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**‘Home Sick’: Exploring the Impact of Receiving a Volunteer Unrelated Donor
Haematopoietic Stem Cell Transplant Far From Home on the Perceived
Coping of Patients Residing in the NHS Highland Region.**

Major Research Project and Clinical Research Portfolio

Volume I

(Volume II bound separately)

Bethany Anderson, MA (Honours)

*Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology (D.Clin.Psy)*

Institute of Health and Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow

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University
of Glasgow

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Chapter 1: Systematic Review

Parental Coping during Paediatric Haematological Cancer Treatment: A Systematic Review using Meta-ethnography.

Bethany Anderson
Mental Health and Wellbeing
University of Glasgow
1st Floor, Admin Building
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH

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

Abstract

Aim: To systematically review and synthesise qualitative research on parental coping during paediatric haematological cancer treatment.

Method: Seven studies were identified following a systematic search of four electronic databases. Quality appraisal of the studies was completed using the Walsh and Downe (2006) checklist. Meta-ethnography was used to synthesise the studies.

Results: The synthesis resulted in nine super-ordinate themes: togetherness, transitional process, 'normal life' changes, support from others, gender specific issues, interpersonal / relationship issues, emotions, roles and practicalities of treatment.

Conclusions: The systematic review indicated that parents utilised a wide variety of coping strategies and that the strategies they used varied by gender and stage of treatment journey. Parents accessed support for coping from varied sources. Parents also needed to overcome barriers such as financial pressures, relocation, accessing support, reorganisation of family, disruption to normal routine and feeling strong emotional distress in order to cope effectively.

Parental Stress and Coping

According to Family Systems Theory (Bowen, 1976) families are made up of interconnected and interdependent individuals. Systems operate through patterns of behaviour and develop their own way of functioning. A non-normative stressor, such as a serious childhood illness, can destabilise the system and can disrupt these normal patterns of functioning. Thus, according to systems theory it is not only the child with the illness that is affected, rather there is a knock on effect for each member of the system as well as affecting the overall functioning of the family as a whole. Thus, the family system is required to cope, adapt and realign to incorporate the child's illness into its way of functioning.

Coping with a child's cancer diagnosis and the prescribed treatment is an additional source of strain to system functioning. Research has shown that this can be a particularly stressful process for parents. Not only do they themselves need to be able to cope, but they must also support their child and any siblings of this child to cope as well. A systematic review by Ljungman et al. (2014) examined the lasting psychological effects for parents of children who survived cancer. This review found that "a substantial subgroup reported a clinical level of general psychological distress, and 21–44% reported a severe level of posttraumatic stress symptoms" (Ljungman et al., 2014, p1). These figures indicate that the stress associated with being a parent of a child with cancer can have significant effects on emotional wellbeing. This finding demonstrates the importance of researching and understanding the issues around parental coping and stressors in childhood cancer in order to try and support parents in maintaining good psychological and emotional health.

A literature review by Kohlsdorf and Anderson (2012) looked at the challenges faced by parents of a child undergoing oncology treatment. This review identified many stressors that parents experience, including changes to their roles, competing demands, financial strain and changes in family dynamics and routines (p122-124). They also suggested that although understanding the difficulties faced by parents was helpful, investigating positive coping and other protective factors aiding parents to maintain emotional and psychological wellbeing throughout the process was also important. When considering the directions for future research, they note “much has been studied regarding family adaptation to treatment and psychopathological symptoms with control groups and normative samples, but little has been investigated concerning how fathers and mothers personally experience cancer treatment of a child” (p125). As such, this systematic review will search for published studies that use a qualitative method with the aim of gaining insight into this ‘personal experience’.

Gibbins et al. (2012) began to address this when they conducted a systematic review, using a thematic synthesis. It included 27 qualitative studies which focused on parental experience of having a child with a cancer diagnosis across different cultures. This review took a broad look at the experiences of parents of children with any type of cancer. They found that nine themes emerged: confronting reality, attempting to gain control, the need for information, continuously adjusting, different coping styles, negative impact, positive outcomes, support, gender and cultural differences. It suggests that health professionals may have a role in promoting a positive experience for parents whose children have cancer.

Haematological Cancers in Children

Haematological cancers (blood cancers) are the most common group of cancers in children and adolescents. Leukaemia accounts for around 31% of childhood cancer, making it the most common form. It is estimated that there are around 500 new cases of leukaemia in the UK each year (www.childrenwithcancer.org.uk). Lymphoma, another blood cancer, accounts for 10 percent of childhood cancers, equating to 160 new cases per year in the UK (www.childrenwithcancer.org.uk).

Treatment for these types of diseases is intense and often lengthy in duration. It is estimated that treatment will take around two years for girls and three years for boys. Treatment involves three stages: induction (with the aim of bringing about 'remission'); consolidation (with the aim of getting rid of any 'hidden' leukaemia cells) and maintenance (with the aim of maintaining remission status). (www.cancer.org, www.macmillan.org.uk). Often children are required to travel and remain away from home for treatment, accompanied by a parent and this can mean a change in environment and a separation from the family unit. These are all challenges which the parent must try to overcome. Due to the particularly intense and long duration of the haematological cancer treatment, and hence the added stressors, this systematic review will focus on research that looks at coping of parents from this particular sub-group. The findings of the systematic review by Gibbins et al. (2012) will be extended by changing the focus to look at coping exclusively amongst parents of children who are undergoing treatment for a haematological cancer. It will also narrow the focus to look specifically at the

treatment phase of the journey as this is a time which presents a unique set of stressors.

Aims

- To explore how parents of children undergoing treatment for haematological cancer cope.
- To do this by systematically reviewing, appraising and synthesising published qualitative research studies.

Review Questions:

With regard to the treatment phase of childhood haematological cancer:

- What coping strategies do parents commonly use?
- What are the important factors in parental coping?
- What barriers are there to parental coping during the treatment phase?

Method

Search Strategy

Prior to beginning the initial search, Dynamed, Cochrane and Campbell library were searched for any existing reviews. No existing reviews were found in this area and therefore, the initial search proceeded.

The EBSCO host was used to search four databases individually: CINAHL, MEDLINE, PsychInfo and Psychological and Behavioural Sciences Collection.

The databases were chosen due to their relevance to the research question and to qualitative methodology. (Atkins et al., 2008)

Search Terms

A broad search strategy was employed with the aim of gathering as many relevant papers as possible. Exact search terms varied according to the available Boolean and Medical Subject Headings (MeSH) within each database. Where available, Boolean terms were 'exploded' to encapsulate as wide a search range as possible. Appendix 2 outlines the exact search process and terms for each database.

A summary of the general process used to search the database is as follows:

1. Bone marrow OR Leukaemia OR Lymphoma OR Myeloma OR Stem cells
OR Leucocytes OR Lymphocyte

AND

2. Parent OR Family OR Mother OR Father

AND

3. Coping OR Adaptation OR Support

Studies identified through this search strategy were reviewed in accordance with the inclusion and exclusion criteria. Papers were initially reviewed by title. Those that the title indicated as not being appropriate were excluded. Those which remained were then reviewed by abstract. Papers for which the abstract content indicated the inclusion criteria were met, were then reviewed by reading the full article. From this, the final set of papers meeting the inclusion criteria was found.

The reference sections of relevant papers were searched with the aim of identifying any further suitable papers. Selected papers' citations were explored using Scopus and Web of Knowledge to search for any further relevant papers which may have not appeared in the previous searches.

Inclusion Criteria

- Qualitative studies
- Main focus of parental coping
- Studies where a child aged 18 and under has a diagnosis of a haematological cancer.
- Looking at coping at treatment stage
- Accessible in the English language
- Published in a peer reviewed journal

Exclusion Criteria

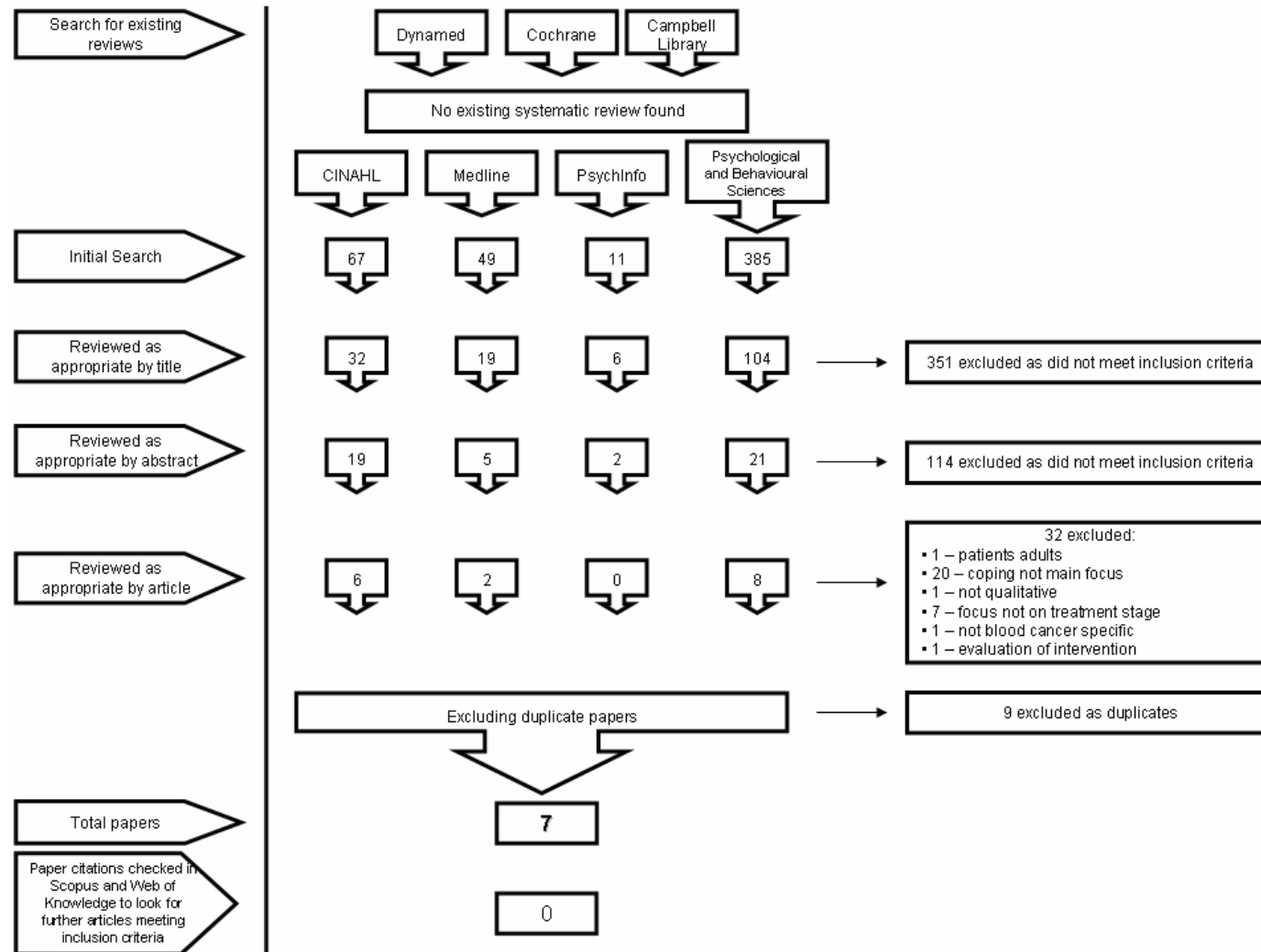
- Duplicate studies
- Books chapters
- Other types of cancer (e.g. solid tumour)

- Studies where main focus is not parental coping
- Studies only looking at other points in the cancer journey (e.g. diagnosis or post-treatment)
- Single case studies
- Quantitative studies

Results of Search Strategy

Figure 1. shows the process of the systematic search method and the results.

Figure 1. Flow Chart of Search Strategy



Quality Assessment of Included Studies

Atkins et al. (2008) stated that “the application of quality criteria to qualitative research is widely debated, and currently there is no consensus on whether criteria should be applied, which criteria to use, and how to use them” (p5). Walsh and Downe (2006), however, state that in order for a meta-synthesis to be useful and clinically relevant in a health care setting, it needs to synthesise good quality studies and accordingly propose that it was therefore important to consider the quality of qualitative research studies when attempting to synthesise findings (p109). Walsh and Downe reviewed existing quality assessments and synthesised them into a useful, comprehensive checklist. This checklist, (Appendix 3) which consists of 12 essential criteria, was used to evaluate the quality of the seven research studies included in this systematic review. Quality ratings were not used as a means of excluding papers from the review; instead they provide a focus for discussion about methodological quality.

Quality ratings were completed by the author and they were also completed by an independent rater¹. The 12 essential criteria were each rated as either not present, partially present or present (0/1/2). On first ratings there was 73% agreement between the two markers. Any inconsistencies were discussed between the markers until consensus could be reached.

The results of the quality appraisal are shown in Table 1. It summarises the sample size of parents, age range of children, diagnosis of the child, method and quality rating percentages. Of the seven studies rated, only two studies met or

¹ A Trainee Clinical Psychologist independent of the research

partially met all 12 essential criteria. Quality ratings for all seven studies however, were found to be reasonably high with ratings ranging from 79% - 92%. "Researcher reflexivity" was the only criterion that received a score of 'not present'. This was the case in four out of seven studies. For this criterion to be met the paper is required to demonstrate that the relationship the researcher will have with the participants during the data collection has been considered and to think about any influence the researcher may have on the research process. They should demonstrate self-awareness and insight and document how this was dealt with. All these considerations are key to qualitative research. It must be considered however, whether the absence of these considerations is a true indication that they had been omitted from the research study, or whether it is a reflection of a restricted word count of a journal, thus requiring authors to edit and cut down their write up, omitting this information (Walsh & Downe, 2006).

Table 1: Quality Appraisal of Included Papers

Author	Year	Sample size	Age of children	Diagnosis	Method	Quality rating
McGrath, P	2001a	12 mothers 4 fathers *	9 months – 10 years	ALL ²	Open-ended audio-recorded interviews transcribed verbatim. Analysed thematically using a phenomenological approach.	79%
McGrath, P	2001b	12 mothers 4 fathers *	9 months – 10 years	ALL	Open-ended audio-recorded interviews transcribed verbatim. Analysed thematically using a phenomenological approach.	88%
McGrath, P. and Chesler, M.	2004	13 mothers 6 fathers	18 months – 8 years	ALL	Open-ended audio-recorded interviews transcribed verbatim. Analysed thematically using a phenomenological approach.	92%
McGrath, P., Paton, M. A. and Huff, N.	2004	3 mothers 1 father 3 children 1 sibling**	12 – 15 years	AML ³	Open-ended audio-recorded interviews transcribed verbatim. Theoretical framework for research is situation in descriptive phenomenology.	88%
McGrath, P.	2005	3 mothers 1 father 3 children 1 sibling**	12 – 15 years	AML	Open-ended audio-recorded interviews transcribed verbatim. Analysed thematically using a phenomenological approach.	88%
Wills, B. S. H.	1999	9 mothers 8 fathers	11 months – 13 years	ALL	Semi-structured interview guide. Analysis based on matrix system.	79%
Wills, B. S. H.	2009	8 fathers	9 months – 14 years	ALL	Semi-structured interview format. Analysis using framework developed by Miles and Huberman (date)	92%

² Acute lymphoblastic leukaemia

³ Acute myeloid leukaemia

* Use same sample

** Use same sample

It is important to note that the McGrath 2001a and 2001b studies use the same sample of participants and similarly the McGrath et al. 2004 paper and the McGrath 2005 paper use the same sample as each other (see Table 1: Sample section). Despite this, each paper focuses on a different aspect of coping and therefore is generating different information about the parents' experience of coping with treatment. It will be important however, to hold this in mind when interpreting the results of the synthesis.

Method of Synthesis

Meta-ethnography is a method used to synthesis qualitative research findings, first proposed by Noblitt and Hare (1988). It is a method of synthesis through induction and interpretation that has been used widely in education and healthcare settings. (Atkins et al. 2008, Pope, Mays & Popay, 2007) As such, it was deemed an appropriate approach for the current systematic review.

The meta-ethnography was completed by following the seven phases as outlined by Noblitt and Hare (1988) (Table 2). The process involved reading the papers multiple times in order to become familiar with them thus allowing the researcher to become 'immersed' in the data. Through examining emerging themes and concepts, the researcher was able to relate the papers to one another in a processed described as 'translating them into one another'. The final step involved building upon the translations from descriptive to explanatory by using interpretation.

Table 2: Noblitt and Hare (1988) – Stages of Meta-ethnography

Stage Number	Phase description
1	Getting started
2	Searching and selection of relevant studies
3	Reading the studies
4	Determining how the studies are related
5	Translating the studies into one another
6	Synthesising the translations
7	Expressing the synthesis

Results

The themes identified by individual papers' authors can be seen in Table 3. Only themes relating directly to the treatment phase and to parental coping were used. In some studies, the diagnosis phase or sibling coping was also investigated and themes relating exclusively to this were not included in this synthesis.

Table 3: Included papers and themes identified by authors

Author	Year	Themes
McGrath, P	2001a	<ul style="list-style-type: none"> ▪ The fathers' response ▪ Men do cry ▪ Implications for the wife ▪ Fathers' adjustment ▪ Family separation ▪ Re-evaluating of values
McGrath, P.	2001b	<ul style="list-style-type: none"> ▪ Normalisation ▪ Impact on parents ▪ Role change / conflict – father ▪ Role change / conflict – mother ▪ Marriage strain ▪ Impact on parent - child relationship
McGrath, P., Paton, M. A. and Huff, N.	2004	<ul style="list-style-type: none"> ▪ Length of treatment protocol ▪ Wanting to be with sick child ▪ Stress of treatment ▪ Stress of invasive technology ▪ Uncertainty ▪ The hospital comfort zone ▪ The ward as sanctuary ▪ The support of other families ▪ The support of allied health

McGrath, P. and Chesler, M.	2004	<ul style="list-style-type: none"> ▪ The fathers' emotional response to pain and shock ▪ Facing the situation – acceptance ▪ Normalcy ▪ Challenging gender stereotypes
McGrath, P., Paton, M. A. and Huff, N.	2005	<ul style="list-style-type: none"> ▪ Relocation ▪ Normalcy interrupted ▪ Life on hold ▪ Rather be at home ▪ Family support ▪ Other support ▪ Father Issues ▪ Male coping strategies ▪ Schooling ▪ Employment ▪ Financial Impact
Wills, B. S. H.	1999	<ul style="list-style-type: none"> ▪ Sources of support for the parents ▪ The coping mechanisms of the parents
Wills, B. S. H.	2009	<ul style="list-style-type: none"> ▪ Social support of the fathers ▪ Effective coping mechanisms of the fathers

After synthesising the papers' findings using the meta-ethnography line of argument synthesis process, nine super-ordinate themes were identified: togetherness, transitional process, 'normal life' changes, support from others, gender specific issues, interpersonal / relationship issues, emotions, roles and practicalities of treatment. Further details on the interpretation process can be found in Appendix 4.

