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Lammie, Claire (2015) *A comparison of coping styles and patterns of accessing support between mothers and fathers who have a child diagnosed with acute lymphoblastic leukaemia (ALL): using interpretative phenomenological analysis (IPA)*. D Clin Psy thesis.

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A comparison of coping styles and patterns of accessing support between mothers and fathers who have a child diagnosed with acute lymphoblastic leukaemia (ALL): using interpretative phenomenological analysis (IPA).

Volume I

(Volume II bound separately)

Claire Lammie (MA Hons)

**Submitted in partial fulfilment of the requirements for the degree
of Doctorate in Clinical Psychology**

University of Glasgow

Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

Acknowledgements

I give my sincere thanks to my research supervisors, Dr Sarah Wilson and Dr Kathleen McHugh. Your support, guidance and reassurance in completing this major research project will never be forgotten. Thank you to Professor Kenneth Mullen. Your insight and advice has been much appreciated. Thank you to Karen Marshall, Anne Clarkin, Jane Belmore and Ali Hall, the Paediatric Oncology Outlook Nurses at Yorkhill who helped with recruitment.

A very important thank you goes to all my supervisors who have supported me throughout training. Thank you to the Clinical Doctorate Programme and to NHS Education for Scotland for providing me with this once in a lifetime opportunity.

To my friends and family within and out with the world of Psychology; I'm so very lucky to have such decent, kind and funny people in my life.

To my D.Clin.Psy family; it has been an honour. Thank you for the memories, for the unwavering support and never ending laughs. I wish you all every success and happiness.

Thank you to my study group; Rona, Katie, Cathy, Jo, Fiona and Niamh. There may have been a lot of cake but there was a lot of studying too. Let's keep the cake part going. To the new Dr J, thank you for being 'my person'.

To Andrew. Thank you for your pride in what I do, for encouraging me to see things from a different perspective and for all the silliness and cherished escapes. "I like who we are when we are with us". Anon.

A very special thanks must go to the Mums and Dads who took part in this project. You selflessly provided an insight in to your experiences in order to help other parents. I am truly overwhelmed and grateful.

Finally and most importantly, to my own lovely Mum and Dad, as with everything in life, this course would have been far harder without your continued love and support. "I would thank you from the bottom of my heart, but for you, my heart has no bottom"
Anon.

This thesis is dedicated to my parents and to Andrew.

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CHAPTER 1: SYSTEMATIC REVIEW

Diagnosis of blood cancer in children: What is the effect on parents' lives?

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Prepared in accordance with guidelines for submission to the British Journal of Health Psychology (Appendix 1)

Word count 7,991

ABSTRACT

Background: Having a child diagnosed with a chronic illness is a stressful time for parents. Cancer care in particular often involves prolonged treatment, invasive procedures and frequent hospital visits. Parents may also have to deal with the secondary challenges that cancer brings such as caring for other children in the family and managing employment responsibilities. Parents will experience a range of emotions, thoughts and fears throughout their child's treatment which may challenge existing coping skills and ways of life.

Purpose: This review aimed to systematically examine and synthesise qualitative studies investigating the experiences of parents who have a child diagnosed with blood cancer in terms of the effect it can have on their lives.

Method: Systematic searches of Medline and Embase (Ovid), CINAHL, PsychInfo and PsychArticles (EBSCO) were conducted. Searches using Google Scholar and European PubMed were also carried out. Eleven articles were initially identified and read, taking into consideration inclusion criteria. Eight articles were deemed to be suitable for the review. Reference lists of these eight selected articles were searched. No new articles were identified through this process. The European Journal of Oncology Nursing and The Journal of Pediatric Hematology/Oncology were also electronically searched using key terms and then hand searched for the time period 2009-2014. Again, no new articles were identified through this process. The quality of the final eight articles was assessed. Meta-ethnography was employed to synthesise the studies.

Results: Nine themes were identified which were concerned with the effect a diagnosis of blood cancer can have on parents' lives. These were: a changed life, differing parental roles, the initial reaction: fear of child's death; methods of

coping and support; a changed perspective; father's avoidance and suppression of emotion; the difficulty with 'normal'; the challenge of painful and invasive procedures and taking positives from the experience.

Conclusions: The review indicated that it may be beneficial to provide parents with some psycho-education regarding the benefits of open communication with each other as well as advice on how to deal with emotionally challenging invasive procedures.

Key words: *Qualitative systematic review, parental experience, blood cancer.*

INTRODUCTION

What is chronic ill health?

Chronic illnesses in children are defined as conditions which have lasted three or more months, which require frequent hospitalizations and/or extensive medical care and are valid diagnoses based on medical knowledge (Mokkink, Van Der Lee, Grootenhuis, Offringa, & Heymans, 2008). Examples of chronic illnesses are: asthma and respiratory problems, diabetes, heart problems and gastrointestinal problems (Newacheck & Taylor., 1992) as well as cystic fibrosis and cancer, including blood cancers (Theofanidis, 2006). A diagnosis of cancer most often involves prolonged treatment, invasive procedures, frequent hospital visits, management of complex medication and subsequent side effects. The diagnosis will understandably affect parents in a variety of different ways. Parents may experience numerous challenges as they manage their child's diagnosis which could include: dealing with the child's challenging behaviour (Svavarsdottir, 2005), trying to access support from people in their wider network (Enskar, Carlsson, Golsater, Mamrin, & Kreuger, 1997) and processing complex medical information (Kohlsdorf & Junior, 2012). Previous research has also shown that the diagnosis understandably has an effect on parents' emotions as they can experience fear, worry (Patterson, Holm, & Gurney, 2004) and helplessness (Jithoo, 2010). In response to the effects of blood cancer, parents will try to adjust to their changed life (Schweitzer, Griffiths, & Yates, 2012). The Oxford Online Dictionary (2015) refers to adjustment as "the process of adapting or becoming used to a new situation". Therefore, adjustment is not only the end

point that parents come to regarding their changed life, but also the means by which they achieve this.

Coping

Selected methods of coping is one of the factors related to adjustment in parents of children with cancer (Grootenhuis & Last, 1997). Greening and Stoppelbein (2007) found that one of the strategies employed by parents of children with cancer involved engaging in avoidance through the use of alcohol or drugs. The authors found that parents' risk of experiencing depressive symptoms and Post Traumatic Stress Disorder (PTSD) symptoms increased when avoidant strategies were employed, indicating that these may not be helpful in the long term. Given that a number of the parents recruited were at risk of both PTSD and possible substance misuse, the authors were aware of their ethical responsibility and sign-posted parents to appropriate community mental health providers. This is a positive part of the study's research protocol.

Patistea (2004) employed the Coping Health Inventory for Parents to explore the strategies used by parents of children with leukaemia. Maintaining a level of hope and optimism, relying on faith and engaging in informative discussions with health professionals were deemed useful. The strategies which were considered more difficult to use were concentrating on work and other interests. One of the article's strengths relates to the fact that the author provided a strong theoretical basis for the study in terms of the conceptual framework. This is used to guide the research as well as to explore previous findings and contributions to the field.

The impact on mental health

A childhood blood cancer diagnosis can affect parents' mental health and well-being. Reinfjell, Lofstad, Nordahl, Vikan and Diseth (2009) used the General Health Questionnaire to measure parents' mental health. The authors state that this is a highly valid and reliable measure which is essential. Using measures which are not valid and reliable may affect the study's findings and impact on the recommendations that are being made. The results demonstrated that fathers of children with leukaemia scored higher than control fathers with regards to anxiety and depression. Risk factors for distress in parents of children with cancer include self-blame (Sloper, 2000), perceived problems with the child's behaviour (Barrera, D'Agostino Gibson, Weksberg, & Malkin, 2004) and avoidance of reminders of the child's illness (Norberg, Poder, & Von Essen, 2011). It is important to note however, that high levels of stress and distress are not a certainty for parents (Sloper, 2000).

The current systematic review

A systematic review exploring the experiences of parents who have a child with cancer was recently published (Gibbins, Steinhardt, & Beinart, 2012). This review, however, did not exclusively focus on blood cancers. Leukaemia is the most common type of cancer in children and has a better prognosis than some other cancers such as brain tumours and bone sarcomas (Cancer Research UK, 2015). Parents of children with blood cancer may therefore have different experiences and be affected in different ways from parents of children with other cancer diagnoses. It is of interest to explore the experiences of this population as it may identify unique parental perspectives, fears and events related to this

diagnosis. It may also identify issues concerning unmet need or gaps in psychosocial support.

Research Question

What are the experiences of parents with a child diagnosed with blood cancer in terms of the effect it has on their lives?

Objective

To explore the consequences of having a child diagnosed with blood cancer in terms of the effects that this has on the lives of the parents using meta-ethnography.

METHOD

Systematic Search of Literature

A systematic search of the following electronic databases was completed following guidance from NHS and University of Glasgow librarians in October and November 2014. Ovid was used to search Embase and Medline databases and the EBSCO host was used to search CINAHL, PsychINFO and PsychArticles databases. Google Scholar and European PubMed were also searched. The Journal of Pediatric Hematology/Oncology and The European Journal of Oncology Nursing were searched first using key terms for the time period 2004-2014. Issues from January 2009 to November 2014 (The Journal of Pediatric Hematology/Oncology) and from February 2009 to December 2014 (The European Journal of Oncology Nursing) were then hand searched.

The search strategy was initially designed to be used within Ovid as this is one of the largest databases. This search was then amended for use within other databases. The search terms which were used within each database, as well as the other search sources and numbers of search results can be found in Appendix 2.

The search strategy for Ovid contained the following subject heading and keyword searches:

1. Caregivers, family, fathers, mothers, legal guardian, parents, guardian*,
carer*

2. Haematologic neoplasms, Leukemia, Leukemia myeloid, Leukemia
Lymphoid, Blood cancer*

Boolean operators (OR and AND) were used to combine search strings.

For the Ovid search, the American spelling for leukaemia was used as this was entered in to the search first. Including the British spelling produced the same number and content of results so was not included. This is evidenced by the fact that articles included in the review use the British spelling.

Search Limits

Limits were set for articles published in the English language between 2004 and 2014. The search was limited to these dates due to improved blood cancer survival rates. These rates have been increasing over the last few decades but there has been further improvement in the last ten years (American Cancer Society, 2012). Treatment developments and better outcome may influence parents' experience and the effect the diagnosis has on them.

Inclusion criteria

- Employs a qualitative method.
- Focuses on the experience of parents in relation to childhood blood cancer.
- Articles which aim to explore the general experience of parents (rather than focussing on a specific factor from the outset such as stress or family functioning/aspects of parental relationship).
- Relates to children/young people under the age of 17.

Exclusion criteria

- Employs only a quantitative method.
- Includes chronic health problems other than blood cancer.
- Includes any other form of cancer such as tumour.
- Articles that exclusively focus on the experience of other family members, for example siblings.
- Parents whose child has subsequently died.
- Parents whose child has terminal (or non-curative) illness.

Quality rating strategy

The quality rating of the articles was conducted using a modified form of the checklist developed for qualitative research by Walsh and Downe (2006). The checklist, together with the rationale for the modifications, can be found in Appendix 3.

The reliability of the modified scale was tested by asking an independent person (a Trainee Clinical Psychologist who was familiar with Walsh and Downe's rating strategy) to rate three articles which were selected at random. The level of agreement in scoring articles was 91% and the items which were not initially agreed on were resolved through discussion. As Walsh and Downe's checklist provided numerical scores, score ranges were assigned verbal descriptors to indicate the quality of the paper. These were 'good', 'acceptable' and 'poor' (Appendix 4).

Synthesis

Meta-ethnography was used to analyse concepts across different qualitative studies and methods. Meta-ethnography is applicable to this systematic review as its use has been growing within health related studies and has been used to explore patient experiences of illness and care (Atkins, Lewin, Smith, Engel, Fretheim, & Volmink, 2008). The method of meta-ethnography was developed by Noblit and Hare (1988). They describe the seven phases of conducting a meta-ethnographic synthesis (Appendix 5).

RESULTS

Conducting systematic searches

When conducting systematic searches there are a variety of sources (databases) to retrieve information from, each with different options for searching and with different ways of coding terms (Barroso, Gollop, Sandelowski, Meynell, Pearce, & Collins, 2003). Furthermore, MEDLINE does not recognise “qualitative” as part of its MeSH terms (Dixon-Woods, Fitzpatrick, & Roberts, 2001). The term qualitative was therefore not used in the Ovid (MEDLINE) database search but was included within the other database searches (see Appendix 2).

Systematic search results

The database search yielded 537 results. Google Scholar identified 35 articles, European PubMed identified four and the key term search of the European Journal of Oncology Nursing and The Journal of Pediatric Hematology/Oncology identified 115. Duplicates were then removed (n=59) and the remaining articles were screened for relevance by reading the title and/or abstract. A further 621 articles were removed, leaving eleven remaining articles which were then read in full. Three did not meet the inclusion criteria which resulted in eight eligible articles. Two articles which had not been identified in the original database search were found within Google Scholar. The reasons for exclusion can be found in Figure 1. Hand searches of the European Journal of Oncology Nursing and The Journal of Pediatric Hematology/Oncology did not yield any appropriate results.

Quality rating results

Each of the eight articles were rated according to Walsh and Downe's (2006) modified quality criteria. According to the descriptive rating strategy described in Appendix 4, four articles were assigned a 'good' rating and four were assigned an 'acceptable' rating. No articles were rated as 'poor'. Quantitative and qualitative descriptions of the quality of the articles can be found in Table 1.

Figure 1. Flowchart of results

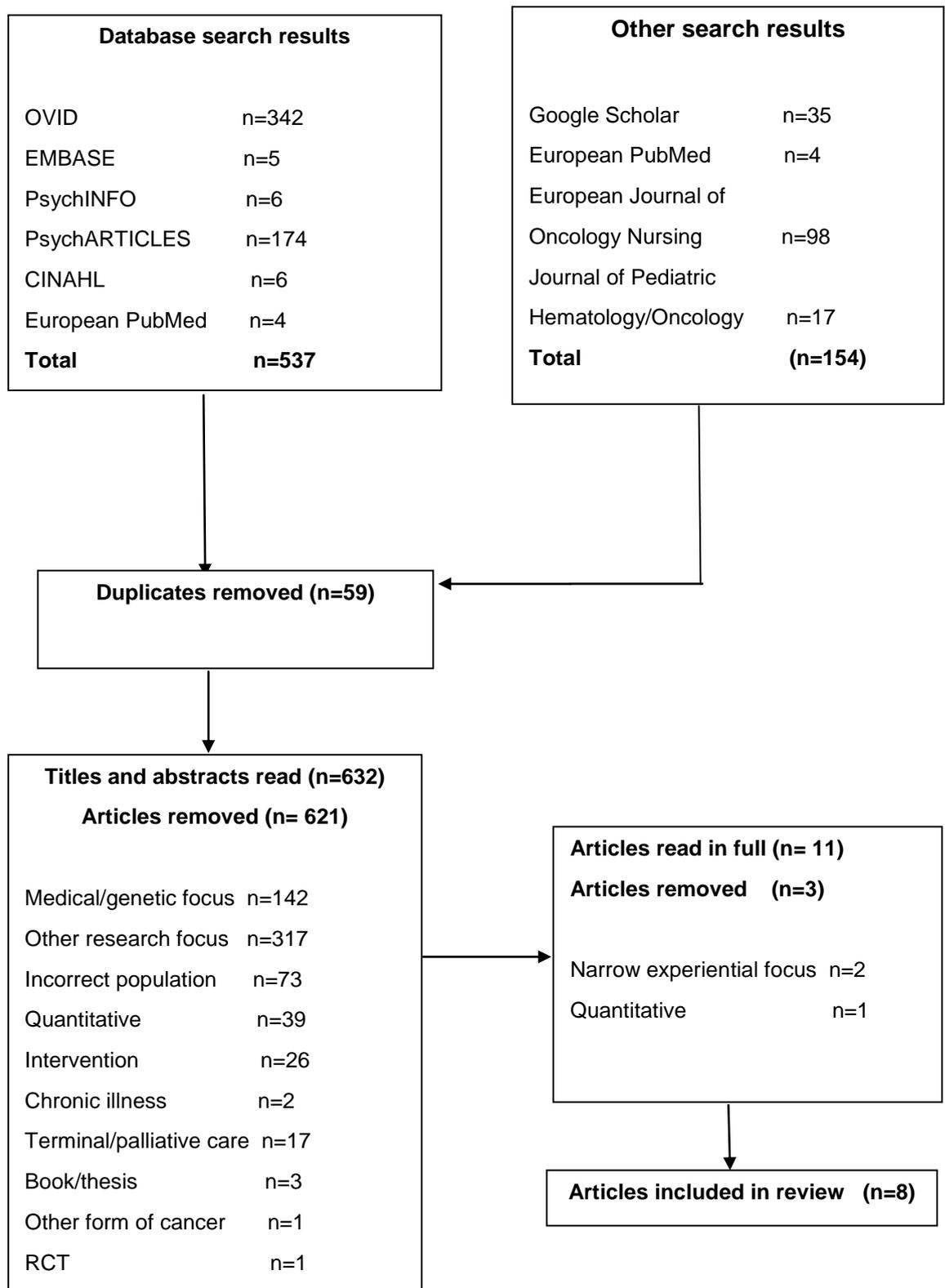


Table 1. Quality ratings of articles (n=8)

