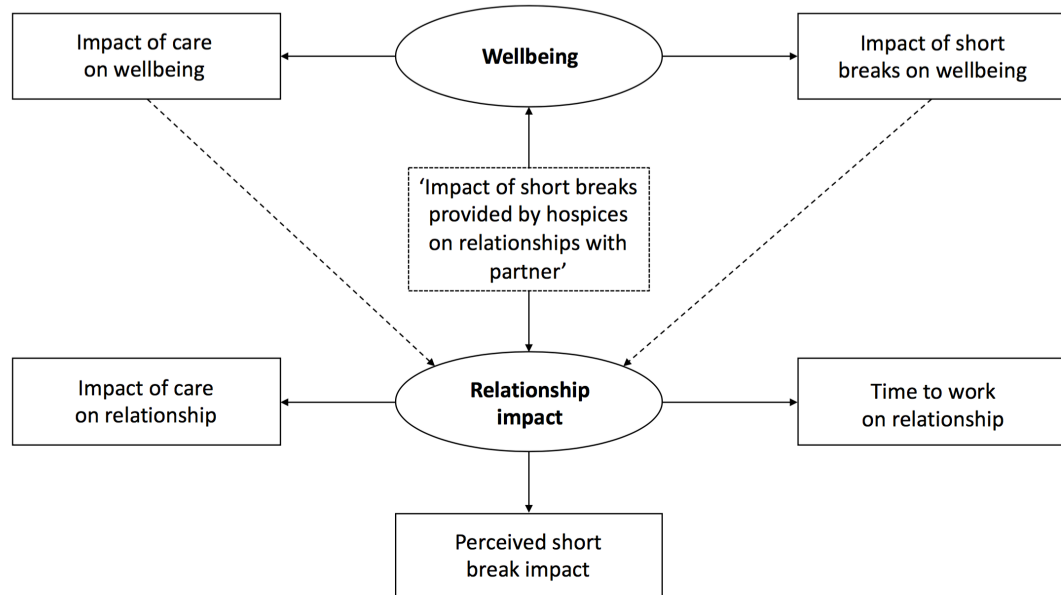


Figure 10.1: Thematic map

10.16.1 Relationship impact

The relationships between parental figures was a central focus of this research and the theme 'Relationship impact' represented this (Figure 10.1). This theme consists of three sub-themes: (1) 'Impact of care on relationship', (2) 'Evaluation of short breaks impact' and (3) 'Time to work on relationship'.

10.16.2 Impact of care on relationship

Twenty-six parental figures (27%) described the impact that care had on their relationship prior to short breaks or when not accessing short breaks. Parents frequently highlighted the link between caring for life-limited or life-threatened children and leading separate lives as a couple. For Parent 69, *"The family operates in two halves; mother with siblings, and father with affected child"*. Likewise, Parent 93 implied that *"without the hospice we would never get a night's sleep or time together as a couple"*. Parent 42 summarised the impact that leading separate lives has:

“In earlier years we didn't have a night carer and one of us had to sleep with the children every night. That obviously causes strain on a relationship”.

It is clear that the strain of care had a negative impact on relationships for a number of parents. For Parent six, short breaks *“helped but our relationship was in trouble already before respite began”*. However, for Parent 13 short breaks came too late, *“our relationship unfortunately had totally broken down by the time we were in receipt of help from our children's hospice”*. The strain placed on relationships and negative impact on relationships is exemplified in the response from Parent 39:

“Before referral to our hospice, my wife and I both felt we were staring into an abyss without any help or support. Things were pretty awful for us back then...it had been several years since our daughter's diagnosis (aged 3) before we were referred to the hospice and this only came about after our relationship had soured to the point of violence within the home”.

Not all the parental figures experienced a negative impact on their relationship due caring, with Parent 91 suggesting that the difficult nature of caring for their daughter brought them closer together:

“In some respects, our daughter's disability has forced us closer than we might have imagined because we have been in very dire and dark situations when we needed each other”.

10.16.3 Perception impact of short breaks on partner relationships

Responses to the open question were coded in terms of a second sub-theme, ‘Perceived short break impact on relationships’. Eighty-six (88%) respondents provided an indication of the impact of short breaks on their partner relationships. Of the 86 responders 64 (74%) stated short breaks had a positive impact and 22 (26%) stated that short breaks had little or no impact on their partner relationship. Several stated that children's hospice short breaks had positively impacted upon their relationships. For example, Parent 76 stated: *“It has saved our marriage and kept our family together”* and short breaks has had a “huge impact” for Parent 24. The explicit, positive impact that children's

hospice short breaks has in maintaining partner relationships is described by Parent 39:

“The services of the hospice became invaluable not only to our daughter but also in regards to the marital relationship. Having that respite played a vital part in keeping our family from falling apart at the seams”.

Most respondents did not directly state that short breaks had saved their marriage or partner relationships. However, there were references to short breaks giving *“time to spend together as a married couple”* [Parent 60], linking to the sub-theme of ‘Time to work on relationship’. Additionally, there are several references to short breaks allowing parents to experience normality in their relationship, such as *“It allowed us to do normal things like go out for meals occasionally”* [Parent 73].

Whilst most parents positively appraised the impact of short breaks on their relationship 26% said that short breaks provided by children’s hospices had made little or no impact to their partner relationships. These perceptions of short breaks impact were mostly associated with using short breaks to spend time with other children, meaning parents *“very rarely/ever get time alone as a couple”* [Parent 20]. Likewise, Parent 92 stated: *“It allows us to spend time with our daughter but doesn’t really give us time for us”*. Parent 32 shared this belief:

“I’m not sure I can validate the impact of the respite received from the hospice on my relationship with my husband as we always have our eldest son with us when visiting the hospice. It does enable us to spend quality time as Mum & Dad with him though”.

For some parents, short breaks had less of an impact on their relationship with their partner for different reasons. For instance, receiving short breaks *“when my husband is at work”* for Parent 18 or being *“tired and overwhelmed”* with other household tasks [Parent 96]. For Parent 26, the partner finding it difficult to hand over care to the children’s hospice resulted in short breaks being spent separately:

“Respite has had a mixed impact on our relationship, not only with my husband but our whole family. My husband finds it very hard to watch others take care of our son, and not to be with him. He doesn't like the setting, and ends up being very grumpy”.

10.16.4 Time to work on relationship

Fifty-five parents (56%) stated that short breaks allowed them to spend time with their partner or to work on their relationship, which contrasted to the time-consuming care routine which normally prevented spending time together as a couple. The time that short breaks allows also appears crucial in facilitating communication between parental figures:

“Respite gives us the time to do something special together that would be more difficult with our child such as go out for a meal or to the theatre. Respite has a positive impact on our relationship as it allows us time to do something fun as a couple away from the day-to-day worries around caring for a child”.

[Parent 79]

“It gives us time to 'chill' without worrying if our daughter is having a seizure, we are more relaxed as we do not have the stress of worrying about her, we can enjoy a meal and chat”.

[Parent 19]

However, Parent 2 and 3 highlighted the importance of using children's hospice short breaks not only to spend time as a couple but also to spend time apart from each other or pursue individual interests as a means of strengthening their relationships:

“Helped us to have much needed time apart - to have space from home and each other. We don't want to spend time together as we have to be co-carers most of the time at home and we don't work well as a team, so communicating can be draining”.

[Parent 2]

“It has a massive positive impact. It gives us time to spend together. But also time to spend on our individual interests which keep us sane. Having a bit of time to do your own thing makes you far less resentful of the time you have to spend caring for your child”.

[Parent 3]

10.16.5 Wellbeing

Parents also felt it was important to describe the impact that caring for a life-limited or life-threatened child had on their lives and what role children's hospice short breaks had in emolliating this impact. Data relating to impact of care developed into the second main theme 'Wellbeing'. In relation to this theme 'Wellbeing' refers to the psychological and physical impact of caring for a life-limited or life-threatened child or young person, in addition to impact on the family as a whole such as other children. Of 98, 31 (32%) of respondents made reference to the impact of caring. The wellbeing theme consists of two sub-themes, 'Impact of care on wellbeing' and 'Impact of short breaks on wellbeing'.

10.16.6 Impact of care on well-being

Aside from the impact that care had on their partner relationship, parents made specific reference to the psychological and physical impact of caring for a child or young person with a life-limiting or life-threatening condition on their well-being. Parents indicated that children's hospice short breaks provided '*a break from being carers*' [Parent 37] or "*allowed us to find sanity*" [Parent 42] suggesting a psychological impact of care on well-being. 'Stress' was a recurring phrase for parental figures who talked about the psychological impact of care such as Parent 47 who felt the stresses of care "24/7".

The physical strain of care was also apparent with parents referencing the need to "*recharge our batteries to continue with caring*" as with Parent 49, or that parents were "*usually exhausted by the time respite comes around*" as in the case of parent eight. Sleep deprivation and exhausting night routines were also frequently discussed as with Parent 46 who stated that "*Nights were often disturbed*". This physical exhaustion that parental figures face may influence how short breaks are used:

"When away we are really tired due to the constant strain of caring for our son, including often being up during the night. So although we enjoy our time away we always need to catch up on sleep and so never manage to go away anywhere exciting".

[Parent 89]

In addition to the psychological and physical impact that care has, several responses outlined their concerns on the impact on the family, especially other children. Parent 26 described feeling *“torn about having to help their brother”* and Parent 46 was concerned about the divide in their family as *“it was always the case of one parent with one child. Often my husband would do things with our older daughter and I looked after our younger daughter. There was nearly always a split.”* The feeling of a divided family was also shared by Parent 69 who felt *“the family operates in two halves; mother with siblings, and father with affected child”*.

10.16.7 Impact of short breaks on wellbeing

In addition to highlighting the impact that short breaks had on their relationship, parental figures also outlined the impact that short breaks had on psychological, physical and family wellbeing. The idea that children’s hospice short breaks gave *“a break from being carers”* [Parent 37] was present in 25 (26%) of responses.

In relation to psychological wellbeing, benefits of short breaks include socialisation and sanity. Several parental figures suggested that short breaks means, *“Feeling not all alone”* [Parent 55]. This view was mirrored by Parent 77 who felt hospice support *“has helped us realise we are not on our own”*. For Parent 57 it was beneficial that *“Hospices lend a listening ear to us as parental figures”*. Sanity was a recurrent concept in the responses of some parental figures. Parent two said they needed *“respite to re-charge our batteries in order to stay sane and get on with our caring role”*, a view shared by Parent 42 *“Respite has allowed us to find sanity”*.

In terms of physical wellbeing the key impact of short breaks was allowing parents *“to catch up with sleep”* [Parent 65]. For Parent 26 the main purpose of short breaks *“is about everyone getting the rest and renewal they need”*. Parent 42 stressed the importance of physical wellbeing and the need to catch up on sleep:

“Respite enables us to sleep and so get less grumpy and be able to find joy in the other small things of life”.

Parents also asserted that children’s hospice short breaks had a positive impact on family wellbeing with Parent 32 proclaiming, *“From a family perspective, the service is totally vital and invaluable”*. In terms of family wellbeing, most parents focused on the fact they could use the time to *“spend quality time with our other child”* [Parent 90] or had *“the ability to just “be a mom” instead of mom and carer for a few days”* [Parent 26]. However, for Parent 26 even this had a downside in regards to the family unit because *“respite is still hard no matter what, because you are reminded of how “not normal” your family is”*.