Togetherness

Four of the seven studies discussed the notion of 'togetherness'. They noted that treatment often meant that families were separated or had to relocate, which was a source of stress and adversely affected coping. (McGrath, 2001a; McGrath, 2001a; McGrath et al., 2004; McGrath et al., 2005).

Practicalities and responsibilities often presented as barriers to 'togetherness' and parents were required to balance this as best they could. To make it possible to

be together with the sick child during treatment, often one parent would give up or take leave from work. Although this aided 'togetherness' for one parent and the sick child, it often meant that the other parent was required to continue working to be the sole financial provider the family. This then restricted this parent's ability to be together with their family (McGrath et al., 2004; McGrath, 2001a). The financial costs of undergoing treatment, for example travel and accommodation costs, acted as an additional stressor to families, further reinforcing the need for a parent to continue working and be separated from their child.

"We have gone from two incomes to one." (McGrath et al., 2005, p110)

When there was more than one child in a family achieving 'togetherness' was even more difficult. Parents were very conscious of the care needs of all their children and this again became a balancing act. Where possible, parents aimed to create 'togetherness' for the other siblings, but as this parent describes, practically this was often very difficult.

It is very hard, because we are trying to keep all the kids together and all that. (McGrath et al., 2004, p231)

Often this was not possible and parents indicated that this was not their preferred way of family functioning.

I couldn't stand it on the basis of separation. I am already feeling like we have got our older child currently farmed out. (McGrath, 2001b, p139)

Despite the difficulties associated with being in the hospital environment and the stresses linked to the treatment process, parents voiced a strong desire to be with their child whenever possible and attempted to create the sense of 'togetherness' for the family.

I could probably go home and go back to doing my work, but at this stage I don't want to. I want to be here. (McGrath 2001a, p137)

Being together as a family was valued highly and it was seen as a key factor in the coping of the parents. It allowed them to feel close to their child and able to provide support, comfort and affection, whilst being fully aware of the most up to date information about the child's treatment (McGrath, 2001a).

"I spend a lot of time at the unit...that's how you cope. I think, it's by coming and going." (McGrath 2001a, p138)

Transitional Process

In all but one paper (n=6) a transitional process of adaptation and coping was described by parents. (McGrath, 2001a, McGrath, 2001b, McGrath & Chesler 2004, McGrath et al., 2005, Wills, 1999 and Wills, 2009).

Parents explained a process whereby the initial stages of treatment were often accompanied by difficult emotions which made it harder for them to accept the situation and to cope confidently with it. Over time, however, they noticed that

they were able to move towards a stance of openness and acceptance of the treatment journey. (McGrath, 2001a; McGrath & Chesler, 2004)

“That is just how it is I guess. That is the bottom line. This is our life and this is what is happening and that is the only thing we can do to deal with it, is exactly what we are doing. It doesn’t get better than this.” (McGrath & Chesler, 2004, p53)

“There is no running away. We’re in this. We don’t want to be but we have to. We haven’t got the answers.” (McGrath & Chesler, 2004, p53)

Parents reported that as they worked through this transitional process, the types of coping strategies they used and found helpful changed. Parents often acknowledged that initially they used denial as a way of coping and protecting themselves from the emotional pain of knowing their child was undergoing a life-threatening treatment. Further on in the treatment process, parents sought other forms of coping, such as information seeking and support from other parents on the ward. (McGrath et al., 2005; Wills, 1999; Wills, 2009). Parents also described a shift in their thinking style which was helpful for coping. They noted that as time went on they adopted a present moment, here and now viewpoint as opposed to thinking about potential future scenarios.

“Literally day by day. Like, oh yes, we are going to do this tomorrow.” (McGrath et al., 2005, p103)

The final element of this transitional process that parents observed was a change in their outlook and what they valued. Many parents noted that the treatment journey allowed them to reassess their priorities and what was important to them as demonstrated by this father:

"I guess it's a major change. It's priority. Whereas once upon a time my career was a very high priority.... right now I couldn't give a damn." (McGrath, 2001a, p139)

Normal Life Changes

Four of the included studies discussed how treatment meant that normal life changed for the family. (McGrath, 2001b; McGrath & Chesler, 2004; McGrath et al., 2004; McGrath et al., 2005)

Parents described treatment affecting many aspects of normal life and interrupting family routines including schooling, employment, social commitments and hobbies (McGrath et al., 2005). Adapting to this 'new normal' was a process which took time and was a source of stress for parents.

"You have to make an enormous transition from normal to damage or disaster control." (McGrath et al., 2005, p102)

In order to cope with these disruptions the parents attempted to try and be as close to the old normal as possible, although they acknowledged that treatment often made this a challenge or at times near impossible. Due to the prolonged

treatment duration, parents were clear that trying to maintain a sense of normality or creating a 'new normal' was an important feature of their coping (McGrath, 2001b).

"They [work mates] don't look on me any differently that I know of. They probably think to themselves how the hell does he do it because we try to conduct ourselves as we always conducted. This is probably one of the most difficult things – to carry on as normal." (McGrath & Chesler, 2004, p54)

When an aspect of normality was experienced, this was greatly appreciated by parents and was noted to be a helpful way of coping with the difficulties of treatment (McGrath, 2001b; McGrath et al., 2005).

"Even if it's to get out and sit under a tree or go to the park. Just to be normal. We sort of got out...we found a little area with a tree that we found to sit under and we would go and sit there." (McGrath, 2001b, p232)

Support from Others

Support from others was acknowledged as being key to parental coping in five of the included studies (McGrath et al., 2004; McGrath et al., 2005; McGrath, 2001a; Wills, 1999; Wills, 2009).

The parents described experiences of gaining support from people from different avenues: spouse, family, friends, school, church, colleagues, parents on the ward and allied health professionals (McGrath et al., 2005; Wills, 1999). Parents

accessed many different types of support from these sources to help them cope practically, emotionally, financially and spiritually (Wills, 1999; Wills, 2009).

“The paediatrician and the doctors at the hospital were very helpful. They told me the necessary information about my child’s condition, and this was what I needed to hear at the time.” (Wills, 2009, p12)

“One of the first days one of the mums grabbed my wife and said ‘oh it’s your first day?’ and she showed us things like the kitchen, that video is a good one, go to the corner bed.” (McGrath et al., 2004, p363)

For some families, who had a smaller immediate network, accessing support from others was difficult. In the following quotation the parent indicates that their own parents live in a different country and therefore they are unable to directly access support from them. They talk of how keeping them updated with their child’s treatment is an added emotional stressor.

“No, I cannot ring my parents. They are in [name country]. In the province they do not have a telephone there so I cannot contact them. My father rings up but he cannot talk. He was crying on the phone. They are so far away.” (McGrath et al., 2005, p105)

Although parents noted the support from others as a strong aid to their ability to cope, they recognised that at times this could be experienced as overwhelming. Often it seemed that this was influenced by the child’s physical health.

"It gets to the stage, I know it sounds terrible, I know they are thinking about us.....I just don't want to speak." (McGrath et al., 2005, p105)

Gender Specific Issues

Gender specific issues were discussed in five of the seven studies. Although patterns of coping and the journey of adjustment appeared to be different for the fathers than the mothers, they did not appear to necessarily fit the typical gender stereotypes (McGrath, 2001a; McGrath & Chesler, 2004; McGrath et al., 2005; Wills, 1999; Wills, 2009).

"He is the talker, toucher, feeler. I'm a leave-me-alone, just-let-me-get-on-with-it type of person. I mean we battle, really battle! We always have done. When I wake up in the morning I'd rather wake up with my own thoughts and process what I need to do for the day. And just of think about it. All he wants to do it cuddle and talk and talk and talk (laugh). And it is just we're opposites. I am quite happy to sit in that ward and not talk to anybody." (McGrath & Chester, 2004, p55)

Three of the papers specifically looked at the coping of fathers (McGrath, 2001a; McGrath & Chesler, 2004; Wills, 2009). They noted that the gender stereotype that 'men don't cry', did not seem to fit these fathers' experiences. Despite this there did seem to be a difference in how they displayed their emotion.

"I think the difference between the husband and wife is.... The wife will cry to someone. The husband will cry along." (McGrath et al., 2001a, p138)

Interpersonal and Relationship Issues

A theme that was present across four of the studies was interpersonal and relationship issues. According to these studies it appears the treatment process puts pressure on the marital relationship, but the effect of this varied. Some couples observed a strengthening and others a strain (McGrath et al., 2001b, McGrath et al., 2004, Wills, 1999; Wills, 2009).

“I was talking to somebody and they said, oh you know, their marriage didn’t make it. I could see that this could happen.... What it is, is when I think there are cracks in the marriage. And I think a few of us won’t make it. Sometimes it brings couples closer together, but I think it’s a time that shows strengths and weaknesses of it [the marriage].” (McGrath et al., 2001b, p234)

How couples communicated and worked together to cope with the stressors of treatment affected the impact on the relationship. Open communication was acknowledged as an important factor in enhancing adaptive coping as a couple, but practicalities of treatment often made this difficult.

“So in those first few days, you know there were lots of hugs and crying and coping with it. But [pause] to put things into words.....you just couldn’t. And um, even now, we talk about it to a degree but previously I’ve had a much better understanding of where [my partner] was coming from. But I think neither of us have got to this stage of comfortably sitting down and talking all this out.....there is no break from treatment when you can just sit down and talk.” (McGrath et al., 2001b, p234)

Some couples took a joint 'team work' approach to the care of their child. They worked on their personal strengths and found that these were complimented by the strengths of their spouse. They placed emphasis on the complimentary aspects of their relationship being an important factor in their coping.

"I think we are the same.....we sort of pull each other.....if one of us has weakness the other one compensates for it." (McGrath & Chesler, 2004, p56)

Emotions

Five of the seven studies discussed emotions as a prominent feature in parental coping (McGrath et al., 2001a; McGrath et al., 2001b; McGrath & Chesler, 2004; McGrath et al., 2004; McGrath et al., 2005).

Parents described experiencing a wide range of different emotions including shock, despair, denial, pain, anger and anxiety. They often described experiencing numerous emotional states, which varied according to the stage of treatment or to the child's health and wellbeing. (McGrath et al., 2001b)

"I couldn't tell you how I feel. Because you fluctuate so much too. But I mean you feel nauseous half the time. And other times you feel dizzy and other times you feel kind of fine. And it just eats away at you. But it eats different parts at different times and different times of day. So no, you cannot describe how you feel. And if you pump your adrenalin up and say I'm feeling great – you can maintain that for a little while. But it does physically affect you. So far as my wife and I would

probably have diarrhoea at some stage every single week. Just stress-related. It is emotions that are ticking over all the time.” (McGrath & Chesler, 2004, p46).

Uncertainty around the success of the treatment and the future was named as a trigger for parental anxiety and this was a key area that presented challenges for coping. (McGrath et al., 2004, and McGrath & Chesler, 2004)

“Like, I have these panic attacks. I’m going along really good and then all of a sudden. Oh! I really panic. Oh god, I have all these thoughts. And I think it is from not knowing.” (McGrath et al., 2004, p363)

Gender differences were noted in the way parents coped with their emotional experiences. Often it was commented that the fathers were less expressive with their emotions and used taking ‘time outs’ as a means of coping.

“I just have to go because I can’t stand to see my little [child] like that.... That is just how I feel. I just have to get out.” (McGrath et al., 2001a, p138)

Roles

Three of the included studies discussed the parents’ roles and how this impacted on their coping experience. Coping with treatment required the family system to reallocate roles and responsibilities. (McGrath, 2001a; McGrath, 2001b; McGrath et al., 2005)

Parents noted that going through the treatment process often necessitated a change in their existing family roles. As previously discussed, often this meant one

parent taking on the caring role for the sick child in hospital, while the other took on the role of breadwinner, looking after the other children and maintaining the household. For some, this required taking on a new role and associated tasks (McGrath et al., 2005). Whilst for others this meant they had to let go of something that they identified with being part of their role. This shift was not always a comfortable experience as described by this mother:

“I’m like this alien person who is no longer needed by the rest of my family because I’m sitting on a hospital bed with a sick child.” (McGrath, 2001b, p233)

Many couples commented that their strategy for coping with these role shifts was to work as a team. They would take turns or one partner would do the jobs that they knew the other would find difficult. For example, one mother talks of how she found seeing her child go under anaesthesia particularly emotionally demanding and therefore her husband took on this role as a means of protecting her and helping her cope.

“His father used to go with him. I hate watching him go to sleep [be put under anaesthesia].” (McGrath, 2001a, p138)

Practicalities of Treatment

The last super-ordinate theme in the meta-ethnography was the practicalities of treatment, which was discussed in two of the papers (McGrath, 2001a; McGrath et al., 2004).

There are physical practicalities of undergoing arduous and aggressive treatment. For the child, physical effects such as fatigue, nausea and weight loss threw up challenges for parents to cope with. Additionally this had knock on effects for the parents themselves to cope with, for example, sleep disruption and poor nutrition.

"It is never a deep sleep because my mind never stops. My mind just does constantly. If I don't remember everything...." (McGrath et al., 2004, p362)

"He was vomiting when he was really sick – couldn't keep anything down. Like he lost 8kg in the first week. And he had no control over his bowels. He has to wear nappies – very hard." (McGrath et al., 2004, p363)

Parents often sought practical solutions to manage these difficulties, as shown by this mother who was trying to get to grips with her child's new medication regime.

"I put a medicine schedule in the diary and I have my alarm clock on. I like to know the name of the medicines so I don't get mixed up." (McGrath et al., 2004, p362).

For other parents a positive environment on the ward aided coping.

"The ward is like a sanctuary, and pain is associated with somewhere else, but here you are to get better." (McGrath et al., 2004, p363)

Discussion

Findings

A systematic review of current literature was completed, yielding seven published journal articles which met the inclusion criteria for analysis. Meta-ethnography was used to synthesise the findings of the included studies. This synthesis produced nine super-ordinate themes: togetherness, transitional process, 'normal life' changes, support from others, gender specific issues, interpersonal and relationship issues, emotions, roles and practicalities of treatment.

The themes of 'togetherness', 'interpersonal and relationship issues' and 'roles', all described necessary processes within the family unit. They included the re-organisation of the family physically (e.g. living arrangements) and functionally (e.g. roles). These processes were described as stressful, but necessary tasks to work towards effective coping. These findings can be understood in the context of Family Systems theory (Bowen, 1976) in which they state a significant event, such as ill health, will disrupt normal family functioning and will require a process of realignment to allow effective operating and coping to continue. This process of change can be experienced as a period of increased stress and disruption by all members of the system. This finding was echoed in Kohlsdorf and Anderson's (2012) review, in which the changing nature of parents' role was found to be a particularly difficult challenge to their ability to cope effectively.

The theme of 'transitional process' came out in this synthesis. It spoke of parents' experiences of moving along a process of transition towards a place of

acceptance, noting that their emotional experience or style of coping often changed along this journey. These findings are similar to those described by Gibbins et al. (2012) who also noted that parents reported working through a transitional process, often from disbelief or denial, towards acknowledging the reality of their situation. Gibbins et al. (2012) reported that parents found that this adjustment was a continual process. These findings indicated that parents coping with the treatment of a child with a haematological cancer are undergoing a similar process as parents of children undergoing treatment for cancer more widely.

This systematic review's findings also indicated that through this transitional process parents were also describing a change in their outlook on life and an increased emphasis on their values. Similarly, Folkman and Greer (2000) found that a shift in priorities and goals towards a more valued-led direction was common in those dealing with serious illness. They linked this to increased psychological well-being, indicating that it could be a protective factor in terms of successful coping.

According to Compas et al. (2012) there are three styles of coping with illness: active coping, accommodative coping and passive coping. They suggest that accommodative coping (adapting to the source of the stress) is linked to more effective adjustment. Findings from this meta-ethnography found that parents often described that their coping changed as time went on, with initially their coping style tending to be passive or disengaged. Their coping style was said to then change towards the end of their child's treatment to become more

accommodating and accepting. (McGrath, 2001a, McGrath, 2001b, McGrath & Chesler, 2004, McGrath et al., 2005, Wills, 1999 and Wills, 2009).

Lazarus and Folkman (1984) suggest there are two types of coping responses: emotion focused and problem focused. Of these they associated problem focused with more adaptive coping. Research by Billings and Moos (1981) indicated that women were more likely to use an emotion focused coping style than men. Although the current synthesis did find gender differences in coping, it also found that often traditional gender stereotypes did not exist and that males did engage in emotion focused coping behaviours and that women would also take a problem focused approach (McGrath, 2001a; McGrath & Chesler, 2004; Wills, 2009).

Moos and Schaefer (1984) discussed a number of factors which can influence a person's ability to use effective coping strategies including: "the accessibility of social support networks and the acceptability of the physical environment" (Moos & Scafer, 1984, p.61). These findings are reflected in the current review. In terms of the acceptability of the physical environment, parents placed emphasis on having an environment which was conducive to recovery, with one paper describing this as the "ward as a sanctuary" or the "hospital as a comfort zone" (McGrath et al., 2004, p363). Obtaining support from others was another key theme which was identified in the current review. The stress-buffering model (Cohen & Wills, 1985) indicates that there are certain resources which appear to be able to reduce the negative impact that life events can have. These resources are said to act as a 'buffer' against stress. One of these resources is reported to be social support. This systematic review found that parents did appear to

experience social support as an aid to coping and therefore it did act as a buffer to stress. Contrary to the model, it found that if the social support was too frequent, intense or ill timed then it could actually be a source of stress (McGrath et al., 2005).

Limitations

The current systematic review synthesised findings from qualitative studies. One of the limitations of qualitative research is the ability for it to be generalised to the wider population. Often the aim of the research is to develop a deeper understanding of the lived experiences of the individual participants and therefore it can be difficult to infer meaning and direct transferability to the wider population as a whole. Within this systematic review, the papers included either came from Australia (n=5) or Hong Kong (n=2). Therefore, it must be with caution that these results are generalised to parental coping in other countries.

The search yielded seven papers, which were written by two lead authors: Pam McGrath, lead author for five included studies and Betty Wills, author for the two remaining studies. This narrow range of authors must be taken into consideration when interpreting the results. There is the possibility that having a small sample of papers, by a small range of authors may introduce some bias and therefore this may shape the synthesis findings. Despite this, the high quality ratings of the included studies should go some way to help ensure that the studies are of good quality and have thought about and accounted for any types of possible bias.

