

THE UNIVERSITY OF HULL

Parenting a Child with Cancer: Positive Psychology and Coping.

being a Dissertation submitted in partial fulfilment of the requirements for the Degree of

Doctor of Clinical Psychology

in the University of Hull

by

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July 2008.

Acknowledgements.

Many thanks to Margaret Riley who agreed to facilitate the recruitment of participants and the support she provided in the initial stages of the research. Thanks to Dorothy for her supervision, input and support along the way.

I am indebted to the families who took part in this study and shared their experiences so candidly. It was a privilege to meet each one of you and to be inspired by your courage and determination, often in the face of great pain.

Lastly, to my family who never seem to tire of picking me up and shouting encouragement to keep going.

Overview.

This portfolio has three parts. Part one comprises a systematic literature review, in which the empirical literature relating to coping of parents of children with cancer is reviewed. Twelve studies were included in the review and from these studies, the coping strategies that parents rated as most useful or most frequently used were synthesised into a bi-dimensional taxonomy of coping. Due to the many and varied measures and conceptualisations of coping the dimensions of approach-avoidance coping and emotion-focused and problem-focused coping were used to organise results into a more coherent and meaningful structure. The reviewed papers were also quality checked and the outcome of the checklist was taken into consideration when outlining results of each study.

Part two comprises a qualitative study, using Interpretative Phenomenological Analysis (IPA) methodology to explore the experiences of parents of children who have been diagnosed with cancer in the previous five years. IPA as a methodology is primarily concerned with the participant's lived experience of an event. There is an assumption that a person makes sense of their experience through the process of interpretation. Through semi-structured interviews with participants, their interpretations of their experiences were collected. The researcher, through the process of analysis, interprets the participant's own interpretation; this is known as a 'double-hermeneutic'. Different levels of analysis of transcripts leads to drawing out of a number of themes from across participants. In this study, positive psychology literature was used as a theoretical guide to focus interviews. Positive psychology is concerned with the study of positive emotions or characteristics, positive relationships and positive organisations, and how

people may draw strength from these. It was hoped that by using positive psychology as a lens through which to explore the experiences of parents of children with cancer, a better understanding may be gained of what may drive or be 'behind' behaviours and strategies so frequently observed in coping literature.

Part three comprises appendixes. These include a reflective statement on the process of conducting the research; the challenges faced and the lessons learnt. In addition, a reflexive statement regarding the researcher's own beliefs, experiences and perceptions that may have impacted upon the research process is included. A worked example of IPA using a section of a transcript is also presented to illustrate the IPA process.

Table of Contents.

Acknowledgements.....2
Overview.....3

Part one: A Systematic Literature Review of Coping in Parents of Children with Cancer.....8

Abstract.....9
Introduction.....10
Method.....14
Results.....16
Discussion.....23
References.....31

Part two: An Exploration of the Experiences of Parents of Children with Cancer:

A Positive Psychology Approach.....36

Abstract.....36
Introduction.....37
Method.....39
Results.....43
Discussion.....64
References.....70

Part three: Appendixes.....	73
1. Reflective Statement.....	74
2. Journal Guidelines for Authors for the Systematic Literature Review....	82
3. Journal Guidelines for Authors for the Empirical Paper.....	86
4. Ethical Approval.....	90
5. Participant Information Leaflet.....	92
6. Consent Form.....	97
7. Interview Schedule.....	99
8. Flowchart Mapping Data Collection.....	101
9. Worked Example of IPA.....	103
10. Reflexive Statement.....	112
11. Quality Control Checklist.....	116
12. Extended Details of Included Studies.....	118
13. Glossary of Medical Terms.....	122

Word Counts:

Systematic Literature Review = 5391 (excluding references).

Empirical Paper = 8672 (excluding references).

Total Portfolio = 26,204 (excluding references).

List of Tables and Figures:

Table 1.1 Study Details.....	28
Table 1.2 Taxonomy of Coping Strategies	30
Table 2.1 Titles of Super and Sub-ordinate Themes.....	45
Figure 2.1 Formulation of Relationships Between Themes.....	63
Table 3.1 Extended Details of Studies Included in Systematic Literature Review.....	119
Figure 3.1 Flow Chart of Data Collection.....	101

Psychology and Health.

Vol. X, No. X, Month 200X, 000-000

L.F. Chasle and D.J. Frizelle.

Psychology and Health.

REVIEW ARTICLE

A Systematic Literature Review of Coping in Parents of Children with Cancer.

This paper is written in the format ready for submission to *Psychology and Health*.

Please see appendix 2 for the Guidelines for Authors.

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Abstract.

A systematic review was conducted to investigate the strategies parents of children with cancer use to cope. Electronic databases were searched for studies meeting inclusion criteria and references of retrieved papers were scanned for further relevant publications. Twelve studies which met the inclusion criteria and reported relevant data were reviewed. A quality control checklist was applied to the reviewed studies and used to synthesise results. Overall, methodological quality of the studies was poor. The measures used to quantify coping were varied and inhibited comparison of results between studies. The coping strategies rated most useful or most frequently used by parents were organised into a bi-dimensional taxonomy of coping to facilitate a more cohesive understanding of overall outcomes of the literature. In general, emotion-focused and approach coping strategies were used most often or rated most helpful by parents. The limits to these findings and implications are discussed.

Key Words: Cancer; Child; Parent; Cope.

Introduction.

While only 0.5% of all cancers occur in children aged 15 years and under, cancer accounted for 20% of all deaths in children aged one to 14 years and 1400 new cases were diagnosed in Great Britain in 2000 (Office for National Statistics, 2004). About one third of childhood cancers are leukaemia, a quarter are brain and spinal tumours, 15% of cases are embryonal tumours and just under 10% are lymphomas. Childhood cancer is about one fifth more common among boys than it is girls and interestingly, children of Asian ethnic origin in Britain have consistently been found to have a higher incidence of lymphomas (Office for National Statistics, 2004).

Due to remarkable progress in medical paediatric treatment of cancer over the last four decades, mortality rates have dropped steeply from just under 30 deaths per million in the 1980's to 10 per million in 1992 for leukaemia. Currently, approximately 75% of all childhood cancer patients in Britain survive for at least five years post diagnosis (Quinn, Babb, Brock, Kirby & Jones, 2001; Steliarova-Foucher et al. 2004). Surgery, chemotherapy, radiotherapy and combinations of any or all of these interventions form the mainstay of treatment for most childhood cancers. Considering this, it is now reasonable to view cancer as a chronic illness that necessitates long-term treatment and that has the potential of relapse, but not necessarily resulting in the death of the child. Accordingly, the psycho-social care of the family of a child with cancer has become more prominent, and a section of this literature will be reviewed here.

The impact of being a child, or the family of a child diagnosed with cancer extends far beyond purely physiological and medical stressors. NICE Guidelines for Cancer in Children and Young People (2005) state:

“The diagnosis of cancer in a child or young person often throws a family into crisis.” (The National Collaborating Centre for Cancer, (2005), p.73).

Svavarsdottir (2004) found that in parents caring for a child with cancer, the most time consuming and difficult care giving activities for both mothers and fathers were giving emotional support to the child with cancer, and to other children in the family. Mothers had particular difficulties with managing behavioural problems and planning family activities. Fathers reported finding managing work, caring for the child and emotionally supporting their partner the most difficult. Therefore, there is data to confirm what human experience already knew; that to be the mother or father of a child with a potentially fatal chronic illness such as cancer is unequivocally difficult, stressful and distressing.

An array of literature concerned with coping, adjustment, appraisal and psychological difficulties experienced by both children with cancer and their family members exists. This systematic review focuses on literature concerning parents of children with cancer and appraises findings to date with regards to how these parents cope. However, one major difficulty with reviewing literature on the concept of coping is that a number of different definitions and theoretical approaches are used to investigate the concept, making it difficult to ascertain what an author may be referring to when they claim to be studying ‘coping’. The concept of coping has an extensive history in psychological writing, including the traditions of animal experimentation and psychoanalytic ego psychology (Lazarus and Folkman, 1984). However, in more recent years Lazarus and Folkman (1984) proposed a theory of a relationship between coping and appraisal which is widely regarded as the accepted understanding of the concept of coping. Lazarus and Folkman (1984) suggest that stress is experienced when a person

appraises their environment to be taxing and/or exceeding their internal resources and/or as threatening to their well-being. Therefore, coping can be defined as cognitive and/or behavioural actions that attempt to reduce or manage stress. Folkman and Lazarus (1980, 1985) (cited in: Aldridge & Roesch, 2007, p.116) and Lazarus and Folkman, (1984) further developed the concept of coping to include two major functions or categories: problem-focused and emotion-focused coping, which group a person's efforts as being either an attempt to alter the problem that is the source of the stress or to regulate emotional distress. For example, the dimension of problem-focused coping includes instrumental seeking of social support and planful problem solving. These coping strategies are proposed to reduce conflict between individuals and their environment. Emotion-focused coping has been proposed to include positive reappraisal of the situation and seeking of emotional support.

Further taxonomies of the concept of coping published within psychological literature have often been with regards to discussion of coping 'styles' (referring to behavioural traits that are stable over time). Many of these definitions try to make sense of how a coping action may be focused towards the perceived stressor. For example, repression/sensitization (Byrne, 1964), (cited in: Lazarus & Folkman, 1984, p.129) vigilance/avoidance (Cohen and Lazarus, 1973), (cited in: Lazarus & Folkman, 1984, p.128) and engagement/disengagement (Compas, Connor-Smith, Saltzman, Thomsen & Wadsworth, 2001), (cited in: Aldridge & Roesch, 2007, p.116). Clearly, there is a wealth of literature on the theory of coping and to date, no single, unanimously agreed definition exists and there are multiple ways that the concept is measured. Therefore, in undertaking this literature review it was essential to attempt to create a more satisfactory

and cohesive synopsis of the many types of coping gathered by the array and heterogeneity of measures used in published studies.

The framework used by Aldridge and Roesch (2007) in their meta-analysis of coping and adjustment in children with cancer, will be replicated in this review. Aldridge and Roesch (2007) maintain that many of the definitions regarding the focus of coping behaviour can be collated within the taxonomy of avoidance vs. approach. Moos and Schaefer (1993), (cited in: Franks & Roesch, 2006, p.1028), explain avoidance coping as an action (cognitive or behavioural) that attempts to put an end to experiencing the stressor and /or the emotional effect. Approach coping, however, is orientated towards resolving the problem or the emotional effect (Roth and Cohen, 1986), (cited in: Franks & Roesch, 2006, p.1028). Despite the obvious overlaps between avoidance vs. approach and emotion vs. problem focused coping, Aldridge and Roesch (2007) maintain that these two taxonomies of coping have endured sufficient scrutiny to be well validated. Thus this framework was used in their meta-analysis (Aldridge and Roesch, 2007) and will be replicated in the current review.

This systematic literature review aimed to synthesise findings from published studies to date, regarding how parents of children with cancer cope. The definition and taxonomies of coping as previously described were utilised. The quality of papers eligible for inclusion was rated and results synthesised. Papers were excluded according to clearly defined criteria. The inclusion of a process of quality control sets this systematic review apart from that of Klassen et al.'s (2007) review on the caregiving experience of parents of children with cancer, since Klassen et al. (2007) did not consider methodological quality of included papers or in synthesis of reported results.

Method.

All papers that quantitatively measured coping in parents of children who had been diagnosed with cancer, and that met basic quality control criteria were included. Due to advances in medical treatment of childhood cancer during the 1980s, literature prior to this time focuses on death and dying, as children's survival rates were significantly lower. Hence, this review included papers dated from 1985 onwards. In addition, studies that had collected data within five years of diagnosis were included. This time frame allowed for any variance in duration of treatment and also attempted to account for effect that stage of illness has been shown to have on parental coping (Swallow and Jacoby, 2001).

An electronic search was conducted using Web of Science, PsychINFO, Cochrane Review Library, Medline, Allied and Complimentary Medicine and CINAHL. Search terms used were: *cancer, child(hood), cope, coping, parent, paediatric, pediatric, oncology*. References of included papers were then checked for further studies that met inclusion criteria.

Inclusion Criteria.

To be included in the review a paper had to:

- Be published in a peer review journal - dissertations and conference papers were excluded on this basis.
- Utilise a psychometric measure of coping strategies, gathering quantitative results.

- The measure had to be administered to a parent (the person/s with the sole parenting responsibility for the child), whose child had been diagnosed with cancer in the five years prior to data collection, but had not died.
- The child of the parent had to be 18 years or younger at the time of data collection.

Quality Checklist.

It is important to be aware of methodological and overall quality of papers being reviewed and for quality to be taken into account when synthesising results. This review was conducted for the purpose of establishing what literature exists on coping in parents of children with cancer, but also was concerned with understanding the area by means of studies that meet a basic quality check. Without a method of quality control conclusions may be drawn from studies that do not have valid results. However, the nature of the population under review (parents of children with a diagnosis of a potentially life threatening disease), does not easily allow for ‘gold standard’ experimental studies to be conducted. A quality control criterion was applied in an attempt to rate studies individually. [See Appendix 11 for details of the quality checklist].

The quality check list was devised specifically for this review but was based on a number of others in circulation (Khan, Riet, Popay, Nixon and Kleijnen, 2001; National Institute for Health and Clinical Excellence: The Guideline Manual, 2007; Downs and Black, 1998, STROBE Initiative, 2008). Quality checklists are generally not devised to assess cross-sectional, non-experimental designs, as this is considered lower in the hierarchy of method quality, hence the need to tailor one specifically for this review.

Lorenzo et al. (2005) conclude that:

“Despite the dozens of quality scales and checklists that have been proposed...many doubt that a generic quality assessment tool that would provide valid in all cases can ever be found.” (p.3).

The checklist was initially piloted on a small number of papers. Once amendments were made to maximise suitability it was then applied to all studies included in the review. An independent researcher scored six reviewed studies using the checklist to assess inter-rater reliability. A one-way random effect model was used to calculate an intra-class correlation score to determine inter-rater reliability of the quality checklist. The correlation score was equal to 0.714. The general rule of thumb is thought to be that a value of 0.7 or above is acceptable for reliability (Streiner & Norman, 2003).

Results.

Search Process.

Electronic database search yielded 471 (this number includes replications) papers which were examined on the basis of the abstract, and resulted in 419 papers being excluded on the basis of not meeting inclusion criteria. If abstracts failed to provide sufficient information the full paper was obtained. Scrutiny of the full text led to a further 34 papers being excluded on the basis of not meeting inclusion criteria. The references of the 18 remaining papers were checked for additional studies but none were found that met inclusion criteria. Eight papers met the inclusion criteria but results did not report the datum required for the purpose of this review. Where possible, authors were contacted and descriptive data for the measure of coping were requested. Five authors failed to respond and one responded stating that data was no longer available,

therefore six papers were excluded. Two authors responded providing relevant data allowing two studies to be included, resulting in a total of 12 studies remaining for review (see Table 1.1).

Quality Control.