10.17 Conclusion

This chapter reported findings from a national online survey. One hundred and twenty-six parental figures currently accessing a children’s hospice in the UK completed the survey. The main measure used in the online survey was the Revised Dyadic Adjustment Scale (RDAS), a pre-validated measure of relationship satisfaction. Parents with low RDAS scores received significantly fewer hours of children’s hospice short breaks than those who had higher RDAS scores. By contrast, the location of short breaks whether at home, at a children’s hospice or a combination of both, made no significant difference to relationship satisfaction for respondents. Survey results confirmed interview findings presented in Chapter Eight, with a child’s challenging behaviour, leading separate lives and financial difficulties all leading to lower relationship satisfaction. However, there was no significant difference in relationship satisfaction for those parental figures who also received short breaks from social care, family or friends. Twenty-five responses were received from divorced or separated parents, with over half stating that having a child with a life-limiting or life-threatening condition was the main reason or one of many reasons for their relationship breaking down.

The final section of the chapter concerned the analysis of an open question. Ninety-eight parents responded to the open question, with two key themes developing from the data; ‘Relationship impact’ and ‘Welfare’. The theme of ‘Partner relationship impact’ consisted of three sub-themes; ‘Impact of caring

on relationship', 'Evaluation of short breaks on relationship' and 'Time to work on relationship'. By contrast the theme of 'Wellbeing' consisted of two sub-themes; 'Impact of care on wellbeing' and 'Impact of short breaks on wellbeing'.

11 Drawing the Threads Together: A Discussion of Findings

11.1 Introduction

It is estimated that 40,000 families in the UK have palliative care requirements for their children (Norman and Fraser 2014). As highlighted in Chapter Three, having a child with a life-limiting or life-threatening condition can place emotional, physical and financial strain on parents, who often experience lack of time for each other, physical exhaustion, financial pressures and social isolation (Miller 2002; MacDonald and Callery 2008; McCann et al. 2012; Malcolm et al. 2014; Remedios et al. 2015). There is some limited evidence to suggest that this also impacts relationships between parents (Vogel et al. 1996; Gold 1997; Contact a Family 2003; Steele and Davis 2006). Both Chapters Two and Three underlined how, since the opening of Helen House in Oxford in 1982, the UK has steered the international children's hospice movement and provided a source of short breaks for parents (Worswick 2000; Devanney and Bradley 2012). Chapter Three demonstrated the positive impact short breaks can have for families with life-limited or life-threatened children and young people (McConkey and Adams 2000; Chan and Sigafos 2001; Neufeld et al. 2001; Horsburgh et al. 2002; MacDonald and Callery 2004; Eaton 2008; Thomas and Price 2012; Remedios et al. 2015). However, there is little research exploring the impact of short breaks on the relationship between parents (Robertson et al. 2011). Exploring the impact of frequency, length and differing models of short breaks provided by children's hospices on partner relationships between parents formed the basis for this thesis.

My research indicates short breaks provided by children's hospices have a positive impact on partner relationships between parents. However, the study also indicated that this perceived impact on relationships between parents is mediated by both factors external and internal to the short breaks provided by children's hospices. The theme of 'Every family is different' is representative of external influences, with each family having differing stressors and protective factors. Parents may face 'Pressure and conflict between parental figures'

through parenting a child or young person with challenging behaviour, may lead separate lives or may have financial disagreements. Conversely the relationship between parents may be protected by 'Alternative short breaks' such as breaks provided by family members. This chapter utilises these external influences developed from semi-structured interview and national online survey findings to redefine the ABCX model of adjustment and adaptation, outlined in Chapter Four, for partner relationships of parents with children or young people with life-limiting or life-threatening conditions (McCubbin and Patterson 1983).

Internal influences refer to those elements which effect 'Short break quality'. My research indicates that if short breaks are of poor quality, parents perceive the short break as having little impact or benefit regardless of how much is received. 'Short break quality' was influenced by 'Building trust' and 'Getting a real break'. When discussing the importance of 'Building trust' parents referred to the frequency of short breaks and staff knowing their child. By contrast, parents referred to the differences in short breaks at home and at their hospice, when referring to 'Getting a real break', with home short breaks often viewed as being intrusive to both family life and their relationship with their partner; therefore, preventing them from getting an actual break.

Following the pragmatic principle of using the most appropriate method to address the research aim and objectives, a two-phase sequential mixed methods design was implemented (Creswell and Clark 2011; Bacon 2012). The first phase utilised semi-structured interviews with parents, currently accessing children's hospice short breaks, to explore the effect of parenting children or young people with life-limiting or life-threatening conditions on their relationship and the impact of short breaks. This informed the second phase, a national online survey, which sought to corroborate and further investigate interview findings. Chapters Seven and Ten presented findings from semi-structured interviews and a national online survey respectively. The first section of this chapter discusses the integrated findings from both the semi-structured interviews and national online survey in the context of literature outlined in Chapters Two, Three and Four. The final section of this chapter explores the

strengths and weaknesses of this study in relation to the methodology and procedure of the study.

11.2 External influences: redefining the double ABCX model of adjustment and adaptation

Findings from semi-structured interviews regarding the impact of frequency of short breaks on relationships between parents were conflicted, with some parents explicitly stating short breaks had positively impacted their relationship by giving them time to spend together and providing opportunities to foster their relationships. However, other findings from semi-structured interviews conflicted with this with some parents stating short breaks had made little difference at all to their relationships. This was despite survey findings that non-distressed couples received significantly more hours of short breaks than those who were distressed, suggesting that short breaks positively impact the relationship between parents. Findings from the online survey also supported short breaks having a positive impact with 74% of respondents saying that short breaks positively impacted their relationships. Those parents who felt short breaks had made little difference to their relationship cited using short breaks for individual activities or other children, rather than spending time as a couple.

Findings from both stages of the research are key in demonstrating the impact of short breaks on relationships between parents is complex and extends beyond numbers of hours and frequency of short breaks received. Complexity arises from external and internal influences on short breaks provided by children's hospice influence their impact on partner relationships. Influences external to hospice short breaks are represented by the themes 'Pressure and conflict between parental figures', 'Leading separate lives' and 'Alternative short breaks'. Influences internal to hospices short breaks however, refer to 'Short break quality' informed by short break frequency and short break model, represented by the themes 'Building trust' and 'Getting a real break'.

As outlined in Chapter Four, The Double ABCX Family Model of Adjustment and Adaptation (McCubbin and Patterson 1983) has been used to explain

relationship or marital adaptation (Karney and Bradbury 1995). The Double ABCX model (Figure 11.1) comprises four components: (aA) initial efforts to cope with an event can lead to additional stressors, a process known as ‘pile-up’, (bB) initial levels of resources which can be enhanced in response to an event and (cC) initial perceptions of an event, which can influence future event perceptions. The subsequent response to the crisis (X) can either be adaptive or maladaptive. In applying this model to the research outlined in this thesis the original stressor to the relationship between parents (a) would be a child or young person with a life-limiting or life-threatening condition and (x) would represent the impact on the relationship between parents. The next section will outline contributory stressors of a modified model, represented by (aA) in the ABCX Model.

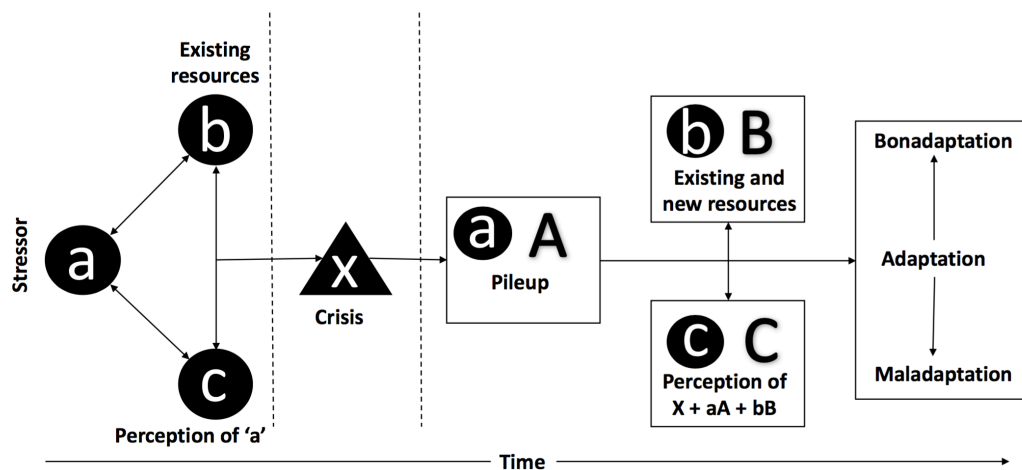


Figure 11.1: Original Double ABCX model of adjustment and adaptation (McCubbin and Patterson 1983)

11.3 External influences: ‘pressure and conflict between parental figures’ as contributory stressors

As indicated in Chapters Eight and Ten, parents participating in both semi-structured interviews and the online survey spoke of the impact of ‘Pressure and conflict between parental figures’ of caring for a life-limited or life-threatened child on their relationship. The theme of ‘Pressure and conflict between parental figures’ concerned numerous pressures such as financial difficulties, leading separate lives and challenging behaviour. This increased pressure faced by parents, resulted in increased conflict in their relationship. The impact of

pressure of caring on families or individual parents is widely reported (Kirk 1998; Chan and Sigafos 2001; Horsburgh et al. 2002; Nelson 2002; Ingleton et al. 2003; Hewitt-Taylor 2005; Mash and Lloyd-Williams 2006; Yantzi et al. 2007; Eaton 2008; Thomas and Price 2012; Hunt et al. 2013; Remedios et al. 2015). The theme 'Pressure and conflict between parental figures' suggested that strain increases as children get older and physically more difficult to manage, with many parents reporting subsequent health problems due to the physical nature of care. In addition, fluctuating health of life-limited and life-threatened children was highlighted as increasing strain and pressure on parents due to 'pile-up' (Bb).

In a grounded theory study of parents' experiences of caring for children with life-limiting conditions, Steele and Davis (2006) found parents reported both emotional and physical impacts due to the pressure of caring. Emotionally, fear and grieving were commonly reported, with some parents experiencing mental health problems such as depression or anxiety. Caring for children or young people with a life-limiting or life-threatening condition had a physical impact, with parents reporting exhaustion, long-term injuries and sleep deprivation. However, few studies have explored the pressure of caring for a life-limited or life-threatened child on the relationship between parents and how short breaks may alleviate this pressure. The present study is novel in relation to pressures faced by parents impacting on the perceived benefits of short breaks on their relationship. In addition to the age of children and fluctuating health, parents highlighted three main contributory stressors, which are outlined in the next three sections: challenging behaviour, leading separate lives and financial pressures.

11.3.1 Stressor 1: Challenging behaviour

The theme of 'Pressure and conflict between parental figures' developed from the finding that challenging behaviour impacts the relationship between parents, leading to increased pressure and conflict. This was a factor not previously considered prior to data collection, but was raised as an important issue by parents during semi-structured interviews. Challenging behaviour referred to aggressive or violent behaviour from a child or young person to one or both of

their parents. Findings from the national online survey confirmed that challenging behaviour impacts on relationship satisfaction, with those parents who experience challenging behaviour from their child or young person having significantly lower relationship satisfaction scores.

Challenging behaviour includes self-injury, repetitive behaviours and aggressive behaviours (Poppes et al. 2010). It was difficult to find evidence from previous literature to support or refute this finding in relation to children's palliative care and the impact of challenging behaviour between parents. However, Malcolm et al. (2012) explored the link between symptomology and two life-limiting conditions, mucopolysaccharide (MPS) and Batten disease. Challenging behaviours experienced included repetitive behaviours, agitation, hyperactivity and sleep disturbance, impacting upon family life. Several studies have suggested that physical problems or chronic pain are linked to presentation of challenging behaviour in children (Stallard et al. 2001; Chadwick et al. 2002; Breau et al. 2003; Chadwick et al. 2008; de Winter et al. 2011); both physical problems and chronic pain are often present in children or young adults with life-limiting or life-threatening conditions. Specific life-limiting or life-threatening conditions such as Rett syndrome or Cornelia de Lange syndrome are associated with challenging behaviour (Poppes et al. 2010). Challenging behaviour has also been found in life-threatening conditions such as cancer (Woolfson 2004).