It is also important to consider that there are two incidences whereby the studies have used the same sample. Although they are looking at separate aspects of coping with treatment and therefore produce different data it is important to acknowledge that this does limit the pool of participants across all the included studies and therefore may bias the results depending on particular individual's general coping style.

Although these limitations affect the generalisability of the findings, they also offer a clear indication as to what the available research base is. It indicates that this is an under researched topic and reflects that it is an area in which there are currently only two key researchers. It clearly demonstrates the need for further research to be done to expand on these findings.

Clinical Implications

The results of this systematic review indicate several clinical implications that could make a positive impact in assisting parental coping during their child's haematological cancer treatment.

Firstly, there is a clear role for health professionals to, where possible, try to promote a positive, calming and recovery focused environment. Making small changes, such as having invasive and painful procedures happen away from the ward, could reduce the association between the ward and with these difficult experiences. Instead the ward would be associated with recovery, allowing the child and their family to relax and be at ease, thus increasing the parents' ability to utilise positive coping mechanisms (Moos & Scafer, 1984). A similar technique

was used at the hospital in the McGrath et al. (2004) paper and this was acknowledged as helpful by parents.

Secondly, health professionals can aim to help parents as they move through the transitional process and associated emotional responses. They can help inform parents of this process and normalise their experiences. The results of this synthesis indicate that parents utilised different methods of coping at different points of their child's treatment journey. Staff could use this information to match the support they provide to the need of the parents at that time. Results also indicated that social support was a helpful tool for coping, yet at times this could feel overwhelming and in fact be a barrier to coping. This highlights that parents need to be able to find a balance between accessing social support and having time alone. Being able to do so would enable more effective coping, however this is reliant on parents being able to self-reflect and understand what it is that they need at any given time.

Results of this review indicated that clear, open communication is key for successful coping. This could be in terms of communication between parents and the medical team, their spouse or their wider system. Parents who communicated openly about their fears, needs and expectations were better equipped to tackle hurdles such as change of roles, high levels of distress and uncertainty. Parents should be provided with access to support that can help them explore their thoughts and feelings and communicate in a way which allows them to move forward and adjust to their situation and cope with the multiple stressors they experience.

Finally, health care professionals can support parents by signposting them to available services and resources to help with practical difficulties and other barriers to coping. Staff should be mindful of families who have a particularly impoverished support network, for example if they have had to relocate for treatment, and help them access support from other avenues. It may be helpful for staff to think together with families about ways in which they can retain as much of a sense of normality as possible and how this can be facilitated in the hospital during their treatment journey. It may be helpful to think about this both in terms of their physical environment on the ward and also thinking about the child's daily routine and social interactions and how these could be adapted to feel as familiar or 'normal' as possible.

Future directions

This systematic review provides evidence of the need for further research to be conducted in this area to help expand current findings. Research conducted in more countries would help to examine the existence of cultural differences of parental coping and help to increase the generalisability of current findings. Further research looking at the role of the health care staff and the input they can have to support parents would be a helpful addition to guide staff in best practice.

Conclusions

This systematic review set out with the aim of understanding the coping strategies commonly used by parents during the treatment phase of childhood

haematological cancer. It aimed to discover what the important factors were in terms of parental coping as well as the common barriers to coping.

The synthesised results indicated that parents used a wide variety of coping strategies and that the strategies they used varied by gender and stage of treatment journey. Parents described working through a transitional process towards acceptance of their family's situation and that when they were able to reach the point of acceptance, they were able to cope more effectively.

Parents accessed support with coping from many different sources. Having access to support, feeling a sense of 'togetherness' as a family and taking each day as it came were all important factors in coping well. Parents, however, also needed to overcome barriers such as financial pressures, relocation, accessing support, reorganisation of family, disruption to normal routine and feeling strong emotional distress in order to cope effectively.

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Chapter 2: Major Research Project

‘Home Sick’: Exploring the impact of receiving a volunteer unrelated donor haematopoietic stem cell transplant far from home on the perceived coping of patients residing in the NHS Highland region.

Bethany Anderson

Mental Health and Wellbeing

University of Glasgow

1st Floor, Admin Building

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow G12 0XH

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Plain English Summary

Background: A stem cell transplant is a medical procedure used to treat cancers and bone marrow failure syndromes that affect the production of healthy blood cells. There are different types of stem cell transplants. This study will look at patients who have had Volunteer Unrelated Donor transplants (VUD).

Across Scotland, patients undergoing a VUD transplant go to Glasgow for treatment. For NHS Highland patients, this means they have to travel great distances (e.g. approximately 170 miles from Inverness, 278 miles from Thurso and 207 miles from Portree) and are often away from home for lengthy periods of time. This may influence how they are able to cope.

Aim: This project aims to examine how travelling a long distance and remaining away from home during treatment affected coping.

Methods: The study interviewed six participants asking them to describe their experiences. Participants each completed a single interview, which was audio-recorded. The interviews took place in Raigmore Hospital, Inverness. Once the interviews were complete they were typed up and analysed to look for experiences shared by participants.

Findings and Conclusions: Results indicated ten themes:

1. Impact of Physical Health

- Participants' poor physical health acted as a barrier to coping. Often patients were too ill to make use of planned coping strategies. On occasions, however, being very ill meant they lacked the energy to miss home or to ruminate which was described as helpful.

2. Ward Life

- The medical routines created structure in the day. Some found this helpful as it matched a highly structured life that they were used to, however, others found this to be a barrier to coping. Isolation and associated restrictions were particularly difficult to cope with.

3. There is No Place Like Home

- Participants found being in a medical environment in a large city very different to home. Making their hospital room feel less clinical by bringing familiar items from home helped. Participants understood that they needed to be in Glasgow to get specialist treatment but described a strong urge to return home as soon as possible.

4. Social Support is Key

- Technology enabled participants to keep in contact with their social network at home. New social connections were made, drawing on support from medical professionals, holistic therapists, domestics and other patients.

5. The Known versus the Unknown

- The unknown was described as a source of stress. Participants tried to cope with this by making the unknown known, often through information seeking. When participants had prior experiences of

being away from home, this gave them confidence for dealing with the distance when down for treatment.

6. Technology

- Technology was used to bridge the distance between participants and their social network back home. Technology was also used as a means of distraction that allowed participants to break up their day.

7. The Role of Thoughts

- Participants found that their thinking style influenced coping. Being positive aided coping, whilst negative rumination did not. Participants used distraction to help deal with their difficult thoughts.

8. Change of Environment

- Changing environment was a key coping strategy. Participants would often access the Friends of the Beatson, the hospital grounds or the Maggie's Centre and saw this as an 'escape' from the medical environment, allowing them a feeling of normality.

9. Moving Along a Journey

- Participants described undergoing treatment as a journey containing highs and lows; some parts of their journey were more difficult to cope with than others. Participants described undergoing adaptation through their journey and that once they had adapted, coping was more effective.

10. Direct Consequences of the Distance

- The distance affected who was able to make the journey to Glasgow, with elderly relatives struggling to do this. The participants needed to be prepared, organising themselves before travelling down. This

included ensuring they brought everything they needed, as they could not leave until the end of treatment. Participants felt constantly aware of how far from home they were.

The results help us understand the factors and resources which helped the participants to cope during their transplant. This information can then be used to help prepare future patients for treatment.

Abstract

This project aims to gather the experiences of patients living within the NHS Highland region who have travelled to Glasgow to receive their allogeneic haematopoietic stem cell transplant. It examines the effects of travelling long distances and remaining away from home for treatment, on coping. The project used a qualitative design, looking retrospectively at participants' experiences. Semi-structured interviews were audio-recorded and transcribed verbatim before being analysed using Interpretive Phenomenological Analysis.

Results of the analysis indicated ten super-ordinate themes: Impact of physical health, ward life, "there is no place like home", social support is key, the known versus the unknown, technology, the role of thoughts, change of environment, moving along a journey and the direct consequences of the distance. The results enhance understanding of the factors and resources which can aid patients' coping. This information will be used to help prepare future patients embarking on their own treatment journey, as well as guiding staff as to how they can best prepare patients and support them to cope during treatment.

Keywords: Haematology, Haemato-oncology, Haematopoietic Stem Cell Transplant, Coping, Support, Distance, Travel

Introduction

Haematopoietic Stem Cell Transplants

A haematopoietic stem cell transplant (HSCT) is a medical procedure which involves the patient undergoing conditioning treatment (chemotherapy and in some instances, total body irradiation (TBI)) prior to receiving stem cells, harvested from bone marrow, peripheral blood or umbilical cord. HSCT is used to treat cancers and bone marrow failure syndromes, such as leukaemia, lymphoma, myeloma and severe aplastic anaemia (NHS Choices, 2012).

Bone marrow transplants can be 'autologous' (patient's own cells are removed, then transplanted back in following a course of high dose chemotherapy / radiation therapy) or 'allogeneic' (a donor's cells are transplanted). In allogeneic transplants, a matched sibling can be used as a donor, but when this is not possible, a non-related donor is used (Volunteer Unrelated Donor transplant (VUD)) (Chen, 2013).

The process of undergoing a HSCT involves an often lengthy hospital admission. In preparation for their transplant, patients undergo a course of 'conditioning therapy' which aims to kill unhealthy cells, allowing room for the new healthy cells to grow. This weakens the immune system reducing the chance of the patient's body rejecting the new cells. Consisting of high dose chemotherapy and sometimes radiotherapy and/or antibody therapy, the conditioning therapy lasts one to nine days, with the transplant being given the following day.

In the period directly after the transplant, patients need to stay in hospital to allow their blood cells to regenerate. The low white cell count and side effects from the conditioning therapy mean that patients at this stage are at high risk of infection and it is therefore important they are in a "clean environment", hence the need for hospitalisation at this stage. The length of stay varies ranging from three to six weeks on average, but in a few cases can be significantly longer (NHS Choices, 2012).

The Beatson West of Scotland Cancer Centre

All patients undergoing VUD HSCT in Scotland will attend the Beatson West of Scotland Cancer Centre (BWoSCC) for their procedure. The BWoSCC in Glasgow is the largest cancer centre in Scotland and is the second largest in the UK with an estimated 8000 new patients every year (www.beatson.scot.nhs.uk, 2013). The BWoSCC is the only accredited centre for VUD transplants across Scotland (Joint Accreditation Committee of Cellular Therapy, 2012). In June 2015 the unit responsible for stem cell transplants and associated treatment moved to newly built facilities at the Queen Elizabeth University Hospital Glasgow.

The NHS Highland region

The approximate population of the Scottish Highlands is 222,370, representing 4.2% of the total population of Scotland (National Records for Scotland, 2012). The land area (26,484 sq km) however represents 33% of Scotland and parts of the Highlands are the most scattered and remotely populated areas of the United Kingdom (www.highland.gov.uk). NHS Highland covers this area, excluding the Western Isles, Orkney and Shetland which have their own NHS Health Boards. In April 2006 Argyll & Bute Community Health Partnership became part of NHS

Highland. Within this region services are provided to a population of approximately 90,500 people across an area of 6,909 sq km (NHS Highland, 2006). Appendix 15 includes a map of the full NHS Highland region. Patients living within the NHS Highland region are required to travel to Glasgow for their VUD HSCT. This can mean they have to travel long distances (e.g. approximately 170 miles from Inverness, 278 miles from Thurso and 207 miles from Portree) and are often away from home for lengthy periods of time during the course of their treatment.

Travelling for Treatment

Long distance travel for treatment has financial implications (McConigley et. al, 2011, Scoggins et al, 2011) and also time cost (Scoggins et. al, 2011); particularly if a family member is accompanying the patient. A study of patients living in rural Australia found that receiving treatment far from home was acceptable to the patients if they had been advised to do it by their physician (McConigley et al (2011, p.6). Receiving treatment away from home means that people are away from their normal social network and the support they would routinely access. This is particularly important as Binger et al., (2012) reported that “the most effective coping strategy [...] was using social support” (p146).

Other studies have investigated the advantages of receiving treatment close to home. Benson (2006) compared patients who received blood transfusions at home, with those who received treatment in hospital. Patients reported the advantages of being treated at home. “Remaining at home during medical therapy or only travelling short distances to a local clinic provides greater comfort for

debilitated patients and is less frightening for paediatric patients” (Benson 2006, p219). A Swedish study looked at VUD transplants, comparing patients who received their post-transplant follow up care within their own home with patients who remained in hospital for their follow up care. They noted that there were positive health benefits to receiving follow-up treatment at home including “fewer days on total parenteral nutrition, less acute graft-versus-host disease grades, and lower transplantation-related mortality rates.” (Svahn et. al, 2002, p4317). Receiving follow-up treatment at home is not currently available within Scotland and patients are expected to attend hospital for this. Overall, these studies indicate clear benefits of receiving treatments within the patients’ local area.

Palmer and Collie (2011) investigated the experiences of patients across Scotland who had travelled to the BWoSCC for their post-VUD follow up care as well as receiving some follow up appointments within their local health board. The study compared the experience of travelling for follow-up care with receiving services locally. The current study hopes to build and expand on this work by looking specifically at the experience during the treatment phase. Palmer and Collie’s participants had varied travel duration to the BWoSCC. Some were relatively short and a round trip could easily be completed within the day (e.g. 40 minutes each way), whilst others were much longer (e.g. 9.5 hours each way). Therefore, to promote a homogeneous group and to aid better understanding of the impact of long distance travel on treatment, the current study will focus on the experiences of people who had to travel distances greater than 100 miles for treatment.

Coping in Cancer

A vast amount of research has looked into the different types of coping styles which people use to try to cope with physical illness. Moos and Schaefer (1984) categorise coping skills into three subtypes: appraisal-focused coping; problem-focused coping; and emotion-focused coping (p.59). According to this theory the type of coping skills used, can determine patient outcomes in terms of quality of life and psychological well-being (Moos & Schaefer, 1984 and Schoulte et al, 2011). Moos and Schaefer note that there are different factors that affect patients' ability to use these coping skills. One of the factors they discuss is "physical and social/environmental factors, such as the accessibility of social support networks and the acceptability of the physical environment" (p.61). This study aims to explore the coping styles and strategies adopted by NHS Highland patients during their VUD HSCT and investigate how they managed to utilise or adapt coping strategies to fit with the available resources.

A quantitative Icelandic study (Hjorleifsdottir et al., 2007) looked at a measure of coping in patients who had received chemotherapy and radiotherapy either close to home or at a facility where they needed to stay away from home for at least 24 hours. Similarities were found in the ways in which the patients in either group coped, indicating that despite the challenges of staying in hospital for treatment, participants managed to utilise coping strategies effectively. It is not clear, however, exactly how long the patients spent away from home. To meet the inclusion criteria to be in the "away from home" group they had to have spent only 24 hours or over in hospital. Hjorleifsdottir et al. describes patients undergoing treatments often lasting between three and five days. The current study aims to

build on this research, looking specifically at VUD patients who have been away from home for a longer period of time thus deepening our understanding of the reality of receiving treatment far from home.

Payne et al. (2000) reviewed literature that examined the consequences of travel for cancer patients. They noted that there was a lack of research addressing the concerns of temporary separation (p201). Travel to cancer treatment was described as “an inconvenience and a particular hardship for many patients. [...] Future studies should broaden their research questions to evaluate quality of life and perceived social support.” (Payne et al., 2000, p203). The present study aims to investigate the experience of the patient in terms of perceived coping and will also consider the patients’ social support and its effect on their coping.

Aims

Aim:

- To examine how the experience of travelling such a distance and remaining away from home for the duration of treatment affects the patients’ perceived coping.

The results of this study may provide a deeper understanding of the factors which enhance patients’ coping. This information can then be used to help prepare future patients as they embark on their treatment journey.

Research Question

Primary research question:

- How did the experience of travelling over 100 miles for treatment, affect the perceived coping of VUD HSCT patients living in the NHS Highland region?

Secondary questions:

- What barriers to coping were present related to patients receiving treatment over 100 miles from home? How were these managed?
- What coping strategies did patients from the NHS Highland region find most useful when receiving VUD HSCT over 100 miles from home?
- Were the coping strategies used when receiving a VUD HSCT over 100 miles from home similar or different to those the patients would routinely use in stressful situations?

Method

Ethical Considerations

The research project went through the NHS Solihull Research Ethics Committee - Proportionate Review Service. The project was registered and sponsored by NHS Highland Research and Development department.

Written consent was obtained from all participants prior to conducting interviews. The participants were made fully aware that they had the right to discontinue the interview and withdraw from the project at any point.

Design

The project used a qualitative design, looking retrospectively at participants' experiences. It is acknowledged that collecting data retrospectively can raise some concerns around the validity of the results as forgetting and distortions in memory have been found to increase over time (Moss & Goldstein, 1979). Due to the high personal salience of a VUD HSCT however, it is believed that the event will be memorable and therefore the use of a retrospective in-depth interview would be appropriate (Moss & Goldstein, 1979; Schroder & Borsh-Supan, 2008). Semi-structured interviews were used to gather the experiences of participants. Participants each completed a single interview lasting between 25 minutes – 55 minutes.

During the development of the interview guide (Appendix 13), drafts were sent to members of the haemato-oncology teams both at the BWoSCC and Raigmore Hospital to provide feedback. As a further way of ensuring the validity of the interview guide, the first two interviews were transcribed and reviewed by the researcher and supervisor to ensure that they were successfully eliciting the desired type of information.

The Sample

Patients living within the NHS Highland region at the time of their treatment, who travelled to Glasgow to undergo a VUD HSCT between the years of 2010 and 2014 were invited to participate in the current study. Sampling from more recent years was chosen as it is considered that recall is likely to be easier in those who have undergone the treatment more recently.

The study restricted the population to those who have had a VUD transplant which was a “9/10” or “10/10” anti-body match. This specifies the degree to which the patient and the donor’s anti-bodies match. This ensured as much of a homogeneous group as possible in terms of treatment procedure.

Recruitment Procedure

The Nurse Consultant in Cancer Care (Haemato-oncology team NHS Highland) sent out participant information sheets (PIS) which asked interested patients to send back written consent for their details to be passed to the researcher. The Nurse Consultant was named on the PIS as an independent contact person. Potential participants were encouraged to contact them for independent advice regarding participation in the study.

At the time of recruitment the potential population from which to recruit was seven people. Of these seven, six agreed to participate in the study. Participant demographic information can be found in Appendix 17.

Data Analysis

Data was analysed using Interpretive Phenomenological Analysis (IPA). IPA is concerned with the “examination of how people make sense of their major life experiences” (Smith et al., 2009). It was therefore thought that IPA would be well suited to answering the research questions. IPA respects each participant as an individual who has experienced a similar event, but acknowledges that how they experienced it would be personal to them. The use of IPA helps clarify how the individuals concerned made sense of these life experiences, whilst looking for any common themes shared by participants. Further information on the process used during analysis can found in Appendix 19.