Systematic search procedures and use of quality control methodology resulted in a total of 12 papers for full review. Two studies were longitudinal (Hoekstra-Weebers, Jaspers, Kamps & Klip, 1998; Goldbeck, 2001) with the latter including a comparison group, two were cross-sectional and included comparison groups (Hardy, Armstrong, Routh, Albrecht and Davis, 1994; Eiser and Havermans, 1992), and the remaining eight studies were cross-sectional in design (Patistea, 2005; Yeh, 2004; Birenbaum, 1990; Trask et al., 2003; LaMontagne, Wells, Hepworth, Johnson and Manes, 1999; Han, 2003; Cardella and Friedlander, 2004; Cayse, 1994). Included studies were assigned a score using the quality checklist. The score corresponds to the number of components included and reported in the study that should affect methodological quality. Generally therefore, higher quality should be represented by higher scores (12+) on the checklist. However, a thorough cross-sectional design study may still score equal to a poorly reported longitudinal study, but the scores serve as a quick guide to methodological quality. All of the studies excluded on basis of quality were also excluded due to the relevant data not being reported. Table 1.2 gives details of all papers reviewed, including quality checklist scores. [See appendix 12 for full table of study descriptions].

Summary of results of reviewed papers.

Longitudinal studies (scoring 12 and 13 on quality checklist).

1. Study reference number 4 (Hoekstra-Weebers et al, 1998), using the Utrecht Coping List at three time points (diagnosis, six months and 12 months post diagnosis) found reduction over time in ‘Active problem focusing’, ‘Palliative reaction pattern’ (e.g. look for diversion and occupy oneself with other things so as not to have to think about the problem and try to feel better by relaxing), ‘Avoidance’, ‘Social support seeking’, ‘Passive reaction pattern’ (e.g. let oneself be totally immersed in the problem, incapable of doing anything about the situation) and ‘Comforting cognitions’. ‘Active problem focusing’ was rated as the most frequently used coping strategy, followed by ‘Palliative reaction pattern’, ‘Avoidance’, ‘Social-support seeking’, ‘Passive reaction pattern’, ‘Comforting cognitions’. ‘Expression of emotions’ was rated as being used least frequently.

2. Study reference number 6 (Goldbeck, 2001), used the Coping Health Inventory for Parents (CHIP) and Trier Coping Scales over two time points (1-2 weeks and 10-12 weeks post diagnosis). A comparison group of parents of children with diabetes or epilepsy was included in this study. It was found that parents of children with cancer reported more ‘Rumination’, ‘Defense’ (optimism and minimisation) and more ‘Information seeking’ than the comparison group. They were also described as seeking less social support than the comparison group. On the Trier Coping Scale, ‘Defense’ coping strategies were rated as most often utilised, followed by ‘Information seeking’, ‘Rumination’, ‘Social support seeking’. ‘Religion’ was reported as the coping strategy used least often. On the CHIP however, ‘Maintaining family integration’ was rated the

most helpful group of coping strategies, followed by ‘Maintaining personal stability’ and finally ‘Understanding of the medical situation’.

Cross-sectional with comparison groups (Scoring 11 and 9 on quality checklist).

1. Study reference number 11 (Hardy et al., 1994), using the Coping Strategies Inventory-Short Version (CSI-S) measured coping in parents of children with cancer with two comparison groups; parents of children with HIV and parents of healthy children. The study reported that parents of children with cancer used ‘Wishful thinking’ more often than parents of healthy children, but less often than parents of children with HIV. Interestingly, parents of children with cancer displayed less ‘Self-criticism’ than parents of healthy children. Overall, parents of children with cancer reported using ‘Cognitive restructuring’ most frequently as a way of coping, followed by ‘Problem solving’, ‘Seeking social support’, ‘Wishful thinking’, ‘Expressed emotion’, ‘Problem avoidance’ and ‘Social withdrawal’. ‘Self-criticism’ was reported as being used least often.

2. Study reference number 13 (Eiser & Havermans, 1992) using the CHIP measured coping in parents of children with cancer with three comparison groups; diabetes, asthma and cardiac conditions. Parents of children with leukaemia stated they found ‘Seeking medical care’ as a way of coping most helpful, followed by ‘Social support and information’, ‘Family support’. ‘Autonomy’ (e.g. caring for oneself) was rated the least helpful.

Cross-Sectional Studies. (Quality scores of 11, 10, 9, 9, 10, 10, 11 and 12 respectively).

1. Study reference number 1 (Patistea, 2005) using the CHIP found that parents perceived coping strategies related to ‘Maintaining family cohesion, co-operation and an optimistic definition of the situation’ as significantly more helpful than ‘Understanding the medical situation’ (thought to be least helpful) and ‘Maintaining social support and psychological stability’. Interestingly, parents who lived in larger cities found ‘Understanding the medical situation’ more helpful than the other two means of coping. Also, parents whose children had continuous remission used all three coping patterns more equally compared to those whose child had relapsed, who relied mostly on ‘Understanding the medical situation’.

2. Study reference number 2 (Yeh, 2004) used the Parental Coping Strategy Inventory and found that parents of children newly diagnosed with cancer rated ‘Learning’ as the most often used coping strategy followed by, ‘Maintaining optimism’, ‘Interaction with spouse’, ‘Interaction with healthy siblings’, ‘Interaction with ill child’, ‘Religious activities’, ‘Searching for meaning in life’, ‘Physical support’, ‘Decision making’, ‘Emotional support’ and ‘Informational support’. ‘Maintaining emotional stability’ was rated as being utilised least often.

3. Study reference number 3 (Birenbaum, 1990) used the CHIP and found that parents reported ‘Maintaining family cohesion, cooperation and an optimistic definition of the situation’ as a way of coping was more helpful than ‘Maintaining social support, esteem and psychological stability’. ‘Understanding the medical situation’ was rated as being the least helpful.

4. Study reference number 7 (Trask et al., 2003) used the CSI and found that parents reported using ‘Problem solving’ most often as a way of coping, followed by

‘Cognitive restructuring’, ‘Social support’, ‘Wishful thinking’, ‘Expressed emotions’, ‘Social withdrawal’, ‘Problem avoidance’. ‘Self-criticism’ was reported as being used least often.

5. Study reference number 9 (LaMontagne et al., 1999) used the Ways of Coping Questionnaire and found that parents accompanying their child in undergoing an invasive procedure as part of their cancer treatment used 60% emotion-focused strategies and 40% problem-focused strategies. Emotion focused strategies included ‘Positive reappraisal’, ‘Self-control’, ‘Escape avoidance’, ‘Acceptance of responsibility’ and ‘Distancing’. Problem-focused strategies included ‘Seeking social support’, ‘Problem solving’ and ‘Confrontive coping’ (e.g. expressing anger).

6. Study reference number 10 (Han, 2003) used the CHIP and reported that parents described ‘Maintaining family integration’ as the most helpful group of coping strategies, followed by ‘Maintaining social support and psychological stability’. ‘Understanding the medical situation’ was reported as the least helpful group of coping strategies.

7. Study reference number 12 (Cardella & Friedlander, 2004) used a subscale of the Religious Coping Scale (RCOPE) to investigate spiritual coping strategies of parents. The subscale used was entitled ‘Religious Coping Methods to Gain Control’. Within this scale, parents reported using ‘Collaborative religious coping’ (e.g. worked with God to relieve my worries) most often, followed by ‘Active surrender’, ‘Pleading for direct intercession’ (e.g. prayed for a miracle) and ‘Self-directed coping’. ‘Passive deferral’ was used least often.

8. Study reference number 14 (Cayse, 1994) used the Parent Perception Inventory, a sub-scale which measures 29 coping strategies. Interestingly, fathers rated

'Praying' as being the most often used and most helpful coping strategy and 'Blaming someone' and 'Smoking' as least helpful and least often used. However, overall, fathers rated problem focused strategies as both most helpful and most often used. The problem focused strategies included 'Obtaining information', 'Looking at options', 'Weighing choices', 'Asking questions', 'Trying to figure out what to do', 'Reading about a problem', 'Trying to change things', 'Using other's advice' and 'Finding and asking for help'.

Coping classifications.

Coping strategies from each measure used in the reviewed studies were classified into one of two major coping dimensions: (a) approach, avoidance and (b) problem-focused, emotion-focused. If a paper already classified the strategies within these dimensions then this classification was maintained. Table 1.2 reports coping strategies within these dimensions.

Of the coping strategies rated most frequently used or most helpful, nine were emotion-focused, four were problem-focused, ten were approach and one was avoidance coping. However, of the coping strategies rated least frequently used or least helpful, eight were emotion focused, five were problem focused, five were approach and five were avoidance strategies. This has simply pulled together the most and the least frequently used or helpful coping strategies, it does not reflect the overall picture, which will be further explored in the discussion section of this review.

Discussion.

Research on coping of parents of children with cancer is sketchy at best and varies enormously in theoretical understanding, scales used to measure coping, culture of participants, stage of illness of child and many other factors. From the current literature base it would be near impossible to definitively conclude what strategies, or even dimensions of coping, parents of children diagnosed with cancer in the previous five years, utilise the most and which are most/least helpful. However, by organising the measured strategies into two taxonomies (Table 1.2), a general picture of what dimensions of coping are used more often or rated most helpful can be determined. By looking at which strategies were rated most highly it can be seen that approach and emotion-focused coping are more heavily weighted. However, not all papers state whether there is a statistically significant difference between the ratings of the different strategies. Research has shown that problem focused coping is more likely to be used if the stressor is perceived to be amenable to change, but emotion-focused coping is employed when the stressor is thought not to be within one's control (Grootenhuis & Last, 1997). Therefore, it may be that parents of children with cancer have low perceived control of the care or well-being of their child and so utilise emotion-focused coping to help manage distress caused by the diagnosis, illness and treatment.

The majority of included studies report that parents consistently rate approach coping as more helpful or frequently used than avoidance coping. Therefore, literature to date seems to suggest that emotion-focused and approach coping are predominant strategies used by parents of children with cancer. However, the role of problem-focused coping cannot be disregarded as some studies suggest that parents draw upon all forms of coping in managing a stressful situation (Miller, 2000; Skinner, Altman &

Sherwood, 2003). It may be that by limiting the time frame of reviewed papers to five years post diagnosis, certain phases in the illness trajectory have been captured in which most parents concentrate coping efforts on managing overwhelming emotions. It could be that studies conducted at different time points may yield differing results. However, this study highlights the fact that different phases of the disease process may generate an assortment of problems for parents that require learning and use of a range of coping strategies.

One major difficulty with reviewing coping is the heterogeneity of measures used across studies. A total of nine different measures were used in the studies included in this review. The most common measure was the CHIP, which did consistently return the result that parents rated 'maintaining family cohesion, co-operation and an optimistic definition of the situation' as most useful. A further difficulty is lack of reporting on psychometric properties of measures. The majority of papers gave reliability coefficients (usually Cronbach's Alpha) of the questionnaire, but few reported more than this. Those papers that used the CHIP (Patistea, 2005; Birenbaum, 1990; Goldbeck, 2001; Han, 2003; Eiser & Havermans, 1992) reference where further psychometric properties are reported, as does the study by Hoekstra-Weebers et al. (1998) for the Utrecht coping list and Cayse (1994) for the PPI. Hardy et al. (1994) however, provide retest reliability and internal consistency values for the CSI, but states that the psychometric properties of the short version of the CSI are still under investigation and so gives no details. A full review of the psychometric properties of measures of coping is outside the remit of this paper. However, it is recommended that for future research, a degree of unanimity should be reached on the most valid and reliable measure, to allow for comparison of and replication between studies.

In addition to the problem of heterogeneity of measures, a variety of other difficulties exist. Some papers only study mothers (e.g. Han, 2003) and some fathers (e.g. Cayse, 1994). LaMontagne et al. (1999) looks at coping during invasive procedures, whereas other studies cover a spectrum of stages of the illness. There is a range in the age of children of the parents taking part and some papers state whether parents are married, divorced or single and others do not. Some studies look only at Leukaemia, (e.g. Patistea, 2005; Eiser & Havermans, 1992), others include all types of childhood cancer. One further difference noticeable between included studies is country of origin. Six studies were conducted in the USA and Canada and one each in the UK, Greece, Taiwan, the Netherlands, Germany and South Korea respectively. Patistea (2005), Yeh (2004) and Han (2003) make comment, in the introduction to their studies as to the potential effect of culture on parents' coping responses and also to social constructions surrounding childhood illness and relationships with doctors. It is also unclear as to whether level of treatment of children with cancer is equally available across countries, but also across families within countries, particularly where health care is privatised. Of particular interest to the author is the distinct lack of papers originating from the UK. One further study was conducted in England (Sloper, 2000), but was excluded on the basis of insufficient data being reported. This is of note, as the UK is arguably unique in having a National Health Service and raises the question whether this health context may also affect parents' coping.

All of these factors may affect how parents appraise stressors thus affecting the coping strategies they may employ to manage the situation. From the literature reviewed to date, it is near impossible to account for all these variables when studying this population but they must be kept in mind when examining conclusions made by authors.

However, the practical and ethical restraints of conducting high quality, controlled studies within this participant population are clear. Therefore, a fair conclusion may be that until more is known and understood about coping of parents of children with cancer, intervention studies to promote successful coping and reduce distress are not feasible. At this point in the literature, rigorous qualitative studies may provide more helpful information in terms of parents' experiences and from this work, meaningful quantitative studies, utilising appropriate measures could be undertaken.

A strength of this systematic literature review is the fact that it attempts to take into account quality of included papers. All studies included had reached a minimum score on a quality checklist and the results section of the review is organised in such a way as to allow the reader to distinguish between papers that scored highly vs. those that scored lower.

A criticism, however, can be found in the classification of coping strategies. This was undertaken following the structure used by Aldridge and Roesch (2007) in their meta-analysis of coping and adjustment in children with cancer. Strategies that had not previously been classified into the taxonomies were classified by the author. Judgements were based on the amount of descriptive information given in each study. The level of this information varied significantly, with some papers giving examples of the items making up the strategies and others merely giving the name of the subscale. It could be argued, that if more information were provided, some categories may have fallen into other dimensions. However, even if this were the case, it would be unlikely to drastically affect weightings as the majority of strategies had been previously listed by Aldridge and Roesch (2007).

In summary, it can be concluded that, based on the current range of studies which differ widely on a number of factors, parents do, during the first five years of their child being diagnosed with cancer, utilise emotion-focused and approach coping strategies more often and also report these strategies to be more helpful. However, some strategies within the emotion-focused dimension are also considered to be least helpful and thus least frequently used. Further systematic literature reviews are needed at different stages of the illness trajectory to determine whether coping patterns of parents change over time. It is also of note that very few papers have been conducted within the UK and this gap in the literature base needs to be addressed.

Having one's child diagnosed with cancer is likely to be extremely distressing, and most parents may need assistance in coping with the situation. However, for professionals to do this effectively there needs to be clarity about which strategies are most beneficial and which can then be included in intervention and care programmes. It seems that rigorous qualitative research is needed, in a U.K. population, to further clarify the situation, before large scale, prospective intervention quantitative studies can be undertaken.

Table 1.1 Study Details.