Due to the paucity of literature available on children's palliative care and the impact of challenging behaviour, literature relating to challenging behaviour and developmental disorders was scrutinised. Past research has found that children who exhibit challenging behaviour place strain on relationships within the family unit (Quine and Pahl 1985; Dyson 1997; Hubert 2011; Gallagher and Whiteley 2013) and is often highlighted as one of the main sources of parental stress (Floyd and Gallagher 1997; Hastings and Beck 2004; Blacher and McIntyre 2006; Plant and Sanders 2007; Mazzucchelli and Sanders 2011; Ludlow et al. 2012; McGill 2012; Griffith and Hastings 2014). Breakdown of relationships between parents is common when a child or young person displays challenging behaviour (Challenging Behaviour Foundation n.d.).

Studies into challenging behaviour in children with learning disabilities provide support for the theme of ‘Pressure and conflict between parental figures’. Challenging behaviour is more prevalent in children with learning disabilities. Parents of children with learning disabilities show increased psychological distress and mental health issues in compared to those of typically developing children (Dunn et al. 2001; Orsmond et al. 2003; Hastings and Beck 2004; Eisenhower et al. 2005; Yannamani et al. 2009; Baker and Allen 2012).

These studies support the notion that partner relationships are put under significant pressure by challenging behaviour, therefore increasing the need for short breaks. The potential impact of short breaks for parents experiencing stresses such as challenging behaviour is supported by the importance of social support as a protective factor against parental stress (Berkman et al. 2000; Dunn et al. 2001; Weiss 2002; Uchino 2006; Ludlow et al. 2012). Chadwick et al. (2002) found that parents who had children with challenging behaviour were likely to express a need for short breaks due to the associated physical and mental strain.

11.3.2 Stressor 2: Leading separate lives

The theme ‘Together but separate’ developed from identifying that parents caring for a life-limited or life-threatened child or young person face pressure on their relationships due to not being able to spend time together. Numerous studies have linked the amount of time couples spend together and partnership satisfaction (Hill 1988; Zabriskie and McCormick 2001; Amato et al. 2007; Claxton and Perry-Jenkins 2008; Johnson and Anderson 2013).

This was supported by findings from the national online survey which found parents who led separate lives, due to the care of their child, had significantly lower relationship satisfaction than those parents who did not lead separate lives. Indeed, most parents emphasised that whilst they may be working together as a team to care for their child and living under the same roof, they were separate as a romantic couple. Even with children who do not have a life-

limiting or life-threatening condition, couples tend to experience an initial decline in shared activities and relationship satisfaction at the birth of their first child (Claxton and Perry-Jenkins 2008; Lawrence et al. 2008; Doss et al. 2009). However, once adjusted to their new child, most couples find time for joint activities again (Claxton and Perry-Jenkins 2008).

Parents perceived two main reasons for leading separate lives as romantic couples; care routines and working long hours. Extensive care routines were often described, with one parent caring for life-limited or life-threatened child and the other spending time with siblings. Secondly, usually at least one parent tended to give up full-time work to care for their child, often resulting in the second parent working longer hours to compensate. The impact of caring and loss of normality, including having to give up work, regular hospital visits or operations, loss of mobility in child or young person, behavioural or emotional changes and medical equipment in the home, is described in research (Wood et al. 2010). In addition to resulting in little time together, parents in both roles frequently talked of conflict arising from resentment. Parents stated it was important to spend more time together as a couple, but in reality found this very difficult to do.

Leading separate lives had a significant impact on the type of communication between parents. Parents had little time to talk to each other and any communication that does occur is practical in nature, around the care of their child, at the expense of emotional or supportive communication. Bodenmann et al. (2007a; 2007b) suggested that when couples do not spend time together, there is less opportunity to express feelings and personal needs; resulting in less mutual understanding and increased negative communication. Further supporting this notion, research by Thompson and Spanier (1983) found that leading separate lives both behaviourally and emotionally is associated with the final stages of relationship breakdown.

This was an important finding in relation to the research aims for two reasons. Firstly, it highlighted the importance that short breaks could potentially have on the relationship between parents, providing time to either spend to spend

together as a couple or to talk about the emotional impact of caring on their relationship. At least one parent stated that short breaks from a children's hospice provided the opportunity to 'patch up the cracks' that can build in a relationship due to the pressure and conflict of caring. Secondly the finding provided an explanation of why separation and divorce rates for this population are low (Horsburgh et al. 2002) despite dissatisfaction with the relationship, it is not practical to separate. Practicality was a crucial factor when discussing relationships, with parents commenting that even if they did want to separate, this would not be possible due to reliance on each other to either work or care for their child.

11.3.3 Stressor 3: Financial difficulties

In addition to identifying the impact of challenging behaviour, the theme of 'Pressure and conflict between parental figures' was also developed from recognising the financial situation of families as a potential source of pressure and conflict within partner relationships. Parents spoke of finances as being a contributory factor to pressure on their relationship, with at least one parent having to give up work to care full-time for their child. This in itself was not a novel finding, past research has outlined the impact of caring for children with complex needs on families' financial situations (Horsburgh et al. 2002; Corkin et al. 2006; Thomas and Price 2012; Hunt et al. 2013; Gardiner et al. 2014). As part of a survey of over 3,500 families Contact a Family (2014), a charity for families with disabled children, explored the financial impact of raising a disabled child. Their results support the theme of 'Pressure and conflict between parents' found in this research. Specifically, their results support the pressure and conflict between parental figures that can arise from financial difficulties; with 93% of parents feeling anxious or stressed, 56% stating they have argued with their partner or children, and 13% stating their marriage or relationship had broken down due to financial difficulties.

Conversely, the findings that formed the theme of 'Pressure and conflict between parental figures' highlighted that those parents who were in a fortunate financial situation either felt less pressure on their relationship or less need to

access short breaks if they could afford their own alternative compared to those parents in a less fortunate financial situation. This would indicate that being in a fortunate financial situation could act as a protective resource (bB).

11.3.4 Multiple contributory influences to stressors

The theme of ‘Pressure and conflict between parental figures’ was further strengthened by online survey findings on multiple contributory factors. As noted in the preceding three sections, both semi-structured interview and online survey findings highlighted challenging behaviour, financial disagreements and leading separate lives as contributing to reduced relationship satisfaction. A related finding was the number of contributing factors experienced by parents and the subsequent impact on relationship between parents. Those parents who had multiple contributing factors had significantly lower relationship satisfaction than those who had fewer or no contributory factors.

11.3.5 Applying stressors to the Double ABCX model

The Double ABCX model of adjustment and adaptation (McCubbin and Patterson 1983) can explain these findings. As outlined in Chapter Four, the Double ABCX Model is able to explain great variation in relationships (Karney and Bradbury 1995) over behaviourist, attachment based and dynamic goal theory explanations of partner relationships. The Double ABCX Model consists of four components: (aA) initial efforts to cope with an event can lead to additional stressors, a process known as ‘pile-up’, (bB) initial levels of resources which can be enhanced in response to an event and (cC) initial perceptions of an event, which can influence future event perceptions. The subsequent response to the crisis (xX) can either be adaptive or maladaptive.

Applying the Double ABCX model to the present research, the initial stressor (a) would be the birth or diagnosis of a child with a life-limiting or life-threatening condition. Existing resources (b) relates to resources available at birth or diagnosis and (c) relates to how parents perceive having a child with a life-limiting or life-threatening condition. In line with the findings and the ABCX Model, challenging behaviour, financial disagreements and leading separate lives would be stressors (aA) which can ‘pile-up’ over time.

Relationship satisfaction between parents would be factor X (Figure 11.2). However, finances could also act a resource (bB) when parents are in a fortunate financial situation, enabling them to purchase private short breaks.

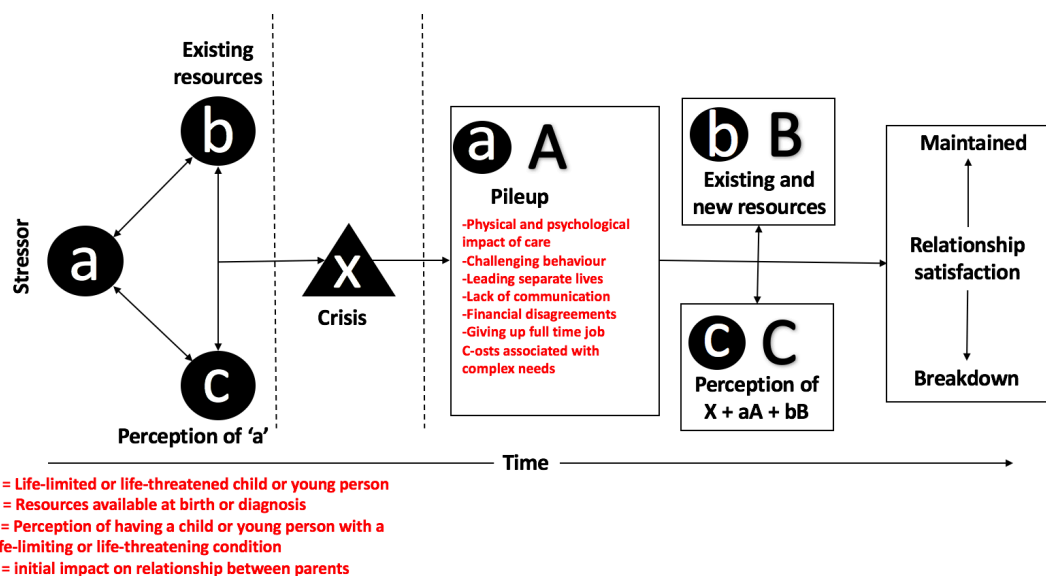


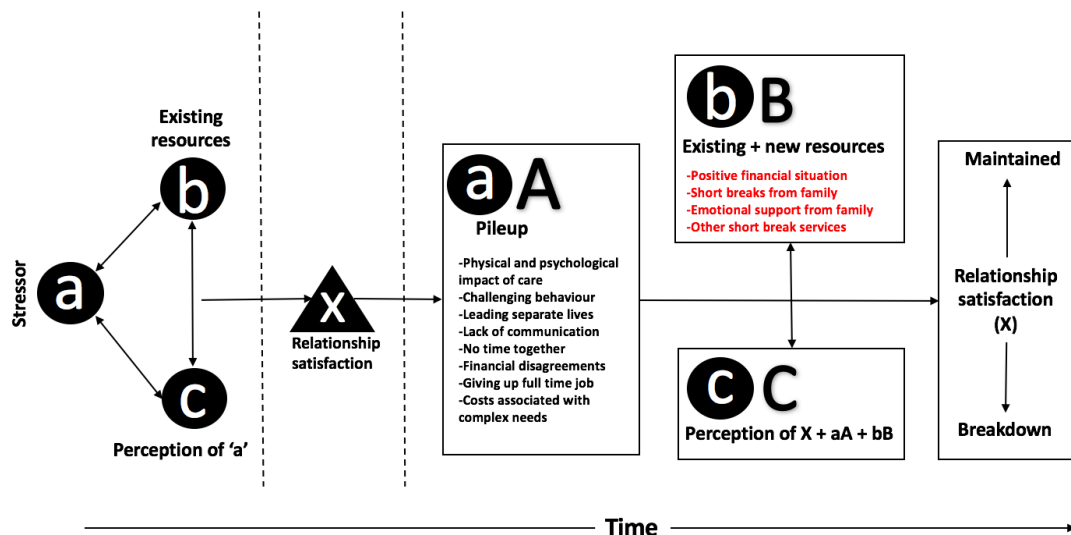
Figure 11.2: Double ABCX model with stressors included

11.4 External influences: 'alternative short breaks' as a resource

The theme 'Alternative short breaks' developed from the finding that the amount of help that parents received from alternative sources to children's hospices impacts the pressure on partner relationships and perceived importance of short breaks received from hospices. Semi-structured interview findings revealed that a number of parents received alternative short breaks from family members, usually grandparents, and for some parents this was perceived as a real break because family members were trusted and knew the child's needs, demonstrating links to the themes of 'short break quality' and 'building trust'. For others, it was close friends who provided alternative short breaks for the parents. With this in mind, those parents who receive 'Alternative short breaks' from family or friends, may face less pressure on their relationship and be less reliant on short breaks from children's hospices (Figure 11.3). This is supported by past research which found that parents saw extended family as a distinct source of short breaks (MacDonald and Callery 2004; Merriman and Canavan 2007; Robertson et al. 2011).