Justification of sample size

The initial aim was to recruit between four and ten participants. According to Smith et al., (2009, p.52) this is the recommended number of interviews for research completed as part of a professional doctorate using IPA. A sample of this size would also be in keeping with suggestions made by Braun and Clarke (2013, p45). By the time interviews five and six had taken place it was felt that many of the same themes were being discussed in each interview and it was agreed that data saturation had been reached.

Setting

Interviews took place within NHS Highland Outpatient Clinics in Raigmore Hospital, Inverness. Telephone interviews were offered as an option, to help facilitate patients who lived some distance from Inverness. No participant chose this option.

Researcher Reflexivity

Finlay (2002) notes that qualitative research should “try to make explicit how inter-subjective elements impact on data collection and analysis in an effort to enhance the trustworthiness, transparency and accountability.” (p.211)

The researcher had clinical experience of working with people with cancer, and therefore had an awareness of commonly experienced difficulties associated with treatments. This may have helped in engaging participants and creating a rapport. As a Trainee Clinical Psychologist working in Inverness and attending the University of Glasgow, the researcher also had personal experience of making frequent journeys from the Highlands to Glasgow. The researcher remained aware of her own reactions and experiences throughout and paid attention to whether this was influencing the analysis.

Results

Results of the analysis indicated ten super-ordinate themes: Impact of physical health; ward life; “there is no place like home”; social support is key; the known versus the unknown; technology; the role of thoughts; change of environment; moving along a journey and the direct consequences of the distance.

Physical Health

Participants noted that poor physical health meant that they felt fatigued, nauseous or that their concentration was impaired, meaning that it was harder for them to employ methods of coping as they had planned. Some participants spoke

of how they had brought down books to read during their stay; in reality, they were unable to concentrate for long enough to make use of them.

“My concentration let me.....because I started, I had books to read. I was going to do all this reading when I was in the hospital, but I really struggled with that. I just couldn’t concentrate on it. I would be reading a chapter and I would have to re-read it because I couldn’t remember what happened in the beginning.” – Interview 6

Participants discussed how they tried to deal with such challenges by trying to adapt activities to be more manageable; for example, they noted that reading a magazine or a newspaper was manageable whereas a novel was not.

Physical health also acted as a barrier to accessing social support. This was particularly true during the ‘conditioning therapy’ part of their treatment.

“Eh.....my parents were coming down once a week to see me, eh.....wasn’t really much aware of them coming down first couple of weeks.” – Interview 2

Although poor physical health was mainly described as a challenge to coping, a couple of participants noted that at times, it aided them to cope as it meant they did not have the energy to feel home sick.

“Em....I think because I was so poorly it didn’t really, I know that’s terrible to say, that it didn’t really bother me.” – Interview 3

Ward Life

Participants spoke of needing to adjust to ward life. They noted that at times the medical procedures, routines, protocols and environment had an impact on their ability to cope.

“Because you’ve got the fan going continuously in the ceiling and you’re on drugs, that are 24 hours a day, there’s a pump next to you and that goes off in the middle of the night, you know so you have to press for the nurse and she will come and re-set it.” – Interview 1

One of the most talked about aspects of ward life was the restrictions when confined to their single room until their blood counts reached a certain level. Participants discussed themes of isolation and loneliness. They noted feeling frustrated which made coping more difficult.

“Em...and....I mean it was a nice enough room, but because I didn’t have much of a view from it I did feel very enclosed, you know, yes people would come in and out but once they were out that was me alone in the room and I didn’t really like that much and all, I found that hard.” – Interview 4

Participants noted that the routine of the ward often dictated what their daily routine was and at times this did not match what they would have ideally liked it to be.

“Um.....particularly at night, you want it to kind of settle down and try and get off to sleep, but you couldn’t do that until they came round and did the meds.” –

Interview 4

Others noted that having a firm routine was helpful as it matched with what their normal life was like and therefore this felt familiar and comforting.

“I need a little bit of structure in my life. I need to have.....sort of....I think it’s with being a teacher you’re used to bells ringing and having set times and doing things. That was fine with me; I quite liked knowing exactly what was going to happen.” –

Interview 6

There is No Place like Home

The contrast between their home life and ward life was discussed. Participants who lived more rurally were used to having pleasant views and no noise pollution. This was in contrast to the busy, noisy, urban setting of the hospital in Glasgow. Participants took time to adjust to their new setting.

“I found it quite alien. At home, I look out a window and can see fields and trees and everything like that. Now in the Beatson I was in a room on my own for five weeks and em....with a tiny little window, and I found it very difficult to, cope with that.” – Interview 6

They indicated that they missed their own environment and in particular their home comforts. Some participants had brought items from home to try to cope, with the

aim of creating a 'home from home' in their hospital room. Others who did not do this, spoke retrospectively about how they wish they had.

"Just being able to lie there in your hospital bed with your own blanket over you em....and your own...just your own things around you, being able to comfort you, are a humungous help." – Interview 5

"I wanted to make it more homely, but maybe that wasn't possible. I was just desperate to get home to my own things. I think looking back I should have maybe taken more things down with me. [...] But looking back I would maybe have taken my own pillow, you know little things to make it more....even things to make it smell more like home." – Interview 6

Many of the participants had spent some time on a ward in their local hospital prior to their transplant, and the difference in their experience of each hospital was discussed. They noted that being close to home meant that they were able to have more frequent visits and from a wider range of people. These factors made coping in a hospital setting easier.

"I spent a long time in hospital in Raigmore, but when, that was like local and I could cope because people popped in and out to see me, and they didn't need to stay long, it wasn't the length of time they spent with me, it was just the contact." – Interview 6

Participants spoke strongly of their desire to return home as soon as possible. Often this became more prominent the closer they got to discharge.

"I was starting to, this was the point when I had recovered enough, I was starting to feel I want out and I couldn't get my mind off it despite how many distractions I had. It was I want out and I want out now!" – Interview 2

Despite missing home, participants understood that they needed to be in Glasgow, as this was the only place that they could receive their treatment. They acknowledged this meant they were receiving treatment from 'experts' in the procedure which gave them confidence.

"I trusted the people down there, you know, obviously. I think they have to do minimum 40 per year don't they, to get the accreditation. I think it's the only place in Scotland so they are obviously experts at what they do and em.... professional.... they know what they are doing so you tend to..... the doctors were very good." - Interview 1

Social Support is Key

Social support was endorsed by all participants as one of their most used strategies. Most had the support of a spouse or a family member in Glasgow with them. Participants also described how their network would take opportunities to make connections, such as colleagues visiting when in Glasgow for business.

“I think he was really my security blanket sort of thing. You could say. Just knowing that he was in Glasgow and that he would be able to come in and visit me once a day, it was, it was really good.” – Interview 4

Social contact was also made by phone or email. Although technology helped bridge the gap created by the distance, it was not seen as providing the same level of comfort and support as face to face contact.

“I mean the phone calls helped every evening but it’s not the same as seeing them in person. So actually having them physically sitting there and eh....talking with them, catching up and stuff like that. It was a huge help.” – Interview 2

As well as receiving social support from existing avenues, participants created new networks of social support in Glasgow. They accessed this support from other patients, the haemato-oncology staff and other hospital staff. Staff members who were not involved in their medical care were frequently named as useful sources of support. For example, participants reported feeling grateful for the conversations they had with domestic staff about everyday life and topics unrelated to their treatment.

“The domestics were some of the best, the cleaners who came in, because they liked to talk to you while they were cleaning the rooms, which was good. It took your mind off things.” – Interview 2

Throughout the interviews it became clear that the personal qualities and attributes of staff contributed positively to the support they offered. Staff were often described as going ‘above and beyond’ their role and appeared attuned to the needs of their patients.

“One of the nurses noticed that I was getting really quite down on my second visit and bought me a dancing turtle, a dancing turtle toy which cheered me no end. I just felt switching it on and having it dance, that was good.” – Interview 2

Known versus Unknown

The unknown was considered to be a source of stress during treatment. Participants described how many aspects of treatment presented as an ‘unknown’, for example if the treatment would work, what the recovery phase would feel like and how much they would miss home.

“I’d been to the MacMillan and saw people get chemo, but I knew this was really strong chemo so I didn’t know what to expect, so that was eh.. a bit of... a bit of a concern.” – Interview 1

Making the unknown, known was said to be a way of coping. People described seeking out the information they needed to cope. An example of this was when participants would travel down to Glasgow for a pre-treatment visit, to see the ward and the facilities and be told about the treatment process; finding out this information and being able to visualise what was going to happen helped them cope.

“You get to meet the nurses, you get to see the eh, Friends of the Beatson, which is along the corridor. And..... em I guess I also got to see a room because one of them was empty. So I actually knew what the environment that I was going into when I was going down.” – Interview 2

Others noted some anxiety around what the answers to their questions might be. In this example leaving the unknown as an unknown was described as a way of trying to cope, as it avoided potentially distressing information.

“My husband has Googled everything, but I just haven’t. Even though I work in a hospital [laughs].” – Interview 3

Participants discussed how aspects of their normal life routine had prepared them for their treatment far from home. For example, some participants had experience of working away and therefore they knew what it was like to be away from home and how to cope with this. The prior experience made potential unknown aspects of treatment a known and therefore participants approached these with greater confidence.

“So because I work in IT, I work two days a week from home and then three days I need to be down in [Scottish City]. So I was staying in a hotel for that anyway, so I was quite used to being away from home and working. So that, aspect didn’t really impact, because I was used to it, to being away from home.” – Interview 2

Technology

Participants described how they used technology to bridge the gap that the distance had created and help them stay connected to their social network. They did this in a number of ways: emails, phone calls, text messages and social media.

“Yes, yes. It was by texts, on my phone. I would get texts every day and I would text them every day. I was able to keep in touch with all of them, which is really good.” – Interview 4

As well as aiding social support, technology such as TV and radio was also used as a means of coping with the long days in the ward. Technology offered an escape from feeling ill, allowing them to participate in a ‘normal’ leisure activity and could enhance positive emotions.

“Of course, you have got the entertainment factor, iPlayer if you want or download something to watch from there. So...so...so..that helped. Again, that’s part of the distraction...and.....there is YouTube, which the domestic eh... cleaners would recommend you watch it, they are usually quite funny.” – Interview 2

Participants acknowledged that contact through technology was not as beneficial as contact in person. It was also noted that technology is not for everyone, for example elderly relatives. Participants did note that they could not fully rely on technology and that it was temperamental. There were experiences where the ward wifi failed, or when they was no mobile network coverage.

“Well there was a wifi, free wifi but it didn’t work, so you know, that would have been quite good.” – Interview 1

Role of thoughts

The particular thinking style participants adopted could either act to aid or hinder coping. Some participants described having an optimistic thinking style which helped them remain positive and believe they were more able to cope.

“I would just sort of blasé it off and go “oh yeah, having a bit of a bad day but things could be worse”, “there are people worse off than me”.....that was my favourite phrase.” – Interview 5

For others, being able to access psychological support enabled them to critically examine their thoughts and move towards a more useful way of viewing things.

“Being able to discuss it with someone opens up new views on it, so if you’re feeling depressed or things are going slow, he can give another view to it.” – Interview 2

Thoughts were also found to be a barrier to coping. Particular thinking patterns lead to elevated levels of anxiety and could be overwhelming. Particularly when they were isolated in their room they noticed patterns of rumination which were found to be unhelpful in terms of their mood and coping.

“The combination of...basically boredom starts you thinking... and once you start thinking, you start thinking negative thoughts and then it starts to snowball.” – Interview 2

Participants often tried to manage this by avoiding thinking about it. Often this was done using methods of distraction such as engaging in activities.

“And eh....they played nice music and they distracted me from my thoughts, and that was good.” – Interview 6

Participants spoke of a change in perspective which occurred as they went through their treatment journey. They spoke of their outlook on life changing and they believed that this helped them feel more able to cope.

“Changes your way of thinking, which in turn changes, changes the way that you cope with things.” – Interview 5

Change of environment

After the period of isolation following the transplant, participants talked of being allowed to leave the ward once their blood counts had risen. Participants described the benefits of going outside, breathing ‘fresh air’, going for walks around the hospital ground or going to the onsite inpatient centre called Friends of the Beatson. Being able to access an environment which was a contrast to the ward, was something participants saw as strongly associated with their ability to cope.

“My bloods were coming up to a certain level, I was allowed out of the unit and to go across to this place, and it was like stepping out of a hospital and stepping into a beauty salon or a plush hotel, it was just beautiful the way they had it.” –

Interview 4

Getting out of the ward and away from a medical environment provided a sense of normality and a space for patients to engage in leisure activities in ‘normal surroundings’. It appeared that a change of environment provided respite away from treatment.

“So, that’s the place that again is a bit like a home from home as well. Because it’s so calming and relaxing, you do think, ok I am not in a hospital, I’m not ill. Albeit you might feel ill once you leave there, or you might not feel your strongest, you still feel like, ok I am sitting in a café or I’m away to do my emails or something like that, or catch up on Facebook, or read a book or something like that.” –

Interview 5

A specific factor described as important for coping was going to an environment which had large windows with nice views. The participants discussed the fact that this was similar to their home environment and the act of sitting and looking at a nice view was calming and relaxing.

“In fact, when I was allowed out of my room I would go across to the café, the Beatson, Friends of the Beatson and all I would do is look out of the window! I

found that comforting. [...] They had huge windows and it was more like, what I am used to at home. And that was comforting yeah.” – Interview 6

Moving along a journey

Participants described their treatment as an unpredictable journey. Physical and emotional health fluctuated and this impacted on a number of things including ability to cope. For some their coping could vary day to day, or was directly linked to their stage of treatment; whereas for others, it was a cumulative effect with coping getting progressively more challenging as the length of their admission increased.

“I think it got harder as my stay in the Beatson went on. At the beginning I sort of could cope with it quite well but toward, you know towards the end of the five weeks I was really struggling with the lack of contact with my family.” – Interview 6

Along this journey participants reported that they underwent processes of adaptation, slowly becoming accustomed to their situation. They noted that adapting to the circumstances allowed them to be better equipped to cope with it.

“But, eh, but you lie there at night trying to get to sleep and the fans going and eventually you do get used to it.” – Interview 1

Consequences of distance

The distance determined who was able to make the journey to visit. It was not possible for certain family members to visit due to their age, meaning the patient

was unable to have them there in person as a support in Glasgow. For others, family members did make the journey but sometimes this could cause added stress for participants, for example, if the weather was bad they found themselves worrying about their relatives travelling.

“In Glasgow you are kind of restricted because it’s, what is it...about 160-180 miles something like that, its em, you know it’s not everybody that can get down there, you know.” – Interview 1

Family members’ commitments at home such as work, other children or pets, often meant that it was complicated for them to make the journey down to Glasgow. Often these practicalities needed to be problem solved in order for the family member to visit.

“Eh.... my parents never used the overnight eh... accommodation, they preferred to go down and come up in a day, because they had my sister at home, they have got eh, well they had two dogs, then it went down to one dog, they have several cats and so there are things they need to be at home for to look after.” – Interview 2

Participants described being able to feel the distance. They were very aware that they were far from home and that this felt very real. They named this feeling as homesickness and noted that it was a difficult emotion to experience.

“I would always think my parents were coming down, and then going back I would then think they are now 170 odd miles away and that was always the hard thing, even though you were talking on the phone to them, it was still the thought of, they are at least 3 hours by car away and it’s a huge distance.” – Interview 2

Being so far from home required participants to be organised and make sure they took down everything they needed. There was a sense of once you were down, that was you down for the duration of treatment. This meant participants needed to think through what they might need and try to predict what would be helpful to pack.

“Going down on the day, the initial packing etc, because I was so far away from home I needed to make sure I had enough clothes to, to last for at least a week because you didn’t know when your parents would be coming down to do washing etc.” – Interview 2

Discussion

The transcripts of six semi-structured interviews were analysed using IPA. The results of this analysis indicated that there were ten themes relating to the coping.

Participants experienced being far from home as challenging. They understood that staying away for treatment was necessary but acknowledged that they would not have chosen things to be this way. They described being aware of the

distance, feeling homesick at times and that their desire to return home intensified the longer they were away.

In keeping with existing literature this study highlighted the importance of social support in coping with cancer treatment (Bingen et al., 2012; Moore et al., 2014; Moos & Schaefer, 1984). Despite the distance presenting a challenge to patients accessing this support, they were able to maintain contact with their existing network. The distance presented practical issues around who could visit and how often but technology offered a means to try and compensate for these practical restrictions.

Moos and Schaefer (1984) noted that the acceptability of the physical environment influenced how able people were able to utilise their coping strategies. This is supported by the results of this study. The analysis drew attention to the benefits that being in a calming, relaxing and non-medicalised environment had on coping. This was seen particularly in participants' descriptions of walking the hospital grounds and attending the Friends of the Beatson. Aspects of the ward environment were experienced as being a barrier to coping, such as the ward routine, the noise of the machines, the isolation and the filtered air system. Participants tried to deal with this by increasing the familiarity and acceptability of their surroundings by bringing items from home to act as comforters and create an environment that was more tolerable and conducive to effective coping. This step however required preparation and often patients had not anticipated that this would be an issue and therefore arrived unprepared.

Payne et al. (2000) found that receiving treatment far from home was a financial burden on patients. Although participants did discuss the financial implications of receiving their treatment in Glasgow they did not indicate that this was felt to have influenced their coping. Some of the studies in the Payne et al. (2000) review took place in countries much larger than Scotland such as Australia. Furthermore, the studies were often addressing minority or immigrant populations. This may mean that they had less of an existing network within these large countries. In the present study many of the participants had family members, friends or connections around the Glasgow area and therefore could often draw on them for help with accommodation which may explain this difference in findings.

When considering the findings in the context of Moos and Schaefer's (1984) three subtypes of coping, it appears that participants used all three types of coping, although emotion-focused coping strategies seemed to dominate. Examples of the emotion-focused strategies used include social support, distraction, emotional disclosure, relaxation, complementary therapies, attempting to suppress negative thoughts or emotions and cognitive reappraisal. Penley et al. (2002) conducted a meta-analysis which looked at the effects of adopting different coping subtypes. They found that in the long term, emotion-focused coping was not found to be as effective. They acknowledged however, that often people adopted emotion-focused coping strategies when they perceived themselves as having no control over the source of stress, and in the short term this can be a functional way of coping. As the present study was exploring coping during the treatment phase, it could be said that participants may have not believed that they had control over

their situation and may have been using emotion-focused coping strategies to cope with the short term duration of their treatment.

Participants tended to say they did not feel they had to alter their usual coping style dramatically due to the distance. This finding is similar to that found in the Hjorleifsdottir et al. (2007) study.