Article (year and author)	Country	Research participants	Qualitative methodology	Quality rating score out of 29 (%) and category
Hill, Higgins, Dempster, & McCarthy (2009)	Northern Ireland	5 fathers	Interpretative phenomenological analysis	23 (79%) Good
Wills (2009)	China	8 fathers	Matrix system (Miles and Huberman)	22 (76%) Good
Kars, Duijnste, Pool, & Van Delden (2008)	The Netherlands	12 mothers and 11 fathers	Grounded theory	23 (79%) Good
McGrath and Phillips (2008)	Australia	3 fathers	Phenomenological approach	18 (62%) Acceptable
Earle, Clarke, Eiser, & Sheppard, (2006)	England	34 mothers	Thematic analysis	22 (76%) Good

McGrath, Paton, & Huff (2005)	Australia	3 mothers and 1 father	Phenomenological approach	19 (66%) Acceptable
McGrath, Paton, & Huff (2004)	Australia	3 mothers and 1 father	Phenomenological approach	20 (69%) Acceptable
McGrath and Chesler (2004)	Australia	13 mothers and 6 fathers	Phenomenological approach	20 (69%) Acceptable

With regards to overall sample size, a total of 62 mothers and 34 fathers were recruited. All eight articles provided a clear rationale for the research; a justification for why the research was taking place or a description of why it could be beneficial. All eight articles were clear about the analytic approach being used and gave an adequate description of this. Only one of the articles mentioned reflexivity (Hill et al., 2009); this is surprising as it is an important component of qualitative research, assisting the researcher in their awareness of how their own interpretations and biases may impact their analysis.

Meta-ethnography

Table 2 details the original themes from each of the eight articles. Through the process of meta-ethnography, nine new dominant themes were identified (Table 3). A theme was included if it was apparent within four or more articles (50% or more). Three themes were identified that occurred only in two or three articles and were therefore not included.

Table 2. Original themes from the eight articles

Article (author and year)	Themes
Hill et al. 2009	<ol style="list-style-type: none"> 1. Adjusting to the diagnosis 2. 'Let's see what has to be done' –taking control 3. The experience of maternal gate keeping 4. 'You try to play it down' – constructing a manageable reality 5. Striving for normalisation 6. 'Re introducing to a proper life again' – putting the illness in the past 7. Experiences of giving and receiving support
Wills 2009	<ol style="list-style-type: none"> 1. The fathers' initial reactions to the child's confirmed diagnosis of ALL 2. Disclosure of the child's diagnosis 3. Social support of the fathers 4. Effective coping mechanisms of the fathers
McGrath & Phillips 2008	<ol style="list-style-type: none"> 1. Experiencing extreme emotional pain 2. Men do cry 3. Withdrawal 4. Time out and physical activity to reduce stress 5. Keeping busy as a way of coping with stress 6. Appreciation when others reach out 7. Anger

	<ol style="list-style-type: none"> 8. Mothers are aware of fathers distress and protect them 9. Facing the situation-lack of choice 10. Normalcy 11. Close involvement of fathers in all aspects of care including care of siblings 12. Fathers efforts at maintaining family home in wife's absence 13. Sharing the care-fathers involvement at hospital 14. Variation from fathers deeply involved to those reluctant to care 15. Father wants to be at hospital with sick child 16. Difficulty of witnessing treatment 17. Advocacy for child patient 18. Work issues 19. The stress of family separation 20. Adjustment over time 21. Financial impact 22. Coping 23. The hospital experience 24. Relationship issues 25. Dealing with the outside world 26. Death and dying
<p>Earle et al. 2006</p>	<ol style="list-style-type: none"> 1. Recommendations from professionals 2. The effect of illness on daily life 3. Barriers to a normal life for children

	<ol style="list-style-type: none"> 4. Parenting concerns 5. Strategies to achieve a normal life
McGrath et al. 2005	<ol style="list-style-type: none"> 1. Relocation 2. Normalcy interrupted 3. Life on hold 4. Rather be at home 5. Adjustment difficult when returning home 6. Family support 7. Other support 8. Father issues 9. Male coping strategies 10. Siblings 11. Schooling 12. Employment issues 13. Financial impact
Kars et al. 2004	<ol style="list-style-type: none"> 1. Being there as a response and a parental need 2. Purposes of being there 3. Ways to express being there 4. Differences between fathers and mothers 5. The reinforcing power of being there 6. Less constructive aspects of being there
McGrath et al. 2004	<ol style="list-style-type: none"> 1. The major AML difference: the confrontation with death 2. Treatment: the juxtaposition of hope with the ever present fear of death 3. The similarity – shock and grief: the generic grief

	<p>dimension</p> <ol style="list-style-type: none"> 4. Acceptance 5. The major AML difference: the length of the treatment protocol 6. The similarity: wanting to be with the sick child 7. The similarity: the stress of treatment 8. The similarity: the stress of invasive technology 9. The similarity: uncertainty 10. The similarity: the hospital comfort zone 11. The ward as sanctuary 12. The similarity: the support of other families 13. The similarity: the support of allied health professionals
<p>McGrath & Chesler 2004</p>	<ol style="list-style-type: none"> 1. Fathers' emotional pain associated with diagnosis 2. Fathers' emotional response to pain and shock 3. Facing the situation-acceptance 4. Normalcy 5. Challenging gender stereotypes

Table 3. Nine new dominant themes

Theme name	Prevalence
A changed life	(7 of 8 articles)
Differing parental roles	(5 of 8 articles)
The initial reaction: fear of child's death	(5 of 8 articles)
Methods of coping and support	(5 of 8 articles)
A changed perspective	(5 of 8 articles)
Father's avoidance and suppression of emotion	(5 of 8 articles)
The difficulty with 'normal'	(4 of 8 articles)
The challenge of painful and invasive procedures	(4 of 8 articles)
Taking positives from the experience	(4 of 8 articles)

A description of the nine new dominant themes

A changed life

All but one of the eight articles made reference to the effect that a blood cancer diagnosis can have in terms of the changes to everyday life.

“I had control over my life and now I don’t feel I have that so much”.

(McGrath & Chesler, 2004, p51).

“Life’s not normal and you know it’s not going to be normal for a long time”.

(Earle et al., 2006, p157).

Parents reported significant changes within their family in terms of their day to day lives and what is ‘normal’ and routine for them. These included practical changes such as different eating habits and varying school attendance as well as more appointments at hospital (Earle et al., 2006). There were also changes to working hours, which could possibly lead to a changed economic situation for the family.

“We have gone from two incomes to one”.

(McGrath et al., 2005, p110).

A blood cancer diagnosis represents an enormous disruption to and deviation from normal life for the whole family. It seems that every facet of life can potentially be affected, from something as simple as meal times to highly important areas such as employment.

Differing parental roles

In terms of parental role, fathers saw their wives as the primary caregiver for their sick child.

“Gillian always pushed me out of the way to do it”.

(Hill et al., 2009, p1273).

“I think the responsibility of that (medication) has gone to my wife. I don’t see the need for me to really interfere for want of a better word”.

(McGrath et al., 2005, p106).

These quotes signify that fathers saw themselves as being on the periphery of their child’s care. Fathers also felt the need to ‘do’ something and saw themselves as being quite practical as they were now essentially in charge of maintaining a normal life at home; cooking, cleaning and taking care of the other children in the family (McGrath et al. 2005., McGrath & Phillips, 2008).

“You know just all the kind of practical things like keeping the house running, changing the car”.

(Hill et al., 2009, p1272).

Even though they had assumed a practical role, some fathers were dissatisfied with this and would have liked more of an opportunity to ‘be there’ for their sick child in the hospital. The fathers, however, tended to not discuss this with their partners. This may be linked with another theme to be discussed in this review titled ‘father’s avoidance and suppression of emotion’ as some fathers have a tendency to mask negative feelings.

The initial reaction: fear of child’s death

The initial effect of a blood cancer diagnosis seems to understandably be an emotional one. When receiving the news, parents described shock, fear, guilt and overwhelming sadness (Wills, 2009), numbness and a sense of unfairness (McGrath et al., 2004) as well as disbelief and denial (McGrath & Chesler, 2004). Parents also often have the immediate assumption when they hear the word ‘cancer’ that it will be fatal.

“Our first reaction was that he was going to die”.

(McGrath et al., 2004 p361).

The fear of death may be influenced somewhat by the fact that parents have little prior knowledge, experience or information about blood cancer (McGrath et al., 2004) and may have misconceptions about the illness for example that it occurs only in the elderly (Wills, 2009). It seems logical to assume that, with a lack of knowledge and mistaken belief about the origin of blood cancer and associated outcomes, parents will experience shock, fear and anticipate a fatal outcome. Education and information has a positive effect on fear; as knowledge increases, the initial fear subsides.

“My base level of understanding is a lot higher....I feel confident and comfortable that it is all under control and squared away”.

(McGrath & Phillips, 2008, p10).

Methods of coping and support

Due to the effects of the diagnosis discussed so far (the emotional impact, disruption to daily life and the requirement to take on roles and responsibilities) it is clear that support and coping skills are incredibly important to parents. This is apparent due to the fact that five of the eight articles made reference to coping strategies (Wills, 2009., McGrath & Phillips, 2008., McGrath, 2005., McGrath et al. 2004., & McGrath & Chesler, 2004). Family support was beneficial to many.

“We are very lucky that we have my parents and his family, his brother, my brother and my grandmother”.

(McGrath, 2005, p105).

Seeking out and being given information on the diagnosis and treatment is also a way of coping as it answers questions and responds to the fears parents have (McGrath et al., 2004., & McGrath & Phillips, 2008). .

“Information helped me to accept it. I can cope now”.

(McGrath et al., 2004, 361).

Fathers also spoke of “time out” which seems to consist of distancing themselves from the situation when possible and spending time doing something that matters to them (McGrath & Chesler, 2004., & McGrath & Phillips, 2008).

“We are still individuals and we still want to do things for ourselves...just talking to other adults and getting away from it all....or anything”.

(McGrath & Chesler, 2004, p48).

The coping strategies fathers utilise seem to link to the theme ‘father’s avoidance and suppression of emotion’ as they spoke of their preference to cope on their own, rather than reaching out to others.

“We need help and support from people. Sometimes we don’t want that support. Sometimes we just want to be insular”.

(McGrath & Chesler, 2004, p49).

For fathers, there seems to be a level of tension in the use of coping strategies (McGrath & Chesler, 2004). There is a belief that they should ask for help and a recognition that this would have some benefit, however, what they *want* to do is withdraw and cope on their own.

A changed perspective

It was clear that the diagnosis and experience of treatment led to a changed parental perspective regarding how to live their lives.

Mother: "I told him (father) you've got to live day to day with this thing. You can't plan ahead".

(McGrath & Chesler, 2004, p52).

When dealing with a childhood blood cancer diagnosis, life seems quite unpredictable and fragile (McGrath et al., 2005). It may be damaging for parents to look too far down the line to the future; if hopes are built then they can be dashed when there are inevitable setbacks or disappointments.

A changed perspective is also indicated by some form of acceptance.

"It is something that I am learning to live with".

(McGrath et al., 2004, p36).

Father's avoidance and suppression of emotion

Descriptions of avoidance and masking or suppressing emotions were present within five of the eight articles (Hill et al., 2009., McGrath & Chesler, 2004., McGrath & Phillips, 2008., McGrath et al., 2005., & Wills, 2009). Avoidance was expressed by withdrawal, an unwillingness to discuss the situation and need to be alone.

Father: "When it was first diagnosed.....I just didn't feel like talking".

(McGrath & Chesler, 2004, p49).

"I go out on my boat for a couple of hours by myself. I used to take someone but I go by myself".

(McGrath & Phillips, 2008, p4).

Suppression was manifested by not crying and not wanting to show emotion to others.

Father: "I deny emotions because I think I can't handle them".

(McGrath & Phillips, 2008, p10).

One reason for avoidance and suppression relates to the need fathers have to be there for their wives (Hill et al., 2009., & McGrath & Phillips, 2008). Another reason may relate to the male stereotype and social norms that men feel they

must live by (Hill et al., 2009., McGrath et al., 2005., & McGrath & Chesler, 2004).

Father: *"It's a man's thing, men do keep things inside....maybe I just bottled more up into myself, a man shouldn't cry"*.

(Hill et al., 2009, p1276).

In times of trial, men often see themselves as the ones who must safeguard and protect the rest of the family. To do this effectively, it seemed that some suppression of emotion is essential (Wills, 2009).

The difficulty with 'normal'

A blood cancer diagnosis and time spent in hospital has an effect on families' engagement with what is 'normal'. Attempts to maintain any sense of normal life was one of the most challenging parts of the treatment process.

"That is probably one of the most difficult things-to carry on and act normal".

(McGrath & Chesler, 2004, p54).

Parents were often advised by medical professionals to try and lead as normal a life as possible, however this was interpreted as an almost impossible task and therefore triggered a level of frustration.

“I don’t think the health professionals realise because they’ve never lived it. They just say carry on with the normal, it’s a bloody silly thing to say because you can’t”.

(Earle et al., 2006, p157).

The diagnosis also seems to affect parents’ beliefs about normal life; they feel that there is no point in attempting to return to normal as there is no such thing as ‘normal’ now.

“It’s never going to be the same as it was before”.

(Earle et al., 2006, p157).

Families who have experienced a blood cancer diagnosis have had their lives changed and they will understandably have anxieties and apprehensions they did not have before (Hill et al., 2009., & McGrath et al., 2005). Parents may feel frustrated and disappointed as they believe ‘normal’ means returning to their old way of life, which must seem near impossible given what they have experienced.

The challenge of painful and invasive procedures

A blood cancer diagnosis requires extensive treatment. This has an effect on parents in terms of stress and distress levels; watching and being involved with painful and invasive procedures is understandably deeply upsetting.

“It is hard watching your child go through it (procedure)”.

(McGrath et al., 2004, p363).

“I thought ohhh practice cannulation on me then don't hurt my daughter”.

(McGrath & Phillips, 2008, p9).

Parents not only feel that they cannot protect their children from harm but are actually directly exposing them to harmful situations (Kars et al., 2008). This will generate feelings of helplessness.

“It is hard to see your child wrestling because they are holding him so tight....it was difficult.....You feel powerless”.

(Kars et al., 2008, p1558).

Invasive procedures work against a parent's natural instinct to act as protector; their child's guardian who shields them from harm. Parents may experience an inner battle; distress at what their child is going through but knowing that it is for the best and that it is the only thing that will help them get through the illness (Kars et al., 2008).