Findings from the national online survey partially support this notion; parents in the survey who received short breaks from family members had significantly higher relationship satisfaction than those parents who did not. However, only 11% of respondents received help from family members, which was fewer than predicted based on findings from semi-structured interviews. This suggests that few parents have access to alternative support outside children's hospice short breaks. Supportive findings from the national online survey for friends as an alternative source of short breaks was inconclusive as too few respondents received any help from friends to carry out statistical analysis. However, findings from the semi-structured interviews suggest not all parents have access to alternative short breaks, depending on individual circumstances. Those who did not receive short breaks from family or friends gave three main reasons for this: age of grandparents, proximity to family and burden of care.

Receiving short breaks from extended family members has previously been explored (Beresford 1994; Kirk 1999; MacDonald and Callery 2004, 2008). MacDonald and Callery, in particular, found that parents often received support from family in infancy, but that as children grew older and needs became more complex, short breaks from family members reduced. This has been compounded by parents feeling uncomfortable in asking family or friends for help, for fear of imposing (MacDonald and Callery 2004, 2008). The increasing physical size of a child means that ageing grandparents have been found unable to provide physical care (MacDonald and Callery 2004, 2008). In relation to friends, MacDonald and Callery found parents felt that reciprocity among friends was imbalanced due to the increasing complex needs of their child. Consequently, parents become increasingly socially isolated from family and friends (Eaton 2008; Ling 2012) and more reliant on short breaks from other sources such as children's hospices (MacDonald and Callery 2008).



a = Life-limited or life-threatening child or young person
b = Resources available at birth or diagnosis
c = Perception of having a child or young person with a life-limiting or life-threatening condition
x = initial impact on relationship between parents

Figure 11.3: Double ABCX Model with resources included

11.5 'Every family is different': factors external to hospice short breaks

An important finding was the concept that every family is different, depending the stressors faced and resources available as represented by the ABCX Model in Figure 11.3, influencing the relationship satisfaction between parents. For example, Debbie and Mark's (South-West) stressors (aA) were low as their daughter's condition was relatively stable and not associated with challenging behaviour. However, they were aware that they were starting to lead separate lives. They had supportive resources (bB) in the form of both practical and emotional support from family and friends. Rather importantly they were in a fortunate financial situation and were able to privately fund daily short breaks. As a result, there is less strain on the relationship (xX) between parents and they were less reliant on short breaks from their hospice.

By contrast, Eva and her husband John lead separate lives due to the care of their son Carl. Carl is seventeen and displays aggressive behaviour, resulting in physical and mental strain for both parents, and has at times caused direct conflict between the couple. In addition to these stressors (aA) Eva feels John's family are unsupportive and this also causes conflict. In terms of resources (bB) whilst they receive little help from family, short breaks are

received from social care in the form of direct payments. In this example, stressors (aA) outweigh resources (bB) and consequently the relationship (xX) between parents is under great strain and will benefit from short breaks. However, findings also demonstrated that internal short break factors need to be considered when the impact of short breaks on the relationship between parents. Two factors identified in the study were 'building trust' and 'getting a real break'.

11.6 Internal influences: 'building trust' and short break frequency

The first novel finding related to internal short break influences concerns building trust between parents and children's hospices, which in turn is influenced by the frequency of short breaks. In fact, semi-structured interview findings highlighted a number of layers to this. Firstly, many parents indicated feelings of guilt or sadness at having somebody else care for their child, especially if the short break was occurring at the children's hospice. It was therefore important to parents that a level of trust was built with staff at the children's hospice through being certain that their child's needs were being met. This is further endorsed by the emphasis that many parents placed on their children enjoying short breaks.

One of the main reasons building trust between parents and staff at children's hospices is important is to encourage parents to utilise short breaks. If short breaks are infrequent, the staff are less likely to know the child well and meet their needs effectively than if taken more frequently. The importance that parents place on hospice short break staff knowing their child's needs is highlighted by the fact that some parents stated they would use a short break service that they considered to be intrusive as long as the staff knew their child's needs.

There is very little research investigating the frequency of short breaks. Research by Robinson and colleagues (Robinson and Jackson 1999; Robinson et al. 2001) found that parents were less likely to access short break services if they were infrequent or did not meet their child's needs, supporting the findings

of the present research. Research has also indicated that infrequent short breaks result in increases in behavioural problems because of staff not knowing the child (Robinson et al. 2001). However, these findings were not directly linked to trust in staff.

The theme ‘Building trust’ is supported by past research which found parents initially struggle to accept short breaks (Neufeld et al. 2001; Eaton 2008); making subtle judgements about the suitability of short break services and whether to accept help (Ingleton et al. 2003). In a study carried out by Thomas and Price (2012), parents accessing short break services spoke of the importance of building trust with providers and the need for well trained staff. Related to the notion of trust are issues of continuity, competency and knowledge of staff, all having been highlighted in past research (Kirk 1999; Eaton 2008; Wood et al. 2010).

11.7 Internal influences: short break model and ‘getting a real break’

There is no previous research exploring the impact of varying models of children’s hospice short breaks on relationships between parents. Findings from the national online survey found that there was no significant difference in relationship satisfaction based on the type of short break received from children’s hospices. Those parents who received short breaks either at home, a hospice or a combination of both, had similar relationship satisfaction scores. Whilst this might initially suggest that the type of short break received makes no significant impact on the relationship between parents, semi-structured interview findings and previous literature of short break models can explain this lack of difference in terms of individual differences.

A key finding from semi-structured interviews was the theme of ‘Getting a real break’, parents perceptions of whether they were getting an actual break, which encompassed two assumptions. First, parents were aware that there was an expectation short breaks were used for rest and recuperation. Secondly, the location and subsequent length of short breaks will often influence whether parents ‘get a real break’. Typically, findings from semi-structured interviews

revealed that breaks in the home tend to be shorter in nature than those provided at children's hospices. This is supported by previous literature, which found short breaks in homes to be three to four hours long (MacDonald and Callery 2004). As such, short breaks in homes were associated with 'firefighting', such as catching up on household chores or sleep, rather than utilising the time to spend together as a couple. However, considering this research highlighted tiredness and physical exhaustion as key pressures on relationships between parents, utilising short breaks in this way could still have an indirect benefit on relationships between parents.

Importantly, home short breaks were associated with intrusion and loss of privacy. When describing parents' experiences of receiving short breaks in the home or in a children's hospice, Eaton (2008) found that parents feel their privacy is not always considered. Whilst intrusion and loss of privacy has been discussed in previous literature (Kirk 1999; Harrigan et al. 2002; Eaton 2008), this finding was original in that the impact of short break intrusion has not been considered in relation to how it impacts the relationship between parents. Findings from semi-structured interviews revealed that the feeling of intrusion reduced potential benefits of short breaks and in some cases negatively impacted on relationships between parents. Having short breaks in the home meant that in addition to not being able to relax, parents feel unable to express emotion or affection with their partner in front of carers. This extended to arguments and conflicts, with parents feeling unable to have an argument in front of carers. Whilst intrusion and home short breaks has been explored before, the finding is novel and meaningful in considering how short breaks can be beneficial to partner relationships.

However, the impact that intrusion of home short breaks has on relationships was not universal and was mediated by two factors: environment and trust. The home environment mediated how much intrusion is felt by parents. Those parents who had a spacious house or a separate location in their home for short breaks, such as a converted garage, did not feel the impact of intrusion. By contrast, those with smaller houses often felt the impact of intrusion much more.

11.8 ‘Short break quality’: factors internal to hospice short breaks

The perceived quality of short breaks is shaped by two internal influences: building trust and getting a real break (Figure 11.4). Building trust is influenced by frequency of short breaks and is associated with hospice staff knowing children and their needs. For example, Mary (South-West) perceived the quality of hospice-based short breaks at her local hospice to be of poor quality because breaks were too infrequent for staff to know her child’s medical needs; consequently, she would not make use of the short breaks offered.

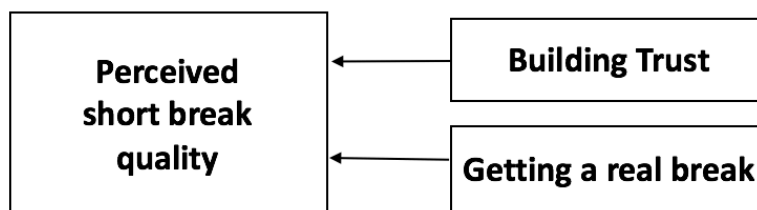


Figure 11.4: Influence of trust and getting a real break on short break quality

11.9 Understanding the intricacy of parental relationships and short breaks required: bringing the modified ABCX model together

The research has highlighted the intricacy of relationships between couples, between parents and children, resources available and the individualised support needed. The impact that children’s hospice short breaks will have on parental relationships varies because every family is different, with their own stressors, resources, needs and family dynamics. To understand children’s hospice short break impact on partner relationships, both external and internal influences need to be considered (Figure 11.5).

Individual family circumstances influence the impact that short breaks have on relationships in two ways. First, the combination of stressors (e.g. challenging behaviour, leading separate lives and financial difficulties) and resources (e.g. positive financial situation and support from family) will determine if the relationship between parents is distressed or non-distressed and how parents perceive their situation. If the relationship between parents is distressed due to high stressors and low resources, short breaks from children’s hospices will be

more beneficial. Secondly, individual circumstances will effect what parents want from hospice short breaks, therefore influencing perceived short break quality and impact on partner relationships.

Applying modified ABCX model to Steve (West-Midlands) demonstrates the intricacy of factors contributing to stress on partner relationships and the beneficial impact that hospice short breaks can have in relieving this stress. Steve's son Bruce requires care twenty-four hours a day, seven days a week; consequently, both Steve and his wife have given up full-time work. This, in addition to extra costs such as heating bills and fuel costs to hospital appointments, has placed financial pressure on the couple (aA). Steve has back problems due to the physical nature of care and is awaiting surgery (aA). Caring for Bruce has led Steve and his wife to lead separate lives as a couple, with Steve sleeping downstairs so he can attend to Bruce during the night (aA). Increased financial pressure and lack of time together place inherent pressure on the relationship between Steve and his wife. In addition, Steve tends to be the primary carer for Bruce resulting in a lack of time with his wife or his daughter. Steve's narrative demonstrates the partitions that can exist between couples and between parents and their children due to the nature of caring for children with life-limiting or life-threatening conditions.