Strengths and Limitations

This piece of research allowed an in-depth exploration of the experiences of VUD HSCT patients from the NHS Highland region who had travelled to Glasgow to undergo their transplant. This research helped gain a deeper understanding of the important factors that influenced their coping away from home. The results will be disseminated with the relevant clinical teams and can be used to inform future patients of what others have found useful before them. Therefore it can be seen that this research has a clear clinical relevance for NHS Highland haemato-oncology patients.

There were a total of seven people who were identified as meeting the inclusion criteria of the study. All were invited to participate, with six agreeing to take part in the research. The high participation rate from the potential population is a real strength of the study. Although the overall sample is small, it is appropriate for the method (Smith et al., 2009).

The main aim of this research was not to generalise the results to the wider population, instead it hoped to gain a deeper, richer understanding into the lived

experiences of the participants. Knowing if these findings can be generalised to others who are in a similar position however, is important to think about, especially when considering the clinical implications of the study. IPA is influenced by idiography and according to Smith et al (2009), “idiography does not eschew generalisations, but rather prescribes a different way of establishing those generalisations.” (p29).

Clinical Implications

The current research findings have three potential avenues for clinical application. Firstly, the results of this study can help inform future NHS Highland patients who are about to travel to Glasgow for a HSCT. This information may go some way in making some of their ‘unknowns’ known. The results of this study may help future patients feel that they have some control in how they cope. This means they can be better prepared in what they take with them to Glasgow. The production of a patient information leaflet, based on the results of this study may be a way of doing this.

Secondly, the results of this study have implications for the hospital team members. The participants of this study discussed how the hospital team became part of their new social support network. This provides evidence that staff need to consider their role in supporting patient coping. The results indicate that this spans much wider than just the direct medical team and in fact participants were drawing on support from various members of the hospital team including auxiliaries, porters and domestic cleaners. It is important to inform these staff members of the role that they can also play in supporting patients during treatment

through small 'everyday interactions. Informing these members of staff the value that participants placed on these interactions is an important action to take.

Thirdly, with the recent relocation of the Haemato-oncology ward in Glasgow, this study provides an insight as to what elements from the old ward would be important to ensure were replicated in the new setting. The participants emphasised the importance of having an alternative environment that they could access, such as the Friends of the Beatson. They highlighted the need to be able to go somewhere which was non-medical and had aspects of familiarity and normality. It is imperative that as this department moves away from its current location, where patients have access to green space, the Maggie's centre and Friends of the Beatson, that this patient group can continue to access a similar environment easily, in order to promote positive coping and emotional wellbeing.

Future Research Directions

The new facilities at the Queen Elizabeth University Hospital include larger windows in patient rooms and access to a holistic treatment room, both of which are things that this study highlighted as important. The new facilities however, are located more centrally within the city and this may present additional challenges to coping, with added noise and less green space. Further research into patient experience of the new facilities would be an interesting next step.

Conclusion

This study has provided an in-depth exploration of the coping experiences of patients from NHS Highland who have travelled to the BWoSCC for their VUD

HSCT. It highlights that being far from home presented many challenges to coping, however participants were able to draw on supports from home, as well as new sources to enable effective coping. In keeping with previous literature social support was found to be key in coping as was a calming and familiar environment. Several clinical implications arose from the results of this study and these shall be disseminated with the relevant team.

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Chapter 3: Advance Clinical Practice I – Reflective Critical

Account (Abstract only)

Moving from a Singular Model to an Integrative Way of Working

Bethany Anderson

Mental Health and Wellbeing

University of Glasgow

1st Floor, Admin Building

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow G12 0XH

Moving from a Singular Model to an Integrative Way of Working

DCP guidance (2010) states that psychologists must be able to draw from a range of different models as required when formulating a case. I therefore use this reflective account as an opportunity to reflect on my clinical practice, looking from when I was an Assistant Psychologist, to how I am currently practicing as a final year trainee. One of the main changes and developments that I think has occurred is the movement from a rigid “text book” single model approach to an integrative way of working.

To structure my reflective account, I chose to use the Driscoll (1994, 2000) “What Model of Structured Reflection”. I found the simplicity of the model useful as it gently guides you round the reflective process whilst allowing me to think about the issues, processes, thoughts and feelings which have been present with me on this journey.

For the true development to be reflected on, I needed to think about how I went through several cycles of this model. Therefore within this reflective account I discuss moving through three cycles of the Driscoll model of reflection. The account finishes with a reflective review; commenting on the process of reflecting on these experiences.

Chapter 4: Advance Clinical Practice II – Reflective Critical

Account (Abstract only)

Working in Teams: How I Fit in and Function

Bethany Anderson

Mental Health and Wellbeing

University of Glasgow

1st Floor, Admin Building

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow G12 0XH

Working in Teams: How I Fit in and Function

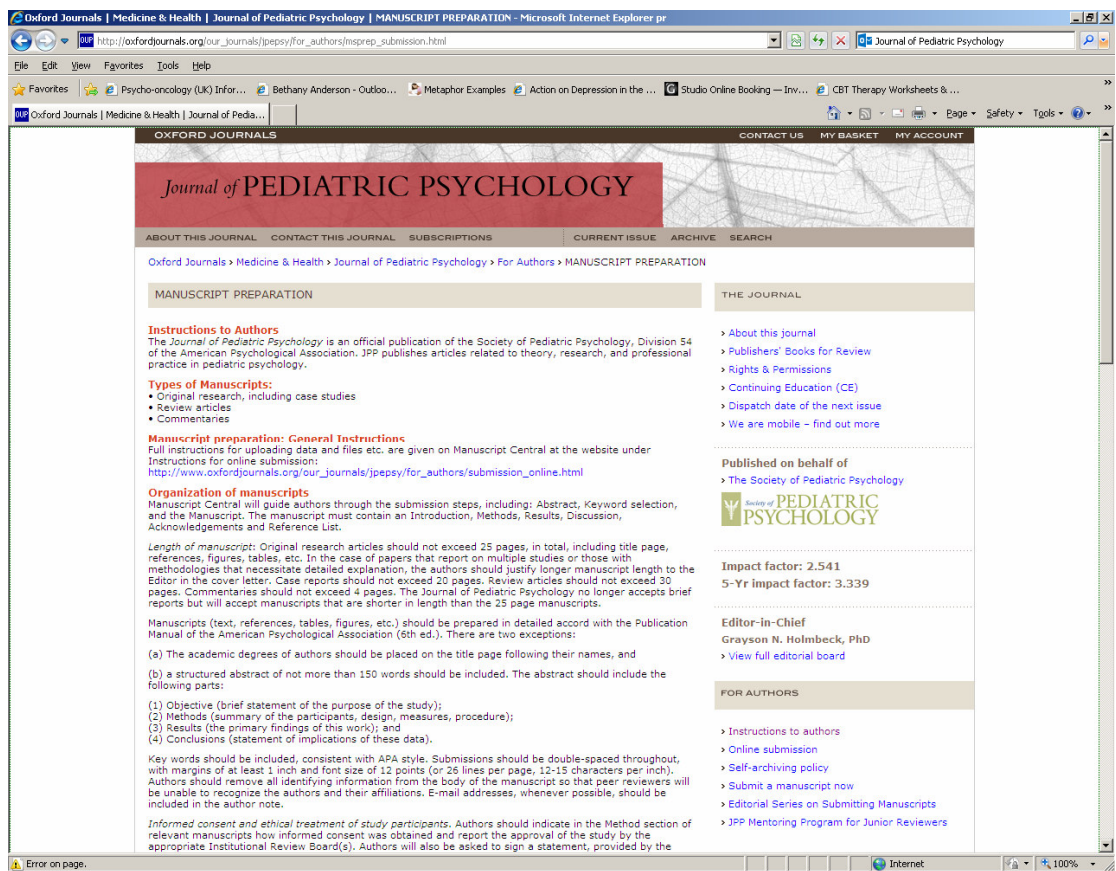
Working in teams is an essential part of the role of the Clinical Psychologist (BPS, 2007). Effective team working is of benefit to the patient, the team and on the wider organisation. Having gained experience of being a member of various teams through my training and employment as an Assistant Psychologist I decided to reflect on my contributions to each of these teams and to think critically to the aspects that shaped my involvement. I go on to reflect on how my team participation has developed across my training journey and think about how I can apply this learning to moving forward to joining new teams post qualification.

To structure this reflective account, I chose to use the Boud, Keogh and Walker model of reflection. I found this model to be a clear and concise structure to reflection. I work through this model three times to allow observation of how the outcome of one experience impacted on what I did next. I wanted the opportunity to reflect on any changes I made, things I did differently and take time to observe how this went, how it made me feel and what I learnt from the process.

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Appendix 1: Guidelines for Submission to Journal of Pediatric Psychology



Full details at:

http://oxfordjournals.org/our_journals/jpepsy/for_authors/msprep_submission.html

Appendix 2: Search Terms by Database

CINAHL search – 17th Oct

SEARCH ID	SEARCH TERMS	RESULTS
S16	S12 AND S13 AND S15	67
S15	S11 OR S14	34,824
S14	(MH "Cell Transplantation+") OR (MH "Hematopoietic Stem Cell Transplantation") OR (MH "Hematopoietic Stem Cells")	5,497
S13	S10 AND S11 AND S12	67
S12	S5 OR S6 OR S7 OR S8 OR S9	146,763
S11	S1 OR S2 OR S3 OR S4	31,260
S10	(MH "Coping+") OR (MH "Family Coping") OR (MH "Compromised Family Coping (Saba CCC)") OR (MH "Coping Support (Saba CCC)")	22,445
S9	(MH "Father-Infant Relations") OR (MH "Father-Child Relations") OR (MH "Adolescent Fathers") OR (MH "Fathers+")	5,170
S8	(MH "Mothers") OR (MH "Mother-Child Relations") OR (MH "Adolescent Mothers") OR (MH "Mother-Infant Relations")	22,423
S7	(MH "Foster Parents")	561
S6	(MH "Family+") OR (MH "Extended Family+") OR (MH "Family Relations+") OR (MH "Patient-Family Relations") OR (MH "Family Systems Theory") OR (MH "Family Attitudes+") OR (MH "Nuclear Family+") OR (MH "Dysfunctional Family") OR (MH "Ineffective Family Coping, Disabling (NANDA)")	146,382
S5	(MH "Biological Parents") OR (MH "Parent-Infant Relations+") OR (MH "Parent-Child Relations+") OR (MH "Parental Attitudes+") OR (MH "Single Parent") OR (MH "Parental Behavior") OR (MH "Adoptive Parents") OR (MH "Adolescent Parents+")	33,288
S4	(MH "Multiple Myeloma") OR (MH "Bone Marrow Neoplasms")	3,429
S3	(MH "Lymphoma+") OR (MH "Lymphoma, Non-Hodgkin's+") OR (MH "Lymphoma, Extranodal NK-T-Cell") OR (MH "Lymphoma, T-Cell, Cutaneous+") OR (MH "Lymphoma, T-Cell+") OR (MH "Lymphoma, B-Cell+") OR (MH "Lymphoma, AIDS-Related") OR (MH "Hodgkin's Disease")	13,958
S2	(MH "Leukemia+") OR (MH "Leukemia, Myeloid, Chronic") OR (MH "Leukemia, Myeloid, Acute+") OR (MH "Leukemia, Myeloid+") OR (MH "Leukemia, Lymphocytic, Chronic+") OR (MH "Leukemia, Lymphocytic, Acute") OR (MH "Leukemia, Promyelocytic, Acute") OR (MH "Leukemia, Lymphocytic+") OR (MH "Leukemia, Erythroblastic, Acute") OR (MH "Leukemia, Radiation-Induced") OR (MH "Hypereosinophilic Syndrome+") OR (MH "Retinoic Acid Syndrome")	11,751
S1	(MH "Bone Marrow Transplantation+") OR (MH "Bone Marrow") OR (MH "Bone Marrow Transplantation, Allogeneic") OR (MH "Bone Marrow Transplantation, Autologous") OR (MH "Bone Marrow Diseases+")	8,360

Medline Initial Search 24th Oct

<u>SEARCH ID</u>	<u>SEARCH TERMS</u>	<u>RESULTS</u>
S14	S11 AND S12 AND S13	258
S13	S6 OR S7 OR S8 OR S9 OR S10	279,314
S12	S1 OR S2 OR S3 OR S4 OR S5	459,235
S11	(MH "Adaptation, Psychological+") OR (MH "Social Support") OR (MH "Cognitive Reserve")	142,407
S10	(MH "Father-Child Relations") OR (MH "Fathers")	8,567
S9	(MH "Mother-Child Relations+") OR (MH "Mothers")	39,757
S8	(MH "Parenting")	10,360
S7	(MH "Family+") OR (MH "Family Relations+") OR (MH "Family Conflict") OR (MH "Nuclear Family") OR (MH "Multigene Family") OR (MH "Family Health") OR (MH "Single-Parent Family")	279,314
S6	(MH "Single Parent") OR (MH "Single-Parent Family") OR (MH "Parent-Child Relations+") OR (MH "Parents+")	107,254
S5	(MH "Bone Marrow Neoplasms") OR (MH "Hematologic Neoplasms") OR (MH "Bone Marrow") OR (MH "Bone Marrow Diseases+")	130,035
S4	(MH "Multiple Myeloma+")	31,839
S3	(MH "Lymphoma+") OR (MH "Lymphoma, Non-Hodgkin+") OR (MH "Lymphoma, Follicular") OR (MH "Burkitt Lymphoma") OR (MH "Intraocular Lymphoma") OR (MH "Composite Lymphoma") OR (MH "Lymphoma, Mantle-Cell") OR (MH "Lymphoma, AIDS-Related") OR (MH "Lymphoma, T-Cell+") OR (MH "Lymphoma, B-Cell+") OR (MH "Lymphoma, Primary Effusion") OR (MH "Lymphoma, Large-Cell, Anaplastic") OR (MH "Lymphoma, T-Cell, Cutaneous") OR (MH "Lymphoma, T-Cell, Peripheral") OR (MH "Lymphoma, Large-Cell, Immunoblastic")	145,775
S2	(MH "Leukemia+") OR (MH "Leukemia, Myeloid+") OR (MH "Leukemia, Myeloid, Acute+") OR (MH "Leukemia, Biphenotypic, Acute") OR (MH "Leukemia, Experimental+") OR (MH "Leukemia, Lymphoid+") OR (MH "Leukemia, Polymorphocytic+") OR (MH "Leukemia, Feline") OR (MH "Leukemia, T-Cell+") OR (MH "Leukemia, Monocytic, Acute") OR (MH "Leukemia, B-Cell+") OR (MH "Leukemia, Megakaryoblastic, Acute") OR (MH "Leukemia, Promyelocytic, Acute") OR (MH "Leukemia, Myelomonocytic, Acute")	196,870
S1	(MH "Bone Marrow Transplantation") OR (MH "Bone Marrow") OR (MH "Transplants+")	99,300

PsychInfo Search - 7TH November

<u>SEARCH ID</u>	<u>SEARCH TERMS</u>	<u>RESULTS</u>
S10	S6 AND S8 AND S9	11
S9	S4 OR S5	37,132
S8	S1 OR S2 OR S3 OR S7	6,850
S7	DE "Leucocytes" OR DE "Lymphocytes"	3,069
S6	DE "Coping Behavior"	38,398
S5	(DE "Mother Child Communication" OR DE "Mother Child Relations" OR DE "Mother Absence" OR DE "Adolescent Mothers" OR DE "Unwed Mothers" OR DE "Single Mothers"	1,284

	OR DE "Mothers" OR DE "Adolescent Mothers" OR DE "Schizophrenogenic Mothers" OR DE "Single Mothers" OR DE "Unwed Mothers") AND (DE "Father Child Communication" OR DE "Father Child Relations" OR DE "Father Absence")	
S4	((DE "Parent Child Relations" OR DE "Father Child Relations" OR DE "Mother Child Relations" OR DE "Parental Attitudes" OR DE "Parent Child Communication" OR DE "Father Child Communication" OR DE "Mother Child Communication")) AND (DE "Family" OR DE "Biological Family" OR DE "Extended Family" OR DE "Family of Origin" OR DE "Interethnic Family" OR DE "Interracial Family" OR DE "Military Families" OR DE "Nuclear Family" OR DE "Schizophrenogenic Family" OR DE "Stepfamily" OR DE "Family Relations" OR DE "Child Discipline" OR DE "Childrearing Practices" OR DE "Family Conflict" OR DE "Marital Relations" OR DE "Parent Child Relations" OR DE "Parental Role" OR DE "Sibling Relations" OR DE "Family Intervention" OR DE "Biological Family" OR DE "Family of Origin" OR DE "Family Therapy" OR DE "Conjoint Therapy" OR DE "Strategic Family Therapy" OR DE "Structural Family Therapy" OR DE "Family Background" OR DE "Family Socioeconomic Level" OR DE "Parent Educational Background" OR DE "Parental Occupation" OR DE "Family History" OR DE "Dysfunctional Family" OR DE "Nuclear Family" OR DE "Interethnic Family" OR DE "Family Structure" OR DE "Birth Order" OR DE "Childlessness" OR DE "Extended Family" OR DE "Family Size" OR DE "Matriarchy" OR DE "Monogamy" OR DE "Nuclear Family" OR DE "Parental Absence" OR DE "Patriarchy" OR DE "Polygamy" OR DE "Schizophrenogenic Family" OR DE "Stepfamily" OR DE "Family Members" OR DE "Adopted Children" OR DE "Adult Offspring" OR DE "Ancestors" OR DE "Biological Family" OR DE "Cousins" OR DE "Daughters" OR DE "Foster Children" OR DE "Grandchildren" OR DE "Grandparents" OR DE "Illegitimate Children" OR DE "Inlaws" OR DE "Orphans" OR DE "Parents" OR DE "Siblings" OR DE "Sons" OR DE "Spouses" OR DE "Stepchildren" OR DE "Family Medicine" OR DE "Family Crises" OR DE "Family Conflict" OR DE "Marital Conflict" OR DE "Extended Family" OR DE "Caregivers" OR DE "Home Environment" OR DE "Social Support" OR DE "Significant Others" OR DE "Relationship Quality" OR DE "Dual Careers" OR DE "Child Guidance" OR DE "Caregiver Burden")	36,366
S3	DE "Leukemias"	909
S2	DE "Stem Cells"	2,399
S1	DE "Bone Marrow"	760

Psychological and Behavioural Sciences Collection – 11TH November

<u>SEARCH ID</u>	<u>SEARCH TERMS</u>	<u>RESULTS</u>
S46	S43 AND S44 AND S45	32
S45	S39 OR S40 OR S41 OR S42	11,074
S44	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR	118,108

