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**Patient experience of admission to critical care unit (CCU) during Haematopoietic Stem
Cell Transplant (HSCT)**

And Clinical Research Portfolio

Volume 1

(Volume 2 bound separately)

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Mental Health and Wellbeing

Institute of Health and Wellbeing

University of Glasgow

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

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Now we can clear out that room I call my study and get on with our lives!

Chapter 1: Systematic Review

Returning to work after cancer: A qualitative systematic review

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Prepared in accordance with guidelines for submission to the European Journal of Cancer
Care (Appendix 1)

Abstract

This article presents a systematic review of qualitative studies investigating the experiences of cancer survivors returning to work. Meta-ethnography was used to select, critically appraise and synthesise the studies. The search strategy involved a search for articles in EMBASE, MEDLINE, CINAHL and PsychINFO databases. A hand search of relevant journals and reference lists was also undertaken. Ten studies were identified for inclusion. Quality was assessed using a rating scale based on a quality-rating framework. Six themes were identified; returning to work means returning to normal, employer and colleague reactions, effects of cancer and treatment on work ability, changed priorities, financial pressure to return to work and advice from health professionals. These themes suggest that cancer survivors strongly link being able to return to work with returning to normal life although it was also clear that there are barriers that impact on this return. This article discusses the relevance of these themes with regard to the treatment and care of these patients.

Keywords: Qualitative systematic review, lived experience, cancer, return to work

Introduction

Every year, approximately 300,000 people in the UK are diagnosed with cancer (Cancer Research UK, 2010). Improvements in early detection and treatment have resulted in an increasing number of cancer survivors (Aziz and Rowland, 2003), the definition of a survivor being an individual who has been diagnosed with cancer and is still living (National Coalition for Cancer Survivorship, 2005). A great many of these survivors will be of working age and returning to work will be an important step in their recovery.

Previous studies examining the experience of returning to work after cancer have highlighted the importance of work for several reasons. It provides a sense of identity and purpose and is a strong source of social connection. Returning to work can also provide a distraction from cancer and can enable the survivor to regain a sense of normality and control (Peteet, 2000). Cancer diagnosis and its subsequent treatment can be a lonely, isolating, abnormal experience. Survivors can feel cut off from their 'normal' life and detached from reality. Therefore, returning to work after cancer treatment can be viewed as an important milestone in the process of recovery. Also, from an economic perspective, it is important to explore and hopefully reduce absences from work through ill health. Greater understanding of the factors that impact on cancer survivors returning to work could lead to a reduction in unnecessary work cessation.

Spelten et al. (2002) in their literature review examined the factors reported to influence cancer survivors' return to work and found that the rate of return to work varies from 30-93% with a mean rate of 62%. They found that return to work was facilitated by a supportive work environment and that manual or physically demanding work is negatively associated with return to work. With regard to disease and treatment related factors, they found that patients

with head and neck cancer, are at a particular disadvantage when returning to work, whereas patients with testicular cancer experience relatively few problems. This variance across cancer types could be due to psychosocial and physical factors, for example, testicular cancer generally affects a younger age group and has a good prognosis however, head and neck cancer tends to affect an older age group and often results in disfigurement, which could impact on return to work. A further literature review by Mehnert (2011) consolidated these findings, reporting that 63.5% of cancer survivors returned to work after a mean duration of absence of 151 days.

Previous studies of people treated for cancer have reported a variety of problems at work including job loss, unwanted changes in work situation, problems with co-workers and diminished work capacity (Maunsell et al., 1999). It is therefore clear that returning to work after cancer is not simply a matter of deciding to do so and being able to slip back into previously filled roles. There are clearly factors that influence how successful a survivor is in their attempt to return to work and it would be helpful to explore these in more detail in order to deepen understanding of this experience.

The majority of the research conducted on returning to work after cancer has used quantitative methods. Although this has provided important information regarding prevalence rates and barriers and facilitators to work return, it has not been able to contribute to the understanding of the experience of returning to work after cancer. The aim of qualitative research is to 'provide an in-depth understanding of people's experiences, perspectives and histories in the context of their personal circumstances and settings' (Spencer et al., 2003). Adopting this approach when conducting research with this population, allows for the possibility of providing insight into the lived experience of returning to work after cancer.

Therefore, this present study aims to systematically review qualitative research on the experience of returning to work after cancer.

Synthesising themes from qualitative studies will not only provide an insight into the unique experience of returning to work after cancer, it could also offer theoretical insight and help to develop appropriate supports or interventions aimed at improving the experience of returning to work after cancer. This is especially important when it is considered that in 2005, the Disability Discrimination Act was extended to cover people with cancer, from the point of initial diagnosis. This means that employers are expected to make reasonable adjustments for individuals living with cancer to enable them to return to work. In order to be able to fully comply with this Act, employers must increase their understanding of the experience of returning to work after cancer. In addition, physicians, cancer care clinicians and occupational health departments may have a role to play in contributing towards survivors' successful return to work and they would therefore benefit from increasing their understanding of such an experience.

Aim

The aim is to explore experiences of returning to work for cancer survivors by systematically reviewing published qualitative studies in this area.

Review question

What is the experience of returning to work after cancer diagnosis and treatment?

Method

Search strategy

The EBSCO host was used to search CINAHL and PsychINFO databases and OVID was used to search EMBASE and MEDLINE databases.

Search terms

A broad search strategy using free text was employed to encompass the diversity of possible themes. All searches were completed using the following terms:

1. Cancer

AND

2. Work OR employment

AND

3. Qualitative OR grounded theory OR interpretative phenomenological analysis OR narrative OR thematic analysis OR experience* OR content analysis OR focus group*

Studies identified by the electronic search were compared to the inclusion and exclusion criteria. A search was also conducted using the reference lists from the selected studies and a hand search of *Psycho-Oncology* and *European Journal of Cancer Care* was completed.

Inclusion criteria

- Studies that solely explored the experience of returning to work for people after they had received a cancer diagnosis
- Studies that used qualitative research methodology
- Participants aged 16 or over

- Published in a peer reviewed journal
- Studies conducted in Western populations

Exclusion criteria

- Quantitative studies
- Case studies
- Studies that were not published in English

Results of search strategy

The search produced a total of 3426 articles. Duplicates were removed and the abstracts of the remaining 180 articles were read and screened for relevance, leaving a possible 27. The hand search of references yielded an additional two studies. Hand searching of relevant journals did not yield any further results. The full texts of all 29 articles were read and examined according to the full inclusion and exclusion criteria. This resulted in a final list of 10 articles which were included in the review. For a flow chart of this process, see Appendix 2.

Method of synthesis

There are a number of ways of conducting a synthesis of qualitative research. Meta-ethnography has been chosen for the current review as it allows for the synthesis of research studies that draw from a variety of qualitative research methods (Ring et al., 2011). Noblit and Hare (1988) and Atkins et al. (2008) outline seven stages for meta-ethnography (Table 1). This synthesis followed these steps in order to select, critically appraise and synthesise the qualitative research studies. As recommended by Noblit and Hare (1988), studies were read and reread to aid familiarity with the detail and content, a list of themes was then created and

interpreted by the author and these themes were then reduced into categories. A line of argument synthesis was then conducted whereby a new level of interpretation is offered based on a previous set of individual studies and explanations. Lines of argument are developed by comparing interpretation, examining similarities and differences and integrating the findings within a new interpretation (Pope at al., 2007).

Table 1: Seven stages of meta-ethnography

Step	Stage	Description of each stage
Step 1	Getting started	Develop a research question
Step 2	Deciding what is relevant for initial interest	Define focus of synthesis Locate relevant studies Make decision on inclusion criteria Carry out a quality assessment
Step 3	Read the studies	Become familiar with the detail and content of the studies Extract interpretative metaphors and emerging themes

Step	Stage	Description of each stage
Step 4	Determine how the studies are related	<p>Create a list of themes and metaphors</p> <p>Juxtaposition of themes</p> <p>Determine how the themes are related</p> <p>Reduce themes into categories</p>
Step 5	Translate studies into one another	<p>Arrange each study into chronological order</p> <p>Compare themes from paper 1 with paper 2 and the synthesis of these two papers with paper 3 and so on</p>
Step 6	Synthesising translations	Higher order interpretation to provide a line of argument synthesis
Step 7	Expressing the synthesis	<p>Discussion and write-up of the results</p> <p>Publication</p>

Quality assessment

The quality of the ten articles in this review was appraised according to the criteria in Appendix 3. These criteria were developed by Walsh and Downe (2006) who reviewed eight previous frameworks for qualitative research, pulled them together and eliminated those which were non-essential. The framework they suggested cover scope and purpose, design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions and relevance and transferability. Each study in this current review was evaluated against a 46-item quality rating scale, which awarded a score of 1 if the criterion was met and 0 if the criterion was not met or it was not possible to determine from the information given. Therefore, each paper was given a rating out of 46, with a score of good (>75%), acceptable (>50%) or poor (<50%). An independent researcher using the same quality rating scale independently rated all studies. The overall level of agreement was good at 85%. Any disagreements were resolved through discussion with the independent researcher.

Results

Quality appraisal

All ten studies were of 'acceptable' or 'good' quality. Table 2 lists a methodological summary and the quality rating for each included paper.

Table 2: Methods used and quality ratings

Authors (Year)	Country	Method	Participants	Quality Rating
Maunsell et al. (1999)	Canada	Qualitative Thematic Content Analysis	- 13 women - All breast cancer survivors - Aged 33-59 - All had returned to work	70% Acceptable quality
Main et al. (2005)	United States of America	'Editing' style of analysis	- 28 participants - 14 male, 14 female - Survivors of a variety of cancers - Aged 24-63 - All but two had returned to work	72% Acceptable quality
Kennedy et al. (2007)	England	Thematic Analysis	- 29 participants - 2 male, 27 female - Survivors of a variety of cancers - Aged 36-66 - All but two had returned to work	74% Acceptable quality

Authors (Year)	Country	Method	Participants	Quality Rating
Amir et al. (2008)	England	Qualitative Thematic Analysis	- 41 participants - 17 male, 24 female - Survivors of a variety of cancers - Aged 26-55 - All had returned to work	80% Good quality
Rasmussen and Elverdam (2008)	Denmark	Thematic Analysis	- 23 participants - 10 male, 13 female - Survivors of a variety of cancers - Half had returned to work	74% Acceptable quality
Johnsson et al. (2010)	Sweden	Narrative	- 16 women - All breast cancer survivors - Aged 44-58 - Half had returned to work	74% Acceptable quality

Authors (Year)	Country	Method	Participants	Quality Rating
Grunfeld and Cooper (2012)	England	Framework Analysis	<ul style="list-style-type: none"> - 55 females - All gynaecological cancer survivors - Aged 24-63 - All had returned to work 	74% Acceptable quality
Tamminga et al. (2012)	Netherlands	Thematic Analysis	<ul style="list-style-type: none"> - 12 females - All breast cancer survivors - Aged 31-51 - All had returned to work 	83% Good quality
Tiedtke et al. (2012)	Belgium	Grounded Theory	<ul style="list-style-type: none"> - 22 females - All breast cancer survivors - Aged 41-55 - Half had returned to work 	80% Good quality

Authors (Year)	Country	Method	Participants	Quality Rating
Grunfeld et al. (2013)	England	Framework Analysis	- 50 males - All prostate cancer survivors - Mean age of 59 - All but four had returned to work	74% Acceptable quality

Synthesis

A list of themes from each of the studies included in this review is displayed in Table 3. Through the process of meta-ethnography, a new interpretation of the dominant themes was developed. This process determined the following six key themes in cancer survivors' experience of returning to work: (i) returning to work means returning to normal, (ii) employer and colleague reactions, (iii) effects of cancer and treatment on work ability, (iv) changed priorities, (v) financial pressure to return to work and (vi) advice from health professionals. Each theme will be discussed in turn. Quotations from study participants appear in italics.

Table 3: Themes identified in the studies included in this meta-ethnography

Authors (Year)	Themes
Maunsell et al. (1999)	Learning the diagnosis and effects on co-workers The treating physician's approach to work issues Apprehensions about returning to work

Authors (Year)	Themes
Main et al. (2005)	<p>Unwanted changes in work situation after treatment</p> <p>Changes in work capacity and attitude to work</p> <p>Patterns of work return and work change following cancer diagnosis and treatment</p> <p>Influences on work following cancer diagnosis and treatment</p> <p>Experience at work after cancer</p> <ul style="list-style-type: none"> - How others respond - Productivity - Effects of cancer and treatment - Feelings about work
Kennedy et al. (2007)	<p>Return to work and changes following cancer</p> <p>Factors influencing post-cancer work decisions</p> <p>Health professionals' advice</p> <p>Experience of work after cancer</p> <p>Effects of the cancer and treatment</p> <p>Support and adjustment at work</p> <p>Attitudes about work</p>

Authors (Year)	Themes
Amir et al. (2008)	<p>The changing importance of returning to work</p> <p>Motivations for returning to work</p> <p>Medical advice regarding work</p> <p>Difficulties back at work</p> <p>The relationship with their employer</p>
Rasmussen and Elverdam (2008)	<p>Disruption of work and working life</p> <p>Re-establishing work and working life</p> <p>Everyday-life without work and working life</p>
Johnsson et al. (2010)	<p>Belonging to the labour market</p> <p>Changed attitudes to work</p> <p>The importance of social support within the work arena</p>
Grunfeld and Cooper (2012)	<p>Meaning of work</p> <p>Disclosure of cancer diagnosis</p> <p>Readjustment to working</p>
Tamminga et al. (2012)	<p>Factors that influence return to work</p> <p>Initial return to work</p> <ul style="list-style-type: none"> - Physical and psychological side-effects - Temporarily altered importance of work

Authors (Year)	Themes
Tiedtke et al. (2012)	<ul style="list-style-type: none"> - Altered work relationships - Other factors <p>Post return to work</p> <ul style="list-style-type: none"> - Stigma - Slow or insufficient recovery over time - Work-related factors <p>Possible solutions</p> <ul style="list-style-type: none"> - Improved guidance - Improved information <p>Away from the sick role and wanting to keep the job</p> <p>Is it worth making the effort to return to their job?</p> <p>Concerned about recovery</p> <p>Doubts about acceptance in the workplace</p> <p>Emotional process</p> <p>Interaction with the social environment</p> <p>Preparation permeated by uncertainty and vulnerability</p>
Grunfeld et al. (2013)	<p>Work and self-identity</p> <p>Work-related implications of treatment side effects</p> <p>Disclosure of cancer</p> <p>Future as a cancer survivor</p>

Returning to work means returning to normal

The first theme identified was survivors' view that returning to work meant a return to normal (Amir et al., 2008; Grunfeld and Cooper, 2012; Grunfeld et al., 2013; Johnsson et al., 2010; Kennedy et al., 2007; Main et al., 2005; Rasmussen and Elverdam, 2008; Tiedtke et al., 2012). Around one third of survivors in Kennedy et al.'s (2007) study spoke of returning to work as a way to regain a sense of normality, embodied in the following quotation:

'Going back to work for me is about just being slightly more normal, because going through cancer isn't normal, and going back to work...going in, enjoying my job, making a difference. And my family seeing me going to work and seeing that I'm not at death's door yet is what I want.' (Kennedy et al., 2007)