Taking positives from the experience

A childhood blood cancer diagnosis is a stressful time for parents and raises many painful emotions, however, several articles discussed the positive effect it

can have on parents and families. Kars et al. (2008) found that the role of caring for and supporting their sick child contributed to and fed the parent-child bond. By 'being there' for their child, parents were fulfilling their parental role and were therefore "exercising a meaningful parenthood" (Kars et al., 2008, p.1557).

Hill et al. (2009) found that fathers interpreted a change in their relationship with their child following a blood cancer diagnosis. One father described how his beliefs about parent-child relationships had developed.

"We got very close.....I think girls bond with their daddy after a while. I never believed that until now really".

(Hill et al., 2009, p1274).

Not only did the relationship with their child improve but parents acknowledged that a blood cancer diagnosis had made them realise how important their family and time together is.

"Now we make more of an effort to do more together".

(Earle et al., 2006, p157).

Parents interpreted that a blood cancer diagnosis had also led to positive changes in their child due to personal growth and development.

“She’s so mature, she’s had to deal with lots of people”.

(Earle et al., 2006, p158).

Looking for the positives may be a form of resilience as families search for and find new meaning within the suffering. There is some small opportunity for personal growth.

DISCUSSION

This systematic review synthesised qualitative research regarding parental experience of a blood cancer diagnosis and the effect this can have on parents' lives. Nine themes were identified: a changed life, differing parental roles, the initial reaction: fear of child's death, methods of coping and support, a changed perspective, father's avoidance and suppression of emotion, the difficulty with 'normal', the challenge of painful and invasive procedures and taking positives from the experience.

Change often accompanies illness therefore it is not surprising that the review found that a diagnosis of blood cancer effects the day to day life and running of the family (Hill et al., 2009., Kars et al., 2008., McGrath & Phillips, 2008., Earle et al., 2006., McGrath et al., 2005., McGrath et al. 2004., & McGrath & Chesler, 2004). Parents also acknowledged that their lives had been put on hold and that they had changed their plans and work commitments in order to look after their sick child (McGrath et al., 2005., Earle et al., 2006). The nature of the blood cancer diagnosis also brought huge medical related changes as parents spent more time at the hospital, an environment which was quite far removed from their 'normal', everyday world.

These changes to everyday life meant that life no longer felt 'normal' and attempts to maintain some semblance of normality was a difficult yet highly valued process for parents. The Oxford Dictionary defines 'normal' as

something which is 'expected' and 'typical'. Normality is therefore somewhat predictable and routine and when events become unpredictable there is uncertainty fear and anxiety (Armfield, 2006). Therefore, a search for normality perhaps represents a need and desire to make life predictable again which could in turn, reduce some anxiety for parents.

Links to previous findings

The results of this systematic review are consistent with findings from previous literature. In a systematic review exploring the impact of childhood cancer on parents' relationships, 5 articles found that there were gender differences in parental coping and role (Da Silva, Jacob, & Nascimento, 2010). This finding is consistent with the current systematic review which reported the theme 'differing parental roles'. This explored the fact that mothers were more likely to stay at the hospital and fathers continued to work and also upheld life at home. Da Silva et al. (2010) also found that fathers retained their role as 'breadwinner', however some men acknowledged guilt associated with this role as they were aware that their wives were almost fully responsible for taking care of their ill child.

Schweitzer et al. (2012) interviewed parents of children with cancer and reported several themes including 'a renewed sense of family' and 'making the most of every moment'. These themes revolve around planning more activities together and being more appreciative of family support and time spent together.

Furthermore, the majority of 6 fathers in a study by Brody and

Simmons (2007) also acknowledged that their relationships with their wives had been strengthened as a result of their child's cancer treatment process. In terms of the current study, these findings relate to the theme 'taking positives from the experience' where parents reflected on the positive changes that had occurred as a result of a blood cancer diagnosis. This included more time spent together, being appreciative of their network of support and experiencing a deepened relationship with their child. This search for the positive may be related to post traumatic growth which is a developing field in cancer research and is defined as "positive changes or transformation such as a higher level of functioning in some life domains" (Ho, Chan, & Ho, 2004, p377). Barakat, Alderfer, & Kazak (2009) measured post traumatic growth (PTG) in adolescents who had survived cancer. PTG was measured as any positive changes identified in the individual themselves, as well as in their relationships with others and their plans for their future. The authors found that the majority of adolescent survivors of childhood cancer were able to describe at least one positive after-effect of cancer which included 'The way I treat other people' 'The way I make friends' and 'How I do my school work'.

Limitations

One limitation of this review arises from there being an element of sampling bias. Parents who are motivated to take part in research may be affected in different ways and have different experiences from those who decide not to take part. This decision could be due to many different reasons; difficulty expressing themselves, a desire to avoid discussing distressing experiences as well as a preconceived notion about what the research will involve.

In addition, one article explored the experience of mothers alone (Earle et al., 2006) and three explored the experiences of fathers alone (Hill et al., 2009., Wills 2009., & McGrath & Phillips, 2008*). Only one article (Kars et al., 2008) made a very brief comparison between the mothers and fathers interviewed. It would have been interesting if articles had employed a method which allowed a comparison to be made. This may have involved recruiting a larger sample and exploring the differences within the themes between genders; were there clear differences in how mothers and fathers experienced their child's blood cancer diagnosis.

* There were quotations included from mothers in this article, however the main focus was on fathers' experiences.

The four articles by first author McGrath were part of the same five year longitudinal study (McGrath and Phillips, 2008, McGrath et al., 2005, McGrath et al., 2004, & McGrath & Chesler, 2004). It is important to note however, that parents from different diagnostic groups were recruited and interviewed (Acute Lymphoblastic Leukaemia, Acute Myeloid Leukaemia and lymphoma). Only two of the four articles were directly related in that they both interviewed the same AML parents (McGrath et al., 2004 & McGrath et al., 2005**). This limits the diversity of the results somewhat, as certain factors such as parents' personality and intellect, will have remained stable over time and will have influenced their experience and interpretation and therefore their responses to questions in the interview. With regards to identifying themes however, the two articles had a different focus and this led to different reflections from parents. McGrath et al. (2004) explored the experience and impact of being in hospital and identified themes relating to invasive technology and support received from medical professionals. McGrath et al. (2005) explored the effect of diagnosis on family and home life and uncovered themes such as 'adjustment difficulties when returning home'.

** The author was contacted to clarify this and kindly provided a response.

In qualitative research, the interpretation of themes can be influenced by the author's own experiences and perceptions. Four of the eight articles included in this review were written by the same first author, which suggests the possibility that there will be some interpretational bias in the results of this review. If authors are using reflexivity which is described as "being aware of his/her effect on the process and outcomes of research based on the premise that knowledge cannot be separated from the knower" (Sage Research Methods 2013) then this interpretational bias should be less likely. None of McGrath's articles made reference to or acknowledged this approach.

Lastly, only two of the eight articles included were from the United Kingdom (UK) which may limit the potential to generalise the findings of this review. Four articles used Australian populations, one was conducted in China and one in The Netherlands. There was also limited demographic reporting within all eight articles with regards to ethnicity. Within the context of this review it is therefore important to consider these issues as culture plays a unique role in coping and particularly help seeking behaviour (Wei, 2007).

It is also important to note that health care in Australia is provided through a combination of government funded and private health insurance. Therefore, many of the parents within this review may have experienced added stressors regarding the finance of their child's health care that parents in other countries, such as the UK, would not have had.

Implications

The fact that mothers are perhaps more vocal about their fears and feelings, whereas fathers are more withdrawn, may represent an asynchrony in coping which has been found to result in partners feeling more isolated from each other (Adams-Greenly, 1986). Conversely, sharing feelings and being open about one's fears and interpretations are linked to more positive outcomes. In a literature review of parental adjustment and coping, a positive association was found between psychological well-being and open communication between partners. This open communication then went on to be positively correlated with how satisfied couples were in their marriage (Grootenhuis & Last, 1997). Therefore, fathers could perhaps be informed of the benefits associated with open communication and could be encouraged to share their feelings with their partner.

Finally, the review found that understandably, having to watch their child experience invasive procedures was very distressing for parents (Kars et al., 2008., McGrath et al., 2004., & Earle et al., 2006). An element of this distress is perhaps due to the fact that parents sense a lack of control; they may believe that there is little they can do to help their child and feel helpless that they cannot take their pain away. Parents could perhaps be given information and education on low level child anxiety management strategies. The British Psychological Society (BPS) (2010) has published Good Practice Guidelines on how to manage invasive and/or distressing procedures for children. These include relaxation strategies such as deep breathing, the use of music and

singing as a distraction and advice on how to communicate with the child during the procedure. Parents could be given condensed information based on this advice so that they can play an actively supportive role in managing their child's distress which may help decrease the feeling of lacking control as well as their own distress.

SUMMARY

This review has shown that a childhood blood cancer diagnosis can affect parents in a multitude of different ways and raises many complex issues for parents. The parental role is challenged as they feel they can no longer protect their child, perhaps creating a sense of lost control. Fathers' gender role is also challenged as men often see themselves as needing to be strong so that the rest of the family can rely on them. Parents are also aware that the life they have created becomes unsettled and unpredictable during leukaemia treatment, with no clear indication of if or when it will ever return to 'normal'. It is important to recognise that despite the challenges parents face, it is clear that many are able to maintain a level of optimism and hope and can take positives from a distressing experience. Psychologically, this can be seen as a hugely protective factor in dealing with distress. A positive outlook and adaptive coping strategies should be recognised and reinforced by medical teams, encouraging parents to acknowledge that they are not in a situation wholly devoid of hope but are moving forward, as best they can, with strength and resilience.

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Chapter 2: MAJOR RESEARCH PROJECT

A comparison of coping styles and patterns of accessing support between mothers and fathers who have a child diagnosed with acute lymphoblastic leukaemia (ALL): using interpretative phenomenological analysis (IPA).

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Prepared in accordance with guidelines for submission to the British Journal of Health Psychology (Appendix 1)

Word count 8,512

PLAIN ENGLISH SUMMARY

Title

A comparison of coping styles and patterns of accessing support between mothers and fathers who have a child diagnosed with acute lymphoblastic leukaemia (ALL): using interpretative phenomenological analysis (IPA).

Background

Acute Lymphoblastic Leukaemia (ALL) is a cancer of the blood which means that the body finds it hard to fight infection as there is an under production of healthy red blood cells. As with any chronic childhood illness, having a child diagnosed with ALL can be a stressful and worrying time for parents, therefore it is of interest to explore how parents cope with the demands of the situation.

Aim and objectives

The aim was to explore the ways in which mothers and fathers coped with their child's diagnosis of ALL and also to explore whether there were differences between mothers and fathers with regards to coping and support.

Recruitment

Each week, participant information packs were placed in the leukaemia clinic at the Royal Hospital for Sick Children (RHSC) in Glasgow, along with posters advertising the study. Parents were able to freely take a pack if they were interested. Paediatric Oncology Outlook Nurses (POONs) also informed parents about the study and invited them to take a participant information pack.

Consent

Parents were told that they were under no obligation to take part and that participation would not have any impact on their child's care. If parents wished to take part they were asked to sign a consent form.

Design

A semi structured interview was designed to ask parents about their experience. This was done by looking at previous research and talking to professionals in Paediatric Clinical Psychology. The researcher was flexible with regards to exploring the topics that parents raised.

Analysis

Five parents (three mothers and two fathers) took part in separate semi structured interviews. The interviews lasted around 60 minutes and were recorded using a digital voice recorder (DVR). The interviews were typed word for word and the data was analysed using Interpretative Phenomenological Analysis (IPA). IPA is a method of analysis that may be used to explore a person's lived experience and the meaning that they take from what they have been through.

Main findings

Four main themes were identified through interviews with parents: the parental role; internal coping strategies; external coping strategies; and looking to the future.

Conclusion

The results demonstrated that parents draw upon various strategies to help them cope with their child's diagnosis of ALL and find a range of formal and informal supports helpful. These included: speaking to other parents; accessing support through CLIC Sargent social work; and living in the moment.

The findings of this study have implications for the Paediatric Clinical Psychology team as well as the medical professionals working with this population, in terms of the way they support the family of the patients they treat. Parents who are new to the haematology service could also be informed of the strategies other parents have found useful in the past. Unfortunately, there were significant difficulties with recruitment which meant that a comparison between mothers and fathers was not possible. This highlights the need for amendments to the recruitment strategy with this population.

ABSTRACT

Background and aims

Leukaemia is a cancer of the blood and is the most common type of childhood cancer with almost 500 new cases every year in the UK. There is a vast amount of research exploring the experiences of parents of children with cancer, however, there is less research focussed on parents whose children are in the maintenance phase of Acute Lymphoblastic Leukaemia (ALL) treatment. This treatment phase usually occurs in the first or second year following diagnosis but can start much earlier. The maintenance phase still involves active treatment but with less visits to and stays in hospital. At this stage, parents have been through the most intense segment of the treatment regimen and may have encountered various challenges and setbacks along the way. Parents who have experienced the ALL treatment protocol may therefore have valuable advice to provide to other parents regarding coping and useful supports.

This study aimed to explore the coping style and patterns of accessing support in mothers and fathers who have a child diagnosed with ALL and who are in the maintenance phase of treatment. The aim was also to explore whether there were differences between mothers and fathers with regards to coping and support.

Methods

Three mothers and two fathers were interviewed separately using a semi structured interview. These interviews were then transcribed and analysed using interpretative phenomenological analysis (IPA).

Results

Four main themes were identified through interviews with parents: the parental role; internal coping strategies; external coping strategies; and looking to the future.

Conclusions

Parents were found to use a variety of coping strategies and accessed various sources of support to help them to deal with their child's ALL diagnosis. These coping strategies could be shared with parents who are new to the haematology service. There were however, significant difficulties with recruitment which means it was not possible to compare mothers and fathers in terms of coping style and types of support accessed. This highlights that the recruitment strategy needs revising if further research is to be conducted in this area.

Key words: parental, coping, support, child, acute lymphoblastic leukaemia.

INTRODUCTION

Childhood Leukaemia

Leukaemia is a cancer of the white blood cells and the two main types are Acute Lymphoblastic Leukaemia (ALL) and Acute Myeloid Leukaemia (AML). In children with leukaemia, the production of healthy blood stem cells is disrupted; abnormal cells are produced which do not go on to mature, resulting in a bone marrow which is filled with immature cells. Due to overcrowding, the bone marrow then has difficulty in producing healthy stem cells (MacMillan Cancer Support, 2011). Leukaemia is the most common form of cancer found in children and accounts for around 30% of all cancer cases. ALL is more common than AML and accounts for 78% of leukaemia diagnoses (Cancer Research UK, 2014). The treatment protocol for ALL involves 6-8 months of intensive treatment which can include: steroids, radiotherapy and chemotherapy. The maintenance phase of treatment involves chemotherapy for up to two years, administered on an outpatient basis. Boys are at a higher risk of relapse than girls, therefore the treatment regimen can last longer for males (Leukaemia and Lymphoma Research, 2015). There have been significant improvements in the success rate of leukaemia care in the last few decades and currently, 76% of children survive the disease for ten years or more (Cancer Research UK, 2014). This encouraging statistic can be attributed to a variety of new medical protocols (Pui et al., 2004., Pui et al., 2009) and a longer maintenance phase of treatment (Pulte, Gondos, & Brenner, 2009).

The challenges of ALL

A leukaemia diagnosis can understandably be a challenging time for families. Parents often have to deal with their child's reaction to their illness whilst also trying to manage and contain their own reactions, as well as the reactions of those around them. They may also have to juggle the care of the sick child with the responsibilities of work and parenting other children in the family (Svavarsdottir, 2005). These challenges have the potential to cause parents significant stress (Norberg, Lindbald, & Boman, 2004).

Conceptualising Coping

When presented with these considerable challenges, parents may draw upon existing coping strategies or seek to develop new ones. Coping is defined as "people's efforts to meet the challenges presented by stressful life situations" (Chesler & Barbarin, 1987, p91) and can be conceptualised as an action taken in an attempt to decrease the stress being experienced (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001).