	S34 OR S35 OR S36 OR S37 OR S38	
S43	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12	5,964
S42	Coping Support	19
S41	Compromised Family Coping	0
S40	Family Coping	79
S39	Coping	11,074
S38	Father-Infant Relations	1
S37	Father-Child Relations	11
S36	Adolescent Fathers	36
S35	Fathers	5,702
S34	Mother-Infant Relations	5
S33	Adolescent Mothers	335
S32	Mother-Child Relations	38
S31	Mothers	20,061
S30	Foster Parents	260
S29	Ineffective Family Coping	0
S28	Dysfunctional Family	356
S27	Nuclear Family	200
S26	Family Attitudes	4,963
S25	Family Systems Theory	159
S24	Patient-Family Relations	104
S23	Family relations	2,285
S22	Extended Family	364
S21	Family	88,348
S20	Adolescent Parents	189
S19	Adoptive Parents	229
S18	Parental Behavior	3,483
S17	Single Parent	498
S16	Parental Attitudes	231
S15	Parent-Child Relations	4,651
S14	Parent-Infant Relations	4
S13	Parents	30,542
S12	Bone Marrow Neoplasms	3
S11	Multiple Myeloma	133
S10	Lymphoma	2,825
S9	Retinoic Acid Syndrome	0
S8	Lymphocytic	277
S7	Myeloid	490
S6	Leukemia	3,487
S5	Bone Marrow Diseases	34
S4	Autologous	348
S3	Allogeneic	223
S2	bone marrow	1,355
S1	Bone Marrow Transplantation	346

Appendix 3: Quality Appraisal Framework (Walsh and Downe, 2006)

Scoring key:

- Not present = 0
- Partially present = 1
- Present = 2

STAGE	ESSENTIAL CRITERIA	SPECIFIC PROMPTS	SCORE
Scope and Purpose	<ul style="list-style-type: none"> ▪ Clear Statement of and rationale for research question/aims/ purposes ▪ Study thoroughly contextualised by existing literature 	<ul style="list-style-type: none"> ▪ Clarity of focus demonstrated ▪ Explicit purpose given such as descriptive/ explanatory, intent, theory building, hypothesis testing ▪ Link between research and existing knowledge demonstrated ▪ Evidence of systematic approach to literature review, location of literature to contextualise the findings or both 	
Design	<ul style="list-style-type: none"> ▪ Method / Design apparent and consistent with research intent ▪ Data collection strategy apparent and appropriate 	<ul style="list-style-type: none"> ▪ Rationale given for use of qualitative design. ▪ Discussion of epistemological/ontological grounding ▪ Rationale explored for scientific qualitative method eg ethnography, grounded theory, phenomenology. ▪ Discussion of why particular method chosen is most appropriate/sensitive/relevant for research given research questions/aims ▪ Setting appropriate. ▪ Were data collection methods appropriate for type of data required and for specific qualitative method? ▪ Were they likely to capture the complicity/diversity of experience and illuminate context in sufficient detail? ▪ Was triangulation of data sources used if appropriate? 	
Sampling strategy	<ul style="list-style-type: none"> ▪ Sample and sampling method appropriate. 	<ul style="list-style-type: none"> ▪ Selection criteria detailed and description of how sampling was undertaken. ▪ Justification of sampling and strategy given. ▪ Thickness of description likely to be achieved from sampling. ▪ Any disparity between planned and actual sample explained. 	
Analysis	<ul style="list-style-type: none"> ▪ Analytic approach appropriate 	<ul style="list-style-type: none"> ▪ Approach made explicit e.g. thematic distillation constant comparative method, grounded theory. ▪ Was it appropriate for the qualitative method chosen? ▪ Was data managed by software 	

		<ul style="list-style-type: none"> package or by hand and why? ▪ Discussion of how coding system/conceptual frameworks evolved. ▪ How was context of data retained during analysis? ▪ Evidence that the subjective meanings of participants were portrayed. ▪ Evidence of more than one researcher involved in stages if appropriate to theoretical stance. ▪ Did research participants have any involvement in analysis? ▪ Evidence provided that data researched saturation or discussion/rationale if it did not. ▪ Evidence that deviant data was sought or discussion/rationale if it was not. 	
Interpretation	<ul style="list-style-type: none"> ▪ Context described and taken account of in interpretation. ▪ Clear audit trail given ▪ Data used to support interpretation 	<ul style="list-style-type: none"> ▪ Description of social/physical and interpersonal contexts of data collection. ▪ Sufficient discussion of research process such that others can follow decision trail. ▪ Extensive use of field notes entries / verbatim interview quotes on discussion of findings. ▪ Clear exposition of how interpretation led to conclusions. 	
Reflexivity	<ul style="list-style-type: none"> ▪ Researcher demonstrated reflexivity 	<ul style="list-style-type: none"> ▪ Discussion of relationship between researcher and participants during fieldwork. ▪ Demonstration of researchers influence on staged of researcher process. ▪ Evidence of self-awareness/insight. ▪ Documentation of effects of the research on researcher. ▪ Evidence of how problems/complications met were dealt with. 	
Ethical dimensions	<ul style="list-style-type: none"> ▪ Demonstration of sensitivity to ethical concerns. 	<ul style="list-style-type: none"> ▪ Ethical committee approval granted. ▪ Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants. ▪ Evidence of dilemmas met and how resolved in relation to ethical issues. ▪ Documentation of how autonomy, consent, confidentiality and anonymity were managed. 	
Relevance and transferability	<ul style="list-style-type: none"> ▪ Relevance and transferability evident. 	<ul style="list-style-type: none"> ▪ Sufficient evidence for typicality specificity to be assessed. ▪ Analysis interwoven with existing theories and other relevant 	

		<p>explanatory literature drawn from similar settings and studies.</p> <ul style="list-style-type: none"> ▪ Discussions of how explanatory propositions. Emergent theory may fit with other contexts. ▪ Limitations / weaknesses of study clearly outlined. ▪ Clearly resonates with other knowledge and experience. ▪ Results / conclusions obviously supported by evidence. ▪ Interpretation plausible and makes sense. ▪ Provides new insights and increases understanding. ▪ Significance for current policy and practice outlines. ▪ Assessment of value / empowerment for participants. ▪ Outlines further directions for investigation. ▪ Comment on whether aims / purposes of research were achieved. 	
TOTAL SCORE			

Appendix 4: Synthesis Process

Primary Interpretations	Secondary Interpretations	Tertiary interpretations
<p>Togetherness</p> <ul style="list-style-type: none"> ▪ Wanting to be with sick child ▪ Separation difficult ▪ Togetherness ▪ Would rather be with child ▪ Rather be at home ▪ Want to be with child ▪ Family separation ▪ Impact of relocation and separation on coping. 	<p>Treatment often meant that families were separated or had to relocate, which was a source of stress.</p> <p>Parents wanted to be with their child whenever possible.</p>	<p>Being together as a family valued highly and was seen as a key factor in coping as a family.</p> <p>Practicalities and responsibilities often presented as a barrier to togetherness and the parents were required to balance this as best they could.</p>
<p>Transitional Process</p> <ul style="list-style-type: none"> ▪ Different types of coping useful at different stages of treatment journey. ▪ Facing the situation – acceptance, ▪ Acceptance of situation ▪ Dealing with issue of “unfairness” ▪ Fathers adjusted as time went on. ▪ Impact on parent-child process transitional process ▪ Long road ahead ▪ Re-evaluating of values ▪ Changing perspectives to cope ▪ Change in outlook/perspective ▪ Maintaining positive attitude. 	<p>Parents observed a change in their outlook and what they valued as treatment journey went on.</p> <p>Parents underwent a process of adjustment towards acceptance</p> <p>Types of coping depended on where about on the transitional process parents were.</p>	<p>Parents worked through a transitional process of adjustment / acceptance and the type of coping they needed varied according to this process.</p>
<p>Disruption to ‘normal’ life</p> <ul style="list-style-type: none"> ▪ Disruption to daily routine ▪ Experiences of normalcy appreciated ▪ Longing for normalcy ▪ Trying to maintain some semblance of normal existence ▪ Moments of normality helped cope. ▪ Keeping a sense of normalcy a challenge ▪ Practicalities of normal life challenging ▪ Uncertainty impacted on organising daily life ▪ Employment had to fit around 	<p>Many aspects of normal life were disrupted due to treatment.</p> <p>Any aspects of normalcy appreciated in aiding coping.</p> <p>Attempts made to try to be as close to normal as possible, although treatment made this a challenge.</p>	<p>Normal life was inevitably disrupted by treatment, which threw up many practical challenges to coping. Parents had to manage these challenges whilst trying to maintain any aspects of normalcy that could continue.</p>

<ul style="list-style-type: none"> hospital visits Schooling disrupted Employment disruption impacted on income. Increase outgoings due to hospitalisation. Relocation uncertainty 		
<p>Support from others</p> <ul style="list-style-type: none"> Family support – helpful if available Social support received from many avenues At times support overwhelming Most support from spouse Support from others families: comfort, shared camaraderie, help each other with care, limits to support. Support of allied health: providing breaks for parents, child's need for personal space. Practical support useful Less people for fathers to talk to. Schooling providing support. Practical / physical help from extended family Medical team as a source of support Other patients on ward Religious rituals 	<p>Support from others helpful when available.</p> <p>At times support could be overwhelming and depended on child's health.</p> <p>Support accessed from many different places.</p> <p>Different types of support sought from others.</p>	<p>Support from others was key to parental coping, with parents accessing practical, emotional, financial, social support.</p> <p>The usefulness of this support depended on the amount and intensity of the support as well as the current health status of the child.</p>
<p>Gender specific issues</p> <ul style="list-style-type: none"> Challenging gender stereotypes Male stereotypes not always apply Fathers' and mothers' seeking support from different sources Fathers use physical activity for coping Fathers used information seeking to help coping Males less expressive of emotions 	<p>Many typical male stereotypes with regards to emotional coping did not apply.</p> <p>Fathers' did show different patterns of coping to their wives.</p>	<p>Although patterns of coping and the journey of adjustment appeared to be different for the fathers and mothers, they did not appear to fit into gender stereotypes.</p>
<p>Interpersonal / Relationship Issues</p> <ul style="list-style-type: none"> Impact on spousal relationship Open communication Stress of coping impact on marriage Lack of opportunity to communicate with spouse Feeling powerless Finding balance between being protective and allowing autonomy 	<p>Coping with treatment had an impact on the spousal relationship:</p> <ul style="list-style-type: none"> a) a strengthening b) a strain <p>Open communication important relationship issue but practicalities of coping with treatment</p>	<p>The treatment process put pressure on the marital relationship, but the effect of this varied with some coupled observing a strengthening and others a strain.</p>

<ul style="list-style-type: none"> ▪ Complementarity in the relationship 	often made this difficult.	How couples communicated through the process and worked together to cope with the stressors of treatment affected the impact on the relationship.
<p>Emotional response</p> <ul style="list-style-type: none"> ▪ Males less expressive of emotions ▪ Uncertainty impacts on emotions ▪ Fathers not always expressing feelings ▪ Emotional distressed experienced as 'abnormal' ▪ Crying ▪ Anger ▪ Emotional equilibrium directly related to child's physical condition ▪ Take 'time outs to cope' ▪ Stress coping with child's emotional reaction ▪ Men do cry 	<p>Fathers' less expressive with emotions and used taking 'time outs' as a means of coping.</p> <p>Strong levels of emotions experienced during treatment period.</p> <p>Range of emotions commonly experienced.</p>	<p>Treatment evoked a range of strong emotions that parents had to cope with. The ways in which they expressed these emotions and coped with them varied according to gender.</p> <p>Often emotions in parents linked to emotions experienced by child.</p>
<p>Roles</p> <ul style="list-style-type: none"> ▪ Care joint effort of parents ▪ Parents take different roles ▪ Taking on new tasks / roles ▪ Provider / breadwinner ▪ Diving responsibility, decision making and care tasks. ▪ Other siblings needs ▪ Trying to maintain role of 'mother' ▪ Taking on difficult jobs for each other – to protect one another 	<p>Having to take on different roles added pressure.</p> <p>Taking on different roles was a necessity.</p> <p>Working as a team to make it manageable.</p>	<p>Coping with treatment requires the family system to reorganise and role and responsibilities to be re-allocated. Practicalities often dictate how this will be done, however efforts were made where possible to try to maintain as much of old role as possible, feeding in to the desire to maintain some sense of normalcy.</p>
<p>Practicalities of treatment</p> <ul style="list-style-type: none"> ▪ Combating boredom ▪ Exhaustion ▪ Poor nutrition ▪ Having to bear witness to child's experience ▪ Invasive procedures and aggressive drugs 	<p>Positive environmental factors on the ward aided coping.</p> <p>Many practicalities of treatment presented as a barrier to coping.</p>	<p>Practicalities of treatment often presented as barriers to coping for parents. Some of these impacted on the parents emotional state. A</p>

<ul style="list-style-type: none"> ▪ Difficult witnessing the treatment ▪ The hospital comfort zone ▪ The ward as a sanctuary ▪ Home base ▪ Associated with recovery ▪ Stress obtaining enough information ▪ Stressed by complexity of treatment 		<p>positive recovery focused calming environment in the ward could help ease these obstacles.</p>
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Appendix 5: Major Research Project Proposal

Abstract

A haematopoietic stem cell transplant (HSCT) is a medical procedure in which stem cells harvested from bone marrow, peripheral blood or umbilical cord are transplanted. This intervention can be used to treat cancers and bone marrow failure syndromes affecting the production of healthy blood cells. In 'allogeneic' transplants (a donor's cells are transplanted) a sibling is commonly used as a donor, but when this is not possible, a non-related donor can also be used (Volunteer Unrelated Donor transplant (VUD)). The process of undergoing a HSCT involves an often lengthy hospital admission.

Across Scotland, all patients undergoing an allogeneic bone marrow transplant from a non-related donor (VUD) will attend the Beatson West of Scotland Cancer Centre (BWoSCC) for their procedure. For patients from the NHS Highland region this can mean they have to travel long distances and are often away from home for lengthy periods of time during the course of their treatment.

This project aims to gather the experiences of patients living within the NHS Highland region who have had to travel to the BWoSCC in Glasgow to receive their VUD haematopoietic stem cell transplant, examining the impact on the patient's perceived coping of travelling such a distance and remaining away from home for the duration of their treatment.

The project will use a qualitative design, looking retrospectively at participants experiences. Semi-structured interviews will be used to gather the experiences and views of participants. The data will be analysed using Interpretive Phenomenological Analysis (IPA).

The results of this study will provide a deeper understanding of the factors and resources which aided patients' coping and resilience. This information can then be used to help prepare future patients embarking on their own treatment journey.

Introduction

Haematopoietic Stem Cell Transplants

A haematopoietic stem cell transplant (HSCT) is a medical procedure in which stem cells, harvested from the bone marrow, peripheral blood or umbilical cord, are transplanted. It is an intervention which can be used to treat cancers and bone marrow failure syndromes affecting the production of healthy blood cells, such as leukaemia, lymphoma, myeloma and severe aplastic anaemia. (NHS Choices, 2012)

Bone marrow transplants can be 'autologous' (patient's own cells are removed, then transplanted back in following a course of high dose chemotherapy / radiation therapy) or 'allogeneic' (a donor's cells are transplanted). In allogeneic transplants a matched sibling can be used as a donor, but when this is not possible, a non-related donor can also be used (Volunteer Unrelated Donor transplant (VUD)). (Chen, 2013)

The process of undergoing a HSCT involves an often lengthy hospital admission. In preparation for their transplant, patients undergo a course of 'conditioning therapy' which aims to kill unhealthy cells, thus allowing room for the new healthy cells to grow. Conditioning therapy also weakens the immune system reducing the chance of the patient's body rejecting the new cells. Consisting of high dose chemotherapy and sometimes radiotherapy and/or antibody therapy, the conditioning therapy lasts one to nine days, with the transplant being given the following day.

Following this, the patient's initial bone marrow ceases production and depending on the intensity of the conditioning treatment, severe symptoms may develop such as sore mouth, diarrhoea and significant infections. In the period directly after the transplant, patients need to stay in hospital to allow their blood cells to regenerate. Due to low blood cell counts regular blood or platelet transfusions will be given until the transfused haematopoietic stem cells start to grow. The low white cell count and side effects from the conditioning therapy mean that patients at this stage are at high risk of infection and it is therefore important that the patient is kept in a "clean environment", hence the need for hospitalisation at this stage. The length of stay varies depending on the type of transplant and conditioning therapy and ranges from three to six weeks on average, but in a few cases can be significantly longer. (NHS Choices, 2012)

The Beatson West of Scotland Cancer Centre

Across Scotland, all patients undergoing an allogeneic bone marrow transplant from a non-related donor (VUD) will attend the Beatson West of Scotland Cancer Centre (BWoSCC) for their procedure. The BWoSCC, in Glasgow is the largest cancer centre in Scotland and is the second largest in the UK with an estimated 8000 new patients being seen every year (www.beatson.scot.nhs.uk, 2013). The BWoSCC is the only accredited centre for VUD transplants across Scotland (Joint Accreditation Committee of Cellular Therapy, 2012)

The NHS Highland region

The approximate population of the Scottish Highlands is 222,370, representing 4.2 per cent of the total population of Scotland. (National Records for Scotland, 2012) The land area (26,484 sq km) however represents 33 per cent of that of Scotland and parts of the Highlands are the most scattered and remotely populated areas of the United Kingdom. (www.highland.gov.uk). NHS Highland covers this area excluding the Western Isles, Orkney and Shetland which have their own NHS Health Boards. In April 2006 Argyll & Bute Community Health Partnership (CHP) became part of NHS Highland. Within this region services are provided to a population of approximately 90,500 people across an area of 6,909 sq km. (NHS Highland, 2006). Please refer to Appendix 3 for a map of the full NHS Highland region. Even within the health board, patients often have to travel long distances to receive treatments and services which are often centralised in Inverness. As previously stated, patients living within the NHS Highland region are required to travel outside the Health Board for their VUD HSCT. This can mean they have to travel long distances (e.g. approximately 170 miles from Inverness, 278 miles from Thurso and 207 miles from Portree) and are often away from home for lengthy periods of time during the course of their treatment.

The HSCT team at the BWoSCC have been piloting virtual clinics using video technology since May 2013. The patient attends a clinic at Raigmore Hospital, Inverness with an experienced senior haematology nurse as facilitator there and an HSCT consultant via video link in Glasgow. This has significantly reduced the requirement to travel to Glasgow for post-treatment follow-up. Patients are still required to attend the BWoSCC for their conditioning therapy and transplant.

Travelling for Treatment

Travelling long distances for treatment can result in many potential difficulties including financial implications (McConigley et al., 2011, Scoggins et al., 2012) and time spent travelling (Scoggins et al., 2012). Despite this McConigley et al. (2011, p.6) found that patients living in rural Australia reported that receiving treatment far from home was acceptable if it had been the treatment of choice advised to them by their physician. Receiving treatment away from home, however, means that people are away from their normal social network and the supports they would routinely access. This is particularly important as Binger et al. (2012) reported that “the most effective coping strategy [...] was using social support” (p146).