Ref No.	N. M=mothers F=fathers	Children's age range.	Country of research	Design	Coping measure	Quality score
1.	41m, 30f.	2.2-16.8 years	Greece	Cross-sectional. Quantitative and qualitative	Coping Health Inventory for Parents (CHIP)	11
2.	171m, 171f. Or 171 couples	<18 years at time of diagnosis	Taiwan	Cross-sectional	Parental Coping Strategy Inventory (PCSI)	10
3.	44m, 38f.	Unknown- but children's hospital	USA	Cross-sectional	CHIP	9
4.	62m, 62f. Or 62 couples	0-16 years	Netherlands	Longitudinal and includes norm-group	Utrecht Coping List	12
6.	25m, 25f. Or 25 couples	0.5-15 years	Germany	Longitudinal with comparison groups.	CHIP & Trier Coping Scales.	13

7.	N=28	11-18 years	USA and Canada	Cross-sectional	Coping Strategies Inventory (CSI)	9
9.	N=20	3 yrs 10 months-11 yrs 8months	USA	Cross-sectional	The Ways of Coping Questionnaire	10
10.	N=200 (all mothers)	1 month-18 years.	South Korea	Cross-sectional and correlational	CHIP	10
11.	N=20	4-7 years	USA	Cross-sectional with comparison groups.	CSI –Short Version	11
12.	N=162	75% <14years. Rest unknown	USA	Cross-sectional	Religious Coping (RCOPE)	11
13.	N=13	4-14 years	U.K.	Cross-sectional. Comparison groups.	CHIP	9
14.	N=23 (all fathers)	3-6 years	USA	Cross-sectional	Parent Perception Inventory (PPI)	12

Table 1.2. Taxonomy of Coping Strategies. *= number of times rated most helpful or most frequently used.

<p>APPROACH AND PROBLEM:</p> <ul style="list-style-type: none"> •Problem solving.** •Seeking medical care.* •Learning.* •Seeking information. •Understanding the medical situation. •Decision making. •Informational support. •Confrontive coping. •Looking at options. •Weighing choices. •Try to figure out what to do. 	<p>APPROACH AND EMOTION:</p> <ul style="list-style-type: none"> •Maintaining family cohesion, cooperation and an optimistic definition of the situation.**** •Collaborative religious coping.* •Cognitive restructuring.* •Maintaining social support and psychological stability. •Maintaining optimism.* •Self-control. •Positive re-appraisal. •Social support seeking. •Active surrender religious coping. •Self-directed religious coping. •Pleading for direct intercession religious coping.
<p>AVOIDANCE AND PROBLEM:</p>	<p>AVOIDANCE AND EMOTION:</p> <ul style="list-style-type: none"> •Minimisation.* •Palliative reaction pattern. •Blaming self/others. •Expression of emotion. •Wishful thinking. •Self criticism. •Escape avoidance. •Distancing. •Passive deferral religious coping. •Eat. •Busy self with other things. •Get away for a while. •Wish problem away. •Sleep. •Ignore problem. •Alcohol/medication/smoking.
<p>PROBLEM:</p> <ul style="list-style-type: none"> •Physical support. •Seeking instrumental social support. •Asking questions. •Try to change things. •Use other’s advice. •Ask for help. 	<p>EMOTION:</p> <ul style="list-style-type: none"> •Pray.* •Humour. •Talk about feelings. •Expression of emotion. •Exercise. •Comforting cognitions. •Seeking stability through religion. •Autonomy. •Interaction with ill child/spouse/sibling. •Emotional support. •Maintaining emotional stability. •Cry. •Search for meaning. •Acceptance of responsibility. •Try to relax. •Change expectations. •Hide feelings.
<p>APPROACH:</p>	<p>AVOIDANCE:</p> <ul style="list-style-type: none"> •Avoidance behaviour. •Passive reaction pattern. •Rumination. •Problem avoidance. •Social withdrawal.

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The Experiences of Parents of Children with Cancer: A Positive Psychology Approach.

This paper is written in the format ready for submission to the Journal of Psychosocial Oncology. Please see appendix 3 for the Guidelines for Authors.

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ABSTRACT. When a child is diagnosed with cancer, parents must manage difficult and often overwhelming emotions in addition to adapting to complex practical changes. To date, research has focused on coping styles and strategies used by parents, but studies are often of poor methodological quality and report a heterogeneity of measures. A study using positive psychology framework and Interpretative Phenomenological Analysis (IPA) methodology was conducted to explore, in depth, the experiences of parents of children with cancer. Ten semi-structured interviews were carried out and systematically analysed. Six super-ordinate and further sub-ordinate themes emerged through analysis and were discussed in the context of a positive psychology approach.

Key Words: Child; Cancer; Parent; Qualitative; Positive Psychology

INTRODUCTION.

In Great Britain, 20% of all deaths in children are due to cancer (Office of Statistics, 2004). Approximately one third of childhood cancers are leukaemia, a quarter are brain and spinal tumours, 15% of cases are embryonal tumours and just under 10% are lymphomas. Remarkable progress in medical paediatric treatment of cancer over the last four decades has led to steep drops in mortality. In the 1980's just under 30 deaths per million occurred and this dropped to 10 per million in 1992 for leukaemia. Approximately 75% of all childhood cancer patients in Britain survive for at least five years post diagnosis (Quinn, Babb, Brock, Kirby & Jones, 2001; Steliarova-Foucher et al. 2004). Surgery, chemotherapy, radiotherapy and combinations of any and all of these interventions form the mainstay of treatment for most childhood cancers.

Unsurprisingly, the impact of being a child, or the family of a child diagnosed with cancer extends far beyond physiological and medical stresses, which in themselves can be very distressing. NICE guidelines (2005) for cancer in children and young people state "The diagnosis of cancer in a child or young person often throws a family into crisis." (p.73). Parents and other family members are faced with the shock and grief of diagnosis, but may also have to manage factors such as work situations, travel costs, staying in hospital, caring for other children as well as caring for the child with cancer. Indeed, the most time consuming and difficult care giving activities for both mothers and fathers have been shown to be providing emotional support to the child with cancer, and to other children in the family (Svavarsdottir, 2004). Mothers were shown to have particular difficulty managing behavioural problems and planning family activities. Fathers reported finding managing work, caring for the child and emotionally supporting their partner the most difficult (Svavarsdottir, 2004). Research clearly supports and

confirms that to be the mother or father of a child with a potentially fatal illness is unequivocally difficult, stressful, distressing and widely impacting.

Previous literature investigating parents of children with cancer is focused on coping strategies parents employ. A systematic literature review by Chasle (2008, in submission) concludes that the majority of research in this area is of poor methodological quality and measures of coping too heterogeneous to allow meaningful conclusions to be drawn and applied to clinical practice. A further conclusion is that research to date has largely been conducted outside of the UK, in countries with a privatised health system (Chasle, 2008, in submission). It could be argued that cultural differences in parenting and family structure and also in health care experiences between countries means results of research may not be easily generalised to a UK population.

Therefore, this study aimed to bridge the gap between the current literature base and paucity of research with parents in the UK with children with cancer under the care of the National Health Service. Researchers are beginning to widen their approaches to investigating parents of children with cancer, for example Kylma and Juvakka (2007) have studied factors engendering and endangering hope in Finnish parents. Hence, a new framework, other than coping, was chosen to underpin the current study (that of positive psychology) and exploratory methodology (Interpretative Phenomenological Analysis – IPA) was utilised to allow for an in depth investigation of parents' experiences.

Seligman, Steen, Park and Peterson (2005) describe positive psychology as “an umbrella term for the study of positive emotions, positive character traits and enabling institutions.” (p.410). One of the key proponents of the positive psychology movement, Seligman (2005), states that “psychology is not just the study of disease, weakness and damage; it is also the study of strength and virtue.” (p.4). This approach expands from

subjective experience, such as well-being, to personal traits like perseverance and wisdom, also taking into account attributes of groups such as altruism, civility and tolerance. Seligman (2005) reports that it is these human virtues that act as buffers against psychopathology, and suggests that instead of using an illness model to examine how to prevent and treat mental health problems, a strengths model should be used. To add to this argument, early literature in paediatric psychology uses resilience and coping models to frame the issues surrounding chronic illness, and are considered as a one-off solution to major stressors, and not as fluid personal styles or attributes (Roberts, Brown, Johnson & Reinke, 2005). Therefore, by combining the theoretical context provided by positive psychology with an exploratory methodology, this research aimed to widen and develop a meaningful understanding of the experiences of parents of children with cancer; both the difficulties they face and also the sources of strength they use. This study aimed to explore the experiences of parents of children with cancer, with the focus on how and where they draw strength from to continue in their life and role as a parent. Semi-structured interview questions were formulated to further investigate and understand what parents of children with cancer experience as being most helpful, using a positive psychology framework.

METHOD.

Design.

Interpretative Phenomenological Analysis (IPA) was used for gathering and analysis of data. IPA is rooted in two major theoretical movements; phenomenology and symbolic interactionism. The objective of phenomenological methodologies is to produce an account of an event or state that is grounded in the individual's personal

understanding of their experience of that event or state. The essence of symbolic interactionism is that individual's meanings are created and obtained through a process of interpretation or the way in which we make sense of our experiences within a social and cultural context. In IPA, the researcher attempts to 'immerse' themselves in the account of the participant in an attempt to interpret the participant's interpretation of their lived experience. This two-stage interpretative process is referred to as a 'double-hermeneutic' by Smith and Osborne (2003): "the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2003, p.51). IPA accepts and works with the assumption that the researcher can never completely or wholly adopt the participant's 'insider's perspective' (Conrad, 1987), as they will continually be influenced by the complex interaction between their own experiences and interpretations. However, the main concern of this methodology is to, as far as possible, gain an insight into participants' interpretation of their experiences and not to create an objective description.

Participants.

The study was facilitated by a Macmillan Nurse from an NHS children's palliative care team in the North East of England, which provides care and support to children with life-threatening illnesses and their families. All study participants were known to the service but were not necessarily receiving active help at the time of the interview.

Eligible participants were the parents or legal guardians of a child (under the age of 18 years) who had been diagnosed with cancer. Since the study was focused on the

continuing process of parenting a child with cancer, parents of children with cancer who had consequently died were excluded. There were no exclusion criteria with regards to same sex couples, single parents or one parent of a couple. Parents judged by professionals in the team to be experiencing significant distress at the time of the research were not approached.

Fifteen families who met the inclusion criteria were invited to participate between August and September 2007. Ten interviews were conducted, two of which were with couples making a total of 12 individual participants. Eight of the ten children had a diagnosis of Acute Lymphoblastic Leukaemia (ALL), one had a solid brain tumour and one was diagnosed with an osteosarcoma. The age range of the children was 5-17 years with an average age of 9.5 years (mode and median = 8 years). Two of the parents interviewed were single mothers and the remainder were married. Two couples took part and were interviewed together; the other participants were all mothers.

Procedure.

Ethical approval to approach and interview parents was obtained from the local Research and Ethics Committee [see appendix 4]. Potential participants received written information about the study [see appendix 5] and verbal and written consent was obtained prior to the interview [see appendix 6] commencing. Participants were informed that all identifying information from transcripts would be removed and pseudonyms used in any quotations utilised in the study. The audio recordings of interviews and written consent forms were stored in keeping with ethical guidelines. All participants chose to be interviewed in their homes. Following the interview, participants were reminded that they could request their data to be withdrawn from the

study at any point before dissemination with no consequences to their child's care. However, no participant chose to withdraw their interview.

Data was collected via the use of semi-structured interviews. The interview schedule was influenced by a phenomenological perspective and was designed with the aim of facilitating the participant to speak freely of their experiences, whilst providing a framework from which to gather meaningful data. The questions were structured using a positive psychology framework and inquired, by means of open questions, about positive emotions and characteristics, positive relationships and positive organisations. The interview schedule was piloted in a role play which was validated by two independent researchers. [A copy of the interview schedule is provided in appendix 7]. All interviews were conducted, audio recorded and transcribed verbatim by the researcher.

Within eight weeks of the interview a written summary of participants' transcripts were sent back to the participants with the opportunity for them to comment on accuracy or to make additional comments. Only one participant returned the summary simply stating she felt it was an accurate account. [A flow chart of the process of data collection can be seen in appendix 8].

Analysis.

Transcribed interviews were checked for accuracy by comparing to the original recording. This began the process of the researcher becoming 'immersed' in the data from an early stage, by listening to each interview three times. Once all interviews were completed and transcribed they were then analysed following similar guidelines to those provided by Smith and Osborn (2003).

Stage 1 – The transcript was read through once to enhance the researcher’s familiarity with the text.

Stage 2 – The transcript was read again with the left margin used to annotate anything interesting or significant found in the text. This stage was also conducted by an independent researcher for two of the transcripts and comments discussed. Sections of two transcripts were submitted to an IPA group of researchers who completed this stage and again, the comments were discussed in the group context.

Stage 3 – The transcript was read for a third time and the right hand margin used to document emerging themes and links to theory began to be established.

Stage 4 – Emerging themes and supporting quotes were printed for each transcript and viewed in order of appearance to enable the researcher to see similar and corresponding themes across transcripts.

Stage 5 – Links between themes across transcripts were made and reorganised, resulting in the creation of super-ordinate themes comprising a number of sub-ordinate themes. In this stage, illustrative quotes from each theme were discussed with an independent researcher to verify that the themes were grounded in the text. From this a master list of sub and super-ordinate themes with supporting quotes was created. [See appendix 9 for a worked example of IPA].

RESULTS.

A consistent pattern of themes emerged across transcripts as well as a rich and varied diversity of experiences between participants. After discussion with two independent researchers, the themes were organised into six super-ordinate themes.

Each theme is described using verbatim quotations to illustrate. Pseudonyms have been used to maintain anonymity. Table 2.1 outlines the super and sub-ordinate themes.

Table 2.1. Titles of Super and Sub-Ordinate Themes.

Emotional and Practical Experiences of Being a Parent of a Child with Cancer.	Response to Trauma.	Strength From Relationships.	This is Not the End.	Resisting the Sick Role.	Control
•Instinctive Response	•Unbelievable	•Other Parents	•Hope	•Humour	•Loss of Control
•Ultimate Responsibility	•Shock	•Family	•Future Orientation	•Fighting Spirit	•Regaining Control
•The Desire to Spoil	•Unbearable	•Friends		•Maintaining Normality	
•Emotional Containment	•Comparing Lots	•From Professionals vs. Isolated at Home			
•Emotional Facade in Front of the Child					

Super-ordinate Theme: Emotional and Practical Experiences of Being a Parent of a Child with Cancer.

This super-ordinate theme comprises sub-ordinate themes attempting to capture the essence of experiences specific to being a parent of a child with cancer.

Instinctive Response.

A drive to cope or to carry on which parents seem to experience as a 'primitive response' to the threatening situation of their child's diagnosis. Parents struggled to put this into words, reflecting the sense of it being a basic instinctual drive.

"Because you don't really know how you'll react until it happens, you can only sort of wait and see, but I have great faith in sort of the human instinct to survive I suppose. I think that's part of it, almost like a survival instinct, it's a very basic, quite a primitive response, which is in place obviously for a reason to get you through difficult times."

Often this drive or instinct was to keep going for the sake of the child or for the protection of the child.

"I don't know, I think it's just something in you what just keeps you going. I mean if we give up, if me and his dad give up, where, where will he be?"