Appraisal influences coping

Coping response is influenced by the appraisal of the situation (Alkan, 2004). Appraisal relates to how an individual interprets a situation and what meaning they take from it. This involves cognitive processes such as judgement and evaluation (Cambridge Dictionaries Online, 2015). An individual's thoughts around a stressful situation are ever changing due to constant appraisals and reappraisals of the event (Folkman & Lazarus, 1988).

In primary appraisal, an individual considers an event in terms of its impact; how it will affect them and their day to day lives. There follows a process of secondary appraisal which involves thoughts and feelings around how the event will be managed or dealt with (Sincero, 2012).

In terms of primary appraisal, it is understandable that parents initially appraise the diagnosis of childhood leukaemia as fatal and see it as a threat (Patistea, 2004). Parents cope with this perceived threat by maintaining a positive attitude, relying on their faith and seeking out information from the medical team (Patistea, 2004). As an example of secondary appraisal, Sloper (2002) discovered that some mothers of children with cancer rated themselves low in self-efficacy and therefore appraised themselves as being incapable of managing their child's illness. This led to the experience of distress which influenced mothers' chosen coping style; they engaged in self-directed strategies in the form of negative self-talk, for example, "I lecture or criticise myself".

Gender differences in experiencing distress, stress and coping

Previous research has shown that there can be differences between mothers and fathers when coping with childhood chronic illness. Goldbeck (2001) demonstrated that mothers of children with cancer were more likely than fathers to access forms of social support. They were also more likely to educate themselves by learning about the diagnosis and were better able to maintain some sense of hope. Despite not reaching a high level of significance, a positive correlation was also found between dis-synchrony in coping and

parental ratings of distress; the more that parents acknowledged differences in the way they and their partner coped, the higher their ratings of distress.

Hoekstra-Weebers, Jaspers, Kamps, & Klip (1998) also reported that fathers utilised active-problem focussed coping more than mothers. This strategy involved trying to develop a different perspective on the problem as well as efforts to problem solve and “work things out” (p29). These differences in coping may be partly due to the socialization hypothesis which states that males and females learn to deal with and manage stress in different ways due to gender stereotypes (Ptacek, Smith, & Zanz, 2006).

It is important to consider that gender differences with regards to parental role may no longer be as apparent as they once were. An increase in dual earner families means that fathers are no longer the sole breadwinners and mothers often share the role of primary caregiver in modern families (Understanding Society, 2013). In terms of chronic childhood illness, this may mean that parents take on ‘non-traditional’ roles in terms of child care and other responsibilities. McGrath (2001) supports this hypothesis as it was found that fathers of children with leukaemia coped by being present in the hospital with their child. They also described crying and trying to access support (although this was perceived as a challenge). These strategies could be classified as emotion focussed, indicating that fathers are not merely focussed on active, problem solving behaviours as a way of coping as was found by Hoekstra-Weebers et al. (1998).

Justification of the current research

Despite evolving parental roles, differences in coping due to gender norms may still be apparent. Therefore, it is of interest to explore whether there are differences in the ways in which mothers and fathers cope with a diagnosis of childhood ALL. Interviewing both mothers and fathers also means that any results will hopefully be applicable to both genders. Lastly, leukaemia is the most common form of childhood cancer and it is hoped that this will help with recruitment as there will be a larger population base to draw from.

Practical implications

It is hoped that the study will give parents the opportunity to discuss the type of support they found useful as well as the coping strategies they adopted and whether these were helpful. The findings may then inform clinical practice within the Paediatric Clinical Psychology team at the Royal Hospital for Sick Children (RHSC). This may take the form of advice for and recommendations to new parents entering the haematology service.

Aim and objectives

This Major Research Project (MRP) is an exploratory study.

Aim: to explore the ways in which mothers and fathers have coped with their child's diagnosis of ALL and also the ways in which they have accessed support.

Objectives:

1. Explore how mothers and fathers perceive the way in which they have coped with their child's diagnosis.
2. Explore differences between mothers and fathers with regards to their coping strategies.
3. Explore differences in the type of support mothers and fathers access and the way in which this is accessed.

METHOD

Ethical Approval

Ethical approval was granted by Greater Glasgow and Clyde Research and Development Department (Appendix 6) and also Derby and East Midlands Ethical Committee (Appendix 7). Two minor amendments were submitted to both of these organisations for approval. The details of and approval for these amendments can be found in Appendices 8, 9, 10 and 11.

Design

Interpretative Phenomenological Analysis (IPA) was employed. This is a method which explores the “human lived experience” (Smith, Flowers, & Larkin, 2009, p32) and has been widely used in previous clinical health literature. Schweitzer, Griffiths, & Yates (2012) used IPA to explore the negative and positive parental experiences of childhood cancer.

Inclusion criteria

- Parents must be married or co habiting with a partner who is also involved with the care of the child.
- Must be fluent in English.
- Must be one of the primary caregivers for the child.
- Child must be under the age of 18.
- Child must have a diagnosis of ALL and currently be undergoing active treatment.
- This diagnosis must be their first diagnosis of ALL.

- Child should be in the maintenance phase of treatment (usually 2-3 years in to treatment but can occur earlier).
- **Exclusion criteria**
- Any other cancer diagnosis.
- A diagnosis with a terminal prognosis.
- Single parents.
- Those not fluent in English.

Sample

Participants were parents of children with ALL who were attending The RHSC, Glasgow for treatment. Around 60+ parents met criteria for the study. The inclusion and exclusion criteria were used to ensure that there was homogeneity within the sample. It was also employed to reduce distress for participants; parents who had lost a child or were caring for a child with a terminal diagnosis may be experiencing very different types of stress compared with parents whose children have a good prognosis. It was hoped that 3-4 mothers and 3-4 fathers would agree to participate in the study.

Semi structured interview design

The design of the interview schedule involved searching for previous related publications and noting the questions that were used (if provided) and the themes that had emerged. Professionals in Paediatric Clinical Psychology were also consulted and they were able to identify areas of clinical interest and need. The interview schedule can be found in Appendix 12.

Recruitment

The researcher placed participant information packs in the leukaemia clinic each week. Two posters also advertised the study (Appendices 13 and 14). Parents were free to take a pack which contained a participant information sheet (Appendix 15), a participation slip (Appendix 16) and a freepost envelope to return the participation slip to the researcher. Parents could also return the participation slip in a sealed box back at the leukaemia clinic if they preferred.

Paediatric Oncology Outlook Nurses (POONs) also informed parents who met the inclusion criteria about the study and asked them if they would like to take a participant information pack. Parents were assured by the POONs that they were under no obligation to take part.

The recruitment period ran from October 2014 to June 2015.

Procedure

The researcher telephoned parents who had returned a participation slip or had asked the POONS to pass on their contact details. An interview appointment was scheduled at a convenient time. Interviews took place in clinic rooms within the Paediatric Clinical Psychology Department at the RHSC.

Before the interview began, participants were asked to once again read the participant information sheet and were asked if they had any questions.

Participants then signed a consent form (Appendix 17) and filled in a demographics form (Appendix 18).

Participants were assured that they did not have to discuss anything that they did not wish to and were reminded that they could access the Clinical Psychologist linked to the study at any point. This was especially important given that the interview may raise upsetting memories or issues that may cause distress. They were also informed about the limits of confidentiality. Excerpts from two separate interviews can be found in Appendix 19.

All interviews were recorded using a DVR and lasted between 46.34 and 67.46 minutes (average length was 60 minutes). At the end of the interview, participants were invited to give their views on how they had found the process and were asked whether they would like to receive a summary of the results. The researcher also checked with parents regarding how they were feeling given the emotional content of the interview.

Data Analysis

Before Interpretative Phenomenological Analysis (IPA) commenced, Smith's (2011) article describing evaluation criteria for studies employing IPA was read. An article classified as "good" was also read. The analysis was conducted in accordance with Smith, Flowers, and Larkin (2009) and informed by Smith (2011).

Smith (2011) recommends that the researcher should explain how the prevalence of themes was determined. In the current study, an emergent theme was included in the results if it appeared within three or more transcripts (60% of transcripts). This is consistent with recommendations by Smith et al. (2009, Section A5, p107).

All participants were asked if they had advice for parents who were new to the haematology service. Only two parents made comments within each emergent theme, therefore the superordinate theme 'coping advice to other parents' was not included in the results. Details of this theme can be found in Appendix 20. Several other themes were identified which reflected the experience of parents, however, they did not directly relate to the aims and objectives of the study. In accordance with Smith (2011), these 'superficial themes' were not included in the analysis but can also be found in Appendix 20.

Extracts from interviews are used to more accurately describe each theme. Smith (2011) recommends that for a sample size of 4-8, an extract from three participants should be included for each theme. The researcher has included extracts from at least three different participants for each superordinate theme.

All extracts are presented in italics and any comments by the researcher are presented in bold. Information removed to protect anonymity such as place names and additional information such as pauses in speech are presented in brackets. Parts of the sentence which have been removed to reduce length are presented with ellipses. Research participants were also provided with a pseudonym. Furthermore, Smith (2011) recommends that each theme should be presented with a short summary, extracts and an interpretation. The researcher has adhered to this in the results.

All interview recordings were listened to fully before any transcription took place. During transcription, the data were anonymised for references to people and places. The recording was then listened to once again and the transcription was checked for accuracy and completeness. The original voice recording was then deleted. Analysis began with several readings of the transcription to gain a familiarity with the data. Comments and ideas were then indicated next to lines in the transcription and these comments were sorted into preliminary themes and sub themes using a table. Divergence within the themes was noted and included in the analysis. Themes were subject to further exploration and editing and at the end of analysis, all five transcripts were read once again with the themes in mind in order to check for accuracy and plausibility.

Elliott, Fischer, & Rennie (1999) suggest that there should be agreement between researchers to ensure validity in qualitative research. Therefore, as a further check on theme plausibility, a fellow Trainee Clinical Psychologist who was familiar with IPA, read and conducted a blind analysis of two transcripts. The themes identified by this individual were compared with the researcher's identified themes. Due to the interpretative nature of IPA, it is understandable that there was variation in the exact wording of themes, however, there was a commonality within theme identification.

Researcher Reflexivity

Throughout the interview and analysis process, the researcher kept a reflective diary containing her own perceptions of the data including beliefs and values.

RESULTS

Participants

The final number of five participants (three mothers and two fathers) is in accordance with recommendations for Doctoral research studies employing IPA (Smith, Flowers, & Larkin, 2009, p51). Braun and Clarke (2013) also state that for IPA, a small to moderate sample size is efficient. A third father had agreed to participate in a telephone interview but could not be reached at the time arranged. Further attempts to contact him produced no response. The final number of participants was therefore less than the recruitment target of 3-4 mothers and 3-4 fathers. This recruitment target had been set in the hope of enabling a comparison of coping strategies and patterns of accessing support *between* mothers and fathers. As this was not achieved, a comparison is not possible.

Demographic Information

All individuals who participated in the study were the biological parent of the child being discussed. Four parents were married and one described themselves as co-habiting. The children being discussed were made up of three girls and two boys.

Further demographic information on the parents taking part and the children being discussed can be found in tables 4 and 5.

Table 4. Demographic Information for Parents

	Mean	Range
Parental age in years	40.2	36-45
Length of relationship with partner in years	14.5	4-25
	Median	Range
Number of other children in the family	1	1-4

Table 5. Demographic Information for children

	Mean	Range
Child age in years	7.2	3-16
Months in to treatment	17.3	7-26

Superordinate and emergent themes

Four superordinate themes were identified during transcription analysis: the parental role; internal coping strategies; external coping strategies; and looking to the future. Within each superordinate theme, recurrent emergent themes were also identified (table 6).

Table 6. Superordinate and emergent themes relating to parents' coping and types of support accessed.

Superordinate themes	Emergent themes
The parental role	Being present in the hospital Being emotionally supportive
Internal coping strategies	Be strong Engage in denial Live in the moment Utilise personal strengths
External coping strategies	Speak to other parents Seek support from partner, family and the wider social network Access formal sources of support Take action Take restorative time
Looking to the future	The belief that life will never be normal again

Description of themes

The parental role

Parents explored the various roles and responsibilities that they had throughout their child's treatment.

Being present in the hospital

All five parents described their role and it was evident that parents took on quite a distinct role; one stayed with the child in hospital and one upheld life at home (four mothers and one father stayed in the hospital). The decision to stay in the hospital was understandably difficult for parents.

“One day you're a family (becomes upset) and the next day you're not. Sorry (line 75-76)...you know you've got a child that's not well but then all of a sudden you're here with your child and your other kids are at home”.

(Ann, line 95-97).

Treatment for ALL starts almost immediately after diagnosis, leaving parents with no time to prepare for the separation they will experience. For Ann, the separation challenges her idea of what it means to be a family; being together. She also appears to experience regret, and possibly guilt, about being away from her other children and considers the benefits in taking on a dual role.

“Looking back, I would say to parents probably to take a night each because, your other kids need you as well”.

(Ann, line 117-118).

For the one father who stayed at the hospital, this decision seemed to be due to his cultural and societal beliefs about male and female roles.

“If I’m in the house I can’t do those things. I can’t do those house chores obviously and the house things, I don’t want to sound stereotypical but the things in the house the woman takes care of”.

(Tom, line 426-428).

Being emotionally supportive

Four parents spoke about the mutual support between themselves and their partner. All three mothers witnessed visible distress in their partners and this was not something they were used to seeing.

“Whereas he (husband) broke down. Completely different. And I comforted him. So I don’t know if the woman should do that but that’s the way it was”.

(Kate, line 160-161).

Kate alludes to the fact that the role of comforter was new to her and describes stereotypical beliefs about stress responses; men should be strong and women should be comforted.

The one remaining father presented a contradiction within this theme as he described a lack of communication between him and his partner;

“You know something, we haven’t really talked, it’s (pause) we haven’t really talked to tell you the truth. About how we’ve felt”.

(Frank, line 250-251).

Frank pauses which signifies that the lack of communication with his partner was perhaps not noticeable at the time and it is only now, when he is asked to reflect on the experience, that he becomes aware that it was absent.

Internal coping strategies

Internal strategies draw upon a parent’s individual approach to dealing with the stress of their child’s ALL diagnosis and includes personal beliefs and strengths as well as unique perspectives.

Be Strong

At some point in their transcript, all five parents either alluded to or explicitly referred to ‘being strong’ as way of coping.

“I think it’s almost like a focus, to be able to focus and not fall apart and break down (line 288-289)... I don’t like my children to see me not coping (line 297)...it’s like putting a face on”.

(Kate, line 295-297).

“You could say a strong person is being there with the family and going through the pain and the suffering with them, my interpretation is not. It’s being there, looking after them, but in his own time, away from the family, dealing with it and

coming to terms with it (line 579-582)... Man is strong. Women are emotional and weak so I need to hold them all together, keep them safe”.

(Tom, line 586-587).

Kate refers to “putting a face on” which indicates that ‘being strong’ is a pretence; it is a role that is being played. This protects others from further distress and may also protect herself. Tom appears to think that the opposite of being strong is “being emotional” which he perceives as a sign of weakness. Being emotional would also mean that he cannot fulfil his paternal role-to look after other members of the family. There is also a solitary aspect to Tom’s coping as he describes coming to terms with the experience on his own, “away from the family”.

Engage in denial

Parents described denial as a coping strategy. This was more apparent in fathers.

“He (husband) wants to bury his head in the sand about a lot of things”.

(Jane, line 723).

“Yes for (name of partner). I don’t know if you want to say more bury head in the sand and not deal with it”.

(Kate, line 174-175).

Both mothers use the phrase “bury his head in the sand” which visually implies that there is an absence of the use of all senses; fathers can be avoidant of the reality they are facing.

The two fathers also described the used of denial.

“It wouldn’t sink in and I wouldn’t allow it to sink in cause I was like, if I accept it that means it’s real and I was like, no that can’t be”.

(Tom, line 97-99).

Live in the moment

Three parents explained that looking too far ahead was not helpful to them. It was evident that this involved rumination regarding the future in terms of outcome.