Similarly, the majority of participants in Amir et al.'s (2008) study expressed a strong desire to return to work in order to 'get back to normal' as evidenced by this interviewee in his 20s with testicular cancer, who returned to his very demanding job after four months sick leave and shortly after finishing his course of chemotherapy:

'I wanted to get back to work as soon as possible...work was the normal life I had before and that's why I focused on it.' (Amir et al., 2008)

It appears that being unable to work as a result of cancer and treatment side-effects disconnects cancer patients from their normal life and a sense of achievement and a step towards reconnecting with their pre-cancer life is gained when they can finally resume their working life. This view is demonstrated well in the following quotation:

'As I pulled my bike out of the garage this morning, I felt like an ordinary man again. One who goes to work. Other people observe you when you are at home during the

morning. It is okay to go for a walk, but you are not an ordinary person, taking a walk, when you should be working. I am still at a productive age. The neighbours will ask you 'when are you going back to work?' That is what it is all about and you feel like an ordinary fellow being back on track. (Rasmussen and Elverdam, 2008)

To cancer survivors, being at home can feel like being ill, whilst being at work feels like having recovered. Participants in several of the studies spoke of their impatience regarding work resumption because they felt this would offer them an opportunity to leave behind their illness. They wanted to be moving towards being their old self again, which included resuming their working role. The quotation above illustrates the fact that survivors can feel that returning to work proves to observers that they have recovered. Similarly, some survivors spoke of needing to prove to themselves that they were better as illustrated by this 54-year-old breast cancer survivor:

'It proves to me that I am healthy and normal that I have my work. The ordinary day I have proves to me that I am healthy and normal.' (Rasmussen and Elverdam, 2008)

Employer and colleague reactions

All but one of the studies discussed the reactions participants had from their employer and colleagues to their cancer diagnosis (Maunsell et al., 1999; Main et al., 2005; Kennedy et al., 2007; Amir et al., 2008; Johnsson et al., 2010; Grunfeld and Cooper, 2012; Tamminga et al., 2012; Tiedtke et al., 2012; Grunfeld et al., 2013). Almost all participants in all of the studies disclosed their diagnosis to their employer and colleagues. Some chose to openly disclose their diagnosis to everyone whereas others preferred to limit their disclosure to only those that they felt it was necessary to inform. Hesitancy to disclose to colleagues was related to concerns about not feeling emotionally ready within themselves to discuss their cancer,

anxiety around being stigmatised and also being labelled as a ‘cancer patient’. They feared disclosure would result in being asked inappropriate or embarrassing questions or would result in them being viewed as an attention-seeker, as demonstrated by the following quotation:

‘What I didn’t want is people thinking you know ‘Oh look he’s letting everybody know he’s got cancer.’ What is it? Munchausen’s? Is that what you call it, where you get sympathy for being ill?...So I didn’t want people thinking ‘Oh God here he goes whining on about it.’ (Grinfeld et al., 2013)

The papers in this synthesis reported that survivors received both positive and negative responses to their disclosure. In general, most found employers and colleagues to be supportive. Several of the studies reported that participants had found great comfort in being supported by employers and colleagues who kept in touch with them during the course of their sick leave. A participant in Amir et al.’s (2008) study was especially positive about the support she received from her manager and colleagues throughout her cancer journey. They kept in contact throughout the course of her treatment, arranged transport for her family when needed and even attended appointments with her when required:

‘I couldn’t have done it without them. It was absolutely fantastic and then when I had my second operation they were just as supportive, they were brilliant. And when I wanted to come back to work I came back on a very slow return and they looked after me every step of the way.’ (Amir et al., 2008)

Several of the studies discussed employer reaction during the transition back to work and how accommodations were made in order to make this easier for survivors. This is demonstrated in the following quotation:

'...I asked if I could come back, and 'yes of course you can come back' and I say: 'can I come back and work half my hours and then see?' and they said 'of course', that was all fine 'you just try and see what you can handle'...' (Tiedtke et al., 2012)

Several of the studies reported finding that survivors felt able to return to work slowly and take time off when they felt unwell or go home early if they were struggling. Some employers took it upon themselves to make these changes in order to facilitate easier return to work:

'One thing that changed was the travel. I had been travelling for 13 years. At least 9 months of the year I would be on the road Monday through Friday. When I came back, they said, 'No, you're not going to travel. You need to be close to your physician, your family.' (Main et al., 2005)

This quotation indicates that the employer had considered adaptations that would be necessary for the survivor given their health status. This positive employer reaction would most likely have made return to work easier for that particular survivor. Following on from this, some studies made reference to the fact that although initial support was provided and allowances were made, sometimes they tailed off after a period of time, leaving the survivor feeling less supported and under pressure to return to their previous level of functioning:

'I thought hold on a second...I'm supposed to be having a day off, I'm not getting paid for it and the whole point was to chill, forget about work and here you are putting pressure on me...I couldn't quite work out in my mind what was going on really in that he'd been supportive, but I didn't see that as being supportive.' (Kennedy et al., 2007)

This reduction in level of support could lead to the survivor feeling overwhelmed and in need of further time off, so it is important that initial supports are continued until it is determined by both parties that they are no longer necessary. All of the studies that explored reactions of employers and colleagues made reference to unsupportive or negative reactions that survivors encountered. Survivors in several of the studies spoke about feeling that colleagues were uncomfortable around them once they knew they had cancer, as illustrated by the following quotation:

'[Co-workers] want to be encouraging but they don't know what to say...They are uncomfortable talking to you...Sometimes, in the corridor, it seemed like people were saying: 'Ah, she's the one who's got cancer'...You see them in the washroom and they don't know what to say,...it's like they're in a hurry...People seem uncomfortable...That got on my nerves, it...it annoyed me.' (Maunsell et al., 1999)

Further to the realisation that people felt uncomfortable around them, some of the survivors reflected on why this might be with some feeling that it could be due to cancer being a reminder of people's own mortality:

'There were some of my work colleagues who I could tell were very uncomfortable about it. I think people still believe that when you are diagnosed with cancer, it's an automatic death sentence. And so it makes them very uncomfortable, brings them too close to their own mortality.' (Main et al., 2005)

Others reflected that colleagues perhaps viewed cancer as a taboo subject and were not sure how to approach it, perhaps fearing they would say the wrong thing.

Effects of cancer and cancer treatment on work

All of the studies included in the current review discussed the effect that cancer and the treatment of cancer had on individuals as they returned to the workplace. The factor that most commonly impacted on survivors' return to work was fatigue. Fatigue is a common side effect of chemotherapy and radiation treatment and can leave patients feeling overwhelmed by exhaustion as expressed in the following quotation:

'Occasionally days where the tiredness just sweeps over you and I'm almost past those but for the first five years the fatigue, it is the only word that you can describe is extreme...fatigue, where you just don't have the energy to get up.' (Kennedy et al., 2007)

Clearly, experiencing this level of fatigue is likely to be a stumbling block to returning to full capacity at work. Other side-effects that impacted on work ability included some that were dependent on the type of cancer or treatment such as lymphoedema, bowel and urinary problems, difficulties with speech, nausea, sores, pain, mood difficulties, personality change and cognitive difficulties. Participants also spoke about having to take frequent time off work, either to attend ongoing appointments or as a result of becoming ill due to their susceptibility to infection. They spoke about the guilt they felt about taking frequent time off and how this added to overall pressure and worry.

In addition to the physical side-effects experienced, participants in some of the studies made reference to the emotional strain they experienced after cancer and how they found this difficult to contend with as they returned to work and resumed their 'pre-cancer' life:

'Okay you are back, and the cancer is gone. You're cured; you have had radiation, what is the problem? What is the problem? The emotional strain afterwards that is

your problem your personal battle. You cannot confront your colleagues with that, you just can't.' (Rasmussen and Elverdam, 2008)

The impact of this myriad of side effects often resulted in survivors experiencing a loss of confidence and being plagued by doubts that they could manage their work role:

'You come back with less confidence than you had when you went sick. I don't know, it's probably too many things have happened as a result of what I've had in the last year and a half.' (Grunfeld and Cooper, 2012)

Some survivors spoke of being concerned that they would be letting their colleagues and employers down due to their reduced capacity for work:

'It would worry me that I'd be letting the company down and not meeting deadlines because I wouldn't want to inflict stress on myself, I would be sitting there watching, doing some work but not doing it at the pace they would want.' (Kennedy et al., 2007)

Survivors spoke of adjustments they had made and allowances they have given themselves, to enable them to manage the side effects they experienced and to reduce the impact this had on their work. This included allowing themselves more time to complete tasks, decreasing their working hours and being more assertive about roles they were assigned:

'I am much more protective of myself at this point. It's like, you know, I'm not going to do that. They said, 'Well you're going to do triage.' I said 'No, I'm not.' (Main et al., 2005)

Changed priorities

Participants in all of the studies reported changed priorities regarding work following cancer. Many discussed how their experience of cancer had led them to question the relevance of work and to re-evaluate their priorities. The following quotation illustrates this change in perspective:

'I totally reviewed things that I determined were important in my life, so that I could devote what energy I could to those things and let the rest of it go. So there is a prioritization there about what you do with your life...I think males are so hung up on that anyway, about defining themselves by their work.' (Main et al., 2005)

This quotation touches on the survivor's re-evaluation of what is important in their life and how they would like to choose to spend their time and energy. Further to this, survivors spoke of taking this changed perception of the importance of work, back into the workplace with them and the influence this had on their day-to-day functioning in work:

'I think cancer affects your views about everything and obviously work is a big part of it. It sort of put things into perspective and you don't think things are as important. I don't get stressed about things at work...I think it gives you the attitude that you enjoy every day and I would never worry about work or let it dominate me now.'
(Amir et al., 2008)

Survivors spoke about re-evaluating their work-life balance and attaching much less importance to paid work compared to their family life:

'...I also don't want to work full-time anymore, not right now, I also want to do things here, I also want time together with X (daughter), in this I have indeed been shaken up...' (Tiedtke et al., 2012)

Other participants spoke about their changed attitude to work and how important it now was to them to find work that was meaningful to them. Survivors in Grunfeld and Cooper's (2012) study spoke of wanting to undertake work that was 'fulfilling' or 'worthwhile' rather than for purely financial reasons. The following quotation further describes the desire to make changes:

'...when your heart is not in what you're doing-you're bound to have occasion when you either verbalize it or subconsciously feel it. 'I wish I were doing something else'. I just was a follower back then [before diagnosis]. I didn't proactively go out there and try to find something [meaningful].' (Main et al., 2005)

This highlights the change in work attitude. As a result of their cancer experience, this participant has changed their attitude to work and their behaviour within the work environment. Grunfeld and Cooper (2012) described a number of survivors who spoke of being at a 'crossroads' in their life as a result of their cancer experience and feeling that they wanted to make significant changes in their working life such as changing occupation or gaining further education:

'It [cancer] makes you evaluate your whole life and what you really want out of life...For years I've been thinking about doing a degree part-time and that's rather focussed me on that.' (Grunfeld and Cooper, 2012)

In addition to considering changing career path, survivors in several of the studies spoke about experiencing a decrease in their ambition and work-related aspirations as evidenced by the following quotation:

'I'm not nearly as ambitious as I was...I would like enough money to be able to live comfortably...I'm not aspiring to have loads of money, that's not...what its about, it's about enjoying life and getting a balance between work and home.' (Kennedy et al., 2007)

For survivors, it's important to get back to work as it is a clear sign of returning to a normal and healthy life. However, at the same time, survivors of cancer often reflect on the importance of work and wish to make changes to the roles or professions they held prior to their diagnosis.

Financial pressure to return to work

Several of the studies highlighted financial pressure as being a significant factor in returning to work (Main et al., 2005; Kennedy et al., 2007; Amir et al., 2008). The following quotation from Main et al.'s study describes the financial pressure that some survivors experience:

'I want decent health insurance, good time off, but my real priority is getting out of debt. I don't know if it [the cancer] is going to come back, so it is important to me to clean up my mess. What's important right now is that I get out of debt so I don't leave my family with a huge burden.' (Main et al., 2005)

Almost half of the participants in Kennedy et al.'s study (2007) indicated that financial pressure was their main reason for returning to work. Survivors can be left feeling that their only choice is to return to work in the face of mounting debt and financial responsibilities. One participant, a 61-year old widow explained:

'I didn't feel as though I had any choice not to return to work...I live alone and I've got a mortgage, and at that time I'd got my youngest son still going through university and so to an extent he was still a bit dependent.' (Kennedy et al., 2007)

This feeling of pressure is echoed in Amir et al.'s (2008) study. Participants discussed how necessary it was for them to return to work due to the costs incurred as a result of being diagnosed with cancer and receiving treatment over an extended period of time. Several interviewees in this study spoke of building up significant debts on their credit cards or falling behind with mortgage payments due to earning less as a result of sick leave. This was especially true for participants who had low levels of financial protection due to their occupation or when they were off work for a longer period than was covered by sick leave: usually 12 months. This study found that financial pressure was also an issue for participants who had been securely employed for many years and therefore entitled to six months full sick pay and another six months on half pay. The following quotation is from a participant in this study who was employed as a health professional and had received almost six months full pay but felt pressured to return to work as she explained when asked about her reasons for why she returned after less than six months off:

'Purely financial. I didn't feel quite ready physically and I still felt a bit wobbly mentally and emotionally but I was coming to the end of my full pay and I just couldn't afford to go on to half pay if...financial things hadn't been a factor I would have perhaps wanted another month and then gone back.' (Amir et al., 2008)

It is difficult to know the correct time to return to work after cancer and it is probably best left to the individuals themselves to decide when they feel ready. However, being under

financial pressure is clearly a factor that influences some survivors to return to work before they feel ready and pushing themselves in this way could cause them to become unwell.

Advice from health professionals

Five of the studies (Maunsell et al., 1999; Main et al., 2005; Kennedy et al., 2007; Amir et al., 2008 and Tamminga et al, 2012) made reference to the advice provided by health professionals regarding return to work. These studies all reported that very little, if any, advice was given by medical professionals regarding work:

'I was very pleased with the treatment that I received from both my consultant and the breast care nurses. I was given lots of information about breast cancer and its effects but I wasn't given any information about what I should do about work.' (Amir et al, 2008)

Maunsell et al. (1999) reported that for the participants in their study, the 'question of work and what to expect in terms of the effects of the disease and the treatments on work capacity were not discussed'. Most of the participants reported that they were left with the impression that their period of treatment would be a 'difficult time' and therefore their only option was to stop work throughout the course of treatment. Kennedy et al. (2007) reported that working had never been discussed in medical appointments for just under a third of participants and many queried whether their doctor even knew whether they worked or not. Tamminga et al.'s (2012) reported that their participants thought it important to have more guidance from health professionals with regard to returning to work.