"I suppose it brings out a strength in you that you didn't know that you had, but you had to for the sake of your child, if it was for you, you would have given up the ghost a long time ago. But because it's for her you've got to do it..."

Hoghghi (2004) defines the central activities of a parent as care, control and development. Care, according to Hoghghi (2004) is the combination of activities that are aimed at meeting the 'survival needs' of the child. These survival needs comprise physical, emotional and social domains across the developmental stages. It could be

argued that the drive to fulfil the survival needs of the child have their basis in an evolutionary psychological understanding of the parent. At a time when the child or part of the parent's domain is being threatened by death or prolonged suffering, an instinct to protect and to continue the survival of the child is heightened in the parent, to a degree that perhaps is not regularly experienced by parents in western society where threat to a child's life is arguably more limited than elsewhere in the world.

Sub-ordinate Theme: Ultimate Responsibility.

This theme is closely linked to the Instinctive Response theme, but describes the belief parents hold that they are ultimately responsible for the care and protection of their child. Even in the context of the doctors and nurses caring for their child, it seems the parents still feel as though the fundamental provision of care should only and can only be fulfilled by them

"I know I've got to keep you know, going and not go to pieces otherwise the whole household will just collapse really. And I know at the end of the day if they don't have me, they haven't got anybody."

"...it's been hard to look after her. As much as I wouldn't have ever not done it or wanted anybody else to do it, I could have only, it would have had to have been me, I think the fact that I'm quite patient has just helped..."

In the medical setting of cancer treatment, where the parents may feel as though they have little control (see further theme) this belief may express itself in highly organised information gathering and vigilance about the administration of medication for example.

"...she's your responsibility and people make mistakes....And I ask for tests to be done, anything hasn't been done for while, shouldn't we be doing this, 'cause she hasn't had it

done since May, hasn't she, you know, yeah, ok then. And I will chase and chase until I get results. I don't believe that no news is good news, I believe you've gone through the net at that point (laughs), tell me the results and then I'll go away."

Sub-ordinate Theme: The Desire to Spoil.

Parents would appear to experience a desire, once they have been told their child is ill, to 'spoil' them. A range of ways in which this desire is manifest is apparent, some parents referring to maintaining boundaries and discipline, others talking about materially spoiling their child and yet others referring to the amount of time and affection the child with cancer receives in comparison to siblings. There is also a range in the response to the common desire to spoil; some give into it, others resist it.

"It's difficult because your instinct is to pander and to spoil and to overprotect, but your common sense tells you it's gonna backfire on you later on when you've got some ruined brat that you can't do anything with."

"...it must be very difficult 'cause it's always Joe gets the attention first. They come home from school and he's got something new, he's sat there with things, and I do, I do try to be aware of that, but I, I do spoil Joe, unfortunately...With everything, with things, with time, even like sleeping in my bed. He started that off when he got poorly because he wasn't sleeping very well and he was in pain. He had a lot of pain in his legs so we had to do stretches and things all night with him, and it was just a comfort thing. He just wanted to be next to me and if he was content with that I was perfectly happy. And he still does, and the others will say sometimes 'can we sleep in your bed?' (laughs). Which I did feel very awful, he's getting so much of me, but then in another way he needs it."

It is interesting to consider what may trigger this desire to lavish the child and to allow relaxation of boundaries. What is also interesting is the use of the word 'spoil' which suggests a belief, probably socially constructed, that to give into this desire would somehow damage or ruin the child. It may be that in the context of the child's life being under threat, a deep drive to express or lavish love may be magnified in a similar way to how the instinct to protect is evoked. However, in some parents, the response to this desire is controlled in an attempt to maintain the character of the child for the future, presumably a point in the future when the parent envisages the child being well again.

It could be argued that the Instinctive Response and Ultimate Responsibility themes are universal experiences which transcend cultural boundaries, however, the following themes are arguably social constructions of western parenting.

Sub-ordinate Theme: Emotional Containment.

Bion (1961) emphasised the role of the mother as emotional container for the infant's anxieties, impulses and emotions. The task of the mother is to 'digest', contain or make sense of these feelings and hold them for the child so that it is then bearable for the infant to experience and feel these emotions, impulses and anxieties. While none of the children of the parents in this study were babies and the age range varied greatly, parents still communicated a common experience of having to emotionally contain their child. Children being treated for cancer may experience times of immense anxiety, fear, anger and other potentially overwhelming feelings and impulses. The parents in this study saw it as their role not only to be the focus of these emotions but also to digest and make meaning of them for the child.

“Basically it was teaching children to deal with their emotions, and it was by one of the things was validating the emotion. Not saying ‘oh stop being silly’ or something like that and one of the things and I used to say to her was, you know if they had to do something that she didn’t like, like put an NG tube in when she was awake, she would be crying, and I would just give her a big hug and say ‘look Alison you know, you’re being ever so brave, I would cry too if they was doing it to me ‘cause I wouldn’t like it either’ and it was basically a case of saying, you know, you’re not on your own, everybody would feel like that. It’s just making sure that she know that she’s not being silly, she’s not being a baby, that she’s got every right to feel like that, and a lot of the time that helps, so that was another thing, you know, was to sort of like, let her know that she had every right to be as upset as she was and I think that helps as well.”

Sub-ordinate Theme: Emotional Facade in Front of the Child.

Due to the homogeneous demographic of the participants, (White, British), it is possible that they may have been influenced by prevalent social discourses concerning ‘good parenting’. One of these discourses may regard the limits of emotional expression that is acceptable in front of a child, particularly expressions of grief, fear and anxiety.

“...I wouldn’t have dreamt of being upset in front of him or falling apart or becoming depressed or whatever because I couldn’t do that in front of James, because it was so important, I think, to his recovery and the way that he handled it.”

Although logic, like that demonstrated in the quotation above has face-validity, as far as the researcher is aware there is a paucity of evidence about whether or not displays of emotion in front of the child affects their recovery. However, despite this it seems the

parents interviewed for this study had a strong belief that it was their role to ‘keep it together’ in front of their child.

Super-ordinate Theme: Response to Trauma.

The DSM-IV-TR (American Psychiatric Association [*DSM-IV-TR*], 2000) diagnostic criteria for Post Traumatic Stress Disorder (PTSD) states that in order to develop PTSD a person must have:

“...been exposed to a traumatic event in which both of the following have been present:

(1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others (2) the person's response involved intense fear, helplessness, or horror.”

Arguably the experience of being a parent of a child diagnosed with cancer fulfils these criteria, it is not being suggested that parents go on to develop PTSD. However, this domain attempts to encompass the range of responses that parents experience related to the traumatic nature of the event.

Sub-ordinate Theme: Unbelievable.

Parents describe a sense that, often in the initial stages of diagnosis and treatment, their experiences don't feel ‘real’ or as though it is not actually happening to them. At its most extreme this sensation is known as dissociation; a common response to trauma. However, there are degrees and it seems some parents experience a sense of unreality.

“And he was, there was always a lot of, you know, it was just a feeling of watching a movie type of thing, it wasn’t really happening to you.”

“It was unbelievable because you didn’t feel it was happening to you, you almost felt as though um as though somebody was going to wake you up.”

Sub-ordinate Theme: Shock.

Shock is defined as the emotional or physical reaction to an unexpected and usually unpleasant event. It is therefore unsurprising that parents describe this as a common experience.

“...and he said no I’ll wait and I said no just, and then he told me, and it just, absolutely knocked me out the building, absolutely knocked me out the building. That’s how surprised I was by it...”

Sub-ordinate Theme: Unbearable.

A sense of finding the situation too much to bear was a theme common across transcripts. The quote below, illustrating this theme is an interview with a husband and wife talking about the first few nights after the diagnosis.

“...I don’t know, I remember actually, those first few nights that we sat on the sofa...

Part b: Desperate...

Part a: It was, it was, I don’t think...

Part b: Long days, long days.

Part a: If I’m honest, I don’t think I’ve ever felt quite so desperate. I remember thinking, I remember thinking I’m gonna ask the nurse for some drugs (laughs), but I am, I want something, because I felt so physically in pain, but it wasn’t, it, it was just all,

you know, it was just the pain of seeing her so ill and I was so utterly terrified and scared. As the night time approached every night, for probably about the first five, five to seven days that we were there, I just felt like I couldn't get through another night, I couldn't get through. Do you remember? I, I just think we sat and cried through the night almost every night, sort of silently."

Although reacting to the traumatic news of your child having cancer is in no way a linear process, it may be interesting to know whether parents further in time since diagnosis express more feelings of being overwhelmed, perhaps as the shock and the disbelief of the situation begins to fade and the reality of the diagnosis is grasped more fully.

Sub-ordinate Theme: Comparing Lots.

Some parents spoke about how they felt the experience of having a child with cancer had changed or shifted their perspective on life. They no longer worried about things they regard as trivial. A similar experience described is that of being 'encouraged' by seeing other families managing situations that parents appraise to be worse than their own. It is an interesting phenomenon that once people are dealing with a situation that would originally have been highly negatively appraised, their appraisal shifts to become less negative.

"...and one mother came in just after us and they didn't even know what was wrong with her son, they'd um some sort of tumour in his brain, but they couldn't tell her what was wrong and I'm thinking how awful's that! You know at least I know what's wrong with my son and that it's curable, this poor mother's having to, you know, deal with a child

who they don't know what's wrong with him and they don't know if they can put it right, so I think that sort of encouraged me...".

Super-ordinate Theme: Strength from Relationships.

Magni, Silvestro, Carli and De Leo (1986), (cited in: Baider, Cooper, Kaplan and De-Nour, 1997, p.94), have shown that social support serves as a buffer to the effect of a childhood diagnosis for the parent. Pot-Mees (1989), (cited in: Baider, Cooper, Kaplan and De-Nour, 1997, p.94), also demonstrated provision of social support has a positive effect on parent's adjustment both during and after hospital treatment. Additionally, adequate information and an empathic attitude in professionals dealing with the family has been shown to have an enhancing effect on parental coping (Barbarin and Chesler, 1984), (cited in: Baider, Cooper, Kaplan and De-Nour, 1997, p.94). Unsurprisingly, the strength that parents drew from their relationships with professionals, other parents whose children were also diagnosed with cancer and from their family and friends are themes that emerged strongly across transcripts, as illustrated by the following quotations.

Sub-ordinate Theme: Other Parents.

"I mean it was also another thing that made you feel better was, as you're going down the line, as you're getting on with your treatment you see new people coming in, and it was old, parents of children who were already being treated, they helped you, just as when the new ones came in and you knew what they was going through, what they had

to go through, you could help them as well. They was like a conveyer belt of help really, of parents, so that helped, the fact that you could help somebody else deal with it...”.

Sub-ordinate Theme: Family.

“...but I think it’s the family, the family really does come into help. We feel, again incredibly lucky um, in that respect, that we’ve kinda got parents helping, my parents and they’ve been, again, a tower of strength for us, they’ve been phenomenal, a help and er, you know, would have been so much more difficult without them

Part b: Oh yeah, definitely. And as, especially when we’ve had to be in hospital with Jenny if you can know that your other children and your home are being looked after, that just means everything really. I mean if we hadn’t have had that, it would have been worse somehow. No, definitely from, from, from the, from day one we’ve had that, and I know not everybody does have that so we are lucky.

Part a: Both of our parents...

Part b: Just descended on us really...

Part a: ...made sacrifices above and beyond...”.

Sub-ordinate Theme: Friends.

“Yeah they have, they’ve been brilliant, they’ve been, so supportive and, you know, sort of helping at home if I’ve been in hospital. That first, that first week they were here, sort of cleaned up, ‘cause obviously I’d left to just go out to take him to the hospital and um, that was it, didn’t come home till the following week, I think I came home once. But they just supported me, um, especially the first, I think the first month and the first few weeks...”

Sub-ordinate Theme: From Professionals vs. Isolated at Home.

An overwhelming number of quotations were obtained to illustrate the emotional, practical and medical support and depth of relationships provided by healthcare professionals.

“Yeah I can, I, I think I’ll always remember that night really, as scary as it was, but just how amazed I was at how fantastic these people were at dealing with two basket cases (laughs). Not just were they sorting Lisa out, we were like two, you know, it’s it’s, in such a mess weren’t we? But they were just brilliant at coping with us and telling us what to do, and I, I think we needed to be told just how to be that night and they did, they got us through it didn’t they. Fantastic.”

However there were also a number of parents who felt quite ‘frightened’ about going home after having become what one parent described as ‘institutionalised’ during their stay in hospital, whilst their child underwent treatment. Some parents felt that going home was isolating and they described feeling let down by the lack of support for them and their child away from the hospital.

“...but I honestly thought there would have been, and everybody said the same, that when you come home you have to cope with it on your own. I actually went, I had to go to the doctors about something else and I was talking to her and I mentioned this to her, before this other lady obviously came to see me but I must admit I just felt it was ten months too late really...”

Super-ordinate Theme: This is Not the End.

This super-ordinate theme encompasses sub-ordinate themes that communicated the range of actions, cognitions and emotions that parents experienced with regards to holding on to the hope that their child would get better and ultimately not die from the cancer.

Sub-ordinate Theme: Hope.

Hope is a concept that has a history of being hard to define and has different meanings in different contexts. In recent positive psychology literature, Snyder (2000), (cited in: Carr, 2005, p.91), conceptualised hope as involving both the belief that a pathway to a desired goal can be found and also that one has the agency or motivation to use the pathway. This definition of hope removes it from a purely emotional understanding and places it further into a cognitive and volitional conceptualisation. Averill, Catlin and Chon (1990), (cited in: Snyder & Lopez, 2005, p.258), demonstrated that hope flourishes when there is a probability that a valued goal can be achieved and obstacles faced are not appraised as insurmountable. This conceptualisation of hope is congruent with the essence of the theme emerging from the text. Parents certainly have a goal in mind, usually the survival of their child, and hope seems to become stronger when a pathway becomes clearer. These pathways seem to differ among parents, some view the medical team as providing the pathways and yet others, the belief that praying will help their child provides a goal directed pathway.

“Um, yeah so that’s been an important, for me, totally important fact is that from day one we were told that, day one we were told that um, you know, there’s a 99% chance of recovery. And I just, I just clung to that from the beginning.”

“...it (praying) made me feel better, it gave me something to hold on to, at least I felt as though I could help her in some sort of a way, even if it did nothing, at least I felt better for trying to help.”

Sub-ordinate Theme: Future Orientation.

This theme is closely linked with and may stem from hope. Perhaps parents that believe that pathways to desired goals exist and have the motivation to travel them, inevitably allow themselves and seem to encourage their child to imagine what it may be like when the goal of survival is achieved. The following illustrative quotation seems to refer mostly to actions that are undertaken due to a mindfulness of the future hoped for.

“Like I used to take my crafts with me and it was, I would do some sewing or knitting whilst I was there and it’s ‘oh I’m knitting a cardigan for Sophie’. And it’s like, one, it’s practical, two, it’s something I enjoy doing, it takes my mind off it a bit and number three if you’re knitting her a cardigan you’re staying focused on the fact that she’s gonna be there to wear that cardigan. You know, what’s the point in knitting her if she’s gonna peg it sort of thing. It sounds awful but you know what I mean. It’s a positive thing. I’m knitting her it because she’s still gonna be there to wear it. Um, and I still make a point even now of saying things to her like, ‘oh just think, in a couple of years time you’ll be at x school’ and things like that and pointing out that I’m still 100% that she’s gonna be there. Not even mention the fact that she might not, so you’ve got to still point out that fact that she’s you know. You’ve got to try and um, think positive...”