Bruce is unable to access short breaks run by local social care as they cannot meet his health needs, removing one potential resource (bB). No practical support is received from family because they have seen how rapidly Bruce's health can decline (bB). Bruce demonstrates the complexity surrounding finding suitable short breaks. Alternative sources of short breaks may be available but parents will be unable to utilise the short breaks if they do not meet the child's needs. As a consequence, children's hospice short breaks are extremely important to Steve. Steve openly admitted it was initially difficult to hand over care to the children's hospice, but he knows that his local hospice can meet Bruce's needs, demonstrating trust. Both Steve and his wife find home short breaks intrusive and therefore value longer short breaks at the hospice, allowing both opportunities to recuperate and spend time together as a couple.

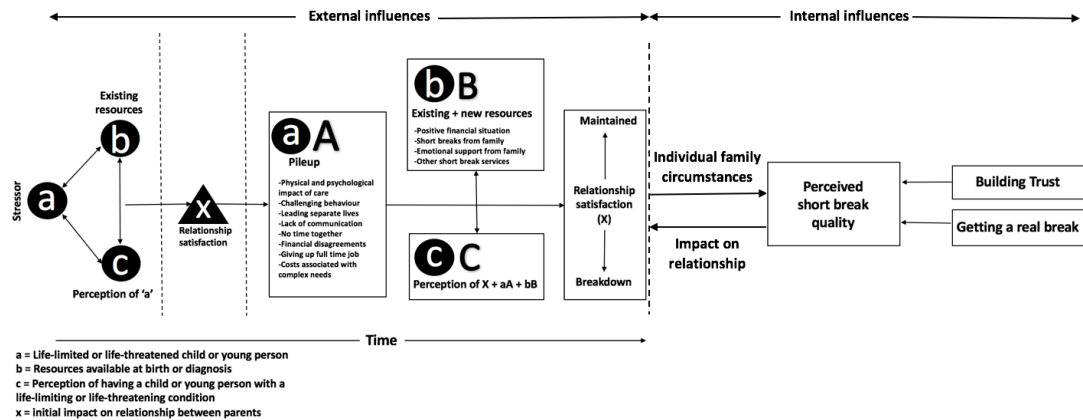


Figure 11.5: Modified ABCX model for the impact of children's hospice short breaks on partner relationships

11.10 A final consideration: 'children before relationship'

The final theme of 'children before relationship' highlighted the complex dynamic between couple relationships and parental relationships with other children, with parents concern for their other children taking priority over their relationship as a couple. Whilst parents had openly spoke about the pressures their relationship had been put under due to caring for a life-limited or life-threatening child, they still believed that short breaks should mainly be used for the benefit of their other children.

All but one of the parents interviewed for the research had other children and it was clear that the majority of these parents felt a great deal of guilt and regret at having to spend so much time caring for their brother or sister with a life-limiting or life-threatening condition at the expense of healthy siblings. Parents were very aware that having a child with life-limiting or life-threatening conditions meant that healthy siblings were faced with difficult issues like illness and death at earlier ages than their peers, with concerns over the emotional impact it had. Parents were also conscious that their other children were missing opportunities and experiences that 'normal' families would have such as going on holiday or having friends over to stay.

Previous literature concurs with findings from this study that suggest siblings of children with complex needs can be impacted (Gaab et al. 2014; Malcolm et al. 2014). Older children who have a younger sibling with a life-limiting or life-threatening illness experience significant life changes, almost living a

completely new life to what was known before (Woodgate 2006; Nolbris et al. 2007), often becoming young carers themselves (Gaab et al. 2014). Children who become young carers are more likely to experience high anxiety and psychosomatic symptoms (Hamama et al. 2008). Woodgate (2006) suggests that siblings lose their role within the family and face enduring sadness.

Studies have also found that siblings of children with life-limiting or life-threatening illnesses face unequal parental attention (MacDonald and Callery 2008; Dauz Williams et al. 2010; Read et al. 2011; Gaab et al. 2014). Numerous research studies have also found that siblings exhibit psychological (Sharpe and Rossiter 2002; Woodgate 2006; Hamama et al. 2008; Besier et al. 2010) and behavioural problems (Hamama et al. 2008; Besier et al. 2010). There are few studies exploring parents' understanding of the impact on healthy children, but one study found that mothers were acutely aware of the impact on healthy siblings of children with Prader-Willi syndrome (Mazaheri et al. 2013). Additionally, Eiser (1993) found that children's adjustment to their sibling's illness is an additional stress factor for parents.

Therefore, parents interviewed saw short breaks as opportunities to focus on their other children, taking them out on activities with short breaks or going on holiday with longer ones. Research has found social care short breaks gave parents a break from focusing on one child and giving time to spend with siblings; benefits of being able to spend time with other children has been reported elsewhere also (MacDonald and Callery 2004; Beresford et al. 2007; Wilkie and Barr 2008; Welch et al. 2012). This finding has important practical implications when considering the impact that short breaks may have on the relationship between parents, because parents made it clear that their children have priority over their relationship when utilising short breaks. So, although short breaks may be offered as opportunities for couples to spend time together, they are still likely to utilise it for their children.

11.11 Methodology discussion

The research benefited from using pragmatism as the philosophical underpinning for the research. Pragmatism has a long history, resulting in

researchers getting confused about what pragmatism is (Cherryholmes 1992; Bishop 2015). One of the most common misconceptions is that pragmatists are entirely utilitarian in nature or 'just do what works' (Cornish and Gillespie 2009; Morgan 2014). This is a gross misunderstanding of pragmatism; mixed-methods research can benefit from applying pragmatic principles of putting the research aim and objectives first and foremost (Tashakkori and Teddlie 2003; Creswell and Clark 2011). Placing emphasis on the research aim and objectives resulted in the most suitable research method, mixed methods, being chosen (Creswell and Clark 2011). Secondly, pragmatism benefitted this research by embracing the epistemological and ontological divisions between quantitative and qualitative approaches (Bryman 2006a; Dures et al. 2010; Morgan 2014). Pragmatism does this by acknowledging the differences between qualitative and quantitative approaches, but rather than see them as incompatible (Howe 1988), pragmatism views them as two different perspectives on objectives to be resolved (Bishop 2015).

A further strength of the research methodology was the use of a mixed methods design in answering the research aim and objectives. A strength of this design was combined methodologies, enhancing the study and providing greater depth to findings by approaching the research aim and objectives from two different perspectives, one qualitative and one quantitative (Johnson et al. 2007).

Utilising a mixed methods design meant that the weaknesses of the two methods used, semi-structured interviews and surveys, offset each other (Bryman 2006a; Johnson et al. 2007; Teddlie and Tashakkori 2009; Creswell and Clark 2011). Semi-structured interviews provide rich data, but lack generalisability and surveys provide generalisability, but lack the depth of semi-structured interviews. Just as importantly the sequential timing, semi-structured interviews informing survey design, improved the face validity of the survey.

The use of thematic analysis for both the semi-structured interview and survey open question data had both strengths and weaknesses. The main strength of thematic analysis is that unlike other forms of analysis such as phenomenology, it is not tied to a specific philosophy or worldview. However, the flexibility of thematic analysis is often also one of the main criticisms (Howitt and Cramer

2014). There is little guidance on how to conduct a thematic analysis and procedures followed are often poorly described (Braun and Clarke 2006; Howitt and Cramer 2014). This potential weakness was overcome by adhering to Braun and Clarke's (2006) guidelines for carrying out thematic analysis.

Whilst the semi-structured interviews had an interview guide, adhering to the set questions was avoided, allowing a degree of flexibility around the topic of short break impact on relationships. However, this approach had both advantages and disadvantages. On the positive side, the flexible and open nature of the interviews was important in building rapport with the interviewees. Building rapport and putting interviewees at ease was important as the topics under discussion were potentially sensitive (Lee and Renzetti 1990). Additional benefits of semi-structured interview flexibility were being able to naturally ask questions as the interview developed and the discovery of new topics that had not been considered before. For example, a number of parents stated that they worry about the impact having a child with complex needs has on their other children and therefore would rather use short breaks for the siblings than themselves as a couple. This finding is relevant to the research aim and objectives, and may not have been found with a rigid interview schedule.

Allowing flexibility within the semi-structured interview is not without pitfalls; most notably an increased workload. A flexible interview schedule invariably led to longer interviews with some content that was not wholly relevant to the research objectives. In turn, longer interviews increased the amount of work required during transcription (Britten 1995; Alcock and Iphofen 2007). Nonetheless, the benefits of exploratory interviews seemingly outweigh the negative additional work.

An additional strength of the study methodology is the sample consisted of both mothers and fathers. Men are typically difficult to recruit to psychological or nursing research (Polit and Beck 2008, 2009; Macdonald et al. 2010; Polit and Beck 2013). Forty percent of those who took part in the first phase, semi-structured interviews, and sixteen percent of those who took part in the second phase, the online survey, were males. No participants in either the interviews or

survey were same-sex couples; this could be considered a limitation. However, it is hard to determine the extent of the drawback, as there is no previous literature on the number of same-sex couples who have a child or young person with a life-limiting or life-threatening condition.

Another possible limitation of the study methodology was the survey being distributed online rather than distributed via post. It could be argued that this limits the population the survey can reach (Jones et al. 2008). However, there are drawbacks to distributing a paper survey via post including cost of printing and postage, time involved in designing, data protection surrounding addresses, manual data entry and low response rates (Cope 2014). By contrast the online survey was distributed via participating hospices, low-cost in terms of development and distribution, and data is automatically populated into an excel spreadsheet- significantly reducing workload and potential for human error in data entry (Jones et al. 2008; Duffett et al. 2012; Cope 2014).

11.12 Chapter summary

Key findings and themes from the study were discussed in context of literature previously presented in Chapters Two, Three and Four. Findings from both semi-structured interviews and the national online survey indicated the impact that short breaks have on the relationship between parents is shaped by both external and internal influences, represented by the themes ‘Every family is different’ and ‘Short break quality’ respectively. The theme of ‘Every family is different’ and related themes were used to redefine the double ABCX family adjustment and adaptation model (section 11.2). Contributing stressors (section 11.3) to the relationship between parents were influenced by the themes ‘Pressure and conflict between parental figures’ and ‘Together but separate’. The theme of ‘Alternative short breaks’ gave insight into a resource (section 11.4) that parents may make use of, through breaks from family members.

In contrast to external influences, internal influences related to the quality of short breaks (section 11.8) provided by children’s hospices. Short break quality was directly related to the themes ‘Building trust’ (section 11.6) and ‘Getting a

real break' (section 11.7). 'Building trust' was linked to frequency of short breaks with increased frequency being associated with knowing children's needs. 'Getting a real break' related to type of short break, whether it be in the home, hospice or a combination of the two. Whether parents felt they were getting a real break was mediated by their individual circumstances and expectations of short breaks. The subsequent and concluding chapter outlines the implications of these findings for practice and provides suggestions for future research.

12 Conclusions, Implications for Practice and Recommendations for Future Research

12.1 Introduction

This study used a sequential mixed methods design to explore the impact of children's hospice short breaks on partner relationships between parental figures. The mixed methods design enabled the impact of short breaks to be investigated utilising two complementary methods: semi-structured interviews and a national online survey. Findings demonstrated that the impact of short breaks on the relationship is mediated by both external and internal influences.

External influences related to individual family differences, such as challenging behaviour, leading separate lives, financial disagreements and lack of family support, all of which can increase pressure on relationships between parents. Internal influences referred to short break quality, which was determined by the model, length and frequency of short breaks. If short break model received did not fit individual needs of families, it was often perceived as burdensome and intrusive rather than beneficial. Building trust was linked to the frequency of short breaks. If short breaks were infrequent, parents did not feel confident that hospice staff were knowledgeable enough to look after their child or young person. In light of these findings, this concluding chapter outlines implications for practice, policy and education, before presenting recommendations for future research and how the initial aims were addressed.