A few participants in Main et al.'s (2005) study described their experiences of receiving health professional's advice about returning to work. On occasion, this advice was neither realistic nor collaborative as indicated by the following quotation:

'Ultimately I was able to get disability. Now my oncologist and I had major disagreements about this. He felt that you should work. People do better when they work. I agree. People do better when they work and you just feel like you have more reason to get up in the morning, but at the same time...just the amount of infectious disease out there [in my job] was pretty stunning and even the docs that I worked with said 'We don't want you here. Not only do you not need to be here, we don't want you here because we are so worried about you and what you're getting exposed to...' (Main et al., 2005)

Participants in Tamminga et al.'s study spoke of the negative attitude displayed by health professionals regarding returning to work. One described her doctor's lack of understanding about why she would want to return to work during treatment because she could financially afford to stay at home. This attitude is evidence that the physician was not able to appreciate the other motivating factors that the survivor could have for wanting to return to work e.g. social support, return to normal, desire for structure and routine. The following quotation outlines a survivor's attempts to get permission from her doctor to return to work, only to be met with resistance.

'I asked my physician in September if I could return to work. I would tell him that I was getting bored at home – the kids go off to school and I stay at home alone and I get anxious. I think that if I got to work I will have something to distract me. And he [my physician] said: 'Where do you want to be? At home or in the hospital?' And I

said, 'I prefer to stay at home.' And he said, 'well, stay there...when I see that it is alright for you to go to work I will tell you.' (Main et al., 2005)

A few participants in Amir et al.'s (2008) and Kennedy et al.'s (2007) studies reported that they were advised to return to work whenever they felt ready. The following quotation details the advice given by a breast care nurse:

'She said it's completely down to the individual as to how you are, some people have a year off and others, like myself, carry on throughout. It depends on the individual. But they touched on a lot of the personal side...affecting your home life and work life.' (Kennedy et al., 2007)

This is an example of a cancer survivor feeling that their decision to return was left to them. This piece of advice could enable the survivor to feel more in control of their return to work and consequently, more in control of their life. Although the nurse in this example did not provide specific advice on when was best to return to work, opening up this dialogue by discussing the subject of work return, meant the survivor felt that the subject of work had been discussed which is more positive than other survivors who reported that the subject of work return was never discussed.

Discussion

This review synthesised qualitative data about cancer survivors' experiences of returning to work in order to facilitate greater understanding of this experience. The following six themes emerged from the literature: returning to work means returning to normal, employer and colleague reactions, effects of cancer and cancer treatment on work, changed priorities, financial pressure to return to work and the advice from health professionals.

The synthesis of the studies in this present review found that many cancer survivors equate returning to work with returning to normal life, a finding which supports previous literature which has recognised the normalising role of returning to work in a cancer survivor's journey (Spelten et al., 2002). In keeping with the findings of this review, previous research has found that cancer patients report the experience of cancer as representing a distressing loss of normalcy and control (Muzzin et al., 1994). It is therefore understandable that many cancer survivors exhibit a strong desire to recreate the normal life they had before their cancer and returning to work is a large part of that. In Western cultures, where all the reviewed studies were conducted, it is the norm for healthy adults to be in employment. Therefore, stepping back into employment can be conceptualised as stepping away from the sick role. It proves to others, and to the survivor themselves that they are firmly on the road to recovery.

This review found that the level of disclosure of cancer diagnosis from survivors was very high. Apprehension about disclosure was related to concerns about not feeling ready to discuss their cancer, fear of being stigmatised or labelled, concern about being asked inappropriate or embarrassing questions and fear of being viewed as an attention-seeker. Synthesis of the studies has found that on the whole, when survivors did disclose, they found their employers and colleagues to be sympathetic and supportive. It is clear, however, that cancer remains a difficult subject to discuss in the workplace. For multiple reasons, work colleagues can feel uncomfortable about discussing the subject of cancer. Previous research has suggested that cancer continues to have a strong cultural association with death, pain and suffering (Haylock, 2006) which could cause work colleagues to feel uncertain about the most appropriate way to engage with someone who is living with cancer. The perceived lack of public awareness about the causes of cancer and the effects of treatment can result in

survivors being reluctant to disclose for fear of misconceptions and inappropriate labels. Previous research has shown that conceptualisations of cancer are often focused around cancer being a life or death battle (Flannagan and Holmes, 2000). This can make it difficult for observers to see the life beyond cancer. Previous literature has recommended that employers be provided with more information about the rehabilitation of cancer survivors back into work after treatment as this will help them to provide appropriate support and will hopefully make work return easier for survivors (Morrell and Pryce, 2005).

It is clear that survivors experience a myriad of symptoms as a result of cancer and its treatment. This is in keeping with previous research which has found that cancer patients experience symptoms related to their cancer site and type of treatment, that cause difficulties in returning to work (Mellette, 1985). Experiencing these symptoms is likely to have a negative impact on a survivor's ability to perform in their work role. Reduced capacity or tolerance for work can easily lead to a reduction in confidence and an increase in self-doubt. This can cause survivors to feel that they are letting colleagues and employers down and to fear for their future as a worthy employee. In order to decrease the chance of survivors feeling this way, employers should be aware of the common side effects of cancer and its treatment and must be willing to make adjustments and alter demands in order to facilitate survivors' successful return to work. In addition, employers may benefit from developing an understanding of the issues facing survivors in addition to general side effects and work towards creating a destigmatising environment in the workplace. Survivors themselves could also benefit from being made aware of the prevalence of these symptoms so that they can appreciate the likelihood of needing to make adjustments and be kinder to themselves in allowing this.

The changed priorities of survivors was an area discussed in all of the studies reviewed in this synthesis. It appears that the experience of having cancer leads many survivors to question the importance of work and there was evidence of survivors re-evaluating their priorities in light of this revelation. Many changed their work-life balance in order to spend more time away from work, some spoke of their desire to find more meaningful and rewarding employment, while others spoke of changing direction in their careers and pursuing long held dreams such as further education. Others spoke of reduced ambition in the work place as a result of now viewing work as less important than they had previously. For survivors, it is important to get back to work, as it is a clear sign of returning to a normal and healthy life, however, it is clear that survivors often reflect on the importance of work and wish to make changes to the roles or professions they held prior to diagnosis. Previous research has evidenced this change in priorities which has been conceptualised as being in line with the theory of cognitive adaptation which states that following threatening events, individuals will attempt to find meaning in a negative situation in order to help them cope (Taylor, 1983).

Synthesis of the studies found that survivors are often under financial pressure to return to work earlier than desired. The presence of financial pressure as a result of having cancer is not a new phenomenon. Previous research has found that 91% of cancer patients' households in the UK suffer loss of income and/or increased costs as a direct result of cancer (Macmillan Cancer Support, 2006). In addition to loss of income due to sick leave, there is increased expenditure associated with cancer e.g. travel to appointments and parking fees and this combination can be a 'double whammy' at a time when cancer survivors are already experiencing heightened stress and anxiety (Brooks et al., 2011). The findings of this review are in line with previous research which has reported that cancer patients often feel pressured to return to work too soon because of worries over financial matters (Cooper et al., 2013). It

is understandable that financial pressure can result in survivors pushing themselves to return to paid employment before they are ready; however, it must be considered that there are also financial costs of returning to work too early. Survivors could become unwell as a result of pushing themselves too far and evidence suggests that survivors who return to work too early experience greater fatigue (Pryce et al., 2007). This could result in them taking more time off work on sick leave, which would subsequently increase the financial pressure they are finding themselves under. At a time of great stress, financial concerns are an additional pressure that could be reduced if there was a greater understanding of the recovery trajectory from cancer.

This review found that survivors received very little, if any, advice from health professionals regarding returning to work. Physicians and other cancer care clinicians are perhaps not appreciating the role they can play in facilitating return to work. It is understandable that health professionals can be apprehensive about providing advice regarding to work return, as it is such a unique experience, decided by individual factors; but, simply opening up the dialogue about returning to work can be helpful for survivors as it allows them the opportunity to discuss their thoughts on the subject and to seek advice if they wish to. In light of the lack of advice supplied by health professionals, Peteet (2000) suggested that patients who are new to the oncology service should be routinely screened for evidence of work-related issues. Previous literature has argued that health professionals require to have insight into the experience of cancer itself if they are to support survivors appropriately, recommending that qualitative studies exploring experience of cancer is a useful way to provide this insight (Carter, 1989).

The World Health Organisation (WHO) now classifies cancer as a chronic life threatening illness instead of a terminal disease, which illustrates the fact that life after cancer must be explored in order to improve outcomes for cancer survivors (Doyle and Kelly, 2005). As survival rates grow, it is likely that perceptions will continue to shift and living with cancer will become less feared and more culturally acceptable. This review has found that in order to reintegrate to a rewarding and appropriate working life, cancer survivors need support, advice and adaptations from a variety of sources.

Limitations

There are a number of limitations to this current review, which should be considered. Firstly, it is important to consider that there may be a sampling bias in the reviewed studies as the survivors who agreed to take part may have been motivated to do so because they had particularly strong feelings about their experience of returning to work. It could be that survivors who had encountered no difficulties in their return to work were less motivated to take part and therefore their views would not be represented. Therefore, it is important to emphasise that the results of the current review are suggestive and not conclusive. Additionally, several of the papers included in this review focused solely on the experience of breast cancer patients which could mean that the results of this review are skewed towards the specific experience of breast cancer patients and may not be representative of the experience of patients with other types of cancer.

Secondly, the studies selected for this synthesis used different qualitative methodological and theoretical approaches. There is an argument that it is not meaningful to combine studies from different theoretical standpoints (Dixon-Woods et al., 2001), however, the opposing

argument states that combining qualitative research from different epistemological basis is valid and enriches the analysis (Doyle, 2003).

Implications

The current review suggests that many survivors of cancer are eager to return to work, however, they do experience difficulties in returning to their previous roles and it is conceivable that this return to work would be enhanced by employers having a greater understanding of the likely effects of cancer and its treatment. This knowledge could also guide them in implementing adjustments that would benefit survivors. Increased awareness of the issues cancer survivors face when returning to work could lead to improvements in creating a destigmatising environment in the workplace. The fact that the many survivors recognise that their priorities and attitudes to work have changed indicates that their experience of cancer has altered their views and perspective on life. It can be helpful for cancer survivors experiencing such changes to receive peer support, for example buddying, support groups, internet forums. It is also clear that a number of survivors feel under financial pressure to return to work before they are ready. In light of this, perhaps changes to the incapacity benefit for cancer survivors could be considered to incorporate the length of time it takes to recover from cancer and its treatment. Finally, survivors have reported that they receive very little advice from health professionals regarding the subject of work return. Encouraging and facilitating health professionals to open up this dialogue in appointments with survivors would enable them to feel that this important part of their lives is being considered. It would also enable them to be signposted to the most appropriate agency for further support.

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Chapter 2: Major Research Project

Patient experience of admission to critical care unit (CCU) during Haematopoietic Stem Cell Transplant (HSCT)

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Lay summary

Critical care is the term used to describe both intensive care units and high dependency units. These units provide expert care for seriously ill patients who require constant, close monitoring and specialist nursing to keep them alive. Previous research has shown that admission to these units can be a frightening and upsetting experience. Blood cancer patients can receive a particular type of bone marrow transplant known as haematopoietic stem cell transplant (HSCT) which has the potential to cure the disease. HSCT is an extremely aggressive cancer treatment and around a quarter of patients who receive the treatment will require admission to a critical care unit after the transplant. Little is known about the experiences of cancer patients who are admitted to critical care as a result of their treatment, therefore the aim of this study was to explore HSCT patients experiences of being admitted to critical care following their transplant. Five patients were interviewed and detailed their experience of this admission. The results of the interviews found six main themes: gaps in recollection, unreal experiences, being in the right place, unexpected and unprepared, role of family and life after critical care. This study has identified potential causes of psychological difficulties following patients' admission to critical care. It has also provided insight into the unique experiences of cancer patients in critical care, which can be compared to the experiences of other categories of patients admitted to critical care. Further to this, providing close relatives of critical care patients with information on likely presentation and behaviour of patients in critical care is also advised. Insight provided from this study can be used to inform clinical practice and can provide the rationale for further research and clinical intervention.

Abstract

Background: Critical care is the term used to encompass ‘intensive care units’, ‘intensive treatment units’ and ‘high dependency units’. These units provide expert care for critically ill patients who require constant, close monitoring and specialist nursing to keep them alive. Previous research has shown that admission to critical care can be a frightening, upsetting and traumatic experience. Haematological cancer patients who receive a haematopoietic stem cell transplant (HSCT) frequently require admission to critical care as a result of this potentially curative but extremely aggressive treatment. No previous research has explored the unique experience of HSCT patients admitted to critical care.

Aim: To gain an in-depth understanding of the experience of cancer patients’ admission to critical care.

Methods: Five HSCT patients who had been admitted to critical care completed semi-structured interviews. Transcripts were analysed using Interpretative Phenomenological Analysis.

Results: Six superordinate themes were identified: gaps in recollection, unreal experiences, being in the right place, unexpected and unprepared, role of family and life after critical care. It was clear that despite the patients recalling potentially distressing experiences from their stay in critical care, they had no regrets about having the transplant and viewed their admission as being worth it. Themes are discussed in relation to relevant literature.

Conclusions: This study offered a unique insight into the experience of being admitted to critical care following stem cell transplant. Implications for the treatment and care of cancer patients admitted to critical care are discussed.

Keywords: Qualitative research, patient experience, haematopoietic stem cell transplant, critical care, intensive care, high dependency.

Introduction

People affected by severe illness often need to be cared for in critical care. Critical care is a term that encompasses ‘intensive care unit (ICU)’, ‘intensive treatment unit (ITU)’ and ‘high dependency unit (HDU)’. These units provide expert care for critically ill patients who require constant, close monitoring and specialist nursing to keep them alive (Adam and Osborne, 2005).

Previous literature in the area of critical care has focused largely on outcomes such as survival rates, cost or functional status following discharge (Brooks et al., 1995). With recent advances in critical care, more patients are surviving critical care unit (CCU) admissions (Angus and Carlet, 2003). This increase in survival rates has meant a shift in focus of research in this field to longer-term outcomes of CCU-treated patients, including mental health, health-related quality of life and cognitive outcomes (Broomhead and Brett, 2002; Dowdy et al., 2005; Hopkins and Jackson, 2006).

‘ICU syndrome’

In the 1950s, as admission numbers to intensive care increased, research identified that many ICU patients developed psychological problems (Egerton and Kay, 1964). Initially, it was thought that these problems were due to the illness which had caused admission to ICU but it was discovered that the ICU environment, routine and care were equally important to the development of the problem which was given the name ‘the ICU syndrome’ (McKegney, 1966). The syndrome is characterised by a wide variety of symptoms, which can include anxiety, fear, restlessness, fatigue, confusion, delirium, hallucinations and disorientation (Mackellaig, 1990).

Dyer (1995a) sought to explore possible causes of ICU syndrome and identified similarities between categories of psychological torture, identified by Amnesty International (1973), and experiences in ICU. The categories of torture identified were isolation, monopolisation of perception, debility, threats, occasional indulgencies, trivial demands, demonstrating omnipotence and degradation and Dyer drew parallels between each category and the experience of being in ICU as outlined in Table 1.