Other studies have investigated the advantages of receiving treatment close to home. Benson (2006) compared patients who received blood transfusions at home, (or within close proximity to their home) compared with those who received their treatment in hospital. Patients reported the advantages of being treated near their home. “Remaining at home during medical therapy or only travelling short distances to a local clinic provides greater comfort for debilitated patients and is less frightening for paediatric patients.” (Benson, 2006, p219) A Swedish study looked specifically at VUD transplants, comparing patients who received their post-transplant follow up care within their own home with patients who remained in hospital for their follow up care. They noted that there were positive health benefits to receiving follow-up treatment at home including “fewer days on total parenteral nutrition, less acute graft-versus-host disease grades, and lower transplantation-related mortality rates.” (Svahn et al., 2002, p4317). Receiving follow-up treatment at home is not currently available within Scotland and patients are expected to attend hospital for this. Overall, these studies indicate clear benefits of receiving treatments within the patients’ local area.

Palmer and Collie (2011) investigated the experiences of patients across Scotland who had travelled to the BWoSCC for their post-VUD follow up care as well as receiving some follow up appointments within their local health board. The study compared the experience of travelling for follow-up care with receiving services locally. The current study hopes to build and expand on this work by looking at the experience of receiving the actual transplant procedure far from home. Palmer and Collie’s participants had varied travel durations to the BWoSCC. Some were relatively short and a round trip could easily be completed within the day (e.g. 40 minutes each way), whilst others were much longer (maximum 9.5 hours each way). Therefore, to promote a homogeneous group and to aid better understanding of the impact of long distance travel on treatment, the current study will focus on the experiences of people who had to travel distances greater than 100 miles for treatment.

Coping in Cancer

Yoo et. al. (2014) described coping within cancer as consisting of two elements, cognitive coping and behavioural coping, which people utilise to reduce and manage the effects of stressful events. A vast amount of research has looked into the different types of coping styles which people utilise to try to cope with physical illness. Moos and Schaefer (1984) categorise coping skills into three subtypes: appraisal-focused coping; problem-focused coping; and emotion-focused coping (p.59). According to this theory the type of coping skills used, can determine patient outcomes in terms of quality of life and psychological well-being (Moos & Schaefer, 1984 and Schoulte et al., 2001). Moos and Schaefer note that there are different factors that impact on patients' ability to use these coping skills. One of the factors they discuss is "physical and social/environmental factors, such as the accessibility of social support networks and the acceptability of the physical environment". (p.61) This study aims to explore the coping styles and strategies adopted by NHS Highland region patients during their stay in the BWoSCC for their VUD stem cell transplant procedure and investigate how they managed to utilise or adapt coping strategies to fit with the available resources.

A study investigating quality of life in head and neck cancer patients found that they used their social network as a source of coping throughout their treatment (Moore et al., 2014). Furthermore Vickberg (2008) found that social support was an important factor in reducing and managing cancer related stress. These findings are of particular importance for the current study as the extended period of time VUD patients may have to be away from home may limit face to face access with their social network. This could therefore be a relevant hurdle to coping. However, with the ever increasing range of communication technologies (mobile phones, email, social networking platforms, instant messaging services and online video-call programmes such as Skype or Face-Time), it could be hypothesised that patients are able to maintain a reasonable connection with their social network even whilst receiving their VUD transplant.

A quantitative Icelandic study (Hjorleifsdottir et al., 2007) looked at a measure of coping in patients who had received chemotherapy and radiotherapy either close to home or at a facility where they needed to stay away from home for at least 24 hours. No significant difference was found in the ways in which the patients in either experimental group coped. This indicated that despite the barriers and challenges of staying in hospital for treatment, the participants managed to utilise coping strategies effectively. However, it is not clear exactly how long the patients spent away from home. To meet the inclusion criteria to be in the "away from home group" they had to have spent only 24 hours or over in hospital. Hjorleifsdottir's study describes patients undergoing treatments often lasting between three and five days. The current study aims to build on this research, looking specifically at VUD patients who will have been away from home for a more prolonged period of time thus aiming to deepen our understanding of the lived experience of patients receiving their treatment far from home and specifically exploring their perceived coping and the factors that helped or hindered this.

Payne et al., (2000) conducted a literature review, examining the consequences of travel for cancer patients. The paper noted that "travel to cancer treatment is described as inconvenience and a particular hardship for many patients. It may be

perceived, or experienced as, a barrier to treatment for some. Future studies should broaden their research questions to evaluate quality of life and perceived social support.” (Payne et al., 2000, p203). It is this gap in the literature that the present study hopes to investigate further. It will examine the experience of the patient in terms of perceived coping and resilience and will consider the patient’s social support and its impact on their coping.

Aims

Primary aim:

- This project aims to explore the experiences of patients who live within the NHS Highland region who have had to travel to the BWoSCC in Glasgow to receive their VUD haematopoietic stem cell transplant.

Secondary aim:

- It aims to investigate how the experience of travelling such a distance and remaining away from home for the duration of treatment affects the patients’ perceived coping.

The results of this study will provide a deeper understanding of the factors and resources which aided patients coping and resilience. This information can then be used to help prepare future patients as they embark on their treatment journey.

Research Question

Primary research question:

- How did the experience of travelling over 100 miles for treatment, impact on perceived coping of VUD HSCT patients living in the NHS Highland region?

Secondary sub-questions:

- What barriers to coping were identified that arise from patients receiving treatment over 100 miles from home? How did they manage these?
- What coping strategies did patients from the NHS Highland region find most useful when receiving VUD HSCT over 100 miles from home?
- Were the coping strategies used, when receiving a VUD HSCT over 100 miles from home, similar or different to those the patients would routinely use in stressful situations?

Participants

Patients living within the NHS Highland region at the time of their treatment, who travelled to Glasgow to undergo a VUD HSCT at the BWoSCC between the years of 2010 and 2014 will be invited to participate in the current study. If the desired sampled size is not able to be obtained from this time period, patients who received their treatment between 2007-2009 will also be invited to participate. Sampling from more recent years will be attempted first as it is considered that recall is likely to be easier in those who have undergone the treatment more recently.

The study will restrict the population to those who have had a VUD transplant which was a “9/10” or “10/10” anti-body match. This specifies the degree to which

the patient and the donor's anti-bodies match. A "10/10" is considered an exact match. This will ensure as much of a homogeneous group as possible in terms of treatment procedure.

Recruitment procedures

The Nurse Consultant in Cancer Care (Haemato-oncology team NHS Highlands) will be asked to act as a gatekeeper to patient identifiable information. They will be asked to compile a list of all patients living within the NHS Highland who have undergone a VUD HSCT within the previously mentioned time period. They will give each potential participant a number. Ten numbers will be chosen at random and the Nurse Consultant will send out information about the study in the form of a participant information sheet and if they wish to take part, asking them to provide written consent for their details to be passed to the researcher to allow contact to be made. No other information will be passed to the researcher. The Nurse Consultant will be named on the participant information sheet as an independent contact person. Potential participants will be able to contact them for independent advice regarding participation in the study. They will be asked to make contact within two weeks otherwise it will be assumed that they do not wish to participate in the project. In this case further participant numbers will be drawn at random and invitations will be sent out. This process will be completed until the project has recruited up to ten participants.

Design

The project will use a qualitative design, looking retrospectively at participants experiences. It is acknowledged that collecting data retrospectively can raise some concerns around the validity of the results as forgetting and distortions have been found to increase over time (Moss & Goldstein, 1979). However due to the high personal salience of a VUD HSCT, it is believed that the event will be memorable and therefore the use of a retrospective in-depth interview would be appropriate in this case. "Recollection as a process of selection can also be seen as valid, if necessarily subjective, source in itself for analysing those aspects of a respondent's life which are interpreted by her or him as being most salient." (Moss & Goldstein, 1979, p93)

Semi-structured interviews will be used to gather the experiences and views of participants. Participants will each complete a single interview lasting up to one hour.

The development of the interview guide questions will include drafts being sent to members of the haemato-oncology teams both at the BWoSCC and Raigmore Hospital to provide feedback. As a further way of ensuring good validity of the interview guide, the first two interviews will be transcribed and reviewed by the researcher and supervisor to ensure that they are successfully eliciting the desired type of information. Any amendments to the interview guide at this point will be completed before recommencing interviews.

Data analysis

The project will use a qualitative research method. Data will be analysed using Interpretive Phenomenological Analysis (IPA). This method of analysis has been chosen as IPA is concerned with the "examination of how people make sense of

their major life experiences” (Smith et al., 2009). It was therefore thought that IPA would be well suited to answering the research questions. This method of analysis would respect each participant as an individual who has experienced a similar event, but acknowledge that how they experienced it would be personal to them. The use of IPA would help clarify how the individuals concerned make sense of these life experiences, whilst looking for any common themes shared by participants.

Justification of sample size

The aim is to recruit between four and ten participants. According to Smith et al., (2009, p.52) this is the recommended number of interviews for research completed as part of a professional doctorate using IPA.

Settings and equipment

Interviews will take place within the NHS Highland Haematology Outpatient Clinic which is based in Raigmore Hospital, Inverness. Telephone interviews will also be offered as an option, to help facilitate patients who live some distance from Inverness. Where possible the patient will be given the option to have the interview scheduled for a date they are due to travel to the department for a review appointment to reduce their need to travel. Appendix 4 highlights the equipment the project will use.

Health and safety issues

To ensure the health and safety of both researcher and participants local policies and guidance will be followed including the long working policy. A completed Health and Safety form can be found in Appendix 6.

Ethical issues

The research project will go through the NHS Research Ethics Committee (REC) – Proportionate Review Service. The project will be registered and sponsored by NHS Highland Research and Development department.

By having the Nurse Consultant in Cancer Care as an independent contact on the participant information sheet it is hoped that this will provide the potential participants with a contact with whom they can discuss the project further without feeling any influence to participate.

Written consent (for participation, recording, transcribing of interviews and publishing of anonymised quotations) will be obtained from all participants prior to conducting interviews. The participants will be made fully aware that they have the right to discontinue the interview and withdraw from the project at any point.

When thinking about ethical considerations it is important to acknowledge that there is a possibility that when discussing the experience of their transplant, participants may become upset or distressed. The procedures outlined in Appendix 3 will be implemented to try to manage any participant distress that may arise.

Data Management

Information collected will be kept in accordance with the Data Protection Act (1998) as well as NHS Highland and University of Glasgow policy.

Financial issues

As it is planned that the equipment will be borrowed from the department the only financial costing for the project will be printing costs and postage costs. Please refer to Appendix 4 for full details of the financial costs of this project.

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811–824

Appendix 6: Author Guidelines for Submission to European Journal of Cancer Care

The screenshot displays the 'For Authors' page of the European Journal of Cancer Care. The browser address bar shows the URL: [onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1365-2354/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2354/homepage/ForAuthors.html). The page features a left-hand navigation menu with sections: JOURNAL TOOLS (Get New Content Alerts, Get RSS feed, Save to My Profile, Get Sample Copy, Recommend to Your Librarian), JOURNAL MENU (Journal Home), FIND ISSUES (Current Issue, All Issues), FIND ARTICLES (Early View), GET ACCESS (Subscribe / Renew), FOR CONTRIBUTORS (OnlineOpen, Author Guidelines, Submit an Article), ABOUT THIS JOURNAL (News, Overview, Editorial Board, Permissions, Advertise, Contact), and SPECIAL FEATURES (Wiley Job Network, Transition to Online Only from 2013, New Books in Oncology). The main content area includes the journal's title, a description as a multidisciplinary journal for cancer research, the editor's name (David Weiler), impact factor (1.564), ISI Journal Citation Reports ranking, and the online ISSN (1365-2354). A prominent 'Author Guidelines' section details the submission process, including the online submission portal, contact information for support, and the requirement for a covering letter. It also outlines the criteria for authorship based on the ICMJE guidelines. A sidebar on the right contains a search bar, a 'Now Published!' announcement for a clinical oncology handbook, and a 'Click here to find out more' button. The bottom of the page shows the Windows taskbar with various application icons and the system clock indicating 13:03 on 23/07/2015.

Full details at: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1365-2354/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2354/homepage/ForAuthors.html)

Appendix 7: University of Glasgow Letter of Approval



University of Glasgow | College of Medical,
Veterinary & Life Sciences

TMcMLC

13th Friday 2014

Bethany Anderson

Dear Bethany

Doctorate in Clinical Psychology Major Research Project

'Home Sick': Exploring the impact of receiving a volunteer unrelated donor haematopoietic stem cell transplant far from home on the perceived coping of patients residing in the NHS Highland region.

The above project has been reviewed by your University Research supervisor and by a member of staff not involved in your project and has now been deemed fit to proceed to ethics.


Congratulations and good luck with the study.

Yours sincerely,

T M McMillan
Professor of Clinical Neuropsychology
Research Director

Doctorate in Clinical Psychology
Programme Director: Dr Hamish McLeod

Appendix 8: NHS Solihull Research Ethics Committee Letter of Approval

 Health Research Authority NRES Committee West Midlands - Solihull The Old Chapel Royal Standard Place Nottingham NG1 6FS Tel: 0115 883 9436		
17 October 2014		
Miss Bethany Anderson Trainee Clinical Psychologist NHS Highland Department of Psychological Services New Craig's Hospital Leachkin Road Inverness IV3 8NP		
Dear Miss Anderson		
Study title:	'Home Sick': Exploring the impact of receiving a volunteer unrelated donor haematopoietic stem cell transplant far from home on the perceived coping of patients residing in the NHS Highland region.	
REC reference:	14/WM/1183	
IRAS project ID:	158316	
Thank you for your correspondence of 17 October 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 09 October 2014		
Documents received		
The documents received were as follows:		
Approved documents		
The final list of approved documentation for the study is therefore as follows:		
Document	Version	Date
Covering letter on headed paper [Invitation Letter]	2	19 September 2014
Interview schedules or topic guides for participants [Topic Guide - Version 1]	1	18 July 2014

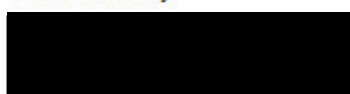
IRAS Checklist XML [Checklist_30092014]		30 September 2014
Letter from sponsor [Sponsor Letter]	1	23 September 2014
Letters of invitation to participant [Invitation Letter - Version 2]	2	19 September 2014
Participant consent form [Consent Form - Version 1]	1	18 July 2014
Participant information sheet (PIS) [Participant Information Sheet Version 2]	2	17 October 2014
REC Application Form [REC_Form_30092014]		30 September 2014
Research protocol or project proposal [Protocol - Version 7]	7	19 September 2014
Summary CV for Chief Investigator (CI) [Bethany Anderson CV]	1	18 July 2014
Summary CV for supervisor (student research) [Sarah Wilson CV]	1	18 July 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/WM/1183

Please quote this number on all correspondence

Yours sincerely



Ellen Swainston
REC Manager

E-mail: nrescommittee.westmidlands-solihull@nhs.net

Copy to: *Ms Frances Hines*

Appendix 9: NHS Highland Research and Development Letter of Approval

Professor Angus Watson
Research & Development Director
NHS Highland Research & Development Office
Room S101
Centre for Health Science
Old Perth Road
Inverness
IV2 3JH



Tel: 01463 255822
Fax: 01463 255838
E-mail: angus.watson@nhs.net

21 November 2014

NHS Highland R&D ID: 1043
NRSPCC ID: NA

Miss Bethany Anderson
Trainee Clinical Psychologist
Department of Psychological Services
New Craigs Hospital
Leachkin Road
Inverness
IV3 8NP

Dear Miss Anderson,

Management Approval for Non-Commercial Research

I am pleased to tell you that you now have Management Approval for the research project entitled: **"Home Sick": Exploring the Impact of Receiving a Volunteer Unrelated Donor Haematopoietic Stem Cell Transplant Far From Home on the Perceived Coping of Patients Residing in the NHS Highland Region**. [Protocol V7 19/09/14]. I acknowledge that:

- The project is sponsored by NHS Highland.
- The project does not require external funding.
- Research Ethics approval for the project has been obtained from the West Midlands – Solihull Research Ethics Committee, (Reference Number: 14/WM/1183)
- The project is Site-Specific Assessment exempt.

The following conditions apply:

- The responsibility for monitoring and auditing this project lies with NHS Highland.



Headquarters:
NHS Highland, Assynt House, Beechwood Park, Inverness, IV2 3HG

Chairman: Mr Garry Coutts
Chief Executive: Elaine Mead
Highland NHS Board is the common name of Highland Health Board

- This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the Research Governance Framework for Health and Community Care in Scotland (2006, 2nd Edition), however prior written notice of audit will be given.
- All amendments (minor or substantial) to the protocol or to the REC application should be copied to the NHS Highland Research and Development Office together with a copy of the corresponding approval letter.
- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be copied to the NHS Highland R&D Office.
- Monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month.

Please report the information detailed above, or any other changes in resources used, or staff involved in the project, to the NHS Highland Research and Development Manager, Frances Hines (01463 255822, frances.hines@nhs.net).

Yours sincerely,



Frances Hines
R&D Manager

cc [Frances Hines](#), R&D Manager, NHS Highland Research & Development Office,
Room S101, The Centre for Health Science, Old Perth Road, Inverness, IV2 3JH

Appendix 10: Participant Invitation Letter



Title: 'Home Sick': Exploring the impact of receiving a volunteer unrelated donor haematopoietic stem cell transplant far from home on the perceived coping of patients residing in the NHS Highland region.

<Date>

Dear <name>

I am writing to let you know about some research that is being completed by a final year Trainee Clinical Psychologist, called Bethany Anderson working within NHS Highland. Bethany is completing the research study as part of her doctoral degree at the University of Glasgow.

Bethany is interested in learning about how the experience of travelling a long distance and remaining away from home for the duration of your stem cell transplant treatment impacted on how you coped.

The enclosed participant information sheet (version 1, July 2014) describes the study. It also explains what will happen if you decide to participate. Please take your time reading the information, feel free to discuss it with friends and family, the research team or myself. Contact details are listed on the participant information sheet.

If you decide that you would like to take part in this project, please let me know that you consent for your details to be passed to Bethany for her to contact you. You can do this by returning the tear-off slip below using the stamped addressed envelope provided or you can phone me and let me know. I will then pass your details to Bethany to make contact with you. Please return your slip within two weeks of the date at the top. If I do not hear from you by this time I will assume that you do not wish your details to be passed to Bethany, and do not wish to be part of the project.

Please feel free to contact me if you have any questions and please be aware that I am independent of the research team.