“What if it’s (ALL) come back and we don’t know it’s come back? (line 1113-1134)...but again it’s a case of we’ll cross that bridge when we get to it (line 1138-1139)...and it’s like, well things are fine at the moment so this is how, this is how we manage at the moment”.

(Jane, line 1144-1145).

A focus on the future increases anxiety as it is a time full of uncertainty. In response to this, Jane tries to focus on the here and now; only the few steps ahead are considered which may be protective and reduce anxiety and fear even in a very small way.

Looking to the future also involves making plans and forming expectations and this can leave parents vulnerable to disappointment.

“It’s not like you can say a month down the line ‘let’s go away’. You can’t do that because there’s no guarantees your child is going to be ok or everything’s going to go to plan so there’s no point in doing that anyway”.

(Kate, line 515-518).

Utilise personal strengths

The three mothers were able to reflect on their own unique, personal strengths that had helped them to cope.

“My positive attitude, definitely my positive way of looking at it. And I’m quite an organised person. That’s definitely helped, definitely those are my main strengths that have helped”.

(Jane, line 1024-1025).

The two fathers were less able to do this.

“I don’t know how to explain that. I don’t really think I’ve got any strengths that could really differ me from another father”.

(Tom, line 554-555).

External coping strategies

It was clear that parents looked externally, out with themselves, for ways of coping.

Speak to other parents

Three parents (two mothers and one father) spoke highly of the advice and support that they had received from those who were experiencing similar challenges. Two parents, however, did not wish to speak to other families in the unit.

“Here’s one for you, another one of my coping things was I didn’t interact with any other parents (line 467)... I didn’t really want to know about anybody else’s problem (line 475)... cause I’d heard a few and it seemed so negative”.
(Frank, line 481-482).

Frank avoids contact with other parents as he does not want to hear negative or traumatic stories. Sharing experiences could automatically trigger a comparison with his daughter, leading to anxiety and worry about whether the same could happen to her.

Seek support from partner, family and the wider social network

All five parents mentioned some form of positive social support that they had received from a wide range of sources.

The two fathers were aware that there was a lack of social support from some people who were close to them and they acknowledged that this was upsetting and disappointing.

“Regarding friends and family. Tried that and it failed. That got thrown back in our faces” (line 634-635).

How did you feel when that happened?

“Really really painful, really hurtful, you know?”

(Tom, line 643-644).

Social support can be hugely positive and can give parents strength, easing their burden even slightly, however when it is clear that support is missing, it can add to their grief and sadness.

Access formal sources of support

Parents in the study accessed various services within the hospital including CLIC Sargent Social Work, Clinical Psychology and the POONs as well as services out with the hospital such as stress management courses.

“Our CLIC Sargent worker, (name), has just been fabulous and anything I’m not sure of, even if it’s not in her remit, well I’ll just ask (name of worker) and she’ll be able to find out who I need to speak to you know. It’s been fabulous”.

(Kate, line 369-371).

Two parents were less inclined to access this type of support.

“I got a note from the job centre saying here’s a carers eh, eh forum thing, where you can meet people but that just went in the bin (laughs)”.

(Frank, line 514-515).

“I have been offered it through the hospital, social work and all the rest of it (line 626-627)...maybe it’s just the way I think, that it’s not going to be beneficial so I’ve never really taken them up on that”.

(Tom, line 631-632).

Tom and Frank seem to have pre-existing beliefs about certain types of support; that it will not be helpful and they are not the type of people who *need* it. Frank refers to the forum as a “thing” and laughs at the thought of it going in the bin which highlights his disinterest and the fact that accessing such a support is almost comical to him.

Take action

There is a general expectation on the ward that parents should take on an active role in their child's care and this seemed to contribute to their ability to cope.

"I was reading up on it (the diagnosis) (line 236)...and preparing myself and asking the nurse lots of questions, 'right what's this medicine for' (line 240-241)... I thought 'well I'm going to need to know this, the more knowledge I have the better'".

(Jane, line 242).

"She (child) gets an NG tube put in and I think, right we're going to have to go home at some point, you'll have to show me how do I do it now and just get on with it (line 105-106)... I need to focus on what we're doing and that's my coping mechanism".

(Kate, line 109).

Jane describes a need to equip herself with skill and information. This seems to help her feel more powerful in what is largely a powerless situation. It seems that having an active role is a focus and form of distraction for Kate.

Take restorative time

Parents identified the benefits, for both the child and themselves, in having time away from the hospital.

“I think that was probably helpful for (name of child) to see your Mum do normal things (line 565-566)...this is our life. We can go on. It’s not all doom and gloom”.

(Ann, line 274-275).

‘Time out’ and engagement with what is normal, valued and routine provides children with the message that life can and will go on. Despite the recognition that restorative time was important, it was understandably difficult to carry out.

“I was probably here for 3 weeks before I left the ward. Cause I felt like (gasp) ‘I can’t leave!’. Do you know that way?”.

(Ann, line 551-553).

The thought of leaving the hospital and her child is clearly anxiety provoking for Ann. This anxiety may be influenced by her appraisals concerning the role she has to play in the care of her child and what will happen if she leaves.

The desire to stay may therefore be protective; if she leaves and something goes wrong this may trigger guilt or a misplaced sense of responsibility.

Looking to the future

Parents were clearly at the stage where they were thinking more about what life would be like for their child in the future.

The belief that life will never be normal again

Three parents expressed a belief that life would never be normal again. This belief seemed to be influenced by the presence of intense anxiety and fear which was not there before.

“You can’t see a time where you’re ever going to be normal or you can’t see a time where you’re not going to be worrying about him getting an infection or anything”.

(Jane, line 520-522).

“I don’t think you can ever go back to normal after this. I don’t think anyone can do that, go back to normal, go back to what it was before. I think there will always be a worry there”.

(Kate, line 460-461).

It is clear and understandable that parents want to move forward and away from the illness, however, there is a threat to this in the form of relapse or infection.

Kate’s repetition of the phrase “go back” perhaps highlights this fear.

Parents also contemplated what could be helpful in dealing with this anxiety.

“It would have been helpful if someone had come in to the ward, who was quite positive, who had got through that first stage (line 597-598)...and shared how they’d got back to being normal cause you don’t ever think you can be normal again”.

(Ann, line 602-603).

Ann is able to identify that some contact with other parents would be reassuring.

DISCUSSION

This study aimed to explore the coping strategies and patterns in accessing support in mothers and fathers who have a child diagnosed with ALL. Through the use of IPA, the results found that four distinct themes emerged: the parental role; internal coping strategies; external coping strategies; and looking to the future. The aim was also to explore whether there were differences between mothers and fathers with regards to these concepts. Unfortunately, the target recruitment number of 3-4 mothers and 3-4 fathers was not met, therefore a comparison is not possible.

The current study found there were differences in how the mothers and fathers who participated coped, but there were also similarities between them. The internal coping strategy 'be strong' was used by both mothers and fathers. The features of being strong seemed to relate to refraining from outward displays of emotion, remaining focussed on the task at hand (see Kate's quote within 'be strong' p75) and processing the situation on their own, without assistance from others (see Tom's quote within 'be strong' p76). This last feature may be associated with the reluctance of the two fathers in the study to access formal sources of support. Being strong appeared to be a surface coping strategy for some parents; they did not *feel* strong or *believe* that they were strong but they took on the role of playing the strong person (see Kate's quote within 'be strong' p75). Previous research exploring the ability of mothers to cope with their child's cancer diagnosis echoes this finding. Fletcher & Clarke (2008) found that there was a difference in how mothers felt about the diagnosis and what they

projected to others; on the outside they were strong, but inside they “were a mess” (p95).

One of the differences between the parents who took part is concerned with the theme ‘engage in denial’. All five parents described that this was more apparent in the fathers within the study. Previous research has shown that the male use of denial has a function-it allows them to suppress their emotion and be there for their partners (Hill, Higgins, Dempster, & MCarthy, 2009., McGrath & Phillips, 2008).

Links with previous findings

The themes uncovered in this study are consistent with previous literature.

Miedema, Hamilton, Fortin, Easley, and Matthews (2010) discussed that parents used a combination of appraisal, emotion and problem focussed coping when dealing with their child’s cancer diagnosis. This finding mirrors the results of the current study which found that parents draw upon a variety of coping strategies. As example, one father described engaging in denial (appraisal focussed) as well as receiving comfort and support from his wife (emotion focussed). One mother spoke about her need for information and the desire to play an active role in her son’s care (problem focussed) and trying to develop and maintain a positive attitude (appraisal focussed).

The current study also found that an absence of social support from those in the social network was a painful experience. Patterson et al. (2004) carried out 7 focus groups with 45 parents of children with cancer. One of the identified themes concerned 'family strains' which related to, amongst other things, an absence of support from relatives. The fact that Patterson et al. (2004) describe this as a 'strain' supports the idea that missing support can be an upsetting experience for parents.

Limitations

Due to the numbers recruited to the study, a comparison between mothers and fathers in terms of coping and support could not be made. It is therefore important to consider the factors that contributed to this difficulty in recruitment. As has been shown in previous literature, having a child diagnosed with cancer raises many challenges (McGrath, 2001., Clarke, Davies, Jenney, Glaser, & Eiser, 2005). Parents within the current study described their own unique challenges, which included: displays of challenging behaviour in their child; the diagnosis of Miller Fisher Syndrome (a rare, acquired nerve disease which is a variant of Guillain-Barré syndrome) and difficulty obtaining time away from work. Parents of children with ALL are clearly a population who are under a significant amount of pressure from a variety of sources. Despite being in the maintenance phase of treatment, it is clear that challenges and pressures remain. Therefore, taking time out to participate in an interview may seem unnecessary and unachievable. There is anecdotal evidence that supports this hypothesis - the POONs reported that several parents, who had been approached to participate, declined as they felt they had too many other responsibilities.

In addition to the challenges that an ALL diagnosis brings, previous research has shown that the diagnosis itself can be traumatic for both the child and the parent and indeed may trigger a post traumatic stress reaction. Stuber, Christakis, Houskamp, & Kazak (1996) found that 79% of mothers re-experienced disturbing images related to their child's illness and 87% of fathers experienced intrusive thoughts. DSM V states that in a PTSD presentation, individuals commonly engage in avoidance behaviours and thought suppression in an attempt to cope with, or mediate their distress when faced with triggers (National Center for PTSD). It is understandable therefore, that a research interview may represent a potentially painful confrontation of triggers associated with trauma and distress, and hence may be avoided.

So it may be that high levels of pressure, numerous responsibilities, the vulnerability to experiencing trauma and utilising denial and avoidance as a coping strategy have all contributed to the low participation rate within the study.

Future Research: how to challenge the barriers to recruitment

It would be of interest to continue to explore the experiences of this population, however, due to the different sources of stress these parents encounter, they may remain a difficult group to recruit. Potential improvements to recruitment should be considered.

Uncertainty concerning participation may have been related to the location of interviews in the current study. This obstacle may have been overcome by providing a map specifying the exact location of the Clinical Psychology

Department within the RHSC. A study by Leventhal, Singer and Jones (1965) provided two groups of students with information on the importance of tetanus inoculation. One group was given a booklet alone and the other was also given a map with directions to the student health centre. The group who were provided with the map were more likely to attend for vaccination. This indicates that this strategy could be beneficial.

There may also have been a reluctance to participate in the current study due to the fact that it required yet another visit to the hospital (parents already regularly attended the leukaemia clinic for appointments with the Haematologist). This may be difficult for parents who worked full time or for those who would have to find alternative child care. Interviewing participants on the telephone may be one way of overcoming this obstacle to participation in future studies.

Telephone interviews can be beneficial when the interview content may prove to be distressing or sensitive for the participant (Novick, 2008).

Implications

Three parents in the study highly valued contact with and advice from other parents who were in a similar situation. It is interesting to note, that even one mother who described purposefully avoiding discussions with other parents acknowledged that she would have liked some formal advice from them, as well as some anecdotes concerning success stories. Therefore, it may be useful if the anecdotal information regarding coping strategies and forms of support was collated and provided to new families entering the Paediatric Haematology Unit. This may especially benefit parents who are reluctant to engage in informal contact with others. Furthermore, the findings from the current study could help

to normalise parental responses to an ALL diagnosis; it is ok for parents to feel overwhelmed and vulnerable and to be concerned that life will not return to normal.

CONCLUSION

This study provides insight in to the coping strategies of parents who have a child diagnosed with ALL. Interviewing parents in the maintenance phase allowed them to reflect on their coping strategies; what and who had helped them to get to this point. It is clear that parents utilised a variety of coping strategies, using what could be described as both internal and external approaches to coping; living in the moment and being 'strong' as well as speaking to other parents and taking some restorative 'time out' from the hospital environment.

The recruitment process was difficult and did not result in the target number of 6-8 participants. This could be due to the fact that parents of children with ALL are a population group who are vulnerable to experiencing various challenges and setbacks including separation from the family (McGrath, 2001), marital conflict (Adams-Greenly, 1986) and the experience of trauma symptoms (Stuber et al., 1996). Recommendations to improve participation in future research includes using telephone interviews which may fit better into parents' schedules and providing maps detailing the exact location of the interview.

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CHAPTER 3: ADVANCED CLINICAL PRACTICE I

Reflective Account: The challenges in being collaborative.

Abstract

This reflective account describes my experiences of working collaboratively with patients in formulation and therapeutic sessions. I recognised that for me, working collaboratively can raise some challenges, especially within a child and adolescent mental health (CAMHS) context where I can be concerned about patients' understanding and capability. I review experiences from my generic CAMHS placement in second year and also from my third year advanced clinical practice placement in Paediatric Clinical Psychology. The process of carrying out this reflective account allowed me to identify areas of development. I was also able to explore some of the reasons behind my caution. Gibbs' model of reflection (1988) guided this account and ensured that I was considering how to change my practice in the future and what impact this may have on future patients.

CHAPTER 4: ADVANCED CLINICAL PRACTICE II

Reflective Account: The experience of conducting research as a Trainee Clinical Psychologist.

Abstract

This reflective account describes my experience of conducting a Major Research Project (MRP) as part of my clinical doctorate training. In this research role I interviewed parents who had a child diagnosed with Acute Lymphoblastic Leukaemia (ALL) who were in the maintenance phase of treatment. In this account, I consider the challenges inherent in qualitative research including issues with recruitment, gate-keeping and attitudes towards my own research. I also spend time discussing the positives and negatives of working within a research field with personal significance and meaning to the researcher. I have used Kolb's experiential learning cycle (1984) to reflect on a significant challenge that arose for me when conducting my MRP and how this enabled me to change and develop my research practice. I note that this reflective process will be beneficial for me in a post qualification role that may require research skills at various points.

APPENDICES

Appendix 1

Guideline for submission to the British Journal of Health Psychology

Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding author's contact details. A template can be downloaded from [here](#).
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions.
- Statement of Contribution: All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each. The Statement of Contribution should be a separate file.

The main document must be anonymous. Please do not mention the authors' names or affiliations (including in the Method section) and always refer to any previous work in the third person.

- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript but they must be mentioned in the text.

- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full and provide doi numbers where possible for journal articles. For example:

Author, A., Author, B., & Author, C. (1995). *Title of book*. City, Country: Publisher.

Author, A. (2013). Title of journal article. *Name of journal*, 1, 1-16. doi: 10.1111/bjep.12031

- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.

- In normal circumstances, effect size should be incorporated.

- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright. For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association.
- Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.