Table 1: Categories of torture and parallels with ICU

Torture	Method	Parallel with ICU (Dyer, 1995a)
Isolation	Solitary confinement	Infectious patient may be physically isolated. Intubation may leave the patient unable to speak and non-verbal communication can be affected by dressings and monitoring equipment. Restricted visiting further increases sense of isolation.
Monopolisation of perception	Barren environment, darkness, bright light, monotonous food, restricted movement	Barren environment of ICU, lack of meaningful stimuli. Movement restricted by vital equipment.
Debility/exhaustion	Semi-starvation, sleep deprivation, exploitation of wounds, constraint	Nutrition is a low priority in ICU and lack of sleep is common.
Threats	Mysterious changes of treatment, threats of death	Possibility of death or disability. Routine procedures can be frightening if the patient does not understand what is happening.
Occasional indulgencies and trivial demands	Favours, promises and rewards for compliance, enforcement of minute	Treatment in ICU sometimes requires denial of patients' requests e.g. being denied analgesia due to concern over respiratory

	rules	depression. These denials may be necessary but if unexplained, can cause the patient to feel confused and deprived for the sake of it. Staff may encourage co-operation by offering rewards, which can reinforce the power imbalance between staff and patient.
Demonstrating omnipotence	Taking cooperation for granted	Co-operation with staff can be taken for granted and patients who do not co-operate can be labelled as being difficult.
Degradation	Hygiene prevented, denial of privacy	Lack of privacy due to being partially clothed in a hospital gown and the curtains around the bed providing inadequate privacy.

Unique stressors of critical care

Previous literature has identified four categories of stressor that are experienced by critical care patients. Each of these stressors could be considered as triggers to the development of psychological difficulties.

Physical stressors

Lack of sleep is a common problem for patients in critical care with one study reporting that over 50% of critical care patients experience sleep disturbances as a result of pain, anxiety, noise, light and frequent nursing interventions which disturb sleep (Chew, 1986). This lack of sleep would be likely to exacerbate any psychological symptoms. Physical stressors could also include thirst, pain and weakness.

Environmental stressors

Critical care units can be described as barren environments and patients often experience a lack of meaningful stimulation, which can act as an environmental stressor. CCUs often have bare walls and ceilings and bright artificial lights which can affect patient's ability to sleep and can result in them being unable to distinguish day from night. Patients can also feel trapped and tied down by equipment needed to keep them alive (Clifford, 1986). They are also subjected to the constant background noise of equipment such as ventilators and alarms and this may lead to sensory overload (Adams et al., 1978). In response to the recognition of such problems, CCUs have been advised to take steps to reduce environmental stressors such as introducing clear day and night periods, allowing natural daylight in where possible and redecorating in colours other than 'hospital white' (Dyer, 1995b).

Emotional disturbances

Previous research has found that patients who have been admitted to critical care often experience impaired cognitive functioning, worries and fear. Patients may experience general fears relating to death or disability (Johnson and Sexton, 1990) or they may experience specific worries related to pain, sounds or sights that they are exposed to. Noise from other patients in distress may cause anxiety, as may overhearing conversations about their own condition.

Communication difficulties

Communication can be difficult in critical care as it is often hindered by either the patient's medical condition or necessary medical interventions such as intubation. If patients struggle to communicate with staff or relatives this can lead to feelings of isolation. In addition, non-verbal communication such as eye contact and facial expression can be hindered by dressings

and equipment. Patients who are feeling isolated due to reduced communication may view visitors as their only link to the outside world, however, in the majority of CCUs, visiting is restricted (Biley et al., 1993) which can leave the patient feeling further isolated.

Post-CCU PTSD

When patients are admitted to critical care they are, by definition, experiencing a critical illness that is life-threatening and many patients recall frightening experiences of CCU (Jones et al., 2000). Therefore, post-traumatic stress disorder (PTSD) is a potential concern and a number of studies have looked at the prevalence of post-CCU PTSD with rates of PTSD after a period of critical illness being estimated to be between 4-25% (Griffiths et al., 2007; Jones et al., 2007).

Davydow et al., (2008) completed a systematic review of PTSD in ICU survivors and highlighted three important issues. First, the prevalence of substantial post-ICU PTSD symptoms is high and these symptoms appear to persist over time. Second, consistent predictors of post-ICU PTSD include pre-ICU psychopathology, greater ICU benzodiazepine administration and post-ICU memories of in-ICU frightening experiences. Third, it was reported that post-ICU PTSD may have a substantial impact on quality of life. Findings from this review highlight how important it is that clinicians are aware of the risk and prevalence of PTSD in ICU patients. Hatch et al. (2011) recommend the development of a validated screening tool to detect psychological disturbance within the ICU, however, given the inherent difficulties of accurately assessing the psychological state of critically ill patients, a screening tool currently remains elusive.

Discharge from critical care

Although discharge from critical care to a general ward is a positive step in the patient's recovery, previous research has identified that this transition can also be a stressful time for patients and their relatives. A meta-synthesis in this area (Bench and Day, 2010) focused on the specific problems faced by patients and their loved ones immediately following discharge from critical care to a general ward; five themes have been identified from the literature, all of which have the potential to influence a patient's physical and psychological recovery. These themes are: physical symptoms, psychological symptoms, making progress, the need to know and safety and security. These findings emphasise the importance of understanding the potential consequences of discharge from critical care as well as those from being in critical care.

Qualitative research

Whilst many studies have looked quantitatively at the prevalence rates of psychological problems post-CCU, few have employed qualitative methods to explore individual experiences of critical care.

First-hand accounts of periods in critical care have described feelings of confusion, paranoia, fear and labile mood (Bowers, 2004) and feelings of shame, being under 'attack' and the importance of being kept informed of what was happening to them (Clark, 1985).

Johnson et al.'s (2006) study found that patients, who had been critically ill in the CCU, reported that they had lost track of time and reality. They experienced disturbing hallucinations and nightmares and they perceived their bodies to be unfamiliar and unreliable. Bowers (2004), an ITU nurse herself, gives a personal account of her admission to

ITU, which includes examples of delusional thoughts. Despite having a wealth of knowledge in ITU processes, she became paranoid that she was being held against her will by staff and she recalls thinking that staff members were ‘smiling assassins’ who were trying to harm her. These qualitative studies highlight how frightening an episode in critical care can be for patients.

Another qualitative study (Hupcey, 2000) found that ‘feeling safe’ was an overwhelming need for patients whilst in critical care. This study identified several needs that influenced the experience of feeling safe. These were: the need to know what was happening to them, the need to regain control, the need to have hope in their recovery and the need to trust critical care staff. When these needs were not met, patients reported feeling unsafe which led them to experience episodes ranging from being upset or frustrated to being distressed, feeling paranoid or fighting against staff.

Cancer patients admitted to critical care

Cancer patients can require admission to critical care secondary to the development of treatment related conditions. Haematological cancers are cancers arising from abnormal blood or bone marrow cells and include leukaemia, lymphoma and myeloma. Haematopoietic stem cell transplantation (HSCT) is a potentially curative treatment for haematological cancers however the treatment is extremely aggressive and potentially life threatening. HSCT requires high dose conditioning chemotherapy and, in some cases, total body irradiation, followed by infusions of stem cells to re-establish haematopoietic function (Mosher et al., 2009). These treatments bring increased risk of acute morbidity. Due to reduced immune system function, patients are at great risk of infection, which can be fatal. Other possible complications include sepsis, respiratory failure and graft versus host disease (GvHD), all of

which can result in the patient requiring admission to critical care (Bird et al., 2011). For this reason, HSCT patients are admitted to critical care more frequently than patients with other types of cancer, with 19% to 40% of HSCT patients requiring admission after transplant (Scales et al., 2008).

When a patient's condition deviates from the expected outcome, such as a transfer to critical care, patients may experience anxiety, depression, fear, emotional isolation and loss of control (Heinonen et al., 2005). Previous literature documents the stressful nature of a CCU admission for any patient and the unique stressors of critical care admission coupled with the unique stressors of aggressive cancer treatment could lead to patients developing mental health difficulties.

There are several reasons why cancer patients' experience of critical care may differ from the experience of other groups of patients admitted to CCU. Unlike patients who are admitted to CCU because of a sudden, medical emergency, cancer patients are often admitted as the result of aggressive cancer treatment to which they have consented. This could mean that cancer patients and their families may have been made aware that such an admission is a possibility, which may ameliorate the psychological impact of the CCU admission to some extent. Cancer patients could also differ from other patients admitted to CCU as they may view their cancer treatment and subsequent admission to critical care as a means of saving their life. Aggressive cancer treatments, which result in admission to critical care, are often the last treatment option available to the patient and therefore they may hold a more balanced view of their stay in CCU due to the awareness that the treatment and subsequent admission also saved their lives.

As survival rates of patients undergoing HSCT and other aggressive treatments has improved over the last decade (Depuydt et al., 2011), it is important to consider the lasting psychological effects of such treatments. A positive outcome of cancer treatment should not be focused on survival alone but should also appreciate the mental wellbeing and quality of life of the patient.

Aims

This study aimed to gain an in-depth understanding of the experience of cancer patients' admission to critical care. A secondary aim was to identify whether there are any steps that can be taken to reduce patients' distress when they are admitted to critical care and if so, what they are. Semi-structured interviews and subsequent Interpretative Phenomenological Analysis were employed to achieve this aim.

Method

Ethical Approval

This study was approved by the University of Glasgow, Ayrshire & Arran Clinical Governance, Beatson West of Scotland Cancer Centre (BWoSCC) Clinical Trials Executive Committee, West of Scotland Research Ethics Committee (Appendix 4) and Greater Glasgow and Clyde Research and Development (Appendix 5). Participants were informed that they had the right to withdraw at any point, with no impact on their medical treatment.

Design

This study used qualitative design, employing Interpretative Phenomenological Analysis, which has its theoretical roots in phenomenology, hermeneutics and idiography (Smith, Flowers and Larkin, 2009). IPA is concerned with the detailed examination of personal lived

experience, the meaning of the experience to participants and how participants make sense of that experience (Smith, 2011). It has been proposed to be a qualitative method particularly suited to health psychology (Smith, 1996).

Inclusion criteria

People were invited to take part if they were aged 18 or over, had a diagnosis of haematological cancer and had been required to be admitted to critical care after receiving a haematopoietic stem cell transplant. They had to have been admitted not less than three months ago and not more than two years ago.

Exclusion criteria

Participants who did not speak English as their first language were excluded.

Recruitment Procedures

Participants were recruited from the BWoSCC and identified through the BWoSCC database. Prior to recruitment, patients who had been identified as meeting inclusion criteria were discussed with their Consultant Haemato-Oncologist who was able to advise as to any reasons why those particular patients should not be contacted. Information sheets were posted to them with a cover letter signed by a Senior Haematology Nurse (Appendix 6). Interested recipients returned the opt-in form indicating their permission for the researcher to contact them regarding the study. Patients who expressed an interest were contacted to arrange a suitable time and place to conduct an interview and to discuss any concerns or questions about the research. Participants were asked to sign a consent form before the interview commenced (Appendix 7).

Research Procedures

Non-directive, semi-structured interviews were used to explore the participants' experience of being admitted to critical care following their transplant, facilitating flexibility within the interview. The participants were allowed to address areas which they viewed as important in detail. Prompts such as 'can you tell me more about that' were used to encourage elaboration on topics. The interview schedule (Appendix 8) was informed by previous research of patients' experience of critical care both by clinical reviews and personal accounts. The interviews lasted between 36 and 97 minutes (mean 59 minutes).

Due to the potentially distressing nature of the topics discussed, care was taken to ensure that the participants felt at ease and that a rapport was developed before discussing the most difficult areas.

All interviews were conducted within the BWoSCC and were timed to fit around pre-arranged appointments in order to be most convenient for the participants. All interviews were recorded and transcribed with identifiers removed.

Researcher Reflexivity

Although IPA aims to generate understanding through participants' perspectives of phenomena, there is acknowledgement that the researcher brings their own pre-existing beliefs to the process and plays an active role in interpreting the data (Reid, Flowers and Larkin, 2005). Therefore, care was taken to acknowledge the researcher's own experiences and beliefs and to consider how these may influence the interpretation of participants' experiences.

The researcher had worked clinically with other populations who have required critical care and this provided insight into the typical challenges faced and potential reactions to this experience. The researcher had no close personal experience of haematological cancer or admission to critical care but was aware that hearing about the experiences of the participants could have an impact on her own personal feelings.

Data Analysis

Interviews were transcribed verbatim by the researcher. Each participant was allocated a pseudonym and other potential identifiers of person or place were anonymised. The transcripts were then analysed following the guidance for practical stages involved in IPA (Smith and Osborn, 2008). Particular points of interest and significance were noted in the margins. This process identified emergent themes, which captured the quality of the participants' experiences. A list of themes was compiled and connections and clusters were extrapolated to create over-arching themes. The over-arching themes of each transcript were then compared to produce a final list of themes to be used as the basis for a report, illustrated with quotations from the interviews. See Appendix 9 for a sample extract of an analysed interview.

With the potential for the analysis being biased by the researcher's beliefs and experiences in mind, two of the transcripts were analysed by a supervisor who had no direct experience of this patient group and no personal experience of critical care. The second researcher was blind to the findings of the first analyst and a comparison of themes was conducted to check the validity of the analyses completed by the first researcher. Although there were differences in the wording of naming themes, they were semantically the same.

Results

Participants

Eight participants were identified as suitable from the BWoSCC database with five completing interviews. Of the three who did not participate, one did not respond to the invitation and two did not wish to take part. The sample obtained comprised of five cancer patients who had been admitted to critical care following a haematopoietic stem cell transplant. This is in accordance with the guidance on number of interviews for research using IPA for professional doctorates (Smith et al., 2009). Participant information is shown in Table 2, using pseudonyms to maintain anonymity.

Table 2: Participant information

Pseudonym	Age	Type of cancer	Reason for admission	Time spent in critical care
Edward	68	Chronic myeloid leukaemia	Pneumonia	Ten days
Andrew	44	Acute lymphoblastic leukaemia	Pneumonia	Three weeks
James	30	Acute lymphoblastic leukaemia	Inflammation of liver	Three days
Ross	39	Acute myeloid leukaemia	Renal failure	Two weeks
Katrina	38	Hodgkin's lymphoma	Renal failure	One week

Six superordinate themes were identified concerning the experience of being admitted to critical care following haematopoietic stem cell transplantation: (i) gaps in recollection, (ii) unreal experiences, (iii) the right place at the right time, (iv) unexpected and unprepared, (v) role of family and (vi) life after critical care. See Appendix 10 for a table of themes and their main dimensions.

Quotations from the interviews have been selected to illustrate each theme; these are presented in italics, with pauses in speech indicated by a series of three dots. The researcher's comments are in bold.

Gaps in recollection

All five participants reported experiencing gaps in their memory of their time in critical care. Some had difficulty recalling their admission, some struggled to remember any details about their stay in critical care and some could not remember being discharged. The following quotation illustrates how one participant struggled to remember how many days he was in critical care and therefore had to rely on his wife's report:

*'What did Janet say, how long was I in for?' (**Ten days.**) 'Ten days? I couldnae have been in there for ten days. Did she say ten days?' (**Mhm.**) 'Ah well, must have been. Must have been in there for ten days. I lost track.'* (Edward)

Several of the participants spoke of almost their entire time in critical care as being a lost memory. They recalled directly before admission and then had very few, fragmented memories until either just before or after discharge to a general ward:

'Getting admitted to ICU I don't remember at all. As I say, that was the time that I started getting unconscious or whatever and I just don't...it's part of the time that I don't remember at all. Em...so from being in one room to the next room...nope.'