Address: Haemato-oncology Department, Raigmore Hospital, Old Perth Rd., Inverness, IV2 3UJ

Tel: 07702 884 876



Thank you for taking the time to read this letter.

Yours sincerely

Christie Lane
Consultant Cancer Nurse

Study Title: 'Home Sick': Exploring the impact of receiving a volunteer unrelated donor haematopoietic stem cell transplant far from home on the perceived coping of patients residing in the NHS Highland region.

Please fill in this section and return using the self addressed envelope if you consent for your contact details to be passed to Bethany Anderson (Trainee Clinical Psychologist).

Name:

Address:

Telephone:

Appendix 11: Participant Information Sheet



1 Study title

'Home Sick': Exploring the Impact of Receiving a Volunteer Unrelated Donor (VUD) Haematopoietic Stem Cell Transplant (HSCT) far from Home on the Perceived Coping of Patients Residing in the NHS Highland Region.

2 Invitation paragraph

You are being invited to take part in a research study. Before you decide if you would like to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

3 What is the purpose of the study?

This project aims to gather the experiences of patients who live within the NHS Highland region who have had to travel to the Beatson West of Scotland Cancer Centre in Glasgow to receive their stem cell transplant. It aims to examine how the experience of travelling such a distance and remaining away from home during treatment impacted on coping.

4 Why have I been chosen?

You have been chosen as you are a resident in the NHS Highland area who has undergone a volunteer unrelated stem cell transplant at the Beatson West of Scotland Cancer Centre. The study is aiming to recruit up to ten participants.

5 Do I have to take part?

No. It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

6 What will happen to me if I take part?

If you decide to take part you will be asked to take part in a single interview session lasting no more than one hour. The interviews will be conducted by Bethany Anderson (Trainee Clinical Psychologist and Chief Investigator). The interviews will take place in the Haemato-oncology department in Raigmore Hospital, Inverness. The interview can also be conducted over the telephone upon request if this would be your preference.

Interviews will be audio-recorded and then transcribed by the researcher. Transcribed interviews will have names of people and places anonymised. The interview will involve questions related to how you coped during your period of treatment in Glasgow.

7 What are the possible disadvantages and risks of taking part?

There is a possibility that when discussing the experience of your transplant, you may recall experiences that make you feel upset. You would be free throughout the interview to stop and take a break or discontinue the interview at anytime. The Researcher will do frequent 'check-ins' with you to check for fatigue or distress and ensure you are happy to continue. If you felt that upon finishing the interview you needed to talk to someone further information will be given regarding where best you can seek further advice or support (e.g. Maggie's Centre at Raigmore Hospital or the local Nurse Consultant in Cancer Care).

8 What are the possible benefits of taking part?

There are not direct benefits of you taking part in this study. However, it is hoped that from your experiences we can begin to understand the factors and resources which helped you cope during

Version 2, 17th October 2014

your stem cell transplant. This information can then be used to help prepare future patients as they embark on their treatment journey.

14 Will my taking part in this study be kept confidential?

Yes. All information, which is collected, about you during the course of the research will be kept strictly confidential. The audio-recording and transcription of your interview will be identified by an allocated participant number only. If any quotes from your interview are used in the final report, a pseudonym will be used. All references to people and places by name will be anonymised during transcription.

Information collected will be kept in accordance with the Data Protection Act (1998) as well as NHS Highland and University of Glasgow policy.

16 What will happen to the results of the research study?

On completion of the research project the completed report will be submitted to the University of Glasgow in July 2015 as the Major Research Project of the Researcher's Doctorate in Clinical Psychology degree. It is hoped that the study would eventually be submitted for publication in a research journal.

All participants will be invited to contact the Researcher if they wish to be sent a summary of the results.

17 Who has reviewed the study?

This study has been reviewed by the NHS Solihull Research Ethics Committee.

18 Contact for Further Information

If you wish any further information or have any questions please feel free to contact a member of the research team below. Alternatively there is an independent named person who is happy to be contacted for further information and is independent of the research team.

For general independent information on taking part in research please visit the INVOLVE website on: www.invo.org.uk/find-out-more/

Name	Role	Contact
Bethany Anderson	Trainee Clinical Psychologist Chief Investigator	Department of Psychological Services, New Craig's Hospital, Inverness. 01463 704683
Dr Sarah Wilson	Academic Supervisor	Mental Health and Wellbeing - University of Glasgow, Gartnavel Hospital, Glasgow. 0141 2113935
Dr Chris Hewitt	Field Supervisor	Beatson West of Scotland Cancer Centre, Glasgow. 0141 3017378.
Chrissie Lane	Independent Contact Person Consultant Cancer Nurse	Raigmore Hospital, Inverness. 07702 884 876

Appendix 12: Participant Consent Form



Centre Number: :
Study Number:
Patient Identification Number for this trial:

CONSENT FORM

Title of Project: 'Home Sick': Exploring the impact of receiving a volunteer unrelated donor haematopoietic stem cell transplant far from home on the perceived coping of patients residing in the NHS Highland region.

Name of Researcher: Bethany Anderson – Trainee Clinical Psychologist, NHS Highland
Name of Academic Supervisor: Dr Sarah Wilson – Senior Lecturer in Health Psychology, University of Glasgow
Name of Field Supervisor: Dr Chris Hewitt – Consultant Clinical Psychologist, Beatson West of Scotland Cancer Centre.

- | | | Please initial box |
|---|---|--------------------------|
| 1 | I confirm that I have read and understand the information sheet dated July 2014 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2 | I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason and without my medical care being affected. | <input type="checkbox"/> |
| 3 | I agree to be audio recorded. | <input type="checkbox"/> |
| 4 | I agree that quotations from my interview may be included in the final written report, which may be submitted for publication in an academic journal. I am aware that the transcript of my interview will have been anonymised for references to people and places before any quotations are taken from it. | <input type="checkbox"/> |
| 5 | I agree to take part in the above study. | <input type="checkbox"/> |

_____ Name of Patient	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

Version 1, 18th July 2014

Appendix 13: Interview Topic Guide

Preamble

"As you know from the information sheet this project aims to gather the experiences of patients who live within the NHS Highland region who have had to travel to the Beatson West of Scotland Cancer Centre in Glasgow to receive their stem cell transplant. It aims to examine how the experience of travelling such a distance and remaining away from home during treatment impacted on coping."

"Can I remind you that you are free to stop the interview at any point or request a break. You are free to withdraw from the study at any point and do not need to provide a reason for your decision. When the report on this research is prepared all participants will be given a pseudonym any quotations used will be identified by pseudonym only. Names of people or places included in the quotation will be anonymised. The interview should take no more than one hour."

** Get patient to sign Participant Consent Form before proceeding**
(for telephone interviews, consent form will be sent out and must have been returned signed before the interview will take place)

Demographic information

"To start I would like to ask you some basic information"

- *What was your place of residence at the time of your treatment? I will use this information to work out how many miles you travelled from your home town to Glasgow.*
- *How long in total did you spend away from home whilst undergoing your transplant?*
- *Were you in employment before starting your treatment?*

** Start recorder**

Topic Guide – prompts indicated by bullet points.

Travel and location

1. *How would you describe your experience of travelling to and staying in Glasgow whilst undergoing your transplant?*
How did being a far from home at this time affect you?
 - *How did being far from home impact on your coping?*
 - *How did you find the travelling the treatment period?*
 - *What would you consider to be the greatest challenges?*
 - *How did you manage these?*

Physical environment

2. *How did you find the physical environment and facilities of the BWoSCC?*

Version 1. 18th July 2014

- Did any aspects of that environment influence the way you coped? (e.g. use of Friends of the Beatson, isolation requirements, family room, availability of WiFi, parking, shops, laundry, relatives overnight accommodation (if used))

Psycho-social Support

3. Tell me about the social support you received whilst in Glasgow? Were you able to keep in touch with family and friends? How did this help you cope?
 - How did your being away from home impact on your friends and family?
 - What changes did they have to make to accommodate this? (e.g. taking time from work, childcare issues etc)
 - Did this have any financial implications? (e.g. costs of travel, childcare, travel)
 - What impact did this have on your relationships?
 - What coping resources did they use?
 - How did you maintain contact with your social circle whilst away for treatment? Was this effective?
 - Did you gain social support from any new sources?
 - How did the distance affect how you used social support as a coping mechanism? (e.g. increased use of social media, email, face time etc.)
 - Did you experience any specific psychological issues related to the distance from your home?
 - What psychological support was available to you during your transplant? (e.g. from psychologist, nursing/medical staff, family/friends)

Routine

4. Undergoing your stem cell transplant will have meant that your normal routine will have been changed (for example employment, family routine). In what way did the distance from home impact on your routine?
 - What aspects about the routine you had in the Beatson helped your coping?
 - What aspects hindered your coping?

Biggest aid to coping

5. What strategies were the most useful in terms of coping?
 - Which coping mechanism do you think helped you most?
 - What was your biggest aid to coping?

Version 1. 18th July 2014

- If you were to give one piece of advice to future Highland patients and/or their families, what would it be?

Previous coping style

6. Do you think being away from home for your transplant meant you needed to use the same or different coping strategies than you would normally use?
 - What accounted for the differences? (if applicable)

"Thank you. That is the end of the interview."

* Stop recorder*

"Thank you very much for taking the time to complete this interview. It is hoped that the results of this study will help us understand the factors and resources which helped the participants to cope during their stem cell transplant. This information can then be used to help prepare future patients as they embark on their treatment journey. If you would like to be sent a summary of the results of the study, please contact me at the email address on your participant information sheet."

Appendix 14: Transcript Excerpt from Interview 1

Interview 1

I wonder to start if you could maybe describe to me your experience of travelling to and staying in Glasgow whilst undergoing your transplant?

Well.... yeh.... well.... eh.... I went down there, I think it was on the train, you know..... because..... you know, day zero when the transplant started; I think that was the 27th March, so yeh I'd been there the week before to get all the chemo. So I went down on the train, with my wife [wife's name], so and em.... that was ok. And then we started..... she was actually staying there, she had managed to get into a B&B.

Great.

The Beatson, you probably know, they've got, they've got flats there which are part of the hospital but em.... we rang up before to try to get in these flats but there were none available at the time.

Ok

So em..... but on the Great Western Road there, there's a few B&Bs that eh... so [wife's name] was there for about... eh.. 10 days, she was there for the chemo and for a few days after the transplant itself. So I got a lot of support from [wife's name], during that... the first part of the process yeh.

And how did you find kind of being away from home at this time? How did that affect you?

It wasn't too bad. Em..... as I say part of my job, I worked for the [company name], so I did spend a lot of time away from home with my job, you know. So... eh... we'd been down there before to meet Dr [X], to sign the consent form and she went through the risks and the process, so I was eh... well prepared for it, with [wife's name] being there as well, so, you know the staying away from home and eh... you know... it's quite normal. I had a good idea what em.... had to come, you know. It wasn't all explained, but you know, so..... but yeh you know it wasn't too bad and em.... yeh I didn't feel anxious or anything like that, but I knew I had to go through the process, so I'd only have a few years to live if I didn't go through with it, you know, I was fairly positive about the whole thing, and I didn't you know, with all the support from [wife's name] so it wasn't too bad.

Appendix 15: NHS Highland Area Map

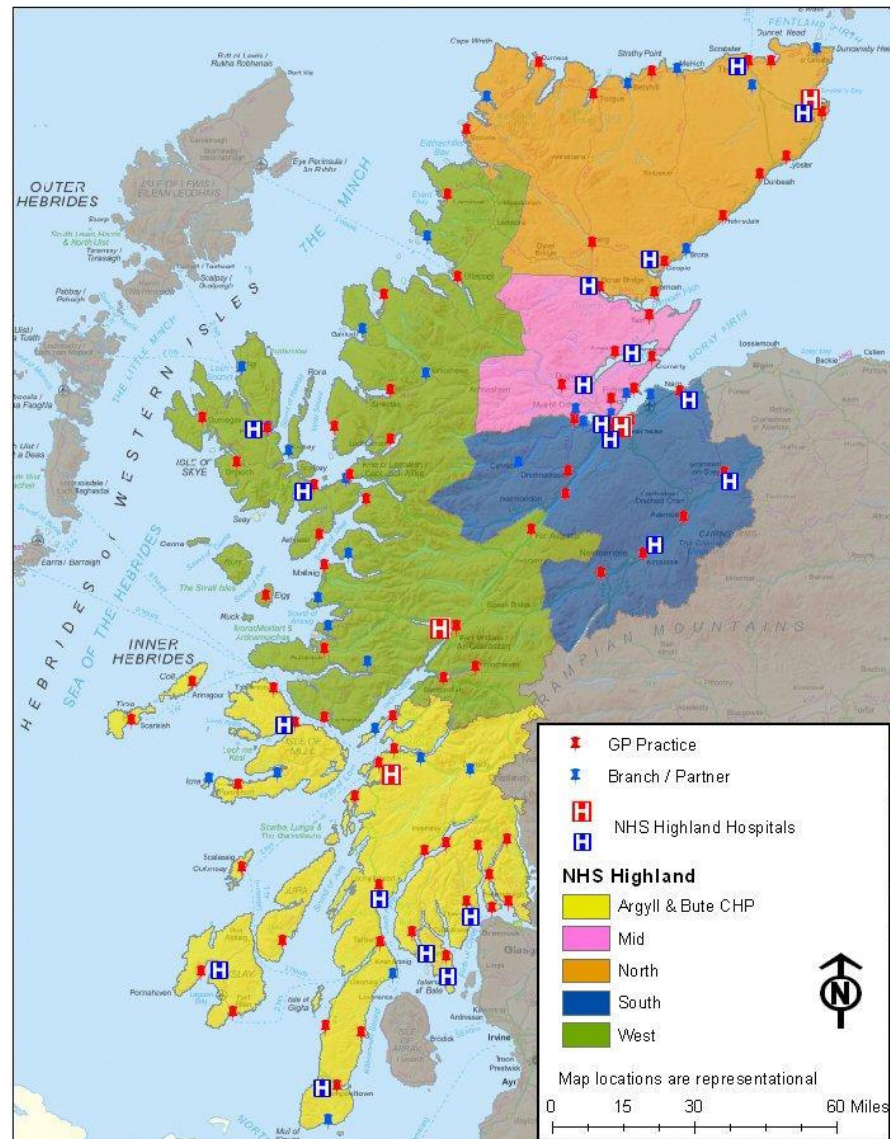


Image retrieved in April 2014 from <http://www.nhshighland.scot.nhs.uk/OurAreas/>

Appendix 16: Managing Participant Distress

The following steps will be taken to reduce the occurrence of participant distress as well as managing any distress that occurs in an effective ethical manner.

- Participants will be told that they can stop and take a break or discontinue the interview at anytime.
- There will be frequent 'check-ins' with participants to check for fatigue or distress and see they are happy to continue. This will be especially important for any telephone interviews where visual signs of distress can not be observed.
- Telephone participants will be asked to have a friend or relative present with them who can take the phone and notify the researcher if the participant is becoming distressed.
- Signposting of information will be provided to participants who become distressed about where best they can seek further advice or support (e.g. Maggie's Centre at Raigmore Hospital or the local Nurse Consultant in Cancer Care).

Appendix 17: Participant Demographic Information

Participant No.	Gender	Age at Interview	Distance Travelled*	Time at BWoSCC
1	M	61	177 miles	4.5 weeks
2	M	45	126.5 miles	7.5 weeks
3	F	53	171 miles	3.5 weeks
4	F	55	171 miles	6 weeks
5	F	23	219.2 miles	5.5 weeks
6	F	50	173.8 miles	5 weeks

*** distanced worked out from Google maps from town/village of residence to the BWoSCC**

Appendix 18: Themes Present in Individual Papers

	Paper 1	Paper 2	Paper 3	Paper 4	Paper 5	Paper 6
Physical health	YES	YES	YES	YES	NO	YES
Medical environment / routine	YES	YES	YES	YES	YES	YES
There is no place like home	YES	YES	YES	YES	YES	YES
Social Support is key	YES	YES	YES	YES	YES	YES
Known vs unknown	YES	YES	YES	YES	YES	YES
Technology	YES	YES	YES	YES	YES	YES
Role of thoughts	YES	YES	YES	YES	YES	YES
Change of environment	YES	YES	YES	YES	YES	YES
Moving along a journey	YES	YES	YES	NO	YES	YES
Consequences of the distance	YES	YES	YES	YES	YES	YES

Appendix 19: Steps of Analysis

Steps of IPA analysis, as outlined by Smith et al. (2009, pages 79-101)

Step	Process
1	<ul style="list-style-type: none">▪ Reading and re-reading▪ Immerse oneself in the data and become “actively engaged with the participants’ world”.
2	<ul style="list-style-type: none">▪ Initial noting▪ Examination of semantic content and language use▪ Initial notes of anything of interest within the transcript.
3	<ul style="list-style-type: none">▪ Developing emergent themes▪ Mapping the relationships and patterns across and between exploratory notes.
4	<ul style="list-style-type: none">▪ Searching for connections across emergent themes▪ Develop a mapping of how the researcher thinks the themes fit together to produce a structure which outlines the most interesting and important aspects of the participant’s account.
5	<ul style="list-style-type: none">▪ Moving to the next case▪ Repeat steps 1-4 for the next transcript, treating the next case on its own terms.
6	<ul style="list-style-type: none">▪ Looking for patterns across cases▪ Look for connections across cases to produce superordinate themes and emergent themes which represent all of the data.

Steps 1-3 were completed by an independent rater (Lecturer in Health

Psychology, Clinical Supervisor) for two transcripts and findings were discussed and compared with lead researcher.

Appendix 20: – Financial Costing

Item	Details and Amount Required	Cost or Specify if to Request to Borrow from Department
Stationary	1 x ream of white paper for cover letters, information sheets and consent forms.	£2.50
	20 x envelopes and postage to send invitations out to potential participants.	A5 envelopes priced as £9.49 for a box of 500. 20 envelopes = 38p
	20 x envelopes and free-post postage for participants to return consent forms if participating via telephone interview.	A5 envelopes priced as £9.49 for a box of 500. 20 envelopes = 38p
Postage	20 x free-post postage to send invitations out to potential participants.	Freepost priced as 69p. 20 x 69p = £13.80
	20 x free-post postage for participants to return consent forms if participating via telephone interview	Freepost priced as 69p. 20 x 69p = £13.80
Photocopying and Laser Printing (includes cost of white paper)	Printing costs for up to 20 cover letters, participant information sheets and consent forms	Black and white printing priced at 5p per sheet. 60 x 5p = £3

Equipment and Software	Laptop with NVivo software programme	Request to borrow from University Department
Measures	N/A	N/A
Miscellaneous	<ul style="list-style-type: none"> ▪ Digital voice recorder with telephone earpiece. ▪ Dictation foot pedals 	Request to borrow from University Department