Appendix 2

Search terms used in database searches

Database	Search terms (Boolean operators AND OR used)	Results	Articles read in full	Articles suitable for review
Ovid (Medline)	Caregivers OR Family, Fathers, Mothers Legal guardian, Parents Guardian*, Carer* AND Blood cancer* OR Hematologic neoplasms,	342	8	5

	Leukemia, Leukemia myeloid Leukemia lymphoid			
EMBASE	Caregiver OR Family, Father, Mother, Custody, Parent, Guardian*, Carer* AND Hematologic disease OR Leukemia, Lymphatic leukemia, Myeloid leukemia, Blood cancer AND Qualitative analysis	5	0	0

PsychInfo	<p>Caregiver OR</p> <p>Family, Father, Mother, Parent, Guardian, Carer</p> <p>AND</p> <p>Leukemia</p> <p>OR</p> <p>Lymphatic leukemia, Myeloid leukemia, Blood cancer, Hematologic neoplasm</p> <p>AND</p> <p>Qualitative method</p> <p>OR</p> <p>Qualitative analysis</p>	<p>6</p>	<p>0</p>	<p>0</p>
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Psych Articles	<p>Caregiver</p> <p>OR</p> <p>Family, Father, Mother, Parent, Guardian, Carer</p> <p>AND</p> <p>Leukaemia</p> <p>OR</p> <p>Blood cancer, Acute lymphoblastic leukaemia</p> <p>(acute myeloid leukaemia yielded no results)</p> <p>AND</p> <p>Qualitative</p>	<p>174</p>	<p>0</p>	<p>0</p>
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	<p>OR</p> <p>Qualitative method, Qualitative analysis</p> <p>* Applied limitation within method section: qualitative</p>			
CINAHL	<p>Caregiver</p> <p>OR</p> <p>Family, Father, Mother, Parent, Carer, Guardian</p> <p>AND</p> <p>Leukemia</p> <p>OR</p> <p>Lymphatic leukemia, Myeloid</p>	6	2	1

	leukemia, Blood cancer, Hematologic neoplasms AND Qualitative method OR Qualitative analysis			
European Pub Med	Parents experience Leukaemia Qualitative	4	0	0

Google scholar	In the title:			
	Parents leukaemia	23	0	0
	Fathers leukaemia	2	0	2 (did not read as both were already found in database search)
	Mothers leukaemia	5	0	1 (did not read as it was already found in database search)

	Fathers lymphoma	3	1	1 (new article not identified in database search)
	Mothers lymphoma	0	0	0
	Fathers hematology	1	1	1 (new article not identified in database search)
	Mothers hematology	1	0	0

European Journal of Oncology Nursing (key term search)	Parent experience Leukaemia	98	0	0
European Journal of Oncology Nursing (hand search)		406	0	0
Journal of Hematology/ Oncology (key term search)	Parent Experience Leukaemia Qualitative	17	0	0
Journal of Hematology/Oncology (hand search)		410	0	0

Appendix 3

Adapted Quality Rating Strategy (based on Walsh and Downe, 2006)

There are 12 essential criteria in Walsh and Downe's checklist. The researcher's adaptation involved breaking these 12 essential criteria down further using some of the specific prompts in the checklist guideline which resulted in 29 criteria. Each of these criteria points was awarded a 1 or 0 indicating whether it was present or not present within the article. The researcher also added further descriptions to several of the criteria to aid her own understanding when reading the articles. These adaptations made it clearer to the researcher whether an article included the essential criteria or not. The additions of the researchers own words are in bold.

Stage	Essential Criteria	Specific prompts included in the guideline modified by the researcher	Present or absent
Scope and Purpose	Clear statement of and rationale for research question/aims/purpose Study thoroughly contextualised by existing literature	1 A statement of focus for research which is clear 2 Rationale for research provided (why is it taking place, what will it add) 3 Questions/aims/purpose 4 Study thoroughly contextualised by existing literature (evidence of an adequate introduction and review of literature)	0/1 0/1 0/1 0/1
Design	Method/design apparent and consistent with research intent	5 Method/design apparent 6 Method consistent with research aim 7 Rationale is given for the method and/or design	0/1 0/1 0/1

	Data collection strategy apparent and appropriate	8 Data collection strategy apparent (interview) 9 Data collection strategy appropriate	0/1 0/1
Sampling Strategy	Sample and sampling method appropriate	10 Sample and sampling method explained 11 Was use of the above justified 12 Was use of the above appropriate	0/1 0/1 0/1
Analysis	Analytic approach explained	13 Analytic approach explained 14 Was the approach appropriate (given the aims of study) 15 More than one researcher involved if appropriate (plausibility checks for example) 16 Participant involvement in analysis (were they asked for feedback, did they read their transcripts) 17 Evidence of data saturation/discussion or rationale	0/1 0/1 0/1 0/1

		not (did they justify why recruitment ceased)	0/1
Interpretation -	Context described and taken account of in interpretation	18 Context described	0/1
		19 Context taken account of in interpretation	0/1
	Clear audit trail given	20 Clear audit trail (sufficient so others can follow decision making process)	0/1
	Data used to support interpretation	21 Data used to support interpretation (quotes provided)	0/1
Reflexivity	Researcher reflexivity demonstrated	22 Researcher reflexivity demonstrated (was there mention of how they considered their own beliefs, attitudes and so on)	0/1
Ethical Dimensions	Demonstration of sensitivity to ethical concerns	23 Ethical approval granted (where from)	0/1
		24 Documentation of how consent was managed (who	0/1

		<p>took consent, what was their qualification, and involvement in study, did they know the participant clinically)</p> <p>25 Documentation of how confidentiality and anonymity were managed (is clear and specific reference made to this)</p>	0/1
Relevance and Transferability	Relevance and transferability evident	<p>26 Relevance and transferability evidence (practical implications and possible impact)</p> <p>27 Linked to theories and previous literature</p> <p>28 Limitations/weaknesses outlined</p> <p>29 Outlines further directions for research (given what was found, what direction could this now go in and how could this be achieved)</p>	<p>0/1</p> <p>0/1</p> <p>0/1</p> <p>0/1</p>

			Total
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Appendix 4

Descriptive Rating Strategy

Rating	Number of items	Percentage of items
Good	22+	75
Acceptable	15-21	50-75
Poor	<15	<50%

Each article included in the review was evaluated against Walsh and Downe's quality checklist which contains 12 essential criteria (made up of 29 items). Each article was assigned either 0 points or 1 point for each of the 29 items, indicating that the item was either clearly present in the article or not. The maximum score an article could therefore receive was 29.

Appendix 5

Noblit and Hare's seven step approach to meta-ethnography.

1. Getting started
2. Deciding what is relevant to the initial interest.
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising translations
7. Expressing the synthesis

Appendix 6

Ethical Approval from Greater Glasgow and Clyde Research and Development
Department



Administrator: Mrs Elaine O'Neill
R&D Management Office Western Infirmary
Telephone Number: 0141 211 1743
E-Mail: Elaine.o'neill2@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d
1st Floor 38 Church Street
Glasgow
G11 6NT

NHS GGC Board Approval

Study Title: A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): using interpretative phenomenological analysis.

Principal Investigator: Miss Claire Lammie

G&C HB Site: Royal Hospital for Sick Children

Sponsor: NHS Greater Glasgow and Clyde

R&D reference: GN14CP522

REC reference: 14/EM/1238

Protocol no: v14; 15/10/14

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
 - a. Recruitment Numbers on a monthly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database. I wish you every success with this research study

Yours sincerely,



Mrs Elaine O'Neill
Senior Research Administrator

Appendix 7

Ethical Approval from Derby and East Midlands Ethics Committee



Health Research Authority

NRES Committee East Midlands – Derby

The Old Chapel Royal Standard Place

Nottingham

NG1 6FS

Telephone: 01158839390

12 November 2014

Dr Sarah Wilson

Senior Lecturer in Health Psychology

University of Glasgow

Academic Unit of Mental Health and Wellbeing, University of Glasgow

Garnavel Royal Hospital, 1055 Great Western Road

Glasgow

G12 0XH

Dear Dr Wilson

Study title: **A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative Phenomenological Analysis(IPA).**

REC reference: **14/EM/1238**

IRAS project ID: **151602**

Thank you for your letter of 11th November 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Assistant Tad Jones, NRESCommittee.EastMidlands-Derby@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research

Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants	v2	15 October 2014
[Advertisement poster]		
Interview schedules or topic guides for participants [interview schedule]	v2	01 April 2014
IRAS Checklist XML [Checklist_31102014]		31 October 2014
IRAS Checklist XML [Checklist_31102014]		31 October 2014
IRAS Checklist XML [Checklist_11112014]		11 November 2014
Other [plain English Summary]	v1	01 April 2014
Other [poster for returned participation slip]	v2	15 October 2014
Other [poster with tear off slips]	v2	15 October 2014
Other [participation slip]	v4	11 November 2014
Participant consent form [Participant Consent Form]	v5	11 November 2014

Participant information sheet (PIS) [Participant Information Sheet]	v5	11 November 2014
REC Application Form [REC_Form_31102014]		31 October 2014
REC Application Form [REC_Form_31102014]		31 October 2014
Research protocol or project proposal [MRP proposal]	v14	15 October 2014
Summary CV for Chief Investigator (CI) [Chief Inv CV]		
Summary CV for student [CV C Lammie]	v1	15 October 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

With the Committee's best wishes for the success of this project. Yours sincerely

A handwritten signature in black ink, appearing to read "P. Jones". The signature is written in a cursive style with a small "P." at the beginning.

Mr Peter Korczak
Chair

Email: NRESCCommittee.EastMidlands-Derby@nhs.net

Enclosures: *"After ethical review –*

Appendix 8

Minor amendment 1 November 2014

Ethical approval from Greater Glasgow and Clyde Research and Development
Department (Email approval)

Dear Claire and Dr Wilson,

Study Title:	A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an interpretative phenomenological analysis (IPA)
EudraCT:	N/A
Sponsor:	NHS GG&C
Sponsor R&D ref:	GN14CP522
Chief Investigator:	Dr Sarah Wilson
Amendment number	1 (addition of Demographics form v3 15/10/2014)

Thank you for submitting the above amendment to the NHS GG&C R&D office.

This amendment has been reviewed on behalf of the Sponsor. I can confirm that it is non-substantial and does not require to be submitted to the REC. However, I would recommend that the REC is notified of this amendment and that details regarding this amendment are included in the next substantial amendment to the REC. You should also notify R&D who will acknowledge this additional document.

Please note that, since this is a non-substantial amendment, there is no need to submit a Notice of Amendment form via IRAS. This is reserved for notification of substantial amendments only. I have, therefore, rejected your request.

Please contact me should you have any queries.

Kind regards,

Emma-Jane

Emma-Jane Gault

Research Governance Officer

University of Glasgow, on behalf of NHS GG&C Sponsor.

Appendix 9

Minor Amendment 1

Ethical approval from Derby and East Midlands Ethics Committee



Health Research Authority

NRES Committee East Midlands - Derby

The Old Chapel Royal Standard Place

Nottingham

NG1 6FS

Tel: 0115 883 9525

19 November 2014

Dr Sarah Wilson

Senior Lecturer in Health Psychology

University of Glasgow

Academic Unit of Mental Health and Wellbeing, University of Glasgow

Garnavel Royal Hospital, 1055 Great Western Road

Glasgow

G12 0XH

Dear Dr Wilson

Study title:	A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative
REC reference:	14/EM/1238
Amendment number:	Minor amendment 1 – Addition of Demographics form
Amendment date:	19 November 2014
IRAS project ID:	151602

Thank you for your letter of 19 November 2014, notifying the Committee of the above amendment.

The Committee does not consider this to be a “substantial amendment“ as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Minor Amendment [Letter from Claire Lammie]		19 November 2014
Other [Demographics Form]	3	15 October 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

14/EM/1238:

Please quote this number on all correspondence

Yours sincerely



Tracy Leavesley

REC Manager

E-mail: NRESCcommittee.EastMidlands-Derby@nhs.net

Copy to:

Ms Joanne McGarry, NHS GGC R

and D Ms Emma Jane Gault

Ms Claire Lammie

Appendix 10

Minor Amendment 2

Approval from Greater Glasgow and Clyde Research and Development

Department

Email approval

Dear Ms Lammie,

R&D Ref: GN14CP522 **Ethics Ref:** 14/EM/1238

Investigator: Ms Lammie

Project Title: A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an interpretative phenomenological analysis (IPA).

Protocol Number: v14 **Date:** 15/10/14

Amendment: Non-substantial Amendment 1, 2 & 3

Sponsor: NHS GG&C

I am pleased to inform you that R&D have reviewed the above study's Amendment 1, 2 & 3 and can confirm that Management Approval is still valid for this study.

I wish you every success with this research project.

NSA01 Nov 2014

Reviewed Documents:	Version	Dated
Demographic form	3.0	15/10/14
REC acknowledgement	---	19/11/14
Sponsor categorisation authorisation	---	23/01/15

NSA02 21.01.15

Reviewed Documents:	Version	Dated
REC acknowledgement	---	21/01/15

Advertisement poster	3.0	21/01/15
Poster with tear off slips	3.0	21/01/15

NSA03 22.01.15

Reviewed Documents:	Version	Dated
REC Acknowledgement	---	26/01/15

Kind Regards,

Research and Development Department

NHS Greater Glasgow and Clyde

Research and Development Central Office

Tennent Institute 1st Floor

Western Infirmary

38 Church Street

Glasgow, G11 6NT

Scotland, UK

Generic: RandD.PRTeam@ggc.scot.nhs.uk

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www.nhs.gov.uk/r&d

Appendix 11

Minor amendment 2

Approval from Derby and East Midlands Ethics Committee



Health Research Authority

NRES Committee East Midlands - Derby

The Old Chapel

Royal Standard Place

Nottingham

NG1 6FS

Tel: 01158839390

21 January 2015

Dr Sarah Wilson

Senior Lecturer in Health Psychology

University of Glasgow

Academic Unit of Mental Health and Wellbeing, University of Glasgow

Garnavel Royal Hospital, 1055 Great Western Road

Glasgow

G12 0XH

Dear Dr Wilson

Study title:	A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative Phenomenological Analysis(IPA).
REC reference:	14/EM/1238
Amendment number:	Minor amendment 21/01/15
Amendment date:	21 January 2015
IRAS project ID:	151602

Thank you for your letter of 21 January 2015, notifying the Committee of the above amendment.

The Committee does not consider this to be a “substantial amendment” as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

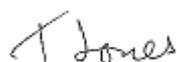
<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	2	15 October 2014
Copies of advertisement materials for research participants [Poster]	3	21 January 2015
Copies of advertisement materials for research participants [Poster with tear off slips]	2	15 January 2015
Copies of advertisement materials for research participants [Poster with tear off slips]	3	21 January 2015
Notice of Minor Amendment [Email from Clair Lammie]		21 January 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

14/EM/1238:	Please quote this number on all correspondence
--------------------	---

Yours sincerely



Tad Jones

REC Assistant

E-mail: NRESCcommittee.EastMidlands-Derby@nhs.net

Copy to: Ms Joanne McGarry, NHS GGC R and D

Appendix 12

Interview Schedule

Today I'm going to ask you some questions relating to your experience of having a child diagnosed with ALL, how you have coped with this diagnosis, what personal strengths have helped in this situation and if you have accessed any support throughout your child's treatment. Do you have any questions before we begin? If there are any questions you do not wish to answer just let me know. If you need a break at any time, we can do that.

The experience

First of all, could you tell me how you found about the diagnosis?

What that was like for you?

Concerns and coping

What concerns did you initially have about your child? Have these concerns changed throughout treatment?

How do you respond to or cope with these concerns?

Is the way that you cope different from the way your partner copes?

Have you noticed if the way you cope has changed over time (from diagnosis to now)?

Has your parenting style changed in any way over the course of the illness?

Skills and strengths

What skills and strengths do you have as an individual that has helped you cope?

What skills and strengths do you have as a family that have helped you cope?

Accessing support

Throughout your child's treatment have you personally accessed any support through hospital services?

Out with the hospital?

a) If parent HAS accessed support

What would you say to other parents about in a similar situation about this type of support?

What has been most/least helpful for you in terms of information, advice, and support?

b) if parent has not accessed support

What has made you decide not to access/or prevented you from accessing support?

Have any issues arisen that you think could have benefited from some support?

Parent's perspective on future and coping

Are there any challenges that you anticipate when your child finishes treatment?

How will you try to manage these challenges as a parent?

Are there sources of support which could be useful in these situations? Who would you turn to for advice and/or support, if required, post-treatment?