12.2 Implications for practice, policy and education

As children's hospices are mostly funded through charitable donations and are also facing reduced funding (Hospice UK and Together for Short Lives 2015), it is pertinent to consider how stretched resources can be allocated to best maintain relationships between parents and hospice staff providing short breaks and meet families' needs. The study found that each family have their own individual circumstances; as such, relationships are impacted differently and each family has their own requirements for short breaks. With this results in mind, implications for practice, policy and education are outlined.

Implications for practice

Initially when parents first access a children's hospice, they may not know what type of short break is beneficial to them and a generic package of care can be given with a set number of home and hospice short break hours. However, parents should subsequently be given opportunities to tailor short breaks to meet their needs to benefit their individual needs and ultimately, their partner relationships. A future option might be to mirror direct payments. Direct payments are provided by Local Authorities to individuals or carers, to arrange care and support to meet individual needs and circumstances (Care Act 2014). Children's hospices could allocate parents a personal short break budget to enable them to make their own decisions on how to allocate their own short breaks based on their individual needs.

Offering truly flexible short breaks to meet the individual needs of families would require investment to expand existing short break models available. According to the latest service provision survey (Devanney and Bradley 2012) only 34% of children's hospices offer short breaks in both hospice and home. Of the remaining hospices, 64% offer short breaks only in hospices and two percent only offer short breaks at home. Currently, hospices offering hospice or home short breaks only would be unable to offer flexible short breaks to meet the needs of individual families and would require financial investment in order to offer this flexibility.

One potential solution to this is integration and collaboration of resources between children's hospices. Hospices already providing short breaks in homes could help the 64% only offering short breaks in a hospice establish short breaks in the home based on their experiences, thereby expanding the number of hospices offering the flexibility of short breaks in both the home and hospice. A second solution may be for children's hospices to re-consider their core business and services offered. Children's hospices currently offer a variety of services in addition to end-of-life care and short breaks (Devanney and Bradley 2012). This study has highlighted the potential benefits of short breaks to the relationship between parents, but hospices also need to determine the beneficial

impact of other services and if necessary re-distribute to provide more funding for short breaks.

The current study demonstrated that challenging behaviour, leading separate lives, financial disagreements and lack of support from family members can place strain on the relationship between parents. It therefore follows that during the referral process, children's hospices could use these factors to determine if newly referred families are at increased risk of relationship breakdown. Those parents identified as being high risk of relationship breakdown could be offered an enhanced level of short breaks, in terms of frequency and length, to help maintain the stability of the relationship between parents. Of course, children's hospices would also need to consider other influences highlighted in this research like 'Short break quality'. The ABCX model could be used both as an assessment and intervention planning tool (Ramisch 2012).

The fact that parents who took part in the study perceived 'building trust' as being a crucial factor in short break quality also has important implications for short break practice. Children's hospices should therefore ensure children and young people accessing short breaks have a consistent core team who are able to confidently meet families' needs. Staff should also be encouraged to build a strong and open relationship with parents based upon families' individual needs and circumstances. The semi-structured interviews made it clear that parents had differing views on what the relationship should be like with hospice staff providing home short breaks. Some parents preferred a relaxed approach in their homes, whilst others found home short breaks intrusive and preferred a more formal relationship. It follows that both of these preferences should be respected and home short break staff should be encouraged to have a candid discussion with parents about how they want short breaks to work in the home, if at all.

Whilst this research was carried out with a focus on children's hospice short breaks, the findings and subsequent practical implications are far wider than this. Short breaks are not limited to children's hospices and palliative care; short breaks are a crucial service within a range of other areas including learning

disabilities (Caples and Sweeney 2011; Mannan et al. 2011; Nankervis et al. 2011), autism (Harper et al. 2013; Dyches et al. 2016; Whitmore 2016), Dementia (Kirkley et al. 2011; Neville et al. 2015; Lavery et al. 2016; Vandepitte et al. 2016), caring for elderly relatives (Evans and Lee 2013; McSwiggan et al. 2017) and mental health (Jardim and Pakenham 2009; Brighton et al. 2016). In a similar fashion to parental figures who have children or young people with life-limiting or life-threatening conditions, short breaks in the above areas provide breaks for carers and could potentially reduce the risk of relationship breakdown. The modified ABCX model could be used by other short break providers to determine those families most at risk and to allocate limited resources appropriately.

Implications for policy

This study also has important implications for policy makers. Keeping families together is high on the government agenda in a bid to reduce the burden on social care and the state. This research clearly demonstrated that couples with life-limited or life-threatened children are at greater risk of relationship break down and that children's hospice short breaks can reduce this risk. Yet statutory funding for children's hospices through clinical commissioning groups (CCGs) contributes an average of just 10% of care costs, in comparison to around 30% for adult hospices (Hospice UK and Together For Short Lives 2015). All hospices, both children's and adults have been under increasing financial pressure with more than two thirds of hospices having statutory funding cut or frozen in 2014/15 (Hospice UK and Together For Short Lives 2015).

In March 2017 NHS England published 'Guidance for using Children's Palliative Care Currency', which outlined the government's new approach to funding children's palliative care based on: (1) the child's age, (2) the phase of their illness and (3) where the care is being provided (NHS England 2017). Whilst this is a positive step forward to improving funding, the current research demonstrates there much more that needs to be done. Firstly, the guidance published only focuses on how clinical aspects of palliative care will be funded and not how non-clinical elements, such as short breaks, will be funded. This

research has clearly demonstrated the positive impact that flexible short breaks can have and that any policy on funding should also include short breaks.

Secondly, the new funding formula for CCGs for the cost of providing children's palliative care varies based upon (1) the child's age, (2) the phase of their illness and (3) where the care is being provided (NHS England 2017). The model does not demonstrate an understanding or funding relating to the long-term stress of parenting children or young people with life-limiting or life-threatening conditions. This funding formula should also consider using the modified ABCX model developed in this research to help identify couples and families who are at additional risk of breakdown. This would allow local funding authorities to allocate additional funding for children's hospice short breaks for those who may be at risk of relationship breakdown.

Implications for education

The research also has implications for the education or training of those healthcare professionals working with couples and families who have children who are life-limited or life-threatened. Research has shown that increased palliative care training or education improves the quality of care and confidence of staff (Bush and Shahwan-Akl 2013; Bailey and Hewison 2014; Croxon et al. 2017). However, training or education for health professionals focuses on end-of-life care and coping with death (Bailey and Hewison 2014; Wilson et al. 2016). Future university courses for palliative care nurses should include education on the impact of caring on the relationship between parents, the importance of short breaks and utilising the modified ABCX model to recognise couples or families who are at greater risk of breakdown.

12.3 Recommendations for research

Findings from this research provide valuable information and knowledge for those practically working with parents who have children with life-limiting or life-threatening conditions; they also provide opportunities for further research. This has resulted in the development of a refined ABCX mode. Five possible considerations for future research include:

1. A longitudinal study to investigate the impact of short breaks across a longer period of time to see how perceptions of short breaks change across lifespans.
2. Further development and refinement of the ABCX model to further understand the impact of children's hospice short breaks on partner relationships. Stressors and protective factors already identified could be explored further in future research. There may also be additional stressors and protective factors that have not been identified; future research could pursue this possibility.
3. A number of further in-depth studies could focus on the specific themes identified in the research to gain a better understanding of these themes. For example, building trust was an important theme for parents. Whilst the present research identified ways of building trust, this could be explored further to understand if there are additional factors influencing trust-building.
4. One limitation of the present study was it being confined to children's hospices in England and Scotland. Any further research could also include the rest of the UK.
5. Further exploration of the impact that short breaks from family members has on relationships between parents and gather information about what these short breaks look like.

12.4 Answering the research aim and objectives

12.4.1 Exploring parents' perceptions of parenting life-limited/ threatened children or young people on their relationships.

Parents outlined the pressures that caring for a life-threatening or life-limited child or young person placed on their relationship. A number of factors were noted to increase pressure on relationships between parents including the child or young person displaying challenging behaviour, disagreements over finances and leading separate lives. Conversely, some factors could be protective factors.

For example, parents who were in a better financial situation felt less strain on their relationship.

12.4.2 Determining if frequent short breaks enhance relationship satisfaction between parental figures compared to those who receive short breaks less frequently or not at all.

Responses from the national online survey revealed that receiving more hours of children's hospice short breaks enhanced the relationship satisfaction between parents. Non-distressed couples were receiving a mean of 388 hours of hospice short breaks per year, compared to 263 hours for distressed couples. Furthermore, parents interviewed believed that frequency of short breaks were important in building trust with the children's hospice. Trusting that their child's needs were being met at short breaks was highlighted as being important to parents. If parents did not feel that trust had been built, they were less likely to utilise short breaks and therefore receive any potential benefit to relationship satisfaction.

12.4.3 Identifying effects on relationships of parents receiving home and hospice-based short breaks compared to those receiving hospice-based short breaks only or home-based breaks only.

The national online survey suggested that the location of short breaks made little differences to relationship satisfaction. However, parents in the semi-structured interviews suggested individual differences mediated the impact of location of short breaks. Hospice short breaks at home were often shorter in length and associated with being an opportunity to catch up on household tasks, whilst short breaks at the hospice were longer in length and associated with getting a real break. Parents associated home-based short breaks with the intrusion of having short break carers coming into their home, with parents feeling unable to relax or show affection in front of the carer. The feeling of intrusion was lessened for parents who had built trust with the short break staff or had a home environment that minimised the impact of intrusion. Short breaks at the hospice were associated with an opportunity to have a real break, but travelling time and paperwork minimise the perceived benefits.

12.4.4 Identifying societal factors influencing partner relationships of families receiving short breaks.

Parents in semi-structured interviews highlighted family, friends and social care as societal factors that could influence partner relationships by reducing strain through practical and emotional support. In particular, they could be an alternative source of short breaks for parents. However, the national online survey only confirmed the influence of short breaks from family members, which were found to significantly improve relationship satisfaction. Semi-structured interviews also found that in some cases family could be a source of conflict for parents, placing strain on their relationship.

12.5 Concluding remarks

This PhD research study sought to explore the impact parenting life-limited or life-threatened children or young people and the effect of short break models on the on relationship between parents. Overall this study has important implications for how short breaks are provided by children's hospices to and the impact caring for life-limited or life-threatened children or young people on parental relationships in general. In particular, it emphasises the impact that children's hospice short breaks have on the relationship between parents is largely determined by individual family differences and short break quality.

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Legislation

Care Act 2014

Children Act 1989

Civil Partnership Act 2004

Education Act 1989

National Health Service and Care Act 1990

Appendix A: Letter of invitation template

[insert hospice logo here]

Dear [name]

We at [insert hospice name] are working with Bournemouth University to research what effect, if any, respite care for your child has on parental relationships. As a user of this service we value your involvement and would like to invite you to take part in an interview with Ashley Mitchell, a PhD student from Bournemouth University. As the enclosed note about the research methods explains, anything you say to him will be confidential and will not affect your care from [insert hospice name].

This is the first stage in a research project that will later involve similar interviews with other families nationwide. We hope to be able to use the results to influence the provision of respite care for families everywhere in the UK.

If you would like to take part, please e-mail ashmitchell@bournemouth.ac.uk or phone Ashley Mitchell on (01202) 962211 by the 18th October.