(Andrew)

'I just eh...I was sitting in the flat and they got the doctor and eh...I don't remember anything from then. I got in the car seemingly, I don't remember getting in the car. The doctor says take him to the hospital and I flaked out and woke up six days later.'

(Ross)

Participants frequently had to rely on information provided by their loved ones in order to piece together the time they were missing, to try and make sense of their admission:

'I would say there's what, three weeks that I've totally lost. And I still...I can only go on my wife's saying, what my sister's saying, what my brothers are saying and things like that.' (Andrew)

This experience of having to piece together the story could be frustrating and confusing, especially when their own thoughts about their time in critical care did not tie in with the reports from their relatives:

***(And what's it like having to piece together that story from other people and not remembering yourself?)** 'It's hard. People are saying you can piece it all together and it'll come back together and the doctor is saying 'There'll be times you won't get back together. That's three weeks of your life you might never ever get back in your life.'* And at the moment, I would say 99% of those three weeks is a blur. I cannae

even...the dates don't tip up wi' the dates that my wife's telt me. The dates arenae tying in. So...that's...it's been a long process.' (Andrew)

Several participants reflected on the protective factor of not being able to recall their time in critical care. Although on one hand they expressed frustration at not being able to recall this time, on the other hand, they appeared to appreciate that this experience might not be one that they wanted to recall:

'It just was kinda...it's six days out of my life that I don't remember. Which is probably a good thing.' (Ross)

'But yeah, I don't remember a hell of a lot. I think I just blocked it out anyway, what I do remember. You know, it's not something I want to remember, so...' (Katrina)

Unreal experiences

All of the participants described experiences that they viewed as being removed from reality. These included strange dreams, nightmares, hallucinations, paranoia and behaving in a way that they felt was out of character for them. The following quotation illustrates Andrew's experience of a 'weird dream':

'In the three weeks that I was unconscious...well I call it unconscious cause I think that's what it is...I had weird dreams. I don't know if that's part of it, being in there. Dreams of my family going on holiday without me and there was a family bereavement. And I got taken away to get my treatment somewhere here. People turning on me and things like that.' (Andrew)

Andrew described experiencing strange dreams in ICU, dreams which included watching his family attend a funeral without him and dreams in which family members turned on him and stated he did not deserve cancer treatment. Understandably, he found these dreams distressing and because of his poor health, he was unable to communicate his distress to the nurses or to his family.

Participants also described experiencing hallucinations. The following quotation from Edward describes an hallucination he experienced when he thought he could see a family member standing outside his hospital room. This vision caused him to worry that he was losing his mind:

'He was standing outside the door. And I'm saying 'What's he doing out there? Is he no coming in?' But Janet said he wasnae there. (Edward laughs). I was like 'Oh my God, I need to get out of here!' (Edward)

Participants described being left distressed by their hallucinations, nightmares or paranoia. For one participant this took the form of believing the nurses were conspiring against him and for another, it involved interpreting medical intervention as an assault:

'I remember having a nightmare. And I don't know if I was hallucinating or if it was a nightmare. That someone was trying to staple my hand...my wrist.' (Katrina)

Several of the participants spoke of behaving in ways which they felt was out of character for them. In the following quotation, Edward described being informed by a nurse that he had shouted at another nurse. Edward viewed this behaviour as completely out of character and the fact he had behaved in this way still troubled him:

'It was a nurse that told me that. That I was shouting. I must have been on drugs or something. I wouldnae...I wouldnae have done that. Definitely wouldnae have. In fact, I tried to find out who it was to apologise but I couldnae find out who it was.'

(Edward)

Andrew also described behaving in a way that was out of character for him, a memory which he found distressing. He recalled pleading with his wife to remove him from the hospital and when she refused he threatened her with divorce and eventually bit her hand:

'I had grabbed Christine's hand and said 'You better get me up this road or we're divorced' and I pulled her hand, I remember. I remember to this day, pulling her hand dead tight in and she said 'I can't, I can't, I can't' and I bit her hand. I literally bit her hand.' (Andrew)

In the above quotation, Andrew recalled being in so much discomfort that he threatened his wife in order to try and convince her to discharge him from the hospital. Reflecting back on this memory, he expressed his horror at the fact he had bitten her. It appeared to be difficult for the participants to reconcile their unusual behaviour with their 'normal' selves. This added to their belief that being in critical care was an 'unreal experience', removed from reality.

The right place at the right time

All of the participants made reference to the fact that being in critical care was the right place for them to be at that time. They understood that it was necessary for them to receive that level of care and they felt comforted by the fact they were surrounded by clinicians they viewed as experts in that field of medicine:

'And you're in the right place. For what you need. They're used to it. And I think, probably because I was moved from here (cancer ward), I thought, 'These people know better how to deal with this problem than the doctors do here.' Here they know about the cancer but there they would know about the renal failure. So I felt that they would know, cause I trusted the doctors here so I thought 'Well if they've sent me then it must be the right place for me.' (Katrina)

Participants spoke of appreciating the necessity of being in critical care. They understood that everything that was done by the medical professionals was done with the best of intentions and they expressed their trust in hospital staff, to do the right thing:

'If I go into intensive care there's obviously people there that are going to be treating me. I feel as though every place that I've been to, there's people there who know their job so...I'm going there for a reason and they'll fix me. Hopefully.' (Andrew)

Several of the participants spoke of finding comfort in the high level of observation they were afforded in critical care. This made them feel safe and reassured that if they were to deteriorate in any way, it would be picked up quickly by the critical care staff:

'It's constant care; it's just on top of you all the time. There's somebody looking at you all the time. They're there, they're no outside a door. It gives you a bit of reassurance, ken?' (Ross)

Ross further elaborated his point by comparing his stay in critical care to a stay in a general ward he experienced after surgery earlier on in his cancer treatment. He felt that he was left unattended for long periods in the general ward, which caused him to feel anxious, and as if

no one cared. He was therefore able to reflect on the high level of observation provided in critical care as being comforting:

'You're no getting left. I sat in the other hospital...I got my neck cut open (...) and I remember sitting in the hospital up in the kinda recovery bit with this drain, sitting there thinking 'Naebdae's bothering wi' me.' (...) I just remember in this other hospital, lying there, having been through this operation to do this thing, going through chemo, everything at the one time and sitting in that room, with this drain, neck stapled here and just thinking 'Naebdae's bothering.' (Ross)

This view of being cared for more intensively in critical care compared to general wards was echoed by Katrina:

'They probably check on you more often, I would think. (...) And there's probably a sense that you're being looked after...not better but people are keeping an eye on you more than when you're in the ward.' (Katrina)

This experience of feeling safe in critical care meant that although participants were keen to get home, they experienced some anxiety about being discharged from critical care to a general ward as echoed in the following quotation:

'I think...it was faultless from a professional point of view. They really...they really looked after me, they did, they did. It was eh...it was the place to be if you're ill, ken? But eh...naw I couldnae fault it. And I wasnae pleased, when it came to saying 'Right you're fit enough to go to the ward', I wasnae desperate to get out of it, ken? The care you were receiving and you felt you were needing it, you didnae...I wasnae desperate to get out of there.' (Ross)

Unexpected and unprepared

All of the participants stated that their admission to critical care was an unexpected event for them. None of them could recall the possibility of requiring critical care being discussed with them before they had their transplant; although several participants conceded that it was possible that the topic was discussed but they failed to remember it:

(So do you remember anyone speaking to you about possible admission to critical care after your transplant?) 'Not that I can remember. Not that I...I would have...if I was told it probably I would thought I would have remembered it...but I don't...I cannae think of being told it. Em...I presume it's probably classed as one of the side effects, I suppose. It obviously happens but I don't remember being told.' (Andrew)

Several of the participants spoke of having made the decision to have the transplant and therefore being told of possible side effects would not have deterred them and they reflected that they therefore may not have paid close attention when the risks were discussed:

'They never stated that I could end up in ICU or any of that. They just told me of the symptoms and...you know...the side effects and all that and...basically I was still willing to carry on with the transplant....so...yip.' (James)

Although participants spoke of being aware of the possibility of side effects as a result of their treatment, it appeared that none of them anticipated just how seriously ill they could become and admission to critical care was an unexpected complication for them:

'I never really thought about it to be honest. I was doing fine. It was totally out the blue. It wasnae something...I didn't expect to take no well. I'd really been quite good, right through my treatment.' (Ross)

In addition to not feeling prepared for their admission to critical care, participants spoke of being unprepared for how weak their stay in critical care left them. Due to not appreciating how ill they had been, they expressed shock that they were not as fit as they expected to be upon discharge:

'Uh huh, she came and collected me (upon discharge). And, as I said, my legs, I couldnae really understand the way my leg...I couldnae move my legs properly. I think it was the...must have been doing...must have been drugs or something, doing something to my legs.' (Edward)

Although participants identified that they had not been warned or prepared for their admission to critical care, several of them stated that being pre-warned would not have been helpful to them anyway and therefore was not required:

'I don't think it would have made my stay any better if I'd been warned about it. It's no something that you would want to find out cause you would hope you would never be there I suppose. But I would say when I was admitted, when I knew what was happening, they were good at telling you what was going on. So I don't think it would have mattered if I'd known anything before I went in, to be honest.' (Ross)

Role of family

All of the participants spoke of the role of their family during their time in critical care. All participants identified the positive impact of receiving visits from their family:

'...it was good to see friendly faces, rather than being poked and prodded by doctors and nurses.' (James)

Despite initially finding family visiting as a source of comfort, two of the participants stated that they began to find their family to be a source of stress as demonstrated by the following quotation, where Ross described his experience of his family members asking the same questions about his treatment and progress every day:

'It probably helped me through but as you started...I started getting...no annoyed, but you start wanting home and they just, they can start grating on you when they ask stupid questions. (...) Things that they don't understand. They're asking about 'What's this doing?' and 'What's that doing?' (...) It just got kinda wearing eventually, they're coming in all the time. And the more I wanted to get home, the more kinda, you're thinking, 'Oh here they come again.' (Ross)

This illustrates how Ross initially found daily visits from his family to be helpful, but as he recovered and became focused on being discharged, he began to be irritated by the frequent questioning from concerned family members. Ross' reflection that his family both helped get him through this time and irritated him represent juxtaposition in the experience of family support and these conflicting feelings can be difficult to manage.

Several of the participants stated that the experience of being critically ill was probably worse for their loved ones than themselves as they were unaware of many of the details of their admission due to their level of consciousness, however, their family could recall a great deal more:

'But Janet, she was up every day I was in and she took a couple of weeks off her work. She had it hard right enough. It was probably harder for her than me.'
(Edward)

'...it's something that happened and probably affected my family more cause I didn't know anything about it.' (Ross)

Four of the participants spoke of the desire to return to their family as being their main motivation for recovery whilst staying in critical care.:

'You've just got to keep thinking, you want to see the weans. That was my focus.'
(Ross)

'I've got six grandkids and when I found out I was going to be alright, that was me, I'm going to have the weans a wee bit longer. That's all that mattered to me. And the wife, and the lassies. That's all I worried about.' (Edward)

These quotations demonstrate the motivating role that thoughts of family have on patients' desire to work towards recovery and discharge.

Life after critical care

All of the participants reflected on life after critical care. Two stated that they tried not to look back on this period as they did not find that helpful:

'I don't really reflect on my time there. I didn't like it and that's it really. I don't know. I just don't think about it really. It doesn't pop into my head. It's not a time in my life that I sit down and reflect back on. It was only a few days and that was it, it's gone, so that's it.' (James)

This indicates that James felt it was unhelpful to reflect on his experience of being in critical care. He, and another participant, spoke of their belief that dwelling on the past was unhelpful and it was instead more productive to focus on the future and moving forward.

All the participants spoke of being grateful for everything that was done for them. Although they all reported negative aspects of being in critical care, they all appeared to view their admission as being for the 'greater good'. Edward spoke of experiencing cognitive difficulties as a result of his period of serious illness, however, he was keen to make it clear that he was not concerned about this and still felt that admission to critical care had been worth it:

'I don't think there's much that can be done about it (cognitive problems). But as I said, I'm going to have my grandchildren longer than I thought I would, so I'm not even bothering about it. (...) I mean, I've got my life back haven't I? What more can I ask for?' (Edward)

Other participants reported changed life values and priorities as a result of being seriously ill:

'I probably value life more. And I'm more appreciative of things. (...) I think I used to put too much pressure on myself before and thought 'You need to be more perfect, you need to do a better job at work, you need to be a better mother, you need to lose five pounds or whatever. But that's not important anymore. It's important to be healthy.' (Katrina)

Katrina reflected on the difference between her anticipation of life after the transplant and the reality. She had felt that as she was young and otherwise healthy, she would bounce back

from the transplant and her recovery would be most similar to the ‘best possible scenario’ discussed by her doctor:

‘I thought ‘Ok, stem cell transplant, four weeks and I’ll be back to normal’, you know, I’ll be doing all these things, maybe not quite as much but your mentality is that you’ll be the same person and you’re not afterwards. It changes everything.’

(Katrina)

Katrina had not anticipated becoming as unwell as she did and she felt adapting to this discrepancy between her imagined recovery and her real recovery was one of the most difficult parts of life after critical care.

Several participants reflected on the fact that the passage of time since their critical care admission has allowed them to reflect on it in more depth than they were able to at the time:

‘I didn’t...know what was going on so it didn’t bother me. And by the time I knew, I was much better and there wasn’t that concern anymore so it was ok. I do dwell on it now and again and think ‘That’s quite weird’. What it’s made me see is that you don’t know when you’re going to die.’ (Katrina)

Discussion

This research has elicited the lived experiences of individuals admitted to critical care following haematopoietic stem cell transplantation. The interpretation of interviews resulted in six themes; gaps in recollection, unreal experiences, the right place at the right time, unexpected and unprepared, role of family and life after critical care.

As found by previous research, the participants reported gaps in their recollections of their time in critical care. Eisendrath (1982) concluded that confusion and memory disturbance were the defining features of ICU syndrome. An earlier qualitative study with ICU survivors found that no recall of the ICU admission period was common (Adamson et al., 2004). In a paper based on follow-up data, Griffiths and Jones' (2007) review of 20 years of intensive care reported that many patients do not recall their ICU stay. In support, they cite a large follow-up study that found 38% of patients admitted to ICU had no recall of any of their stay (Granja et al., 2005). This lack of recall means that patients have gaps in their understanding of what has happened to both themselves and their family (Griffiths and Jones, 2001).

Similar to a study by Granberg et al., (1998), several participants in this current study initially stated they had no recollection at all of their stay in critical care, however, after being asked open questions about features of a typical stay in critical care, they started to talk about memories they had of their admission.