Super-ordinate Theme: Resisting the Sick Role.

Themes within this super-ordinate theme attempted to capture parent's efforts to resist the pull in both them and their child toward 'acting' sick. Three emerging themes were identified which illustrate the different ways in which parents seemed to achieve this.

Sub-ordinate Theme: Humour.

Lefcourt (2001, 2002), (cited in: Carr, 2005, p.227), has shown that humour is an effective coping strategy, demonstrating that people with higher scores on measures of humour display less stress related symptomatology in response to a stressful life situation. In addition Carver et al. (1993), (cited in: Snyder & Lopez, 2005, p.624), and Rottona and Shats (1996), (cited in: Snyder & Lopez, 2005, p.624), present results that indicate that humour can be a positive asset in recovery from illness.

"I think a lot of the time it was the calling her daft names, you know the stuff that you do at home, having a laugh, and we'd laugh about some of the nurses and that. One of them we didn't particularly like, one at x general and every time she went out the room we'd have a laugh and a snigger about her and make fun of her..."

Sub-ordinate Theme: Fighting Spirit.

This is a well researched 'adjustment style' in adult oncology (Greer and Watson, 1987), (cited in: Moorey & Greer, 2003, p.12), and is procured from appraising cancer as a challenge and is usually linked to optimism and hope. Adult oncology patients who are viewed to have a 'fighting spirit' usually take an active role in their recovery, seek appropriate information and attempt to live as normal a life as possible. These factors can be seen also in parents of children with cancer, as shown by the following theme.

“...but then when push comes to shove and it’s something really important do you sort of pander to them and sort of say ‘oh yes you’re sick and yes you be an invalid and be weak’, and you know, don’t fight it, or do you say ‘oh come then get on your feet let’s go and do what needs to be done and get on with it’.”

Sub-ordinate Theme: Maintaining Normality.

A further way parents seem to enable themselves and their child to resist the sick role and to procure a fighting spirit is to maintain a sense of normality or routine. The term ‘normal’ emerged quite often within interviews and raised the question for the researcher of ‘what is normal?’ However, it seems that an outsider’s view of what is normal does not matter, it is the parent’s attempts to maintain what is considered to be normal within their family structure, that is important.

“So we can’t, we’ve just got to try and live as normal a life as possible, and that’s it...Just everyday things, um, you know, going on holiday, going out, just trying to plan things as a normal family would do.”

“I always pushed Kate, even when she was on chemotherapy, ‘we’re getting up today, we’re going to have a bath, you’ll feel better’, ‘I’m tired’, ‘but then you’ll have something to be tired about, you’ve walked down the ward, struggled to walk down the ward, walk down the ward, you’ve had a bath, you’ll feel better, when you come back I’ll change all your bed, fresh pyjamas and you’ll feel better’. Hay hoo, you know, she’ll go and do it, sit and do her homework, yet there were a lot of children just with curtains round, feeding tubes in which I wouldn’t go along with...”.

Super-ordinate Theme: Control.

Some theorists (Heckhausen and Schulz, 1995 and White, 1959), (cited in: Snyder & Lopez, 2005, p.203), purport that the drive to be in control is a central motivating guide to human behaviour and development. Griffin and Rabkin (1998), (cited in: Snyder & Lopez, 2005, p.203) show that people facing chronic illness who have a greater sense of perceived control display less anxiety and depression symptomatology. It is perhaps no surprise therefore that parents of children with cancer experience an overwhelming sense of loss of control but then engage in ways of regaining their sense of perceived control, whether that be through exercise, prayer or vigilance about the care their child is receiving.

Sub-ordinate Theme: Loss of Control.

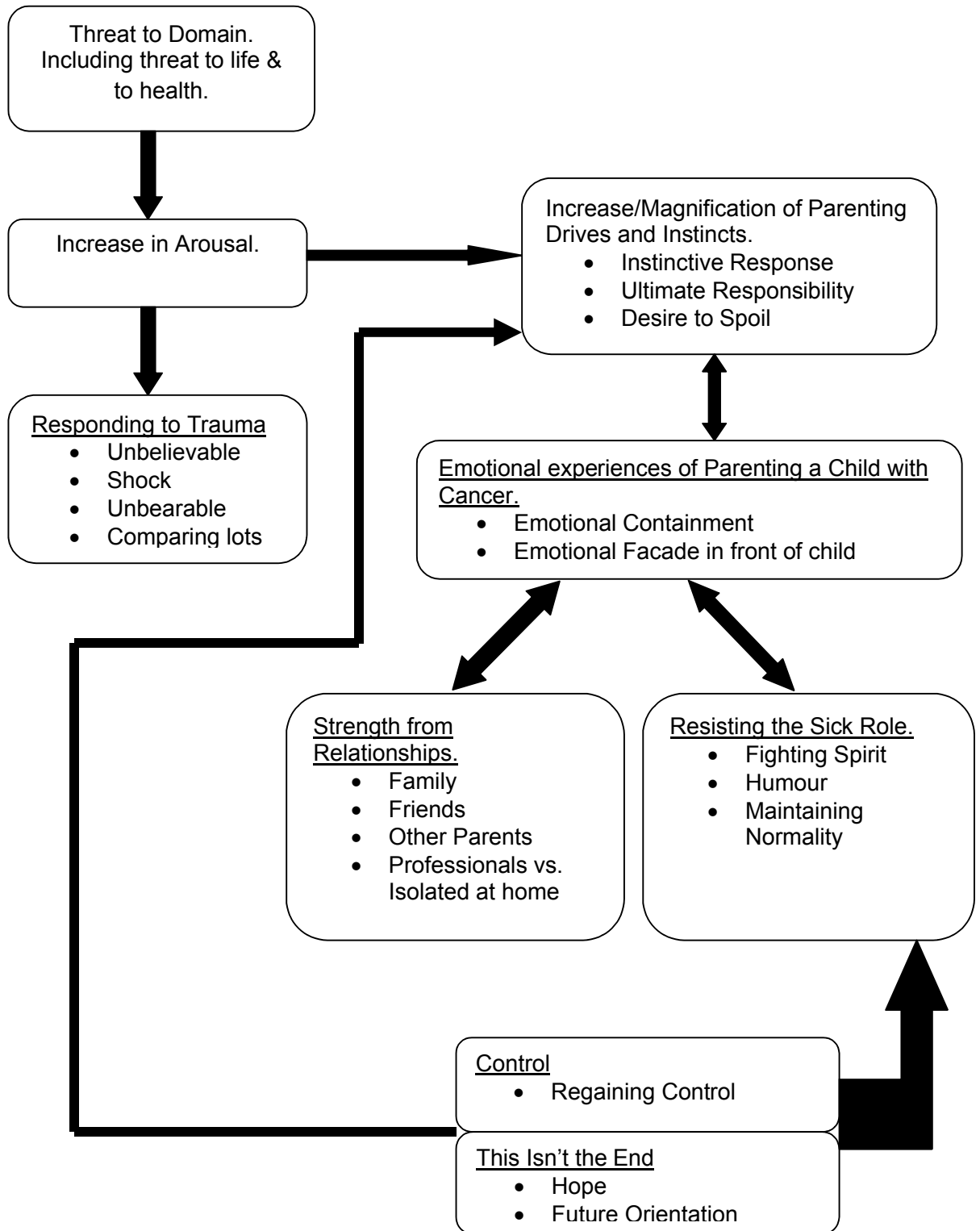
“With him I do feel out of control it doesn’t matter what I ever do for him, it’s not necessarily going to keep him alive. You know whereas the other come home with problems, or they’re upset or can’t do this, or we need something, I can always do it, I’ve got an answer for it or you know, I sort of. Problems at school, I can go in and it’s sorted out, with him it is it’s almost like you’ve lost control of that, so although he’s my priority, it might not be enough. And it’s always sort of in your mind, you know, you’re thinking all the time about it. There’s not much you can do.”

Sub-ordinate Theme: Regaining Control.

“I go to step aerobics three times a week, um, just because I enjoy if I’m really tired and I go do that, I feel like I can continue for hours more. I feel so much better doing it, and

that is almost like a control thing. When I've been there I feel more in control of things than when I did before I went."

FIGURE 2.1. Formulation of Relationships Between Themes.



DISCUSSION.

The organisation of the super and sub-ordinate themes is the researcher's interpretation of the text and its meaning. Human experience cannot easily be categorised into mutually exclusive or independent groups. Therefore, it is thought that overlap and relationships exist between themes. Figure 2.1 starts the process of formulating how the experiences described within themes may relate to each other. One theme that emerged but has not been reported (as it fell outside the positive psychology remit of this paper), was the theme of 'Living with the Prospect of Death'. Parents describe how the thought of their child dying haunts them even though prognosis may be relatively positive.

"With him I do feel out of control it doesn't matter what I ever do for him, it's not necessarily going to keep him alive...so although he's my priority, it might not be enough. And it's always sort of in your mind, you know, you're thinking all the time about it. There's not much you can do."

Parents' experience of living with the prospect of death and other threats that manifest when one's child has been diagnosed with cancer has been conceptualised as a 'threat to domain'. A common response to threat is an increase in arousal. Since the threat in this case includes the threat of death or serious injury to a loved one, some parents would appear to initially respond with shock and disbelief due to the traumatic nature of the situation. However, this research also suggests that parents experience a magnification or a 'kicking in' of a fundamental parenting instinct to protect and increase chances of their child's survival. This seems to manifest in taking ultimate responsibility for the care of the child and also a desire to 'spoil' or lavish affection upon the child at the expense of 'common sense'. In addition to the more universal instinctual experiences

are the arguably socially constructed experiences of wanting to protect the child by putting on a facade when with them and also containing the child's own difficult and potentially overwhelming emotions and impulses. To be able to continue to do these tasks effectively, parents appear to rely on relationships within their social support network to provide additional strength. For some parents it is their friends and family who are indispensable, but for others a huge amount of strength is gained from relationships with professionals and with other parents sharing similar experiences. Parents also appear to resist falling into a 'sick role' and this includes both themselves and their child. They appear to do this by attempting to maintain as much normality in life as possible, by engendering a fighting spirit in themselves and their child, and retaining a sense of humour in the difficult times. At different points throughout the process of diagnosis and treatment of their child, parents would appear to experience a strong sense of loss of control which may endanger their view of themselves as a good parent and also may bring with it the threat of hopelessness. In response to this, parents seem to engage in a number of tactics, varying between individuals, to regain a sense of control. Whilst maintaining a sense of control, parents are also likely to experience hope, as they can see pathways to the goal of their child's survival and ultimate recovery and also to have the motivation to travel these pathways. Hope manifests as parents think about and consider the child's future, often looking to a point when they envisage the child being well.

There are a number of points to be noted from this conceptualisation of the study results. Firstly, this study aimed to go beyond the outward appearances that are often measured by coping studies, to explore in depth the experiences of parents. In the coping literature, strategies that are employed are usually organised into styles of

coping, the key styles being approach or avoidant coping and emotion or problem focused coping. Within these styles it is thought that specific strategies can be either 'functional', e.g. developing a realistic action plan, or 'dysfunctional', e.g. developing unrealistic plans (Zeidner and Endler, 1996), (as cited in Carr, 2005, p.216). However, what this research begins to show is that it is perhaps more valuable to explore and understand what the meaning of the coping strategy is for an individual parent before judging whether it is functional or dysfunctional. For example, the parent who states she goes to aerobics three times a week, could be said to be engaging in avoidance coping, however, the meaning of this behaviour for her was that it allowed her to feel more in control of the situation. Similarly, religion is often construed as being emotion-focused and avoidant coping, but clearly to one parent in this study it was a very practical, problem-focused behaviour that she used to enable her to feel as though she was dealing with a situation that otherwise may have left her feeling helpless and hopeless.

It can be seen that the results of this study could be linked to specific coping styles outlined in previous coping literature (Chasle, in submission). For example, future orientation could be described as an approach and emotion focused behaviour, and seeking strength from friends, family and professionals has obvious overlaps with social support seeking behaviours commonly measured by coping scales. Therefore, it is not thought that coping is no longer a valid avenue of research, but arguably needs to be viewed from a more idiosyncratic perspective that does not lose sight of the meaning of coping behaviours within coping styles for the individuals engaging in them. The measurement of coping behaviours and the classification of them into styles, gives a good overview of the outward expressions of how parents may try to keep going through the diagnosis and treatment of their child with cancer. However, if this knowledge is to

be transferred to clinical implications for families, who may be in crisis but who also may be in need of minimum additional help to avoid reaching crisis, then positive psychology may provide a more appropriate focus of research for this population.

Therefore, this study has started to bridge the gap between what is already known about how parents of children with cancer cope and the meaning or interpretation they ascribe to these coping styles or strategies. Positive psychology provides a new lens through which to investigate and conceptualise parents' experiences. It is arguably less judgement laden than some of the coping literature but still provides a theoretical structure to many of the themes emerging in this research, e.g. the theme of Hope. Hence, it is important to obtain greater insight into the meaning parents ascribe to their experiences as this underpins measured coping strategies.

Clinical Implications.

There are a number of clinical implications to be gleaned from this study. Firstly, it is important that staff who are working with children and their parents are well trained in dealing with distress in parents whilst maintaining meaningful relationships with them, as this seems to be a great source of strength to parents. However, this may result in parents who live far from the treatment centre feeling unsupported and isolated on returning home. This is arguably a reason to provide more funding and resources to teams that work with families in the community so they are better able to meet not just the medical but emotional and psychological needs of parents and children also. Secondly, parents could be facilitated in finding ways that enable them to regain a sense of control, procure resistance to the sick role and how best to draw strength from their relationships. This needs to be done in a non-judgemental way, allowing for

idiosyncratic meanings of different behaviours, beliefs and attitudes held by different parents, even within families. Also, with regards to the wider family, it seems grandparents are a major source of strength to the parents, but may be isolated from support themselves. There is therefore face validity for an argument for the care of wider family members who may expend a great deal of emotional energy in helping parents and children but who may not have access to help or support themselves.

The implications of this research for clinical psychology, relate to the support that is provided directly to parents of children with cancer. It is unusual for Clinical Psychologists to work with more than just a few families who may be experiencing psychological crisis. However, this research could provide a basis for suggesting a preventative approach should be taken when working with families of children with cancer. For example, training medical staff who are involved with families on a more day-to-day basis in basic therapeutic skills and psycho-education concerning the different ways in which parents may respond to their child being diagnosed with cancer and where they may be enabled to draw strength from. Historically clinical psychology has been chiefly concerned with distress and pathology, it is arguable that positive psychology and the outcomes of this study provide a spring board for a different perspective; one of prevention and promoting well-being, both in research and clinical practice.

Several criticisms of this research exist, one being that, due to the use of IPA methodology, the results of this paper are not generalisable to the larger population of parents of children with cancer. However, IPA methodology does provide a way of looking at experiences of parents in depth. Hence, this research has provided a spring

board for further investigation of families who are undergoing care within the NHS for childhood cancer.