Advice to others

What advice would you give parents whose child has just been diagnosed with ALL?

What coping strategies/forms of support would you advise them to use?

Appendix 13

Advertisement Poster



Study title: A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative Phenomenological Analysis (IPA).

Do you have a child diagnosed with acute lymphoblastic leukaemia?

Are they currently in the maintenance phase of treatment?

Are you currently in a relationship and cohabiting with your partner?

If you answered yes to all 3, we invite you to take part in a research study looking at the experiences of parents who have a child with this diagnosis.

Participation involves

one interview

lasting around 60 minutes and **can be done over the phone.**

Please take an information pack which includes a participation slip.

Appendix 14

Advertisement poster with tear off slips



University
of Glasgow



NHS
Greater Glasgow
and Clyde

Study title: A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative Phenomenological Analysis (IPA).

Do you have a child diagnosed with acute lymphoblastic leukaemia?

Are they currently in the maintenance phase of treatment?

Are you currently in a relationship and cohabiting with your partner?

If you answered yes to all 3, we invite you to take part in a research study looking at the experiences of parents who have a child with this diagnosis.

Claire Lammie

c.lammie.1@research.gla.ac.uk

Appendix 15

Participant Information Sheet



University of Glasgow,
Department of Mental
Health and Wellbeing,
Gartnavel Royal Hospital,
Administration Building,
1055 Great Western
Road,
Glasgow,
G12 0XH
Tel: 0141 201 0644

Participant Information Sheet

Study title: A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative Phenomenological Analysis (IPA).

I would like to invite you to participate in a research study looking at the coping styles of parents who have a child diagnosed with acute lymphoblastic leukaemia (ALL). This information sheet will provide you with all of the information you require about the study to help you decide whether you would like to take part.

Why is this study taking place?

This study is a part of my Doctorate training in Clinical Psychology within the University of Glasgow. I am interested in hearing how parents have coped with

their child's diagnosis and if there are any differences in the ways in which mothers and fathers cope.

What will participation involve?

You will first be asked to sign a consent form which says that you are happy to take part in the study.

You will then take part in an interview with the researcher.

This interview will happen only once and will last for around 60 minutes although it can take longer if you wish. These interviews will be held in interview rooms within The Royal Hospital for Sick Children at a time which is convenient for you within the hours of 9am to 5pm. Wherever possible the researcher will try to coincide your interview with any hospital appointments you have, although this may not always be possible due to the availability of rooms. In situations where you are unable to come in to the hospital but would still like to take part, a telephone interview may be possible.

It is important to note that if you decide to take part:

- Your participation is voluntary.
- You can decide to withdraw at any time without having to give an explanation. This will not affect the treatment your child receives.
- You can decline to answer any question without an explanation.
- You can take a break from the interview at any time.
- During the interview, if you disclose that you or someone you know (including your child) is at risk of harm, the researcher will need to discuss this with

members of the Clinical Psychology team. This may then involve further action. This will always be discussed with you first.

- The research study cannot provide travel expenses.

What sort of questions will I be asked?

You will first be asked some general questions such as your age and marital status. You will then be asked about the time your child was diagnosed and what this was like for you as an individual and as a family and what your concerns were at this time. You will be asked about the ways in which you coped and what was helpful or unhelpful about this. You will also be asked about any support you might have accessed such as parent groups and what your experience was of these. You can still participate if you have not accessed any such support.

It is important to know that just because you have been invited to take part in the research, it does not mean that we think you are not coping.

In the interview, it is also ok to say that coping has been very hard and perhaps that at times you have not been able to cope.

Who will have access to my data?

The researcher, Claire Lammie Trainee Clinical Psychologist.

Supervisors; Dr Sarah Wilson, Lecturer within the department of Mental Health and Well Being within Glasgow University.

Dr Kathleen McHugh, Clinical Psychologist within NHS Greater Glasgow and Clyde.

Representatives of the study Sponsor, NHS GG&C, may also look at your information to confirm that the study is being conducted correctly.

What will happen to my data?

The interview will be recorded. This will then be transcribed by the researcher and the voice recording will be deleted. You will be assigned a research identification number and all transcriptions will be anonymised. Therefore, they will **not** contain your name, the name of your child and any other children and any other identifiable information such as your Doctor's name, the area in which you live. Transcriptions will be kept on an NHS encrypted laptop within a password protected word file. The results will then be written up as part of the major research project. In the write up of the study, direct quotes from parents may be used but these will be anonymous. This study report will be saved electronically within the University of Glasgow for future students to be able to read.

Any paper documents containing your details such as your consent form will be kept in a locked filing cabinet within the Clinical Psychology Department in the Royal Hospital for Sick Children. Only the researcher and research supervisors will have access to these forms. Representatives of the study Sponsor, NHS GG&C, may also look at your information to confirm that the study is being conducted correctly.

The study may also be published in an academic journal and at scientific conferences and presentations.

How long will my data be kept for?

Your information will be stored securely in the University of Glasgow, Mental Health and Well Being Department. This is due to the fact that the study may be published and if the research is challenged in any way, the data has to be available for the researcher to look at. After a period of 10 years the study information will be archived securely within the University of Glasgow.

Can I have access to the results?

If you would like, the researcher will send you a summary of the results from the whole research project for your own interest and records.

Are there any benefits to taking part?

There are no direct benefits of taking part to you and your child. However, taking part in the interview will give you the opportunity to discuss the experience of having a child diagnosed with ALL with someone who is not involved in your child's care. It may give you the chance to reflect on how you have dealt with difficult situations as well as your strengths as an individual which have helped you through the process.

Your experiences and how you have coped may also help other parents in the future.

Are there any risks in taking part?

We understand that discussing your child's treatment and how you have coped may be upsetting. The researcher will give you the opportunity at the end of the interview to discuss how you found the interview process as well as how you are

feeling. If you feel that it would be helpful, the researcher can direct you to the Clinical Psychologist who is involved in the study to discuss any issues that the interview may have raised.

What do I do if I want to take part?

There are 2 ways to take part.

Within this envelope there is a return slip. Sign and print your name along with your phone number and either

- a) return this to the researcher in the freepost envelope provided. The researcher will then contact you to arrange a time to conduct the interview or
- b) place the signed form within a sealed box at the clinic within the Royal Hospital for Sick Children. This box will be easily identified with a poster about the research. The researcher will then contact you to arrange a time to conduct the interview.

Who can I contact for more information about this study?

You can contact the researcher, Ms Claire Lammie for more information by sending an email to c.lammie.1@research.gla.ac.uk or via telephone on 0141 201 0644. You can also contact Dr Kathleen McHugh by email at kathleen.mchugh@ggc.scot.nhs.uk.

You can also contact Dr Kenneth Mullen who is a research professional independent of the research study (email Kenneth.Mullen@glasgow.ac.uk or telephone 0141 211 3932).

The researcher is only looking to interview 6-8 parents, therefore depending on how many people offer to take part, you may not be invited for interview. Thank you for taking the time to read this information sheet.

Claire Lammie, Researcher

Appendix 16

Participation Slip



University of Glasgow,
Department of Mental Health and Wellbeing,
Gartnavel Royal Hospital,
Administration Building,
1055 Great Western Road,
Glasgow,
G12 0XH
Tel: 0141 201 0644
Email:
c.lammie.1@research.gla.ac.uk

Participation slip

Study title: A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative Phenomenological Analysis (IPA).

Please return this to the researcher in the freepost envelope provided.

Please **initial** the following boxes:

I am interested in taking part in the research study detailed in the participant information sheet v5 11.11.14.

I agree to be contacted by the researcher to discuss this further.

I agree to the researcher leaving a message if I am unavailable

Delete as appropriate YES/NO

Print name.....

Signature.....

Date.....

Telephone number.....

Mobile Number (optional).....

**Please return your slip in the freepost envelope provided or place in the
sealed research box at the clinic.**

Thank you for your participation. It is greatly appreciated.

Participant Consent Form



University of Glasgow,
Department of Mental Health and
Wellbeing,
Gartnavel Royal Hospital,
Administration Building,
1055 Great Western Road,
Glasgow,
G12 0XH
Tel: 0141 201 0644
Email:
c.lammie.1@research.gla.ac.uk

Participant Consent Form

Title of study: A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative Phenomenological Analysis (IPA).

Name of researcher: Ms Claire Lammie

(Trainee Clinical Psychologist)

Please initial each box:

I confirm that I have read and understood the participant information sheet (v5 11.11.14) for the above study.

I have had the opportunity to ask questions and these have been answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without explanation.

I understand that my interview will be recorded and transcribed and I give permission for this.

I understand that Claire Lammie and the supervising Psychologists (Dr Sarah Wilson and Dr Kathleen McHugh) will have access to the information that I provide and this will be anonymised before the supervisors see the information; representatives of the study Sponsor, NHS GG&C, may also look at my information to ensure the study is being conducted correctly.

I understand that the medical care of my child or my legal rights will not be affected by taking part.

I understand that discussion of some topics may be upsetting for me.

I consent to the research supervisor listening to the recording of my interview

I agree to take part in the above study.

Participant print name.....

Signature.....

Date.....

Researcher print name.....

Signature.....

Date.....

Appendix 18

Demographics Form



Demographics form

Study title: A comparison of coping styles between mothers and fathers who have a child diagnosed with Acute Lymphoblastic Leukaemia (ALL): an Interpretative Phenomenological Analysis (IPA).

Parent information

Research pseudonym.....

Age.....

Gender.....

Marital status.....

Length of relationship with current partner.....

Is partner the parent of child.....

How many other children are in the family.....

Child information

Age..... Gender.....

How many months is your child in to treatment.....

Appendix 19

Excerpts from two participant interviews (Ann and Frank)

559 Ann: Your everyday life, things that you would do. I would always go to the
 560 hairdresser and get my hair done once a week so my husband came in and said "go
 561 get your hair done". Husband had to tell her - had to travel.
 562
 563 Interviewer: Yep.
 564
 565 Ann: So I think that was probably helpful for (name of child) to see your Mum do
 566 normal things. *Importance of maintaining normality.*
 567
 568 Interviewer: Yes.
 569
 570 Ann: That's probably quite important.
 571
 572 Interviewer: Demonstrating to her that.
 573
 574 Ann: (Interjects) This is our life. We can go on. It's not all doom and gloom, do you
 575 know that way? *positivity. importance of maintaining normality (for child).*
 576
 577 Interviewer: Yeh absolutely. That makes a lot of sense.
 578
 579 Ann: I also remember the hair being a big thing for me cause (name of child) had
 580 long hair and I was thinking "how am I actually going to tell her she's going to lose
 581 her hair?" whereas looking back now, that was nothing. But to me, I had to get over
 582 that and I think it would have been helpful for other parents to have shared their
 583 experiences. *side effects of treatment*
 584 *worry, concern.*
 585 Interviewer: Ok, of? ** positive.*
 586 *o more contact with other parents.*
 587 Ann: Of see maybe after you've been in 3 weeks, somebody's whose maybe at the
 588 other side and came out, would be quite helpful. Cause I remember my sister saying
 589 "have you got to know people?" and I would chat to people but I didn't really want to
 590 know their stories because I just couldn't cope. It's a bit em (pause) when you're
 591 pregnant people tell you all their stories about mat em labour and I've never been
 592 one of those people cause I think I don't want to hear anybody else's stories. I just
 593 wanted to hear about people outside. ** wants to hear + stories*
 594 *Δ Avoidance - increase stories are - ??*
 595 Interviewer: Yep. *normality/normal life.*
 596
 597 Ann: Do you know that way? But I think it would have been helpful if someone had
 598 come in to the ward, who was quite positive, who had got through that first stage.
 599
 600 Interviewer: Yeh
 601
 602 *would like controlled, contained contact. Informal contact eg "chats" too risky. Might hear something you don't want to hear.*

264 Frank: Which is, you know, I think the main thing is the leukaemia, the cancer,
265 although the miller fisher did affect her far, far harder, far worse a way than the
266 leukaemia. *side effects and complications*) *other stresser,*

267 Interviewer: Yep.

268 Frank: We used to see kids, all the kids on the ward, they've all got leukaemia or
269 different kinds and they're all running about and I used to think "why isn't (name of
270 *child) running about?" you know they all seemed really happy and even though
271 they're very ill and she was just in her bed, couldn't move. *upward comparison.*

272 Interviewer: So having other children very visible to compare her with

273 Frank: (interjects) Yeh.

274 Interviewer: Obviously compounded that.

275 Frank: It did yeh, that was one of the things.

276 Interviewer: Ok. And so in terms of (mother) then are you aware of what she might
277 do or think about or say to herself in order to get through it? Does she tell you "what I
278 do is...?" *→ only realising it now.*

279 Frank: You know something, we haven't really talked, it's just been eh (pause) we
280 haven't really talked to tell you the truth. *Lack of communication with partner*

281 Interviewer: About?

282 Frank: About how we've felt

283 Interviewer: Ok.

284 Frank: It's just been (name of child) and making sure (name of other child) is ok. I
285 mean (mother) only got home the week before Christmas. *Separation. Makes communication difficult.*

286 Interviewer: Mm hh.

287 Frank: And that's, eh and the 4th of January that's when the restaurant got liquidated
288 and that's another eh bad thing, what are we going to do for money kind of thing.

289 Interviewer: There's maybe just been so much going on. *↓ other life stresses collide.*

290 Frank: There hasn't been time actually (pause) it's just been, even when we're back
291 at the house, you know because (name of child) got this miller fisher she wasn't
292 using the potty, she was potty trained but she sort of reverted right back to being a
293 baby.

294 Interviewer: Yeh. *Regression in child due to stress/treatment (side effects??).*

	Lack of previous knowledge and experience	<p><i>"I just couldn't make sense of it cause it's different if you'd been warned or if you knew the symptoms then you could sort of think about it. It's just when you think nothing like that's going on it's just like a bombshell".</i></p> <p>(Tom, line 81-82).</p>
The challenges of ALL treatment	Side effects and treatment complications	<p><i>"I also remember the hair being a big thing for me cause (name of child) had long hair and I was thinking "how am I actually going to tell her she's going to lose her hair?".</i></p> <p>(Ann, line 579-581).</p>
	Other life stressors continue	<p><i>"It was a busy restaurant and there were staffing problems and eh it was just a nightmare".</i></p>

	<p>Being separated from family</p>	<p>(Frank, line 89-90).</p> <p><i>“Well one day you’re all together (cries) doing your normal things and you know, you’ve got a child that’s not well, but then all of a sudden you’re here (hospital) with your child and your other kids are at home”.</i></p> <p>(Ann, line 95-97).</p>
<p>Changes an ALL diagnosis brings</p>	<p>Changes to the child</p>	<p><i>“She’s went from being a quiet wee girl to quietly confident and more sociable in a lot of ways and I don’t know if she would have become like that or if it’s because she’s had to deal with so many different people”.</i></p> <p>(Ann, line 1348-1350).</p>

Abstract

Title A comparison of coping styles between mothers and fathers who have a child diagnosed with acute lymphoblastic leukaemia (ALL): using interpretative phenomenological analysis.

Background Acute Lymphoblastic Leukaemia (ALL) is a cancer of the white blood cells. It occurs most frequently in children under 15 and in adults between the ages of 15-25 (MacMillan Cancer Support, 2011). This will understandably be a stressful time for parents which will require the reliance on coping strategies. Parents may also use different strategies from each other; Goldbeck (2001) found that when compared with fathers, mothers more frequently used social support seeking strategies, information seeking and religious coping.

Aims To explore the coping strategies parents use when their child is diagnosed with ALL. The study will also examine whether there are differences in coping between mothers and fathers and whether there are different patterns in accessing support.

Methods A semi structured interview will be conducted with parents. It is hoped that six parents will participate (three mothers and three fathers). Interpretative Phenomenological Analysis (IPA) will be used to analyse the interview transcripts.

Application It is hoped that the research will add to the current literature which details the ways in which parents cope with chronic childhood illness. This knowledge may then enhance provision of support and information for parents when their child is diagnosed with ALL.