The fragmented nature of memories for the stay in critical care and the high proportion of delusional memories, such as nightmares and hallucinations, make it difficult for patients to make sense of what has happened to them (Jones et al., 2000). Research has found that absent memories of time in critical care can be harmful for patients (Griffiths et al., 1996). Lack of recall can mean that patients do not appreciate how ill they have been and therefore can have unrealistic expectations of their recovery and can be disappointed when they view their recovery as being slower than it should be. This was reflected in this current study as several participants spoke of being dismayed at their weakened state upon discharge. Also, patients who have no recall of their stay in critical care may find that their gaps in memory are filled by delusional or paranoid memories (Jones et al., 1994).

Unreal experiences can be pleasant, unpleasant or sometimes frightening. They can cause patients to worry that they are losing their minds. Recent studies have reported the incidence of dreams and nightmares during admission to critical care as 10% (Rundshagen et al., 2002), 38% (Green, 1996) and 47% (Strahan et al., 2003) with themes such as death, travelling and fear being common. Granja et al. (2005) found that 51% of followed-up ICU patients reported experiencing dreams and nightmares during their ICU stay and 14% of the patients reported that the experiences were still disturbing them six months later.

The experience of lying in a hospital bed in critical care, with very limited stimulation, can be likened to experiences of sensory deprivation and the ‘unreal experiences’ reported by the participants in this current study are incredibly similar to the experiences others have described as occurring as a result of sensory deprivation. Heron (1957) conducted a study in which participants were deprived of sensory stimulation and found that prolonged exposure to a monotonous environment had deleterious effects. The individuals displayed impaired thinking, childish behaviour, and experienced hallucinations. This is in line with the experiences described by the participants in this current study. They all reported either confusion, out of character childish behaviour or hallucinations. Previous research has commented on how the environment of critical care can contribute to the experience of sensory deprivation due to the plain décor, repetitive noise of machines and limited interaction (Dyer, 1995a). Attempts have been made to address this lack of stimulation but the findings from this study suggest that patients in critical care are still experiencing sensory deprivation and the resulting psychological sequelae, suggesting that further research has to be conducted on the most appropriate way to provide stimulation in both visual and auditory form.

All the participants in this current study made reference to the fact they were grateful for the intervention of the critical care team and felt they had been in the right place at the right time. Even participants who reported negative experiences from their time in critical care were able to frame these experiences as being for the 'greater good'. It was clear that the participants took comfort in the high level of observation they were afforded in critical care as it made them feel 'safe'. Consequently, there was evidence that participants felt anxious about their discharge from critical care down to a general ward where they were aware they would not receive as much attention. This is in keeping with previous literature, which has found that critical care patients can become anxious around discharge. Bench and Day (2010) conducted a meta-synthesis of qualitative research on discharge from critical care, finding that many participants stated that they felt safer in ICU, partly due to the increased monitoring and observation. Chaboyer et al. (2005) found that patients discharged from critical care to a general ward were left feeling unimportant as a result of the shift to less focused care and attention that is common in general wards due to higher nurse: patient ratios.

This study found that all the participants felt that their admission to critical care was unexpected which caused them to feel unprepared. Although they all stated they did not think that the possibility of admission to critical care as a result of their transplant was discussed, they acknowledged that their poor memory of this time may have been a factor. Three participants also stated that as they had already made the decision to have the transplant, they may have purposely chosen to ignore the information about the risks as they were aware that nothing would deter them from undertaking the transplant. Haematopoietic stem cell transplantation is often the last treatment option available to cancer patients and therefore it is

understandable that patients may deem it unnecessary to debate the risks of the treatment as refusing the transplant would almost certainly lead to death from cancer.

It is interesting to note that the majority of the participants felt that there was little point in providing information about critical care to potential patients. Some reflected that critical care is a unique experience that would be different for everyone so providing information about another person's experience would not be helpful. Others felt that providing information prior to admission could be frightening for patients and it would therefore be better to keep them informed once they had been admitted.

All of the participants spoke of the role of their family during their time in critical care. They all reported visits from family were a source of comfort and reassurance. Previous literature has identified that close family members can help to keep patients informed and orientated (Eisendrath, 1982) and helps them to keep their sense of identity and to avoid feelings of loneliness and isolation (MacKellaig, 1987). Morse (1997) found that 'anchoring to significant others' helps patients to maintain a sense of self, identity and reality. Family can help to reduce fear in the patient and can offer hope, with a degree of security against anxiety and confusion (Granberg et al., 1998). Although it is clear from previous research that regular visits from family can be helpful, two participants reflected that their family's daily presence actually became a little wearing at times. It is therefore important to be aware of the energy levels of critical care patients and to judge the amount of visiting time they can accommodate given their level of fitness as having too high a level of interaction may be overwhelming for patients.

Several of the participants spoke of the strain their family members had experienced during their admission. It is well recognised that relatives may be stressed by the experience of a loved one being in critical care which has been reflected by findings of high levels of stress, anxiety and depression in family members (Auerbach et al., 2005; Paparrigopoulos et al., 2006). The experience of family members of transplant patients in critical care is made doubly complex by the fact that research has also found that spouses of transplant patients may be at risk for adverse psychological effects as a result of their role in providing care for a partner undergoing haematopoietic stem cell transplantation (Sabo et al., 2013). These findings indicate the importance of providing support to the families of these patients.

Several of the participants reflected on their family as being their main motivation for working towards recovery and discharge. This is reflected in a previous qualitative study in which ICU patients described close relatives as being their reason to live and to continue their struggle to survive as they did not want to fail their loved ones by giving up their fight for life (Engstrom and Soderberg, 2007).

Participants spoke of their life after critical care with several of them making reference to changed values and priorities. This echoes previous literature which has found people often re-evaluate what and who is important in their life after a critical illness (Engstrom and Soderberg, 2007). In addition, previous research has found that stem cell transplant patients can experience renewed relationships and a greater appreciation of life (Andrykowski et al., 2005). For several participants, the passage of time allowed them to view their stay in critical care more clearly. They could now appreciate just how ill they had been whereas they had not been able to appreciate this at the time. This finding suggests that critical care patients may be liable to experiencing psychological distress related to their admission months after

the experience has passed as the reality of their critical illness becomes apparent and health care professionals should monitor this.

Two participants stated that they did not think about their time in critical care and focused only on the future. This finding is similar to another qualitative study in which 37% of patients who had been in ICU, stated that they no longer thought about being critically ill, six months after discharge (Russell, 1999). It is unclear whether these participants were choosing to look forward instead of backward because they found this to be more helpful for them or whether they found it too distressing to look back on their time in critical care and were trying to protect themselves from potential upset.

There is a growing recognition that the goals of critical care must extend beyond patient survival and should include shared, multi-disciplinary collaboration to prevent and manage the long-term complications often associated with critical care (Angus and Carlet, 2003).

Cancer patients who are admitted to critical care as a result of their treatment face an even more complex experience as they are likely to encounter psychological sequelae from the cancer and its treatment in addition to sequelae commonly found after admittance to critical care. Previous research has found that recovery after stem cell transplantation can involve prolonged physical and psychological setbacks and extreme strain on the patient and their family members (Cooke et al., 2009) and adding the experience of a critical care admission to this journey is likely to further complicate a patient's recovery.

Limitations

Lack of recall could be viewed as a limitation of this study as all of the participants struggled to recall certain aspects of their time in critical care, although the presence of these gaps in recollection is an important finding. On average, the participants in this present study were interviewed 10 months after their stay in critical care and this period of time could have caused their memories to fade. It has been suggested that patients' memories of their stay in ICU are scant after just six to twelve weeks post-ICU, consisting more of a perception rather than specifics after this time has passed (Maddox et al., 2001). Clearly, cancer patients who have been in critical care within the last six to twelve weeks are likely to remain unwell and it would have been unethical to interview them so soon after their admission.

A further limitation is the fact that the author is an IPA novice. Steps were taken to ensure the quality of the analysis, such as an experienced IPA researcher separately analysing two transcripts, but the author's lack of IPA experience should still be considered a potential limitation.

Practical applications

This study has provided an in-depth understanding of the experience of being a cancer patient admitted to critical care following stem cell transplantation. This study has indicated potential reasons for increased incidences of psychological difficulties following cancer patients' admission to critical care. Further to this, insight into the unique experiences of cancer patients in critical care can be compared with other categories of patients admitted to CCU to determine similarities and differences between the separate groups and the reason for any differences identified. Insight into the experience of being a cancer patient admitted to critical care can be used to inform clinical practice and can provide the rationale for further

research and clinical intervention. A further application of this research could be to provide close relatives of CCU patients with information on likely presentation and behaviour of patients in CCU which could reduce the likelihood of them being distressed by aspects of their relative's behaviour.

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Chapter 3: Advanced Clinical Practice I – Reflective Critical Account Abstract

Communication through consultancy: increasing confidence in an unfamiliar role

Abstract

The following reflective account focuses on my experience of communicating psychological knowledge to colleagues through the role of consultancy. I have been required to provide consultation to colleagues as part of my role within the specialist service where I am on placement. This experience was chosen as it enabled me to realise that I could gain confidence from stepping into unfamiliar and challenging roles, such as consultation. In addition, providing consultation has clearly demonstrated to me, the importance of disseminating psychological knowledge in this way and this is considered with relevance to the Health and Care Professions Council's Standards of proficiency, Applied Psychologists and Psychology in NHS Scotland (2011) and Delivering for Mental Health (2006).

Employing Gibbs' (1988) Model of Reflection, I reflect on my first experience of stepping into the role of consultant. Progressing through the stages of the model, I consider the impact of my thoughts and feelings and how I could approach the role differently in future in order to increase the benefit for consulting clinicians and to increase my own confidence in this role. I then employ Gibbs' model a second time in order to reflect on my subsequent experiences of providing consultation.

Finally, I consider my previously held views on the role of consultant and how these have been influenced by my reflections. I consider what these experiences have meant for my professional development over the course of my training and for my future career as a qualified clinical psychologist.

Chapter 4: Advanced Clinical Practice II – Reflective Critical Account Abstract

Incorporating the role of researcher into the professional identity of a clinical psychologist

Abstract

The following reflective account focuses on my development as a researcher, my relationship with research supervision and the importance and challenges of incorporating the role of researcher into my professional identity as a clinical psychologist.

Having previously used Stoltenberg, McNeill and Delworth's Integrated Developmental Model of Supervision (1998) to aid my reflections of clinical supervision, I felt it would be interesting and helpful to adapt this model and use it to reflect on my experience of research supervision. Progressing through the stages of the model, I reflect on the development of my skills and confidence as a researcher. I also employ Rolfe, Freshwater and Jasper's (2001) framework of reflective practice to further enhance my reflections. I then consider the role of research and evaluation in my current placement and the challenges faced when clinical psychologists aim to incorporate research into their daily working lives.

I detail how vital it is to incorporate research into the professional role of clinical psychologist in order to conform with the Health and Care Professions Council's Standards of proficiency and the National Occupational Standards for Psychology. I then consider my past beliefs about my ability to be a competent researcher and how these have been influenced by my reflections before concluding with a critique of the model employed in the account.

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Appendix 1: Guidelines for submission to the European Journal of Cancer Care

European Journal of Cancer Care

Author Guidelines

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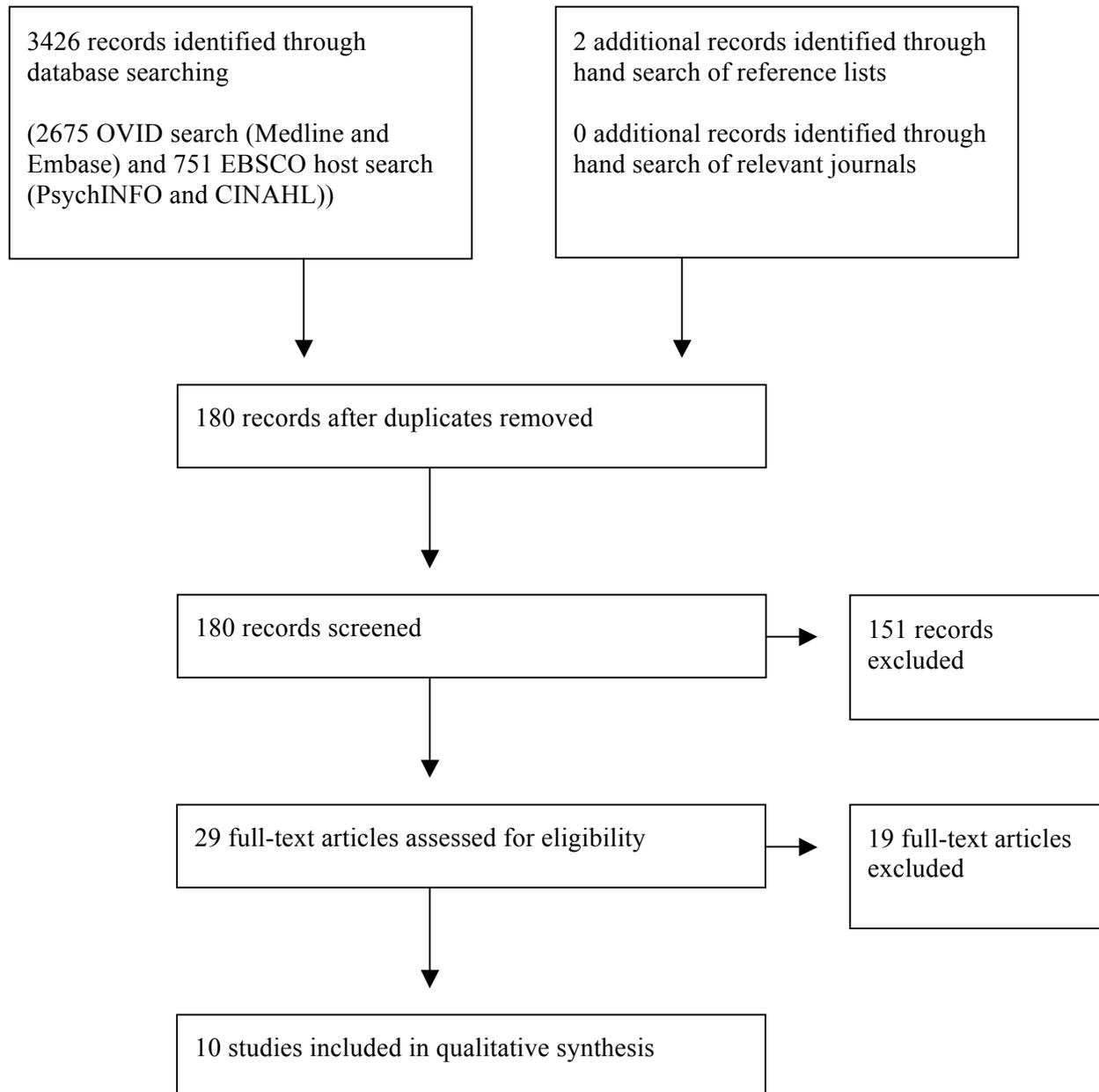
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Appendix 2: Flow Chart of Search Results



Appendix 3: Quality Rating Criteria

Stages	Essential Criteria	Specific Prompts
Scope and purpose	<p>Clear statement of, and rationale for, research/aims/purposes</p> <p>Study thoroughly contextualized by existing literature</p>	<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 contextualize the findings, or both
Design	<p>Method/design apparent, and consistent with research intent</p> <p>Data collection strategy apparent and appropriate</p>	<ul style="list-style-type: none"> • Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate • Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate?
Sampling strategy	Sample and sampling method appropriate	<ul style="list-style-type: none"> • Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling

		<p>strategy given</p> <ul style="list-style-type: none"> • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained
Analysis	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 package or by hand and why? • Discussion of how coding systems/conceptual frameworks evolved • How was the context of data retained during analysis • Evidence that the subjective meaning of participants were portrayed • Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/rationale if it was not
Interpretation	<p>Context described and taken account of in interpretation</p> <p>Clear audit trail given</p>	<ul style="list-style-type: none"> • Description of social/physical and interpersonal contexts of data collection • Evidence that researcher spent time ‘dwelling with the data’, interrogating it for competing/alternative explanation of phenomena • Sufficient discussion of

	Data used to support interpretation	<p>research processes such that others can follow ‘decision trail’</p> <ul style="list-style-type: none"> • Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation lead to conclusions
Reflexivity	Researcher reflexivity demonstrated	<ul style="list-style-type: none"> • Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher’s influence on stages of research 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	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 fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed
Relevance and transferability	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 explanatory literature

		<p>drawn from similar settings and studies</p> <ul style="list-style-type: none">• Discussion of how explanatory propositions/emergent theory may fit 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 outlined• Assessment of value/empowerment for participants• Outlines further directions for investigation• Comment on whether aims/purposes of research were achieved
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Appendix 4: West of Scotland Research Ethics Committee Approval

WoSRES

West of Scotland Research Ethics Service



Mrs Cara Diamond
24 Elm Drive
Cambuslang
Glasgow
G72 7LR

West of Scotland REC 1
Ground Floor, Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 24th January 2013
Direct line 0141-211-6270
Fax 0141-211-1847

Dear Mrs Diamond

Study title: Patients' experiences of admission to critical care unit (CCU) during Haematopoietic Stem Cell Transplant (HSCT)
REC reference: 12/WS/0301
IRAS project ID: 118674

Thank you for your letter of 08 January 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC on 22nd January 2013. A list of the sub-committee members is attached.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Laura Sawiuk, laura.sawiuk@ggc.scot.nhs.uk.