Many themes emerged from transcripts that were outside the remit of this study, including the idea that some parents expressed that as individuals and/or a family unit they had been made stronger by their experiences of cancer. Therefore, it may be that research into post traumatic growth of families may be a fruitful avenue of research potentially shedding additional light on how families not only survive the trauma of childhood cancer but also how they may grow and mature from it. Again, a more systemic approach to research in this area may provide insight into the experiences and functioning of wider family members, adding to the literature already covering the experiences of siblings of children with cancer.

In conclusion this study used a new lens, (that of positive psychology), through which to explore the experiences and interpretations of parents of children with cancer. Transcripts were extremely rich and it was a privilege to share in the stories of the families who took part. However, there is still much to explore in this area and further research is warranted, but it seems important not to lose sight of meanings parents of children with cancer ascribe to their own lives. In order to maximise positive outcomes and minimise risk of distress, knowledge and understanding of these meanings should remain central to all researchers and health professionals working with this remarkable group.

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Appendixes:

Appendix 1:
Reflective Statement.

Reflective Statement of Researcher.

The experience of conducting this research project on parents of children with cancer has been a rich and diverse one, with many lessons learnt. I will begin by reflecting on the concept of clinician vs. researcher and the implications of this throughout my research, and then move on to consider wider experiences of interviewing participants. I will then consider how I viewed my research on completion, and how this compared to my initial ideas. To conclude I will reflect briefly on my choice of journals for each paper.

The research was conducted as part of my training to become qualified as a Clinical Psychologist. The training includes academic, research and clinical components. Learning to conduct a clinical interview, both assessment and therapeutic has been central to the training, and for which many new skills have been acquired. This learning was already well under way once I commenced my research interviews with participants. Much of my reflective diary is concerned with the struggle to differentiate the skill set needed to be a researcher compared to that of a clinician. I don't think I anticipated this to be a problem when I first embarked on the research.

Formulating a problem is key to the work of a clinical psychologist, and something one endeavours to be able to do within sessions, as well as when reflecting on sessions. However, I found myself transferring this skill inappropriately to research interviews. During the early interviews I would often catch myself making interpretations or summarising in an attempt to make sense of what the participant had been saying. On reflection I think part of this was driven by simple habit, but I can also see the role of my

own needs and feelings. I often experienced discomfort at not 'offering' participants some 'label' for their emotions or an attempt at normalising or making sense. I felt as though I was allowing their experience, often painful, to 'hang' in the room, somewhere in the space between us. I realised throughout this process that I relied on the skills of summarising or making sense of feelings, to help the client/participant feel heard. At an early stage in the interviews I began to explore new ways to convey my 'hearing' of the participant's experiences, and drew on Gestalt ideas to help me.

Latner (2000) asserted that gestalt therapy is built around two central ideas. Firstly, that the most helpful focus of psychology is the experiential present moment and secondly, that everyone is caught in webs of relationships. Gestalt therapy focuses more on process (what is happening) than content (what is being discussed). The emphasis is on what is being done, thought and felt at the moment rather than on what was, might be, could be, or should be. Gestalt therapy is a method of awareness, by which perceiving, feeling, and acting are understood to be separate from interpreting, explaining and judging using old attitudes. I tried to take these ideas of being fully present in the moment in the subsequent research interviews, in an attempt to fully hear the participants' stories and to keep my questions as open as possible. One must remember that in IPA the researcher's interpretation does have an important role, but as much as possible this double hermeneutic should be delayed until the analysis stage. I certainly, in no way, achieved the pure habitation of the researcher role, with no 'contamination' from my clinical experience. However, I felt I underwent an important process in learning how to facilitate participants in the telling of their experiences, in as open a manner as possible.

Some of the wider issues encountered in conducting research interviews were, firstly, issues of power differentials. Throughout the research process I felt it important to reflect on how certain factors about myself and participants may affect how the interviews were experienced. I often wondered if the presence of an audio recorder changed what participants shared. I noticed that participants would often continue to speak once the interview had formally ended and the voice recorder switched off. Sometimes this was to ask about the purpose of the research, other times it was to tell me something more personal, like developing religious faith, which had helped them. Audio recording interviews is almost unavoidable in a thorough IPA study, but it is important to recognize that this technique likely had an impact on the participants' telling of their experiences.

Secondly, a certain amount of information was provided about the researcher on the information leaflets received by possible participants. This information outlined that the researcher was a student training to be a clinical psychologist. It is still unclear as to how either of these two facts may have influenced participants. However, when one participant questioned me as to what my full role was, and I explained that I was involved in clinical work, she exclaimed "Oh no! You haven't been watching my body language have you?". I wondered if she felt threatened by my clinical experience, whereas it is possible others may have felt comforted by it. It is also interesting to reflect on the image that the word 'student' conjures in people's minds. Some parents assumed I was studying for my under-graduate degree, others knew more about my stage of training. Either way, this possibly affected the power balance within the relationship.

A more concrete point was learned in the research process, that on reflection I would have altered, was the wording of the research title provided for participants. On the information leaflet the research was entitled 'The Positive Psychology of Parenting a Child with Cancer'. In retrospect I think the use of 'Positive Psychology' was unnecessary and potentially led to confusion. A number of participants used the term 'positive parenting' in their interviews, despite this being a term that was never used in the research information provided to them or by me. Other parents were quite defensive at first, possibly thinking that I was going to question them about what positives had come out of their child having cancer. It seems that these words took on different meanings and connotations for different people. Since the aim of IPA is to explore in depth the experiences of the participants in as open a manner as possible, whilst maintaining a sense of the area being explored, in the future I would choose to make the title of the research that is available to participants as open as possible. I certainly would not use psychological language that refers to a theoretical persuasion but can hold other meanings to non-psychologists.

Lastly, a number of thoughts and feelings arose from conducting the interviews that have remained with me. One observation I made about participants was that even if externally they seemed to be managing and adapting to difficulties in much the same way and to the same extent as one another, they did not always describe the same internal experience. One participant felt quite strongly that she was not coping, and talked of being quite overwhelmed and depressed, whereas another spoke of her strength of determination to keep going. Yet, to the outsider there were engaging in very similar behaviours and functioning to similar levels. My interpretation of this is that it is

important to conduct rigorous qualitative research that explores in depth people's experiences and attempts to look beyond observable behaviours.

In relation to my experience of the parents who expressed the view of themselves of not coping and were struggling with life, I began to realise some of my own assumptions and constructions. I started to question whether I had assumed, going into this research, that all parents who were practically managing the situation of having a child with cancer, would also be able to identify sources of strength and articulate these. It became clear to me that I did hold this belief. I felt uncomfortable with parents who found it difficult to speak of being strong or identifying what helped them, because in their experience they weren't strong. Upon reflection of my feelings of discomfort, I wondered if perhaps there was a social discourse about the role of sadness, and whether it is actually viewed as an emotion to be rid of.

Interestingly, a number of participants described the experience of not having a choice in coping, for example one participant stated:

"Because I just think, um people used to say I don't know how you cope with it. And my attitude was well what do you do, do you sit in a corner rocking backward and forwards on medication, you know, 'cause you can go down that road if you want to. Um, but then what good does that do you know, what are you doing then? You're the ill person then. And you've got people feeling sorry for you which I couldn't do with, I never have been one for that. But I think it's a time that you need to be more positive, when something like that kicks in really." (Quotation from Transcript three).

To me this seemed to imply that those parents who were not coping had chosen to do so or had admitted defeat in some form, although I don't think this is what the participants were suggesting. However, it led me to consider why it is that some people 'admit defeat' or 'choose' to be depressed. I realised that this question was in fact the essence of the question driving this research. The aim was to explore what experiences led parents to feel as though they were strengthened in their role as a parent to a child with cancer, but also inevitably, to explore the experiences of those who felt as though they had little strength in the face of their child's illness. It was this latter part that I had not anticipated exploring when I first began the research, but have come to appreciate that it is the other, equally important, side of the coin.

The systematic literature review was written in accordance with the guidelines for Psychology and Health Journal. This journal was selected as it purports to reach a wide range of health professionals but also places an emphasis on psychological theory. Therefore, since the concept of coping has mostly been investigated within psychological literature, it was felt that Psychology and Health offered a good balance of theoretical underpinnings and relevant clinical audience. The empirical paper was written in accordance with the guidelines for the Journal of Psycho-social Oncology. A strength of the journal is that it purports to be read by varying professionals working in the oncology field. It was believed that it was important for this research to be disseminated with professionals other than psychologists, as psychologists only work with a small minority of the population being studied. It is generally nursing staff, medics and social workers who are involved in the day to day care of parents of children with cancer and it is this population the author wanted to target to increase knowledge

and influence practice. In addition, this journal specialises in publications concerning the psychological and social impact of cancer, which is the very focus of the empirical paper.

Reference:

Latner, J. (2000). The Theory of Gestalt Therapy. In *Gestalt Therapy: Perspectives and Applications*. Nevis, E. (Ed.). Cambridge, MA: Gestalt Press

Appendix 2:

Journal Guidelines for Systematic Literature Review.

Instructions for Authors

INTRODUCTION

Submission of a paper to *Psychology & Health* will be taken to imply that it represents original work not previously published, that it is not being considered elsewhere for publication, and that if accepted for publication it will not be published elsewhere in the same form, in any language, without the consent of editor and publisher. It is a condition of the acceptance by the editor of a typescript for publication that the publisher automatically acquires the copyright of the typescript throughout the world.

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On submission of the manuscript authors will be required to indicate whether there were any possible conflicts of interest in the conduct and reporting of research (e.g. funding by an organisation or participation by an individual that might benefit financially from the research). Potential conflicts of interest must be reported in the Acknowledgements section of the manuscript. All manuscripts must include a statement confirming that the research had obtained relevant local ethical approval and was carried out in accordance with universal ethical principles (see Emanuel, E.J., Wendler, D. & Grady, C., 2000. What makes clinical research ethical? *Journal of the American Medical Association*, 283, 2701-2711).

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Appendix 3:
Journal Guidelines for Empirical Study.

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20-40 typed pages

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Appendix 4:
Ethical Approval.

This page contained a confirmation letter from NHS Ethics Committee confirming approval of the study. This was part of the thesis examined in viva, but has since been removed for anonymity.

Appendix 5:
Participant Information Leaflet.

Participant Information Sheet.

The Positive Psychology of Parenting a Child with Cancer.

We would like to invite you to take part in a research study. 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 study if you wish.

Part 1 of this leaflet tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1.

What is the purpose of the study?

The purpose of this study is to explore the positive emotions, strengths and organisations, parents of children with cancer, may use to help them to parent their child. Positive Psychology is simply the study of positive emotions, strengths and positive organisations.

This research aims to explore this area in order to equip professionals to better harness and build up the strengths of families in similar situations.

The research is being carried out as part of an educational qualification.

Why have I been invited?

This study is being supported by x (Macmillan Nurse) of the x service. You have been invited because you are the parent of a child with cancer who lives in this locality.

Fourteen other parents from this service have also been invited to take part.

Do I have to take part?

It is up to you to decide. We will describe the study and go through this information sheet with you. We 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.

What will happen to me if I take part?

If you agree to take part in the study you will:

- Be contacted by telephone by the researcher. They will arrange a suitable time for you to meet at your convenience. You will be asked if you would prefer to meet at x clinic, or in your own home, it's up to you.

- When you meet the researcher, they will give you a signed copy of your consent form to keep and answer any further questions you might have. They will then spend approximately one hour asking you questions about your views. The questions will be focused on the positive emotions, strengths and organisations you feel you use to parent your child with cancer. You will also be asked a few descriptive questions about you and your child, for example, the age of your child. The interview will be audio taped. It would be best if the interview could be done without any children present. This means you are able to speak more freely about your experiences.

- Within eight weeks of the interview, you will be sent a written summary of your interview through the post. You will be invited to give written feedback on the summary, which can be as little or as much as you like, or not at all.

A sample of the interviews will then be analysed and an overall summary of the study sent to all parents who took part.

The audio recordings of the interviews will be kept completely confidential and will only be heard by the researcher and the educational supervisor. The interviews will be transcribed (typed out), and every transcript will be anonymised and all identifiable material removed. It is likely that the final report will include quotations from interviews, but these also will be anonymised and no one will be able to be identified.

The audio recordings of the interviews will be kept on hard disc and stored with the anonymous transcripts in a locked filing cabinet on The University premises. These will be kept for five years and then destroyed.

What are the possible risks or disadvantages of taking part?

The main potential risk of taking part in this study is due to the sensitive nature of the questions asked in the interview. There is a possibility that talking in depth about parenting your child with cancer may cause you to become upset or distressed. If, at any point during the study, you or the researcher is concerned about your emotional well-being, a referral will be made to the x team. It is likely that you will be offered an appointment with the Clinical Psychologist in the team, if you would like one.

What are the possible benefits of taking part in the study?

We cannot promise the study will help you but the information we get from this study may help improve the service offered to other families in similar situations.

It is also possible that you may find it helpful to talk about the positive emotions, strengths and organisations that you use to enable you to cope and to parent a child with cancer.

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 will be addressed. The detailed information on this is given in Part 2.

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.

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 decision.

Part 2.**What will happen if I don't want to carry on with the study?**

You are free to drop out of the study at any point. If you do, all information already gathered will be destroyed, including the audio recording of your interview, and transcript. Not carrying on with the study will not affect your involvement with the x service in any way.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the Patient Advice and Liaison Service (PALS) on 01482 623065.

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential, and any information about you that leaves the x clinic will have your name and address removed so that you cannot be recognised.

The data collection will be through interview and any written feedback you choose to give. The interview will be audio recorded and then transcribed (typed out).

The audio recording of the interview will be only listened to by the researcher and the educational supervisor, for the purposes of transcribing it (typing it out) and analysis. It will then be kept in a locked cabinet. The transcription and the written feedback will be anonymised and all identifiable information removed.

The audio recording of the interview will be stored on hard disc. The anonymised transcripts, written feedback and audio recordings will be stored in a locked cabinet in the University premises and then destroyed after five years.

However, if at any point during the interview something is mentioned concerning the safety and well being of either you or someone else, including your child, the researcher may be obliged to share this information with another professional.

What will happen to the results of the research study?

The results of the study will be put in to a final report, which will be evaluated as part of the researcher's Doctoral Degree. The report will then be submitted for publication in scientific journals.

Once all the information is collected and analysed, you will be sent an overall summary of the results of the study.

Who is organising the research?

The research is being organised by an employee of the Humber Mental Health Teaching NHS Trust, as part of the requirement for the Doctorate in Clinical Psychology.

Who has reviewed the study?

All research in the NHS is 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 a favourable opinion by Hull Research Ethics Committee.

Further information and contact details:

1. General information about research.

www.psych.bbk.ac.uk/ipa/ - A web site about the method of data analysis being used in the study.

2. Specific information about this research project:

Laura Chasle - Principle Researcher.

Email:

Phone: Messages will be collected within 48 hours.

Address:

3. Advice as to whether you should participate:

Macmillan Nurse.

Address:

Phone:

4. Who to approach if you are unhappy with this study:

Educational Supervisor of the study.