With kind regards

[Name of contact at children's hospice]

Appendix B: Participant information sheet



Information about the research

Understanding the impact of children's hospices on parental relationships

We would like to invite you to take part in interviews that form part of a PhD research project. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the research if you wish.

(Part 1 tells you the purpose of this study about what it will involve for you. Part 2 gives you more detailed information about how the research will be carried out).

Ask us if there is anything that is not clear or if you want more information. Take time to decide whether or not you wish to take part.

Part 1

1.1 What is the purpose of the study?

The purpose of this study is to gain an understanding about how different models of respite care and support from children's and young people's hospices impact on parental relationships. It is hoped that this will increase our knowledge of respite support provided by children's and young people's hospices and give parents a chance to share their opinions and experiences. The study will have two stages, interviews and a national questionnaire. You are being asked to take part in stage one, the interviews.

1.2 Why have I been invited?

You have been invited to take part because you are a parent of a child or young person currently being provided with respite care from a children's hospice.

1.3 Do I have to take part?

It is up to you to decide. You will have received this information sheet in advance of any interviews to help give you time to decide. You will be able to contact the researcher prior to interviews taking place, to ask any questions you have about the research. On the day of the interviews the researcher will describe the study and go through this information sheet again, to answer any further questions you may have. The researcher will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

1.4 What will I have to do/ what will happen if I take part?

You will be asked to take part in a face-to-face interview with a PhD researcher from Bournemouth University, talking about topics relating to the respite care provided by your children's hospice and whether you feel they impact on your relationship with your partner. There will be specific topics to discuss, but there is also flexibility to discuss any further areas of interest. The interviews will be audio recorded for analysis. Your interview recording is confidential and only the research team at Bournemouth University will have access. Interviews will take place at a time and location that is convenient for you, whether that be home, at your hospice or, for local families, Bournemouth University. The length of the interview will depend on your answers, but could be up to an hour.

1.5 Expenses

If you decide to take part in the interview at a location other than home, reasonable travel expenses will be reimbursed.

1.6 What are the possible disadvantages and risks of taking part?

The main risk is that the topic of parental relationships and other related areas of discussion may be sensitive depending on your life experiences. Every attempt will be made to approach the interview in a sensitive and empathetic manner. You will be able to pause the interview at any point or pass on any question that you don't feel comfortable answering (although there is no intention of asking uncomfortable questions). If you do find that participating in the interviews has caused emotional distress, support has been arranged with your hospice and the Samaritans.

1.7 What are the possible benefits of taking part?

Many parents welcome and benefit from opportunities to talk about their experiences. This research will give you the opportunity to voice your opinions and experiences about the respite care you and your family receive from your hospice. It is hoped that findings from the research will impact on how respite care support is given by children's hospices, potentially helping other families in a similar situation to you.

1.8 What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer as a result of participating will be addressed. The detailed information on this is given in Part 2.

1.9 Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

This completes Part 1. If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decisions.

Part 2

2.1 What will happen if I choose to withdraw from the research?

You are free to withdraw from the research at any point including prior to interviews, during interviews and after interviews have taken place. Any information or data already collected will be destroyed. However, it will not be possible once data has been collected from the interviews to destroy it once it has been included as part of a thesis or publication. You will still receive reimbursement for any travel costs even if you choose to withdraw.

2.2 What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the PhD student who will do his best to answer your questions (Ashley Mitchell- 01202 962211). If you remain unhappy and wish to complain formally, you can do so to Jane Hunt (Lead Supervisor- 01202 961571) or the Bournemouth University Health and Social Care Research administration team (01202 962119 or hscresearch@bournemouth.ac.uk).

Confidential emotional support is available through the Samaritans (08457 90 90 90 or jo@samaritans.org). Relate is an organisation that specialises in relationship counselling (0300 100 1234). However, this is not a 24-hour service.

2.3 Will my taking part in this study be kept confidential?

Yes, your taking part in this study will be kept confidential. Your interview will be recorded using a Dictaphone. Your interview will then be transcribed into a printed text. At this point, any personal details that may identify you such as name and specific location will be anonymised to maintain confidentiality. In accordance with data protection laws and Bournemouth University policy all of your personal information and interview data will be physically locked away or stored on a password protected computer. Any personal details such as your home address, email address or phone number will be destroyed after the interview has taken place. However, if you wish to be informed of results, a method of contact will be retained for longer in a secure location.

2.4 What will happen to the results of the research study?

Results will be analysed and discussed in a PhD student thesis at Bournemouth University. It is also intended that results be published in a scientific publication. Direct quotations may be used, but at no point will you be identified in either. If you wish to have access to the general results once the study has completed please tell the interviewer. Results will also be distributed to your local children's hospice.

2.5 Who is organising and funding the research?

The research has been undertaken as part of a PhD through Bournemouth University and under the guidance of a supervisory team experienced in the work of children's hospice care. The research is being funded by both Bournemouth University and Julia's House.

2.6 Who has reviewed the study?

This research has been looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Oxford Research Ethics Committee.

Thank you for taking time to read through this information sheet. If you have any further questions regarding the research or wish to take part please contact Ashley Mitchell (lead researcher) at ashmitchell@bournemouth.ac.uk or (01202) 962211. An interview time and location that is suitable for you will be arranged.

Appendix C: NRES ethical approval



NRES Committee South Central - Oxford B

Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Lewin's Mead
Bristol
BS1 2NT

Telephone: 0117 342 1333
Facsimile: 0117 342 0445

20 September 2013

Mr Ashley Mitchell
PhD student
Bournemouth University
B112a, Bournemouth House
Bournemouth University
19 Christchurch Road, Bournemouth
BH1 3LH

Dear Mr Mitchell

Study title: 'Can we fix it?!': Understanding the impact of children's hospices on parental relationships of life limited and threatened children and young people
REC reference: 13/SC/0270
IRAS project ID: 117354

Thank you for your letter of 30 August 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Siobhán Bawn, NRESCommittee.SouthCentral-Oxfordb@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

A Research Ethics Committee established by the Health Research Authority

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

| Document | Version | Date |
|---|---------|-------------------|
| Evidence of insurance or indemnity | | 09 July 2012 |
| Interview Schedules/Topic Guides | 2 | 04 September 2013 |
| Investigator CV | | 08 May 2013 |
| Letter of invitation to participant | 3 | 04 September 2013 |
| Other: CV for Supervisor: Dr Hunt | | 08 May 2013 |
| Other: CV for 2nd Academic Supervisor: Dr Mayers | | 08 May 2013 |
| Other: CV for External Supervisor: Mr Edwards | | 08 May 2013 |
| Other: Educational assessment 1st Review Feedback | | 07 March 2013 |

A Research Ethics Committee established by the Health Research Authority

| | | |
|---|-----|-------------------|
| Other: Lone Working Guidance | 1 | 01 July 2013 |
| Other: Letter from Sponsor - Sara Glithro | | 19 August 2013 |
| Other: General Risk Assessment Form | 1 | 04 September 2013 |
| Participant Consent Form | 3 | 04 September 2013 |
| Participant Information Sheet | 3 | 04 September 2013 |
| Protocol | 1 | 19 December 2012 |
| Questionnaire: Validated (Spanier 1979) | | |
| REC application | 3.5 | 14 May 2013 |
| Response to Request for Further Information | | 01 July 2013 |
| Response to Request for Further Information | | 30 August 2013 |
| Summary/Synopsis | 1 | 08 May 2013 |

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

| | |
|-------------------|---|
| 13/SC/0270 | Please quote this number on all correspondence |
|-------------------|---|

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'PP Foy'.

Mr Chris Foy
Chair

Email: NRESCommittee.SouthCentral-Oxfordb@nhs.net

Enclosures: "After ethical review – guidance for
researchers" [Emailed]

Copy to: Jonathan Parker

Appendix D: Participant consent form

Hospice Number:

Interview Number:

Participant Identification Number for this interview:

CONSENT FORM

Title of project: Understanding the impact of children's hospices on parental relationships

Name of Researcher: Ashley Mitchell

Please initial box

1. I confirm that I have read and understood the information sheet dated.....
(version.....) for the above study. I have had the opportunity to consider
the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at
any time without giving a reason. ☐
3. I understand that I am taking part in an interview that will be audio-taped and that
anonymised quotations from the interview may be used in a PhD student thesis and
future publications. ☐
4. I understand that relevant sections of my data collected during the study, may be
looked at by individuals of the research team from Bournemouth University. I give
permission for these individuals to have access to my data. ☐
5. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Version 3

13/SC/0270

04/09/13

Appendix E: Interview guide

Topics for interview informed by literature and aims

Read through of participant information sheet, outlining research and signing consent form.

- Outline who I am e.g. Bournemouth University PhD student and the overall topic of research.
- Read through P.I.S. and outline what to expect during interviews.
- Answer any outstanding questions and sign consent form.

Information about child receiving short breaks

- ‘I am interested in the impact of parenting a child with complex needs. Could you tell me about your son/ daughter receiving short breaks’?
- Follow up questions will revolve around getting more information about the child’s condition and the nature of their care.

Parents’ contribution to care

- How is parent’s contribution to care split?
- The level of care required and time it takes.
- Do parents take on set roles of care or are roles flexible?

Parent’s perception of parenting a life limited/ threatened child

- To be a very open question but focused on parents overall thoughts and beliefs on being a parent of a child with complex health needs, both difficulties and positive aspects.

Difficulties on marital relationship/ family unit

- What impact/ effect (if any) does having a child with complex needs have on the family unit.
- Specific focus on the impact/ effect on relationship with spouse or partner.

Societal factors effecting parental relationships

- Are societal factors such as religion or faith important?
- Public perception towards families with disabilities or complex health needs.

Differences between short breaks at home and at hospice

- What level of support do you receive from your hospice? (If not already discussed).
- What are the negatives and positives of hospice care versus community care?
- Frequency of care versus length of care.
- Different types of care and support received and how they help.

Other factors

-Are there any other areas or topics that you think are relevant to this research?

Interviews will end with the researcher thanking the participant(s) for their time, explaining what will happen with the interviews and reminding them how they can contact the researcher if they have any concerns.

Appendix F: Interview transcript extract

Amy: And I think actually, God this is so difficult for you, each child is so different and actually you know, knowing what our child is people who look after him. Umm and you see that's the thing I think, those parents with more tricky children.... Is it the 20th today? Umm more tricky children probably... it's so difficult to help the family where as there are easier children to look after (laughs).

Interviewer: It's to do with that degree of complexity and the amount of training....

Amy: Yeah that's right yeah.

Interviewer: ...because you as parents, you're the expert on your child and then you need to be reassured that person who's looking after your child has a similar level of training.

Amy: And I'll be honest, you know, you're not.... when you're looking after it twenty-four seven, sometimes your just flipping grateful (laughs)

Interviewer: Yeah...

Amy: ...and you're not particular bothered whether they're trained. You know, you're just thinking 'you know what? I need to sleep. I need wash up'. So actually that's never really.... I know that sounds dreadful...

Interviewer: No no, I mean that's an honest answer. That's...

Amy: But that's really the focus. Are they skilled enough? Are they trained enough? Are they (sighs) you know... and I have had... I've had that back, that comment given back that 'actually we don't have the staff at the moment that are trained', and I'm thinking you know what how.... How incapable I am in the state I am to look after him, anybody would be better than me (laughs).

Interviewer: So it's just that sheer exhaustion, you're willing to take any kind of....?

Amy: Yeah whatever (laughs).

Interviewer: Yeah, yeah.

Amy: So you're not actually... that doesn't actually.... You're not, you know you're not thinking 'I need the perfect...' you know I don't know what other families are like, but ours isn't... I mean Frank isn't medically, he's just flipping hard work. He's heavy. He's big. He's....