Confirmation of ethical opinion

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

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

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

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

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

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

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

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

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

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

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		15 November 2012
GP/Consultant Information Sheets	3.0	24 January 2013
Interview Schedules/Topic Guides	1.0	06 November 2012
Investigator CV	C Diamond	15 November 2012
Investigator CV	S Wilson	07 August 2012
Letter of invitation to participant	2.0	12 December 2012
Other: Email from Cara Diamond		08 January 2013
Participant Consent Form	2.0	12 December 2012
Participant Information Sheet	3.0	08 January 2013
Protocol	1.0	06 November 2012
REC application		19 November 2012
Response to Request for Further Information		14 December 2012

Response to Request for Further Information	08 January 2013
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Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

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

Further information is available at National Research Ethics Service website > After Review

12/WS/0301	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

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

Yours sincerely



On behalf of
Dr John Hunter
Chair

Email: sharon.jenner@ggc.scot.nhs.uk

*Enclosures: List of names and professions of members
who were present at the meeting and those who submitted written
comments*

*"After ethical review – guidance for
researchers" [SL-AR2]*

*Copy to: Mr Nathaniel Brittain
Dr Sarah Wilson, University of Glasgow
Mr Nathaniel Brittain, NHS Greater Glasgow and Clyde Research and
Development Central Office*

Appendix 5: Greater Glasgow and Clyde Research and Development Approval



Coordinator: Dr Nathaniel Brittain
Telephone Number: 0141 211 8544
E-Mail: Nathaniel.Brittain
Website: www.nhsggc.org.uk/r&d

31st January 2013

Dr Sarah Wilson
Department of Mental Health and Wellbeing
Administration Building
Gartnavel Royal Hospital
Glasgow
G12 0XH

NHS GG&C Board Approval

Dear Dr Wilson

Study Title: Patients' experiences of admission to critical care unit (CCU) during Haematopoietic Stem Cell Transplant (HSCT)
Principal Investigator: Dr Sarah Wilson
GG&C HB site: Beatson West of Scotland Cancer Centre
Sponsor: NHS Greater Glasgow and Clyde
R&D reference: GN12CP411
REC reference: 12/WS/0301
Protocol no: Version 1.0 – 06/11/2012
(including version and date)

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

Conditions of Approval

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

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

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

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

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Nathaniel Brittain
Research Co-ordinator

Cc: Cara Diamond, Trainee Clinical Psychologist, Stroke Psychology Service, NHS Ayrshire & Arran

Appendix 6: Cover Letter



Department of Clinical Psychology, Beatson West of Scotland Cancer Centre, 1053 Great Western Road, Glasgow, G12 0YN

Dear (name),

“Patients’ experiences of admission to critical care unit (CCU) during Haematopoietic Stem Cell Transplant (HSCT)”

My name is Cara Diamond and I am a Trainee Clinical Psychologist, studying at the University of Glasgow. As part of my training, I am interested in learning about the experiences of individuals with a cancer diagnosis who have been admitted to critical care as a result of treatment for cancer. I enclose an information sheet for you to read over.

If you decide that you would like to take part in the study, I will contact you to arrange a time for an interview. This interview could take place in the Beatson West of Scotland Cancer Centre, or over the telephone if you would prefer. Either option would involve a discussion of up to 60 minutes to find out about your experience of admission to critical care. In order to make sure that I fully understand your views, the discussion will be tape-recorded. All information will be treated with the utmost confidentiality. However, you will understand that if something is revealed during the discussion that suggests you or anyone else is at risk of harm, then it is my duty to share this information with other appropriate professionals.

If you would like more information, please do not hesitate to contact me by telephone on (insert telephone number) .

Yours sincerely,

Cara Diamond

Trainee Clinical Psychologist

Supervised by;

Dr Christopher Hewitt
Consultant Clinical Psychologist

Laura Meehan
Senior Nurse, Haematology

Appendix 6: Participant Information Sheet



Department of Clinical Psychology, Beatson West of Scotland Cancer Centre, 1053 Great Western Road, Glasgow, G12 0YN

“Patients’ experiences of admission to critical care unit (CCU) during Haematopoietic Stem Cell Transplant (HSCT)”

Thank you for reading this information sheet. I would like to invite you to take part in a research study. My name is Cara Diamond and I am a Trainee Clinical Psychologist at the University of Glasgow. I am interested in the experiences of individuals with a cancer diagnosis who have been admitted to critical care. You have been given this sheet, as you may be able to help me in this study. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. I would be grateful if you would take the time to read the following information carefully and please feel free to discuss with others if you wish.

Please ask any questions you have. You can email me at c.diamond.1@research.gla.ac.uk or you can telephone me on (insert telephone number). If you leave a message, I will get back to you as soon as possible.

My supervisors for this project are Dr Sarah Wilson (Sarah.Wilson@glasgow.ac.uk or 0141 211 3921) and Dr Christopher Hewitt (christopher.hewitt@ggc.scot.nhs.uk or 0141 301 7378) who can also be contacted in order to discuss the project.

What is the study about?

I am interested in understanding your experience of admission to critical care. This type of research might help to inform other people who are undergoing treatment that may require them to be admitted to critical care and it may help to improve the critical care experience.

Why am I being asked to participate?

We are asking people who have been admitted to critical care after haematopoietic stem cell transplant or high-dose chemotherapy, within the last two years, to take part in the study.

Do I have to take part?

It is up to you whether or not you wish to participate in the study. If you decide to take part you are still free to withdraw from the study at any point in time. If you choose not to participate or decide to withdraw from the study at any time, this will not affect your medical care.

What will I have to do if I take part?

If you decide to take part I will arrange a convenient time to talk with you. This discussion could take place in the Beatson West of Scotland Cancer Centre or over the telephone, depending on which you would prefer. This interview would last for up to 60 minutes and I will ask you questions about your experience of admission to critical care. The interview will be recorded to make sure that I carefully understand your experiences and our conversation and to ensure that I will be working with a complete version of everything you have said to me. There are no right or wrong answers, the research just aims to find out about what you think and to learn more about your personal experience.

Is there a down side to taking part?

It is possible that our interview may cover topics that are difficult or upsetting to talk about. However, if you do not want to continue you can end the interview, or have a break, at any time. If you feel upset at all following the interview, I will be available to talk with you.

Alternatively, the department's Consultant Clinical Psychologist, Dr Christopher Hewitt, will also be available to talk with you.

What are the possible benefits of taking part?

There are no direct benefits to you in taking part in this study. However, the information that we learn from the study may help us understand more about the experience of being admitted to critical care. It may also help inform others who are undertaking treatment that may result in them having to be admitted to critical care. It may also help medical staff better understand the experience of critical care admission so that they can provide the best support for people.

Will my taking part in this study be kept confidential?

The medical clinician responsible for your treatment, usually your Consultant at the Beatson, will know that you are taking part in the study. Everything that you say during our interview will be kept strictly confidential and no one but myself will have access to the recordings of the interviews. After the interview, the recording will be transcribed and names of people and places will be removed so you cannot be identified from the transcript. When the transcription has been checked for accuracy and completeness, the recording will be deleted. The transcript will be identified by a code only. Information linking transcripts and names will be stored securely and separately from the transcripts. Your name, or other identifying information will not appear in any reports. With your permission, we may want to use quotations from your interview in the report, but anything that will identify people or places will be removed from the quotation.

Are there any circumstances when information shared by me during the interview would not be kept confidential?

The analysis of the interview data requires that a sample of the transcripts will also be read by my supervisors; they will not be able to identify the source of the information.

Everything you say during the interview will be kept private. However, if you tell me anything that suggests that you or anyone else is at risk of harm, then it is my duty to share this information with other appropriate professionals.

What will happen to the results of the research study?

If you wish, I will provide you with a summary of the results of the study. The final results and conclusions of the study may be published in a scientific journal and will form part of my qualification in Clinical Psychology. No one participating in this study will be identified in any publication arising from this work.

Who has reviewed the study?

The study has been reviewed by the Course Team for the Doctorate in Clinical Psychology, Mental Health & Wellbeing, University of Glasgow to ensure that it meets important standards of scientific conduct. It has also been reviewed by the West of Scotland Research Ethics Committee to ensure that it meets important standards of ethical conduct and by the R&D department of NHS Greater Glasgow & Clyde, the study Sponsor.

What happens next?

If you are interested in being part of this project, please complete the tear-off slip below and return it in the stamped addressed envelope provided (no stamp required). Once this opt-in form has been received, you will be contacted in order to arrange a suitable time to sign a consent form and complete an interview.

If you have any questions or wish to discuss the project further, you can email me at c.diamond.1@research.gla.ac.uk or you can telephone me on (insert telephone number). If you leave a message and I will get back to you as soon as possible.

My supervisors for this project are Dr Sarah Wilson (Sarah.Wilson@glasgow.ac.uk) and Dr Christopher Hewitt (christopher.hewitt@ggc.scot.nhs.uk) who can also be contacted in order to discuss the project.

If you wish to discuss the project with a person who is independent of this research, you can contact Dr Kenneth Mullen (Kenneth.Mullen@glasgow.ac.uk).

Thank you for your time.

Research Study: "Patients' experiences of admission to critical care (CCU) during Haematopoietic Stem Cell Transplant (HSCT)"

I am/am not interested in participating in the study.* (Delete as appropriate)

Researcher: Cara Diamond, Trainee Clinical Psychologist (University of Glasgow)

Participant Name:

Signature:

Telephone Number:

Appendix 7: Consent Form



Department of Clinical Psychology, Beatson West of Scotland Cancer Centre, 1053 Great Western Road, Glasgow, G12 0YN

Subject number -

“Patients’ experiences of admission to critical care (CCU) during Haematopoietic Stem Cell Transplant (HSCT)”

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my medical care being affected

I understand that sections of my medical notes may be looked at by the research team and Sponsor where it is relevant to my taking part in the research. I give my permission for the research team to have access to my records

I understand that the medical clinician who is involved in my care (GP and Doctor or Nurse at the hospital) will be informed of my participation in the research

I understand the interview will be recorded solely for the purpose of the research study as described in the Participant Information Sheet and will be kept confidential

I understand that anonymised quotations from my interview may be published in reports from this research

I agree to take part in the above study

Name of Participant

Date

Signature

Researcher

Date

Signature

Thank you for taking part in this study.

Appendix 8: Interview Schedule



Department of Clinical Psychology, Beatson West of Scotland Cancer Centre, 1053 Great
Western Road, Glasgow, G12 0YN

Semi-structured interview schedule

Interview Guide

“Patient experience of admission to critical care unit (CCU) during Haematopoietic Stem
Cell Transplant (HSCT)”

Before

1. Can you tell me what led to your admission to the Critical Care Unit?
2. Was this your first admission to CCU?
3. Were you aware you might be admitted to CCU as a result of your treatment?
4. Did you know anything about CCU before your admission?
5. Did anyone tell you what admission to CCU might be like?

During

6. Can you tell me about your experience of CCU?
 - How was your sleep?
 - Did you receive visitors?
 - Who talked to you during this time?
 - Can you tell me about the environment around you?

7. How did you feel at the time?

8. What were the best/worst aspects?

9. Can you tell me about your discharge from CCU?

After

10. How do you feel about your time in CCU now?

11. How has your life changed (if at all) since your stay in CCU?
 - Can you tell me about any negative changes?
 - Can you tell me about any positive changes?

12. Is there anything you wish you had known about CCU before you were admitted?

13. If you were talking to someone who was going to be admitted to CCU, what would you tell them?

14. Is there anything that the staff could have done differently that could have helped you?

15. Before we finish, is there anything about your experience that we have not covered that you would like to share?

Examples of prompts

- Can you tell me more about that?
- How did that make you feel?
- What does that mean for you?
- Could you give me an example of that?

Thank you for taking the time to participate in this study.