Email:

Phone:

Appendix 6:
Consent Form.

Version 2. 15.10.07

Patient Identification Number:

Consent Form.

Title: The Positive Psychology of Parenting a Child with Cancer

Researcher: Laura Chasle

Please initial box

1. I confirm that I have read and understand the information sheet dated 15.10.07 (version 3) 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 any reason, without my medical care or legal rights being affected.

3. I agree to my interview being audio recorded. I understand the recording will be transcribed by the researcher and that the transcript will be anonymised. I understand the recording will be kept confidential.

4. I agree to the possible use of verbatim quotations being used in the final research report, but understand all identifiable information will be removed.

5. I agree to being sent a written summary of my interview within eight weeks.

6. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix 7:
Semi-Structured Interview Schedule.

27.03.07 Version 1.1

Interview Schedule

Can you tell me a bit about you and your child.....(the child with cancer)?

- Always lived in the area?
- Who else is in the family?
- How did you find out your child was ill?

What have been your experiences in continuing to fulfil your role as a parent in the difficult times?

What positive emotions have helped you to carry on being mum/dad to your child?

- Personal outlooks on life
- Beliefs you hold about life, the future, your children, illness?

What personal strengths have helped you carry on being mum/dad to your child?

- Characteristics that you have drawn on?
- Personal outlooks on life?
- Beliefs you hold about life, the future, your children, illness?
- Your strengths?

Which positive emotions and strengths do you think have been most important in helping you to carry on parenting your child?

Do you think these strengths and emotions that you've talked about have developed because of the situation or were they already part of who you are?

What things outside of you as a person, in your experience, have helped you carry on parenting your child(ren)?

- Other family/friends
- Services
- Groups/organisations
- Other families in similar situation

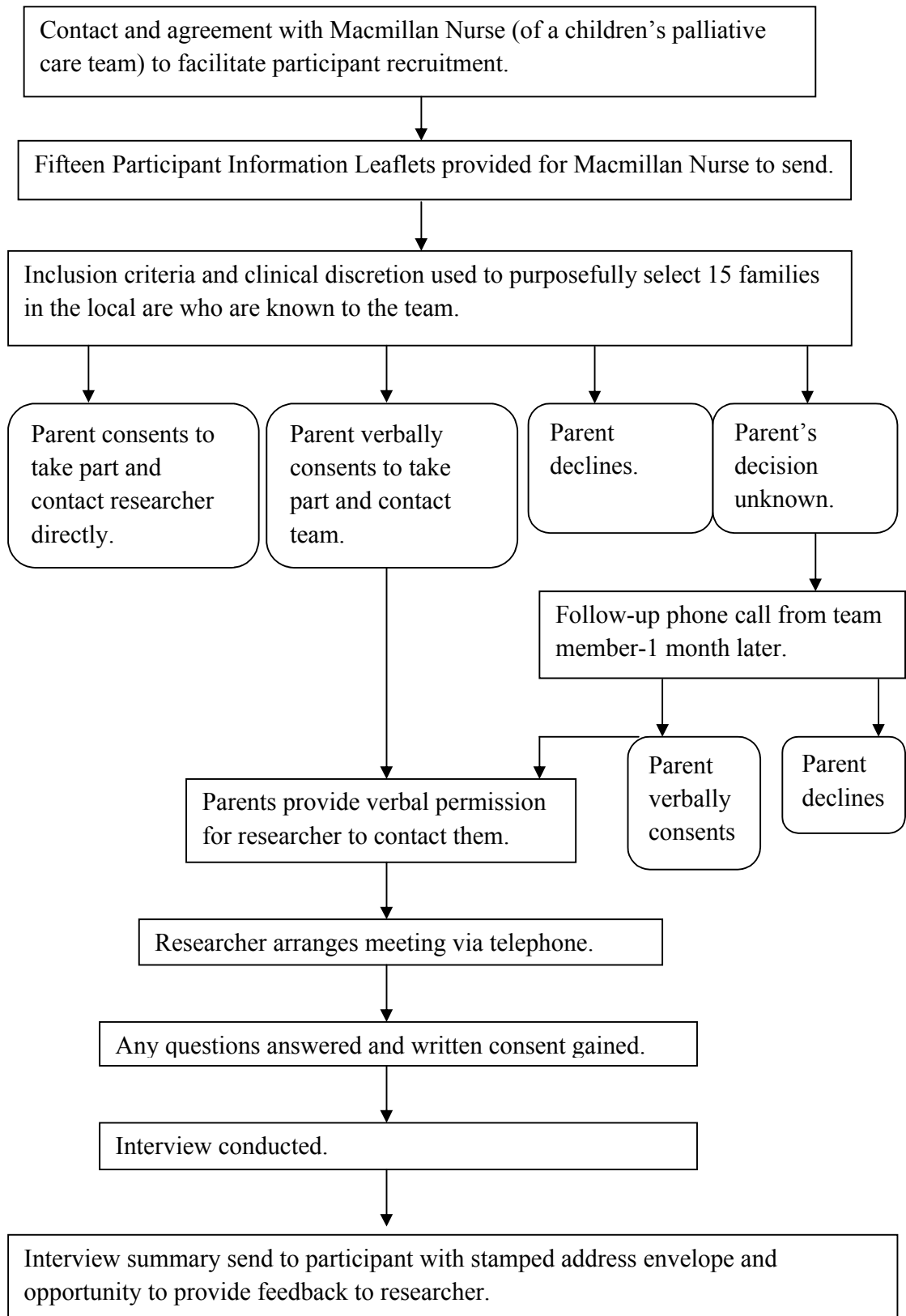
Which of these organisations have you experienced to be the most important to you?

- Did you already have access or were part of them before your child was diagnosed?

Is there anything else that you haven't mentioned so far, either your personal strengths, positive emotions or things outside of you, that you have experienced as being vital in enabling you to continue in your role as a parent and carry on in this difficult time?

Appendix 8:
Flow Chart of Data Collection

Figure 3.1 Flow Chart of Data Collection.



Appendix 9:

Worked Example of Interpretative Phenomenological Analysis.

Worked Example of Interpretative Phenomenological Analysis – Creation of

Themes.

To outline the IPA methodological process, an example, using a section of transcript nine, is described, highlighting each stage of analysis, resulting in super and subordinate themes. The following excerpt was from an interview with a mother/father couple describing their experiences before diagnosis and the first few days after.

Participant Interview Excerpt.

122 Part a: Still a shock, but a little bit of relief for me as well 'cause I just thought, right, now we start and get her better, now we know, where as with Ian (husband), Ian was just totally shocked because I had said to Ian a few times, I think there's something wrong, I think there's something wrong. And probably just typical bloke, you know, oh she'll be fine, well what did the doctor say, well the doctor said she's alright she must be alright. But you have a sixth sense don't you?

128 Part b: *I think, I think, um, the way we dealt with it, I think Pippa (wife) seemed to um, be convinced there was something wrong...and I didn't. And I, at the time I believed in the doctors 'cause we had several attempts, several trips to the doctors, who were confirming what I thought, that she was fine, she's fine, she's fine, she's fine. So I was saying to Pippa she's fine, she's, being over-reactive, so um, really, actually right up to the minute of the diagnosis I, I mean, I was there 'cause Pippa had taken Lynsey out to the toilet when the, the...*

135 Part a: Consultant.

136 Part b: *consultant came in to deliver the news, and up, up till that point I just thought there won't a problem. And looking back now I can see how bad she looked.*

138 Res: yeah.

139 Part b: *But I couldn't recognise it or wouldn't recognise it. I don't know if you have this in-built barrier there, whatever, I don't know, er, I wouldn't say I was embarrassed*

by it, it just, I just couldn't accept there was anything wrong, you just think, there's nothing wrong.

143 Res: Yeah, it's one of the hardest things to accept?

144 Part b: Um, to the point where, I think he said, I, I, I've got some news for you, where's your wife? And I said she's taken Lynsey to the toilet. So we'll wait till your wife comes back to give you the news, and I said, honestly just tell me what it is, give us the tablets and we can just leave. Get Sunday lunch. That's how blarney I was about it, and he said no I'll wait and I said no just, and then he told me, and it just, absolutely knocked me out the building, absolutely knocked me out the building. That's how surprised I was by it, where as oppositely, Pippa had been carrying the fears for quite a while, looking back, but I also think that, this, then turns into something else then, it turns into something else where I think Pippa almost in a way had weeks of preparing herself, knowing that something was wrong to getting the news and knowing about it, to me being so shocked by this news, and it took me I, I, couldn't, I just felt like I was thrown into such a massive turmoil and mess, I couldn't snap out of, and um, and it effected me quite badly really. I struggled quite a lot, struggled to come to terms with this news that I'd been given. And this is how you work together as a team. Pippa, I thought was a tower of strength at that time, and I was just, I, just, a mess, just didn't know what to do and was looking to her for strength as well. Very very difficult time, which I think is the hardest thing to put it into words really.

Level One Analysis.

The transcript was read, for the second time and the left hand margin was used to annotate anything of interest, any observations about what was said, the words used or contradictions within the text. Level one analysis for this excerpt was as follows:

Relief from diagnosis. Something can be done. Shock.	122 Part a: Still a shock, but a little bit of relief for me as well 'cause I just thought, right, now we start and get her better, now we know, where as with Ian (husband), Ian was just totally shocked because I had said to Ian a few times, I think there's something wrong, I think there's something wrong. And probably
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Denial? Trust medics. Unknown knowledge.	<p>just typical bloke, you know, oh she'll be fine, well what did the doctor say, well the doctor said she's alright she must be alright. But you have a sixth sense don't you?</p> <p><i>128 Part b: I think, I think, um, the way we dealt with it, I think Pippa (wife) seemed to um, be convinced there was something wrong...and I didn't. And I, at the time I believed in the doctors 'cause we had several attempts, several trips to the doctors, who were confirming what I thought, that she was fine, she's fine, she's fine, she's fine. So I was saying to Pippa she's fine, she's, being over-reactive, so um, really, actually right up to the minute of the diagnosis I, I mean, I was there 'cause Pippa had taken Lynsey out to the toilet when the, the...</i></p>
Denial? Trust?	<p>135 Part a: Consultant.</p>
Denial or couldn't accept illness.	<p><i>136 Part b: consultant came in to deliver the news, and up, up till that point I just thought there won't a problem. And looking back now I can see how bad she looked.</i></p> <p>138 Res: yeah.</p>
Defence/denial. Self-protection. Can't accept.	<p><i>139 Part b: But I couldn't recognise it or wouldn't recognise it. I don't know if you have this in-built barrier there, whatever, I don't know, er, I wouldn't say I was embarrassed by it, it just, I just couldn't accept there was anything wrong, you just think, there's nothing wrong.</i></p> <p>143 Res: Yeah, it's one of the hardest things to accept?</p>
Defence/denial. Can't believe. Shocked/overwhelmed. Thinks that preparation reduced shock for wife.	<p><i>144 Part b: Um, to the point where, I think he said, I, I, I've got some news for you, where's your wife? And I said she's taken Lynsey to the toilet. So we'll wait till your wife comes back to give you the news, and I said, honestly just tell me what it is, give us the tablets and we can just leave. Get Sunday lunch. That's how blarney I was about it, and he said no I'll wait and I said no just, and then he told me, and it just, absolutely knocked me out the building, absolutely knocked me out the building. That's how surprised I was by it, where as oppositely, Pippa had been carrying the fears for quite a while, looking back, but I also think that, this, then turns into something else then, it turns into something else where I think Pippa almost in a way had weeks of preparing herself, knowing that something was wrong to getting the news and knowing about it, to me being so shocked by this news, and it took me I, I, couldn't, I just</i></p>

<p>Turmoil.</p> <p>Sense of no control of emotions.</p> <p>Gained strength from his wife.</p> <p>Inexpressible.</p>	<p><i>felt like I was thrown into such a massive turmoil and mess, I couldn't snap out of, and um, and it effected me quite badly really. I struggled quite a lot, struggled to come to terms with this news that I'd been given. And this is how you work together as a team. Pippa, I thought was a tower of strength at that time, and I was just, I, just, a mess, just didn't know what to do and was looking to her for strength as well. Very very difficult time, which I think is the hardest thing to put it into words really.</i></p>
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Level Two Analysis.

Level two of the analysis process involved reading the text for a third time and using the right hand margin to annotate emerging themes or repeated patterns found in the text. In this level of analysis links were started to be made to theoretical concepts. This level of analysis is a generally higher level of analysis compared to level one.

<p>Relief from diagnosis.</p> <p>Something can be done.</p> <p>Shock.</p> <p>Denial? Trust medics.</p> <p>Unknown knowledge.</p> <p>Denial? Trust?</p>	<p>122 Part a: Still a shock, but a little bit of relief for me as well 'cause I just thought, right, now we start and get her better, now we know, where as with Ian (husband), Ian was just totally shocked because I had said to Ian a few times, I think there's something wrong, I think there's something wrong. And probably just typical bloke, you know, oh she'll be fine, well what did the doctor say, well the doctor said she's alright she must be alright. But you have a sixth sense don't you?</p> <p><i>128 Part b: I think, I think, um, the way we dealt with it, I think Pippa (wife) seemed to um, be convinced there was something wrong...and I didn't. And I, at the time I believed in the doctors 'cause we had several attempts, several trips to the doctors, who were confirming what I thought, that she was fine, she's fine, she's fine, she's fine. So I was saying to Pippa she's fine, she's, being over-reactive, so um, really, actually right up to the minute of the diagnosis I, I mean, I was there 'cause Pippa had taken Lynsey out to the toilet when the, the...</i></p> <p>135 Part a: Consultant.</p> <p><i>136 Part b: consultant came in to deliver the news, and up, up</i></p>	<p>Regaining control.</p> <p>Solution focussed.</p> <p>Response to trauma: shock</p> <p>Response to trauma: disbelief.</p> <p>Instinctual knowledge.</p> <p>Response to trauma: disbelief/denial.</p>
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Denial or couldn't accept illness.	<i>till that point I just thought there won't a problem. And looking back now I can see how bad she looked.</i>	Response to trauma: disbelief.
Defence/denial. Self-protection. Can't accept.	138 Res: yeah. <i>139 Part b: But I couldn't recognise it or wouldn't recognise it. I don't know if you have this in-built barrier there, whatever, I don't know, er, I wouldn't say I was embarrassed by it, it just, I just couldn't accept there was anything wrong, you just think, there's nothing wrong.</i>	Protection against trauma/psychological defence
Defence/denial. Can't believe.	143 Res: Yeah, it's one of the hardest things to accept? <i>144 Part b: Um, to the point where, I think he said, I, I, I've got some news for you, where's your wife? And I said she's taken Lynsey to the toilet. So we'll wait till your wife comes back to give you the news, and I said, honestly just tell me what it is, give us the tablets and we can just leave. Get Sunday lunch. That's how blarney I was about it, and he said no I'll wait and I said no just, and then he told me, and it just, absolutely knocked me out the building, absolutely knocked me out the building.</i>	Psychological defence against fear. Response to trauma: shock/overwhelmed.
Shocked/overwhelmed. Thinks that preparation reduced shock for wife.	<i>That's how surprised I was by it, where as oppositely, Pippa had been carrying the fears for quite a while, looking back, but I also think that, this, then turns into something else then, it turns into something else where I think Pippa almost in a way had weeks of preparing herself, knowing that something was wrong to getting the news and knowing about it, to me being so shocked by this news, and it took me I, I, couldn't, I just felt like I was thrown into such a massive turmoil and mess, I couldn't snap out of, and um, and it effected me quite badly really. I struggled quite a lot, struggled to come to terms with this news that I'd been given. And this is how you work together as a team. Pippa, I thought was a tower of strength at that time, and I was just, I, just, a mess, just didn't know what to do and was looking to her for strength as well. Very very difficult time, which I think is the hardest thing to put it into words really.</i>	Loss of perceived control. Response to trauma: Can't process event.
Turmoil. Sense of no control of emotions. Gained strength from his wife. inexpressible.		Strength gained from relationship with wife.