Introduction

Conceptualising coping

Coping is defined as "people's efforts to meet the challenges presented by stressful life situations" (Chesler & Barbarin, 1987, p.91).

Within the context of paediatric cancer, Yeh (2003) conceptualised parental coping as involving the following factors; confrontation of reality (the initial phase of coping), management of treatment issues (gaining medical knowledge and information), cognitive and affective shifting (dealing with emotional fluctuations due to setbacks, side effects and positive news), recognition of the situation (deriving meaning from the situation) and adjusting properly (adapting to their new daily situation).

Coping strategies

Acute Lymphoblastic Leukaemia (ALL) is a cancer of the white blood cells which occurs most frequently in children under 15 and in adults between the ages of 15-25 (MacMillan Cancer Support, 2011). ALL has been chosen as the focus for this study due to the fact leukaemia is the most common type of childhood cancer (Cancer Research UK, 2014). Due to this increased prevalence it is

perhaps more likely that the recruitment target will be met than if other forms of cancer were looked at. In addition, more parents will be affected by this diagnosis and therefore any findings and service improvements will have a wider potential impact on parents.

As with any chronic childhood illness, (ALL) can place a huge strain on the family and parents will face many challenges including child care and juggling employment responsibilities with medical appointments.

In a qualitative study exploring the impact of childhood cancer on the family, coping strategies were identified within the themes of appraisal focussed, problem focussed, and emotion focussed coping behaviours (Patterson et al. 2004). Appraisal focussed strategies were described as the family finding different ways to think about, describe and appraise their current circumstances, with the aim of dealing with stress. The most frequently used appraisal behaviour which was used by 47% of parents in the study revolved around maintaining a level of optimism and hope. Other appraisal strategies included denial and making comparisons with other families. Problem focussed behaviours were more practical and 'action' based and were used by 73% of parents. These included seeking information, being organised and planning ahead. Lastly, emotion focussed coping strategies could potentially be seen as involving both positive and negative behaviours; laughing, celebrating improvements, seeking support and also crying and hiding ones feelings.

Chelser and Barbarin (1987) described that a combination of coping strategies can be employed by parents when dealing with childhood cancer, including searching for information about the illness, acceptance, optimism and hope, open communication, being flexible and taking one day at a time.

Differences in coping

Mothers and fathers may use different coping styles. Goldbeck (2001) found that when compared with fathers, mothers more frequently used social support seeking strategies, information seeking and religious coping. They may also prefer different coping strategies as Hill et al. (2009) found that fathers preferred actively 'doing' something in order to cope with the experience of their child's ALL diagnosis, rather than dealing with emotional aspects of the experience.

A difference in coping may prove helpful in some situations as Van Dongen-Melman et al. (1998) demonstrated that parents coped in a way that played to their own strengths and made up for the limitations of their partner. For example, one parent would attend emotionally difficult appointments such as lumbar punctures due to the fact that their partner struggled with these.

The way in which parents cope can have an impact on their psychological well-being as Norberg et al. (2004) found that a more frequent use of active problem solving (acting immediately and having goals) and less frequent use of avoidance behaviour (drawing back from problematic situations) was related to lower levels of anxiety and depression in parents.

Justification of current research

Men and women react to and manage stress differently (American Psychological Association 2010). Due to this, much can be learned by talking to both mothers and fathers who have experienced childhood cancer in their family. Research has also shown that despite a child's survival, fears can still persist (Van Dongen-Melman et al. 1998).

This study is looking to recruit parents whose children are in the maintenance phase of treatment, which despite still involving active treatment, is out with the acute phase associated with initial shock and denial. It will be of interest to see which strategies are viewed as most useful throughout their child's treatment process.

Practical implications

Silver and Baima (2013) state that as part of cancer prehabilitation, newly diagnosed cancer patients should be prepared for treatment in the hope of optimizing their health before treatment begins, leading to better physical and psychological outcomes for patients. Despite this finding, psychological needs are perhaps not currently being fully met as the Managed Service Network (MSN) Annual Report (2013) found that parents of children with cancer perceived a lack of psychosocial support and a lack of signposting to support groups and resources. It is therefore hoped that this study will give parents the opportunity to discuss the type and amount of support they find useful and at what stage of treatment. This may then influence the information that parents

are provided with when their child is diagnosed with ALL. It is also hoped that the research findings will inform clinical practice within the Paediatric Clinical Psychology Unit at The Royal Hospital for Sick Children.

Aim and objectives

This MRP is an exploratory study of parental coping style in parents with a child diagnosed with ALL.

The aim is to explore whether there are differences in coping style and accessing support between mothers and fathers.

Objectives:

1. Explore how mothers and fathers perceive the way in which they have coped with their child's diagnosis.
2. Explore differences between mothers and fathers with regards to the way in which they have coped.
3. Explore differences in the type of support mothers and fathers access.

Design

Purposive sampling will be used due to the fact that participants are being selected according to specific criteria.

Participants will be interviewed using a semi structured interview. The researcher will first conduct an exploratory pilot with 2-3 participants who meet the inclusion criteria and will ask for feedback on the interview questions and process. Feedback may result in some changes to the interview schedule, however the data from these initial interviews will still be used for the study. Any amendments to study documents will be re submitted for ethical approval before being brought into use. Pilot participants will be recruited in the same way as described within the recruitment procedures section below.

The interview questions are guided by current literature as well as the experience of professionals in the field. Although the interview will be semi-structured and the researcher will be open and flexible to what participants want to share, a topic guide will assist in carrying out the interview. This will look at the following areas:

- i The experience
- ii Accessing support
- iii Skills and strengths
- iv Concerns and coping
- v Parents perspective on future and coping
- vi Advice to others

The Interview Schedule can be found in Appendix 12.

The data generated from interviews will be analysed using Interpretative Phenomenological Analysis (IPA). IPA is used to explore an individual's personal world, experiences and the meaning they attach to them. It is widely used within health psychology which makes it applicable for this research. Smith, Flowers, and Larkin, (2009, p. 52) recommend a sample size between 4 and 10 people for IPA. As mothers and fathers experiences are being compared as two separate groups, the aim is to recruit 6-8 parents in total (3-4 mothers and 3-4 fathers if at all possible). Previous Doctorate of Clinical Psychology trainees have recruited participants from the Paediatric Psychology Department and have been able to meet their required participation target for qualitative research. In addition, there are currently over 60 families in the service who would meet this criteria, therefore looking for 6-8 participants seems feasible.

Participants

Participants will be parents of children with ALL who are attending for maintenance treatment (usually year 2 or 3 of treatment but can occur earlier) at The Royal Hospital for Sick Children, Glasgow. The researcher is not looking to recruit parental dyads and will instead be looking for only one parent from a couple to take part. The reasons for this are as follows:

1. The aim of the study is to compare mother's views on how they have coped with father's views. Therefore, it is necessary that mothers and fathers are interviewed independently and not together as this may lead

to more of a 'joint parenting role' reflection rather than a singular reflection as a mother/father.

2. If both parents in a dyad were to participate this may make childcare more challenging for families. i.e. no one to be at home for childcare.
3. Recruiting parental dyads requires both parents to be on board with participation. This may affect participant numbers.
4. If dyads took part, parents may potentially 'confer' and discuss their potential answers before the interview.
5. The literature states that childhood illness can cause stress and can affect marital function and the marital relationship (O'Brien 2001). If parents were interviewed together, the researcher may have to spend time managing the dynamics between parents. The aim of the study is to compare coping styles between genders, not to analyse the content of interviews in terms of communicative characteristics. Parents may also be less likely to discuss challenges that have arisen in their relationship and how these were dealt with if their partners was present.
6. Research has shown that fathers can be reluctant to express themselves fully regarding their feelings and struggles. This is due to the fact that they feel they must be strong for their partner and children (McNeill 2004). Interviewing fathers alone therefore provides them with the opportunity to discuss their experiences openly without having to provide comfort, reassurance or positivity to their partner.
7. Interviewing mothers and fathers singularly and not as part of a dyad will also be done in the hope of obtaining the widest possible perspectives

from parents. If parental dyads are used there may be duplication of information as some coping strategies may be shared.

Inclusion and exclusion criteria

Inclusion criteria

- Parents must be married or co habiting with a partner who is also involved with the care of the child.
- Must be fluent in English.
- Must be one of the primary caregivers for the child.
- Child must be under the age of 18.
- Child must have a diagnosis of ALL and currently be undergoing active treatment.
- This diagnosis must be their first diagnosis of ALL.
- Child should be in the maintenance phase of treatment (2-3 years in to treatment).

Exclusion criteria

- Any other cancer diagnosis.
- A diagnosis with a terminal prognosis.
- Single parents.
- Those not fluent in English.

Recruitment Procedures

There will be 3 recruitment strategies:

1. Boxes containing information packs will be left at the reception desk of the maintenance clinic at The Royal Hospital for Sick Children. A poster will be placed on the front of the box detailing the main requirements to take part (Appendix 13). In the information pack, parents will find a participant information sheet (Appendix 15). This will inform them that if they wish to take part they can either return the included participation slip (Appendix 16) to the researcher in the freepost envelope provided or place it in a clearly identified sealed research box back at the clinic.
2. A poster with tear off slips (Appendix 14) with the researcher's email address will be available at the maintenance clinic. Parents will then be able to contact the researcher requesting more information or an information pack. The researcher will post a pack out if required.
3. The help of (POONs) will also be important for the study. Nurses will inform parents who meet the inclusion criteria about the study and ask them if they would like an information pack. Parents will be told they are under no obligation to take part. If they wish to find out more or participate in the study then the nurse will give them an information pack. Again, participants will be told that they can either return the enclosed participation slip in the freepost envelope or place it in the sealed box signposted clearly in the clinic they attend.

Freepost envelopes will be addressed to the researcher at Mental Health & Wellbeing, Administration Building, Gartnavel Royal Hospital, Glasgow G12 0XH

Research Procedures

The researcher will contact parents who have returned a participation slip via telephone and schedule an interview at a convenient time. In exceptional circumstances, if parents cannot come to clinic but strongly wish to participate, interviews can be conducted over the phone. There is evidence that qualitative interviews can be carried out over the telephone. Birch et al. (2014) used telephone interviews to interview parents of children referred to a weight management programme.

Before the interview begins, participants will be asked to sign a consent form (Appendix 17) and fill in a demographics form (Appendix 18) which will collect basic information regarding the parent and the child such as age, marital status and gender. In instances where interviews will be conducted over the phone, participants will be sent out a consent form to sign along with a freepost envelope to return this to the researcher before the interview is scheduled to take place.

At the end of the interview, participants will be invited to give their views on how they found the process. They will also be asked whether they would like to receive a summary of the results.

All interviews will be recorded using a digital voice recorder. When not in use, the recorder will be stored in a locked filing cabinet within the Clinical Psychology Department at the Royal Hospital for Sick Children. After each

interview has taken place, the researcher will upload the voice file to an NHS encrypted laptop as soon as is feasibly possible whilst still on NHS premises. Once this is done, the researcher will then be able to take the encrypted laptop out with NHS premises to transcribe the voice file. Word files will also be password protected. Once the interview has been transcribed and checked for completeness and accuracy, the voice file will be deleted. The researcher will email the transcribed documents to her own NHS Greater Glasgow and Clyde email account and save them in a folder. This is a secure account.

Settings and Equipment

Interviews will take place within rooms at the Royal Hospital for Sick Children. A transcription kit consisting of a foot pedal and software to listen to the voice files will be used. These can be borrowed from the Doctorate of Clinical Psychology course and will not incur a cost.

Data Analysis

Interpretative Phenomenological Analysis (IPA) has been used to look at parent's experiences of their child's illness, including cancer. Schweitzer et al. (2012) used IPA to explore how parents express both negative and positive experiences of childhood cancer and Jordan et al. (2012) employed IPA to look at the experiences of parenting a child with chronic pain.

In accordance with IPA, all interview recordings will be listened to fully before any transcription takes place. During transcription the data will be anonymised

for references to people and places. The transcription will then be checked for accuracy and completeness. The transcriptions will be printed to make for easier analysis and so that statements can be highlighted and written next to. These paper copies will be kept in the researchers locked filing cabinet within the Clinical Psychology Department at the Royal Hospital for Sick Children. Analysis will begin with several readings of the transcription to gain a familiarity with the data. Significant comments will then be indicated next to each line. These comments will then be sorted into themes and sub themes. This process will be repeated with all transcribed interviews and the themes will then be compared. The research supervisor will read and blind analyse a sample of transcripts. The themes identified by the research supervisor will then be compared with the researcher's identified themes as a check on plausibility (Smith, Flowers, & Larkin 2009, Section A 5)

Throughout analysis, the researcher will keep a reflective diary containing her own perceptions of the data including beliefs and values.

Dissemination

The study will be edited to meet with journal requirements for potential publication. At this stage, it has not been decided which potential journals will be submitted to as it will depend on the study outcome.

The results may also be presented to the Paediatric Clinical Psychology Department in the form of power point presentation.

Participants will be asked if they would like to be sent a summary of the results.

This will be done at the end of the study.

Health, Safety and Ethical Issues

Researcher Safety Issues

It may be distressing for the researcher to hear the stories that parents have to share regarding their child's diagnosis and illness. Protocol for dealing with this is described in a Health and Safety form which is included in submission to ethics.

Participant Safety Issues

It may be that taking part in the interview causes participants some distress. Therefore, they will be advised at the start of the interview that: they can withdraw at any time with no explanation, they do not have to answer all questions and they can take a break. Participants can also be referred on to a Clinical Psychologist within the haematology team if they wish to discuss any issues that participation has raised. Further protocol is explained within the Health and Safety form described above.

During the interview, if participants disclose that they or someone they know (including their child) is at risk of harm then this will be discussed with members of the Clinical Psychology team. A statement detailing this is on the Participant Information Sheet and participants will be reminded of this again before they take part in the interview.

Ethical Issues

The research will be submitted to the West of Scotland Research Ethics Committee for approval.

Participants will be asked to provide written consent and will be told that all information they provide is strictly confidential. They will be informed that the interview will be recorded then transcribed and that the research supervisor involved in the study will read some of the transcriptions as a check on validity of interpretation. Participants will be asked for their permission for this to be carried out as part of the process of gaining consent.

All information regarding clients will be kept in accordance with the Data Protection Act (1998). Participant's transcriptions will be anonymised for references to persons and places and participants will only be identifiable through their assigned participant identification number. Direct quotations from transcriptions will be included in the final thesis and any publications which may arise from it; however these will also be anonymous. Participant's returned participation slips, consent forms and demographics forms will be stored in a locked filing cabinet within the Clinical Psychology Department at the Royal Hospital for Sick Children. After transcription, all digital recording files will be deleted. The researcher and research supervisors will have access to the documents related to the study, as well as representatives of the study sponsor, NHS Greater and Glasgow and Clyde who may access the data for audit purposes.

A plain English Summary will be submitted to members of the Carers and Users of Services in Clinical Psychology Training (CUSP) group for blind review.

Financial Issues

Research costs information is contained within Appendix 22.

Timetable

Outline to the University	November 2013
Draft Proposal to the University	January 2014
Final Proposal to the University	April 2014
Submission to ethics	October 2014
Data Collection	January-March
Analysis and Write up	April-May 2015
Draft to supervisors	June 2015
Summary of results to participants	July 2015
Submission	July 2015

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Appendix 22

Research Costs and Equipment

Trainee Claire Lammie Year of course 2 Year of intake 2012

Item	Details and amount required	Cost or specify if request to borrow from department
Stationary	A4 envelopes for the information pack	50 envelopes 1.90
Postage	A5 envelopes for participants to return participation slip	50 envelopes 1.00
	Freepost license	University have license
Photocopying and laser printing	First class return x 50	50 x.69 34.50
	250 black and white sheets	12.50
Paper	250 sheets paper	1.25
Measures	NA	Subtotal 0
Miscellaneous	Transcription kit	Borrowed from the department
Total		Subtotal 0 50.85

Trainee
Signature.....Date.....

Supervisor's
Signature.....Date.....