Interviewer: How... how old is...?

Amy: So Frankie's ten and he is, you know, we're most likely to lose him in the next two years but he has been a... you know, a Tasmanian devil. You know, just

to try and conjure up a picture for you, and that's hard work. Umm as in you know, just physically demanding. So I can see that from an organization trying to help a family, I mean like ours where the demands are young, fit, strong.... That's... that's a struggle because it's mainly women in this profession and to be honest if you look at the carers demographics and their ability they're about fifty and not particularly fit. Lovely mother figures, you know loving and caring and heart in the right place but you know ten minutes of Frank and (sighs)...

Interviewer: Exhausted?

Amy: Yeah.

Interviewer: So would you say that's the difficulty with Frank, it's just the physical side of things?

Amy: Yeah, mmmm.

Interviewer: Sorry is that lifting or because he's very active?

Amy: Very active. Yeah. I mean that is changing because obviously with a child that's terminally ill you... you know, you go from... we've gone from that high point and now Frank is starting to deteriorate, so he is slowing down but he is a big boy and now if he trips, 'cos he's still mobile, we're not in a wheelchair.... I think that children in a wheelchair must be far easier to wheel and they might go for walks with children in wheelchairs. It's easier to manage, it's easier to risk assess... So I think probably you've got a structure to run through with questions but what I think is important, is when I say detrimental or.... I do think it's about remembering the sort of child that we have and possibly why as a family we might have not have got the assistance or the care that we felt we should have had (laughs) when we really needed it. So I think... I think yeah, so I guess I wonder if as a family if we are representative...

Interviewer: Of....

Amy: Yeah.

Interviewer: But then your opinion and your insights are still relevant.

Amy: But we are. And that's how we've always gone. We've gone, he's terminally ill. He fits the package, he fits the criteria (whispers) but we're not getting any help (laughs).

Interviewer: So you would say your level of assistance is or was.... Is....

Amy: Well it was, it was. So I would say in the last six months err things have definitely improved for us.

Interviewer: Okay, from (1st hospice)? From theirs?

Amy: Yeah, not to a level that we could do without them but we are now getting, we would say... we would get three hours a day and we would get that if we're lucky, twice a month. So we get six hours a month.

Interviewer: That's not much is it?

Amy: No but do you know what? That's significantly better you see.

Interviewer: Oh yeah, it's better than nothing.

Amy: That's a positive! But you're right. I mean you're right. When you look, you know, yeah yeah. When you say does it help... because it says your looking at parental....

Interviewer: Relationships, yeah.

Amy: Does... does that help our relationship? Well no. It's not enough.... It's not enough time to give you, you know, any significant changes to your lifestyle.

Interviewer: It sounds like it's just enough time to catch a breath before you....

Amy: Yeah, yes.

Interviewer:before you go straight back in again.

Participant: Yes and that doesn't mention the fact that... I mean I've got.... My, my nurse is Laura and I've got to have a six-monthly catch up with her. So you also within that package of having help, you also have paperwork to go through. So I will have an hours meeting with her out of my day to discuss.... So she's able to then manage the sits that she employs people to sit. And so then there's other paperwork. He went in for a weekend respite. All children at (1st hospice) get one weekend a year given to them when they go into the hospice and sleep over night. Well you have to have a pre-meeting before they go in. So there's (pause)....

Interviewer: So sounds like there's a lot of paperwork to organize before you go in?

Amy: There is.

Interviewer: And does that.... Is that to the detriment...?

Amy: Obviously that's time isn't it? That's just time.

Interviewer: It seems like...

Amy: I have to juggle that time because I work. So I have to fit that in and that will take up time when I should be preparing the dinner for the children. So when they come home I'm ahead with the dinner. Well I have my meeting in my

lunch break with Laura or id have to take a morning off work to do longer meetings.

Interviewer: So you work as well?

Amy: I work full time. Yeah.

Interviewer: That must be exhausting?

Amy: It is but we are.... We have decided that as a disabled family that we would try and stay as normal as possible and we know that can't last forever because we know we.... Well in the next two years we're going to hit a... (pause) too much you know? Too much medical. I mean Michael's got to go to Bristol for a week, next week, where he's looking at sleep apnea. So that's a week. So it's.... yeah.

Interviewer: And like you say that's a long period of time?

Amy: Oh yeah. And then I think he's got three weeks where they're going to look at the CPAP where he has the mask over his face. So that's.... that's a longer period of time. So we're just getting down that slippery slope and we're not quite sure how we're going to deal with that, how we're going to juggle that. Now whether (1st hospice) will come to the fore and look at the needs of the family in terms of 'my God, they're going to need help', I don't know. They may well. I guess we have to say as a family we've.... We have always managed and we have always worked it and whether when we get absolutely desperate, whether they've got the capacity to then step in, I don't know. I don't know how other families have found... I don't know.

Interviewer: You... you say...

Amy: ...when they've got to breaking point.

Interviewer: Yeah when they get to breaking point. I mean you say you get six hours a month, so I take it you're not on the highest... because they've got different levels of care haven't they? Because I know some parents get 210 hours and spread that out over the year and they get two or three hours every week. So it seems to vary.

Amy: No I don't, that's interesting. So some families get two or three hours a week?

Interviewer: Some do, it seems to vary depending on the individual circumstances.

Amy: I must admit I probably don't shout that loud.

Interviewer: This was a question I was going to come to and not just with (1st hospice)....

Appendix G: Revised dyadic adjustment scale (Busby et al. 1995)

The RDAS

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

| | | | | | | |
|---|-------------------------|---|--|---|--|---------------------------|
| | Always <u>Agree</u> | Almost <u>Always</u> <u>Agree</u> | Occa- <u>sionally</u> <u>Agree</u> | Fre- <u>quently</u> <u>Disagree</u> | Almost <u>Always</u> <u>Disagree</u> | Always <u>Disagree</u> |
| 1. Religious matters | <u>5</u> | <u>4</u> | <u>3</u> | <u>2</u> | <u>1</u> | <u>0</u> |
| 2. Demonstrations of affection | <u>5</u> | <u>4</u> | <u>3</u> | <u>2</u> | <u>1</u> | <u>0</u> |
| 3. Making major decisions | <u>5</u> | <u>4</u> | <u>3</u> | <u>2</u> | <u>1</u> | <u>0</u> |
| 4. Sex relations | <u>5</u> | <u>4</u> | <u>3</u> | <u>2</u> | <u>1</u> | <u>0</u> |
| 5. Conventionality (correct or proper behavior) | <u>5</u> | <u>4</u> | <u>3</u> | <u>2</u> | <u>1</u> | <u>0</u> |
| 6. Career decisions | <u>5</u> | <u>4</u> | <u>3</u> | <u>2</u> | <u>1</u> | <u>0</u> |
| | <u>All the time</u> | <u>Most of the time</u> | <u>More often than not</u> | <u>Occa- sionally</u> | <u>Rarely</u> | <u>Never</u> |
| 7. How often do you discuss or have you considered divorce, separation, or terminating your relationship? | <u>0</u> | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> |
| 8. How often do you and your partner quarrel? | <u>0</u> | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> |
| 9. Do you ever regret that you married (or lived together)? | <u>0</u> | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> |
| 10. How often do you and your mate "get on each other's nerves"? | <u>0</u> | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> |
| | <u>Every Day</u> | <u>Almost Every Day</u> | <u>Occa- sionally</u> | <u>Rarely</u> | <u>Never</u> | |
| 11. Do you and your mate engage in outside interests together? | <u>4</u> | <u>3</u> | <u>2</u> | <u>1</u> | <u>0</u> | |

How often would you say the following events occur between you and your mate?

| | <u>Never</u> | <u>Less than once a month</u> | <u>Once or twice a month</u> | <u>Once or twice a week</u> | <u>Once a day</u> | <u>More often</u> |
|---|--------------|---------------------------------------|--------------------------------------|-------------------------------------|-----------------------|-----------------------|
| 12. Have a stimulating exchange of ideas | <u>0</u> | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> |
| 13. Work together on a project | <u>0</u> | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> |
| 14. Calmly discuss something | <u>0</u> | <u>1</u> | <u>2</u> | <u>3</u> | <u>4</u> | <u>5</u> |

Appendix H: Survey pilot instructions

Dear Parent,

Thank you for volunteering your time to test this online survey.

The aim of the survey is to understand the impact of respite or short breaks from children's hospices on the relationship between parents. The survey will be distributed at a national level, but before this happens your input and feedback would be greatly appreciated. The online survey can be found at the following address:

<https://www.surveymonkey.com/s/LXJWT7N>

Specific feedback on the following would be helpful. You do not need to answer all these questions, but they should give you an idea on the kind of feedback that would be helpful.

Language and Questions

- Are there any typos or spelling mistakes?
- Are there any questions that don't make sense?
- Are there any words you don't understand or you feel don't fit?
- Are the information sections easy to follow and do you feel they contain enough information?
- Were all possible answers covered? Or did you feel restricted?

Structure and Layout

- Does the structure of the survey follow a logical order?
- Are there any broken links?
- Is the presentation clear and easy to follow?
- Is the survey easy to navigate?
- How long did the survey take you to complete?

And any other comments that you think will be relevant and helpful. You can complete this test survey multiple times if you choose to go through it more than once.

Please provide any feedback to ashmitchell@bournemouth.ac.uk, you can either attach a Word document with comments or provide feedback in an email. If you think a phone call would be more useful, let me know via email and we can arrange a time that is convenient for yourself.

Thank you

Ashley Mitchell
PhD Student
Bournemouth University

Appendix I: Survey email invitation template



[Insert hospice logo]

Dear Parent/ Guardian,

For many families children's hospices provide vital support but their value is still under researched and not widely reported. We at Bournemouth University are working with children's hospices nationwide to research what effect, if any, respite care for your child has on parental relationships. As a user of this service we value your involvement and would like to invite you to complete a short online survey, which will ask you about the respite you receive and it's impact on your relationship. The survey can be found at:

<https://www.surveymonkey.com/r/BUhospicesurvey>

The survey is completely confidential and will not affect the care you receive from your hospice. We understand that time can often be limited, but if one or both parental figures could complete the survey individually it would go a long way in helping us understand how respite or short breaks impact your lives.

If you have any questions before completing the survey, please email myself at ashmitchell@bournemouth.ac.uk.

With kind regards,

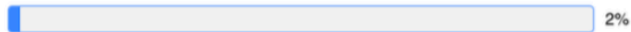
Ashley Mitchell
PhD Student
Bournemouth University

Appendix J: Online survey consent page



Children's Hospice Respite Survey

Introduction and consent page



We would like to invite you to take part in a survey that forms part of a PhD project. Before you decide whether to take part, you need to understand why the research is being done and what it would involve for you.

What is the purpose of the study?

The purpose of this study is to gain an understanding about how different models of respite care and support from children's and young person's hospices impact on parental relationships. It is hoped that this will increase our knowledge of respite support provided by children's and young people's hospices and give parents the opportunity to share their opinions and experiences. You are being asked to take part in a survey.

Why have I been invited?

You have been invited to take part because you are a parent of a child or young person currently being provided with respite care from a children's hospice in the UK.

Do I have to take part?

It's up to you to decide. The survey should take no longer than 15 minutes, is completely confidential and will in no way effect the care you receive from your children's hospice. If you have any questions about the research before you complete the survey, please contact Ashley Mitchell at ashmitchell@bournemouth.ac.uk.

*** 1. I have read and understood the information provided and agree to take part.**

- ☐ Agree
- ☐ Disagree

Move on to next question

Powered by
 SurveyMonkey®
See how easy it is to [create a survey](#).