Level Three Analysis.

This level involved organising emerging themes and corresponding extracts from the text for each transcript so that themes across transcripts could be compared.

Emerging Theme	Supporting Quotation
Regaining Control.	122 Part a: Still a shock, but a little bit of relief for me as well ‘cause I just thought, right, now we start and get her better, now we know...” T9, P5, L122.
Solution Focussed.	122 Part a: Still a shock, but a little bit of relief for me as well ‘cause I just thought, right, now we start and get her better, now we know...” T9, P5, L122.
Response to Trauma: Shock/overwhelmed	<p>122 Part a: Still a shock, but a little bit of relief for me as well ‘cause I just thought, right, now we start and get her better, now we know, where as with Ian (husband), Ian was just totally shocked...” T9,P5,L122</p> <p><i>“...and then he told me, and it just, absolutely knocked me out the building, absolutely knocked me out the building. That’s how surprised I was by it, where as oppositely, Pippa had been carrying the fears for quite a while, looking back, but I also think that, this, then turns into something else then, it turns into something else where I think Pippa almost in a way had weeks of preparing herself, knowing that something was wrong to getting the news and knowing about it, to me being so shocked by this news...” T9,P5, L144</i></p>
Response to Trauma: Disbelief/denial	<p>“...I had said to Ian a few times, I think there’s something wrong, I think there’s something wrong. And probably just typical bloke, you know, oh she’ll be fine, well what did the doctor say, well the doctor said she’s alright she must be alright.” T9,P5,L122</p> <p><i>“...we had several attempts, several trips to the doctors, who were confirming what I thought, that she was fine, she’s fine, she’s fine, she’s fine. So I was saying to Pippa she’s fine, she’s, being over-reactive, so um, really, actually right up to the minute of the diagnosis...” T9,P5,L128</i></p>

	<i>136 Part b: consultant came in to deliver the news, and up, up till that point I just thought there won't a problem. And looking back now I can see how bad she looked." T9,P5,L136</i>
Instinctual Knowledge	<i>"...I had said to Ian a few times, I think there's something wrong, I think there's something wrong. And probably just typical bloke, you know, oh she'll be fine, well what did the doctor say, well the doctor said she's alright she must be alright. But you have a sixth sense don't you?" T9,P5, L122</i>
Psychological Defence	<i>139 Part b: But I couldn't recognise it or wouldn't recognise it. I don't know if you have this in-built barrier there, whatever, I don't know, er, I wouldn't say I was embarrassed by it, it just, I just couldn't accept there was anything wrong, you just think, there's nothing wrong." T9,P5,L139</i> <i>144 Part b: Um, to the point where, I think he said, I, I, I've got some news for you, where's your wife? And I said she's taken Lynsey to the toilet. So we'll wait till your wife comes back to give you the news, and I said, honestly just tell me what it is, give us the tablets and we can just leave. Get Sunday lunch. That's how blarzay I was about it..." T9,P5,L144</i>
Loss of Perceived Control	<i>"...I was thrown into such a massive turmoil and mess, I couldn't snap out of, and um, and it effected me quite badly really. I struggled quite a lot, struggled to come to terms with this news that I'd been given." T9,P5,L144</i>
Response to Trauma: Can't process event/information	<i>"...me being so shocked by this news, and it took me I, I, couldn't, I just felt like I was thrown into such a massive turmoil and mess, I couldn't snap out of, and um, and it effected me quite badly really. I struggled quite a lot, struggled to come to terms with this news that I'd been given." T9,P5,L144</i>
Strength from Relationship with Wife.	<i>"And this is how you work together as a team. Pippa, I thought was a tower of strength at that time, and I was just, I, just, a mess, just didn't know what to do and was looking to her for strength as well. Very very difficult time, which I think is the hardest thing to put it into words really." T9,P5,L144</i>

Level Four Analysis.

Emerging themes were compared across transcripts and re-organised into groupings of super-ordinate themes. If themes in one transcript were not supported by data from other transcripts then that theme was disregarded. In addition, after discussion with an independent researcher, themes that were not felt to be strongly supported by the text were also disregarded. Through this process a number of super-ordinate themes were created each encompassing a group of sub-ordinate themes. Supporting quotations from transcripts were listed with the themes.

Appendix 10:

Reflexive Statement.

Reflexive Statement for Interpretative Phenomenological Analysis Methodology.

Fundamental to an IPA approach is the researcher's reflections upon their own beliefs, experiences and culture and the impact these may have on the research process.

The researcher was a female Clinical Psychology Trainee in their mid 20's who believes that when confronted with adversity people generally look within themselves and outside to relationships and wider environment to gain strength enabling them to survive. Therefore, the research was approached with the attitude that parents participating in the study would not only be able to recognise these sources of strength but would also be able to articulate their experiences of this process. In general, the majority of participants did not challenge this belief. However, there were times when the researcher was aware of holding value laden judgements regarding those few parents that didn't fall in line with this belief. Further details of this are given in the Reflective Statement.

The researcher is from a western culture that arguably has certain beliefs about the role of parents and the value of children. Thus, the researcher believes that a child's physical and emotional well-being and development are paramount, should be protected and nurtured primarily by the child's parents and other adults involved in the child's life. The rights of the child are valued to such a high degree in western culture that if a child's welfare is thought to be compromised, the state has power to remove the child from their biological parent. Therefore stemming from this, inevitably there are degrees

of value placed on different parenting styles and attitudes, which was important for the researcher to be aware of and reflect upon.

An important issue to consider, was the fact that the researcher is not a parent themselves and so only has experience of the parent-child relationship from the perspective of being a daughter. It is likely that participating parents may have assumed this about the researcher. Although no participant mentioned or queried this explicitly, this issue certainly had an impact on the researcher's interpretation of participants' experiences (the double hermeneutic). However, the researcher's supervisor is the mother of two children and many discussions were had where both the experiences of being a daughter and the experiences of being a mother were shared in relation to emerging themes. The strength of emotion felt when engaging with the transcripts, by both researcher and supervisor, from the position of experiencing different roles in life, was an interesting process to reflect upon. In general, the transcripts were moving and emotive which again expressed a belief held by the researcher that the threat of illness and death, particularly to a child, is immensely distressing and painful, even to those not related to the child. Throughout discussions in research supervision it became clear that at times when themes were being linked to theory, the researcher and the supervisor inhabited the mindset of clinical psychologists, and had slightly distanced themselves from the emotions raised when discussing themes from the perspective of being a mother or a daughter. It seemed important to be able to do this to enable theoretical sense to be made of the participants' experiences, and to protect ourselves from distress.

However, it is also important to note that the researcher as a Trainee Clinical Psychologist, upholds participants' experiences as central and of most importance in driving research and clinical outworking. Therefore throughout the research process, the researcher endeavoured to remain 'true' to the telling of participants' stories. If service provision is to help and support parents of children with cancer, inevitably, it is the parents and the families who are best placed to guide the direction of change.

Appendix 11:
Quality Control Checklist.

Quality Control Checklist	YES -1	NO- 0
Does the study address an appropriate and clearly focused question/aim/objective?		
Are the main outcomes to be measured clearly described in the Introduction or Methods section? <i>(if the main outcomes are first mentioned in the Results section, the question should be answered no.)</i>		
Is a clear definition/conceptualisation of coping provided?		
Is the study based on a representative sample selected from a relevant population? a. Is the proportion of those who agreed to take part reported?		
Are the characteristics of the participants included in the study clearly described? a. Is there a clear inclusion/exclusion criterion? <i>(age of child, definition of 'parent', type of diagnosis, time since diagnosis, treatment stage, etc.)</i> b. If there is a comparison or control group, is this clearly defined and measures taken to control confounding factors which may account for results? OR How comparable are the cases and controls with respect to potential confounding factors? <i>(i.e. disease progression, age etc)</i> c. Were pre-existing differences accounted for by using appropriate adjustments in statistical analysis		
Are the number, characteristics or withdrawals (i.e. dropouts, lost to follow up, attrition rate) and/or response rate (cross-sectional studies) described for each group? <i>(Follow up goal for a strong study is 80%)</i>		
Are the staff, places and facilities where the patients were treated representative of the treatment the majority of patients receive?		
Are the measures of coping used appropriate to the question?		
Are the psychometric properties of the measure(s) reported? a. If these are reported, is the measure valid and reliable?		
Are the main findings of the study clearly described? a. Is the data reported relevant to the review? b. If no, has the author provided relevant data on request?		

Based on: Khan, Riet, Popay, Nixon and Kleijnen, 2001

National Institute for Health and Clinical Excellence: The Guideline Manual, 2007

Downs and Black, 1998

STROBE Initiative, 2008

Appendix 12:

Extended Details of Studies Included in Systematic Literature Review

Table 3.1. Study Details.

Ref No.	N. M=mother F=fathers	Types of Cancer	Children's age range.	Time Pd. (Post Diagnosis)	Country of research	Purpose of study	Design	Coping measure	Quality score
1.	41m, 30f,	ALL & AML	2.2-16.8 years	<3months pd	Greece	Explore parent's perception and coping with child's leukemia.	Cross-sectional. Quantitative and qualitative	Coping Health Inventory for Parents (CHIP)	11
2.	171m, 171f Or 171 couples	Leukaemia, Lymphoma & solid tumour	<18 years at time of diagnosis	0.08-9.42 years pd. Only newly diagnosed, group used in review.	Taiwan	To explore parental gender-based similarities and differences in coping.	Cross-sectional	Parental Coping Strategy Inventory (PCSI)	10
3.	44m, 38f.	ALL, Nonlymphoblastic leukaemia & solid tumour	Unknown-but children's hospital	3-17months pd	USA	A) describe parent's coping. B) compare findings to previous papers C) explore concepts of encapsulation and risk	Cross-sectional	CHIP	9
4.	62m, 62f or 62 couples	Leukaemia, Brain tumours, malignant lymphoma, Wilms' tumour, sarcomas, Neuroblastoma, germ cell tumour, Hepatoblastoma	0-16 years	T1 –diagnosis T2-6 months pd T3 – 12 months pd	Netherlands	Concerned with differences in psychological adaptation between fathers and mothers.	Longitudinal and includes norm-group	Utrecht Coping List	12
6.	25m, 25f or 25 couples	Solid tumour, leukaemia, lymphoma	0.5-15 years	T1 -1-2 weeks pd T2- 8-12 weeks pd	Germany	Investigate dissimilarity between couple in coping and its effects of quality of life in family	Longitudinal and includes comparison groups of epilepsy and diabetes.	CHIP & Trier Coping Scales.	13
7.	N=28	ALL, Non-Hodgkin's	11-18 years	1 month pd-1	USA and	To examine	Cross-sectional	Coping	9

		lymphoma, Ewing's sarcoma, Hodgkin's lymphoma, osteosarcoma, brainstem tumour		year post treatment	Canada	relations among distress, coping, social support and family adaptiveness.		Strategies Inventory (CSI)	
9.	N=20	Unknown	3 yrs 10 months-11 yrs 8months	Unknown, but all undergoing invasive procedures for treatment	USA	1. What parents find stressful about invasive procedures. 2. What coping strategies are used. 3. What is the child's level of distress. 4. Are two and three related?	Cross-sectional	The Ways of Coping Questionnaire	10
10.	N=200 (all mothers)	Leukaemia, Neuroblastoma, brain tumour, lymphoma and germ cell tumour	1 month-18 years.	<6 months pd- >1 year pd. But all still undergoing treatment	South Korea	Are maternal stress, coping, social support and illness-related and demographic factors associated with adjustment	Cross-sectional and correlational	CHIP	10
11.	N=20	ALL, Wilms' tumour, Hodgkin's disease, rhabdomyosarcoma, histiocytosis	4-7 years	3 months pd-5 years and 8 months	USA	Investigate patterns of coping among parents and their children with chronic illnesses in comparison with a group of healthy children.	Cross-sectional with comparison groups with HIV and healthy children	CSI –Short Version	11
12.	N=162	Leukaemia, brain tumor, lymphoma, bone neuroblastoma	75% <14years. Rest unknown	41% in remission, 40% undergoing treatment, 18% in remission but	USA	Examine the degree of psychological distress experienced by parents in relation to five religious coping methods.	Cross-sectional	Religious Coping (RCOPE)	11

				undergoing treatment, 2% ended.					
13.	N=13	Leukaemia	4-14 years	Mean= 3.46 years	U.K.	Identify coping patterns in parents of chronically sick children, in relation to child age and chronic disease.	Cross-sectional. Comparison groups: diabetes, asthma, cardiac and epilepsy	CHIP	9
14.	N=23 (all fathers)	Leukaemia most common, but rest unknown	3-6 years	>3 months pd- <2 years pd	USA	Identify and describe the stressors and coping strategies of fathers.	Cross-sectional	Parent Perception Inventory (PPI)	12

Appendix 13.
Glossary of Medical Terms.

Glossary of Medical Terms:

Chemotherapy - The treatment of disease with chemicals, such as cytotoxic (cancer destroying) drugs

Leukaemia - A cancer of the white blood cells. The four main types of leukaemia are

- **Acute lymphoblastic leukaemia (ALL)** - a cancer of immature lymphocyte cells - lymphoblasts.
- **Acute myeloid leukaemia (AML)** - a cancer of the immature myeloid cells. This disease occurs mainly in adults but can also affect children.
- **Chronic lymphocytic leukaemia (CLL)** - a cancer of the lymphocyte cells. The most common type of leukaemia affecting adults. Very rare in children.
- **Chronic myeloid leukaemia (CML)** - a cancer of the neutrophils cells. Rare in children.

Lymphoma - Lymphoma is a cancer of the lymphatic system. There are two main types of lymphoma: Hodgkin's disease and non-Hodgkin's lymphoma. Both have similar symptoms: enlarged lymph nodes (glands), tiredness and often heavy sweating, unexplained high temperatures and weight loss. They are often treated similarly but are different diseases.

Osteosarcoma - Osteosarcoma is a type of bone cancer that occurs when the osteocyte cells divide uncontrollably to create a tumour in the bone.

Radiotherapy - The treatment of cancer using radiation (x-rays, gamma rays etc) to destroy cancer cells.

Remission - Remission is when the symptoms of a condition are reduced (partial remission) or go away completely (complete remission).

Tumour – A lump or mass of cells which can be either benign or malignant. Also known as a neoplasm.