Appendix 9: Sample extract of analysed interview

Interviewer's notes	Interview
Memory loss	<p>C – So do you remember receiving visitors at the start of your admission to ICU?</p> <p>Ross – No, no, not at all, no.</p>
Piecing it together	<p>C – Have they told you anything about when they came to see you then?</p>
Strain on family	<p>Ross – They've...aye...well the wife says, when she came in initially, I was getting fed wi' the baby food stuff that they pump into you and I had the two...two kinda big holes where the dialysis tubes were going in to my kidneys and everything and she says it was just horrendous. I was just, ken, lying there. And they...they kinda asked, what was the...what were they expecting. And they says 'Well, in another two days, if he's still kicking about, we'll try and wake him up' so eh...I seemingly didnae respond in the way they thought. I didnae wake up. So they were...eh...aye they would be quite, quite concerned I think. It must have been hard for the wife to hear that. That I might no wake up.</p> <p>C – Sounds like quite a scary time for them but you don't remember any of this, is that right?</p>
Memory loss	<p>Ross – I don't remember any of it, no. I just had these horrible dreams, I don't remember hearing any voices or hearing anything that was normal. Eh...it was this neighbour</p>
Strange dreams	<p>(laughs)...this stalker (laughs)...this random neighbour who I don't...I thought if I had such a vivid dream it would have been about somebody that you know fairly well but...just, he was there all the time. I have a cup of coffee with him every, eh, three months, but he was the one who was...he was stalking me! It was just, as I say, it was just so vivid. It was as if I was there. And he was there.</p> <p>C – So you remember visitors just when you were lucid?</p>
Lost time	<p>Ross – Yes. I mean I went from, as far as I was concerned, I went from being in the flat, talking to the doctor to waking up in the hospital and needing the toilet. Everything in between just was eh...a blur. That time's aw gone.</p>
Lost time	<p>C – And was it good having your visitors coming in and chatting to you?</p>

Family as support	Ross – It was and it probably helped me through but as you started...I started getting, no annoyed, but you start wanting home and they just, they can start grating on you when they ask stupid questions.
Family as a nuisance	C – What sort of stupid questions?
Family as a nuisance	<p>Ross – Just...things that they don't understand. Ken, they're asking about 'What's this doing?' and 'What's that doing?'. And, and, they don't really...But you just get kinda...I got angry. No that I showed it but it just was kinda wearing eventually, they're coming in all the time. And the more I wanted to get home, the more kinda, you're thinking, 'Oh here they come again' (laughs).</p> <p>C – That makes sense. They were just going through the same sort of questions again and again.</p>

Appendix 10: Themes and dimensions

Theme	Dimensions
Gaps in recollection	<ul style="list-style-type: none"> (i) memory loss (ii) lost time (iii) piecing it together
Unreal experiences	<ul style="list-style-type: none"> (i) strange dreams (ii) hallucinations (iii) nightmares (iv) out of character behaviour (v) questioning self
Being in the right place	<ul style="list-style-type: none"> (i) necessary (ii) experts (iii) trust in staff (iv) high level of observation (v) feeling safe
Unexpected and unprepared	<ul style="list-style-type: none"> (i) not warned of CCU (ii) no knowledge of CCU (iii) sicker than expected
Role of family	<ul style="list-style-type: none"> (i) family as support (ii) family as a nuisance (iii) strain on family (iv) family as motivation to recover
Life after critical care	<ul style="list-style-type: none"> (i) changed values (ii) changed priorities (iii) not looking back (iv) admission was 'worth it'

Appendix 11: Major Research Project proposal

Patient experience of admission to critical care unit (CCU) during Haematopoietic Stem Cell Transplant (HSCT)

Abstract

Background

Research suggests that admission to critical care can be both stressful and psychologically traumatic for patients with many patients reporting psychological difficulties such as depression, anxiety and PTSD as a result of their experience. Whilst previous studies have looked at the prevalence and potential causes of these difficulties, few studies have employed qualitative methods to gain an in-depth understanding of a particular patient group's experience of admission to critical care. Cancer patients can be admitted to critical care as a result of aggressive treatment they are undergoing. No previous study has used qualitative methods to explore cancer patients' experience of critical care and therefore this current study aims to explore this area.

Aims

This study aims to gain an in-depth understanding of the experience of cancer patients' admission to critical care.

Methods

Participants will be cancer patients who have been admitted to critical care as a result of their treatment. A qualitative design will be adopted with data collected via semi-structured interviews and subjected to Interpretative Phenomenological Analysis.

Applications

Admission to critical care as a result of cancer treatment is a potential source of psychological distress. This current study aims to gain a greater understanding of this experience, which could identify potential reasons for increased incidences of psychological difficulties and could provide the grounds for further research and clinical intervention.

Introduction

People affected by severe illness often need to be cared for in critical care. Critical care is a term that encompasses ‘intensive care unit (ICU)’, ‘intensive treatment unit (ITU)’ and ‘high dependency unit (HDU)’. These critical care units (CCU) are specialised departments in hospitals that provide intensive care medicine. These units provide expert care for critically ill patients who require constant, close monitoring and specialist nursing to keep them alive (Adam and Osborne, 2005).

Previous literature in the area of critical care has focused largely on outcomes such as survival rates, cost or functional status following discharge (Brooks et al., 1995). With recent advances in critical care, more patients are surviving CCU admissions (Angus and Carlet, 2003). This increase in survival rates has meant a shift in focus of research in this field to longer-term outcomes of CCU-treated patients, including mental health, health-related quality of life and cognitive outcomes (Broomhead and Brett, 2002; Dowdy et al., 2005; Hopkins and Jackson, 2006).

‘ICU syndrome’

In the 1950s, as admission numbers to intensive care increased, research identified that many ICU patients developed psychological problems (Egerton and Kay, 1964). Initially, it was thought that these problems were due to the illness which had caused admission to ICU but it was discovered that the ICU environment, routine and care were equally important to the development of the problem which was given the name ‘the ICU syndrome’ (McKegney, 1966). The syndrome is characterised by a wide variety of symptoms, which can include anxiety, fear, restlessness, fatigue, confusion, delirium, hallucinations and disorientation (Mackellaig, 1990).

Dyer (1995) sought to explore possible causes of ICU syndrome and identified similarities between categories of psychological torture, identified by Amnesty International, and experiences in ICU. The categories identified were isolation, monopolisation of perception, debility, threats, occasional indulgencies, trivial demands, demonstrating omnipotence and degradation. This study explored the role of these experiences in the development of psychological difficulties and considered ways of reducing the incidence of ICU syndrome.

Unique stressors of critical care

Previous literature has identified several categories of stressor that are experienced by critical care patients. Each of these stressors could be considered as precipitants to the development of psychological difficulties.

Physical stressors

Lack of sleep is a common problem for patients in critical care with one study reporting that over 50% of critical care patients experience sleep disturbances as a result of pain, anxiety, noise, light and frequent nursing interventions which disturb sleep (Chew, 1986). This lack of sleep would be likely to exacerbate any psychological symptoms. Physical stressors could also include thirst, pain and weakness.

Environmental stressors

Critical care units can be described as barren environments and patients often experience a lack of meaningful stimulation, which can act as an environmental stressor. CCUs often have bare walls and ceilings and bright artificial lights which can affect patient's ability to sleep and can result in them being unable to distinguish day from night. Patients can also feel

trapped and tied down by equipment needed to keep them alive (Clifford, 1986). Patients are also subjected to the constant background noise of equipment such as ventilators and alarms and this may lead to sensory overload (Adams et al., 1978).

Emotional disturbances

Previous research has found that patients who have been admitted to critical care often experience impaired cognitive functioning, worries and fear. Patients may experience general fears relating to death or disability (Johnson and Sexton, 1990) or they may experience specific worries related to pain, sounds or sights that they are exposed to. Noise from other patients in distress may cause anxiety, as may overheard conversations about their own condition.

Communication difficulties

Communication can be difficult in critical care as it is often hindered by either the patient's medical condition or necessary medical interventions such as intubation. If patients struggle to communicate with staff or relatives this can lead to feelings of isolation. Patients who are feeling isolated due to reduced communication may view visitors as their only link to the outside world, however, in the majority of CCUs, visiting is restricted (Biley et al., 1993) which can leave the patient feeling further isolated.

Post-CCU PTSD

When patients are admitted to critical care they are, by definition, experiencing a critical illness that is life-threatening and many patients recall frightening experiences of CCU (Jones et al., 2000). Therefore, post-traumatic stress disorder (PTSD) is a potential concern and a number of studies have looked at the prevalence of post-CCU PTSD with rates of PTSD after

a period of critical illness being estimated to be between 4-25% (Griffiths et al., 2007; Jones et al., 2007).

Davydow et al., (2008) completed a systematic review of PTSD in ICU survivors and highlighted three important issues. First, the prevalence of substantial post-ICU PTSD symptoms is high and these symptoms appear to persist over time. Second, consistent predictors of post-ICU PTSD include pre-ICU psychopathology, greater ICU benzodiazepine administration and post-ICU memories of in-ICU frightening experiences. Third, it was reported that post-ICU PTSD may have a substantial impact on quality of life. Findings from this review highlight how important it is that clinicians are aware of the risk and prevalence of PTSD in ICU patients. This knowledge should allow for prompt identification and treatment of PTSD.

Discharge from critical care

Although discharge from critical care to a general ward is a positive step in the patient's recovery, previous research has identified that this transition can also be a stressful time for patients and their relatives. A meta-synthesis in this area (Bench and Day, 2010) focused on the specific problems faced by patients and their loved ones immediately following discharge from critical care to a general ward and this study identified six themes from the literature all of which have the potential to impact on a patient's physical and psychological recovery. These findings highlight the importance of understanding the impact of discharge from critical care in addition to the period spent in critical care.

Qualitative research

Whilst many studies have looked quantitatively at the prevalence rates of psychological problems post-CCU, few have employed qualitative methods to explore individual experiences of critical care.

First-hand accounts of periods in critical care have described feelings of confusion, paranoia, fear and labile mood (Bowers, 2004) and feelings of shame, being under ‘attack’ and the importance of being kept informed of what was happening to them (Clark, 1985).

Johnson et al.’s (2006) study found that patients, who had been critically ill in the CCU, reported that they had lost track of time and reality. They experienced disturbing hallucinations and nightmares and they perceived their bodies to be unfamiliar and unreliable. Bowers (2004), an ITU nurse herself, gives a personal account of her admission to ITU, which includes examples of delusional thoughts. Despite having a wealth of knowledge in ITU processes, she became paranoid that she was being held against her will by staff and she recalls thinking that staff members were ‘smiling assassins’ who were trying to harm her. These qualitative studies highlight how frightening an episode in critical care can be for patients.

Another qualitative study (Hupcey, 2000) found that ‘feeling safe’ was an overwhelming need for patients whilst in critical care. This study identified several needs that influenced the experience of feeling safe. These were, the need to know what was happening to them, the need to regain control, the need to have hope in their recovery and the need to trust critical care staff. When these needs were not met, patients reported feeling unsafe which led them to experience episodes ranging from being upset or frustrated to being distressed, feeling paranoid or fighting against staff.

Cancer patients admitted to critical care

Cancer patients can require admission to critical care as a result of aggressive treatment. Patients with haematological cancer who undergo haematopoietic stem cell transplant (HSCT) are among the cancer patients most frequently admitted to critical care with 19% to 40% of HSCT patients requiring admission after transplant (Scales et al., 2008).

Haematological cancers are cancers arising from abnormal blood or bone marrow cells and include leukaemia, lymphoma and myeloma. HSCT is a potentially curative treatment for haematological cancers. However the treatment is extremely aggressive and potentially life threatening. It is often associated with complications such as sepsis, respiratory failure and graft versus host disease (GvHD), which result in the patient requiring admission to critical care (Bird et al., 2011).

Patients who have solid cancers can also require admission to critical care as a result of high-dose chemotherapy treatment. This is most common with testicular cancer patients as this group of patients are frequently given the most aggressive form of treatment available due to their typically young age.

When a patient's condition deviates from the expected outcome, such as a transfer to critical care, patients may experience anxiety, depression, fear, emotional isolation and loss of control (Heinonen et al., 2005). Previous literature documents the stressful nature of a CCU admission for any patient and the unique stressors of critical care admission coupled with the unique stressors of aggressive cancer treatment can lead to patients developing mental health difficulties.

There are several reasons why cancer patients' experience of critical care may differ from the experience of other groups of patients admitted to CCU. Unlike patients who are admitted to CCU because of a sudden, medical emergency, cancer patients are often admitted as the result of aggressive cancer treatment that they have consented to. This could mean that cancer patients have the opportunity to prepare for such an admission and may have gathered information, which could help them to feel better equipped for a stay in CCU. Cancer patients could also differ from other patients admitted to CCU as they may view their cancer treatment and subsequent admission to critical care as a means of saving their life. Aggressive treatments, which result in admission to critical care, are often the last treatment option available to the patient and therefore they may have a more positive view of their stay in CCU as they may feel that the treatment and subsequent admission saved their lives.

As survival rates of patients undergoing HSCT and other aggressive treatments has improved over the last decade (Depuydt et al., 2011) it is important to consider the lasting psychological effects of such treatments. A positive outcome of cancer treatment should not be focused on survival alone but should also appreciate the mental wellbeing of the patient.

Aims

The aim of this study is to gain an in-depth understanding of the experience of cancer patients' admission to critical care. Semi-structured interviews and subsequent Interpretative Phenomenological Analysis will be employed to achieve this aim.

Plan of investigation

Design

This study will use a qualitative design, employing Interpretative Phenomenological Analysis, which has its theoretical roots in phenomenology, hermeneutics and idiography (Smith, Flowers and Larkin, 2009). IPA is concerned with the detailed examination of personal lived experience, the meaning of the experience to participants and how participants make sense of that experience (Smith, 2011).

Participants

Participants will be adult cancer patients who have required a previous admission to critical care as a result of cancer treatment. Participants will be recruited from the Beatson West of Scotland Cancer Centre (BWoSCC) and will be identified through the BWoSCC database.

Inclusion and exclusion criteria

Inclusion criteria will include having a haematological or solid cancer and previous admission to critical care after haematopoietic stem cell transplant or other cancer treatment.

Exclusion criteria will include patients aged under 16 and patients for whom English is not their first language.

Recruitment Procedures

Prior to recruitment, patients who have been identified as meeting inclusion criteria will be discussed with their Consultant Oncologist or Haemato-Oncologist who will be able to advise as to any reasons why those particular patients should not be contacted. Patients who are regularly attending the BWoSCC will be advised of the research by the primary medical staff involved in their care, who will pass on information sheets. These potential participants will then complete a consent form indicating their permission for the researcher to contact them.

For patients who attend less frequently, information sheets will be posted to them with a cover letter signed by their Consultant. These recipients can return the consent form indicating their permission for the researcher to contact them regarding the study. The information sheet and consent form are included as appendix 1. In the event of an insufficient number of consent forms being returned, a member of medical staff will telephone prospective participants to enquire as to whether they received the information sheet and whether they would be interested in taking part in the study.

As this research involves participants whose physical health may be compromised, all potential participants will be offered a telephone interview, which will be arranged for a suitable time. There is little methodological discussion of the use of telephone interviews in the qualitative research literature (Novick, 2008). It has been suggested that telephone interviewing leads to the absence of visual cues (Garbett and McCormack, 2001) which could result in a loss of contextual and non-verbal data and could compromise rapport. However, interviewees could be more relaxed on the telephone and willing to talk freely and to disclose intimate information. Previous research states that qualitative telephone data has been judged to be rich, vivid, detailed and of high quality (Sturges and Hanrahan, 2004; Sweet, 2002).

Research Procedures

Interviews will be carried out on a one-to-one basis. Participants will be reminded of the purpose of the interview and will be told that they can stop for a break or stop completely at any point if they decide they do not wish to carry on. Interviews will last for around an hour.

Interviews will employ a semi-structured approach using a topic guide, which will facilitate flexibility within the interview. This interview guide is included as appendix 2. A non-

directive approach will be adopted by the interviewer, thus allowing the participant to address areas, which they see as important, at length. Prompts such as ‘can you tell me more about that’ will be used to encourage elaboration on topics. The development of topic guides will be informed by previous research of patients’ experience of critical care both by clinical reviews and personal accounts.

Interviews will be recorded and then transcribed and anonymised by the researcher.

Data Analysis

Transcribed interviews will be analysed using Interpretative Phenomenological Analysis. IPA has been proposed to be a qualitative method particularly suited to health psychology (Smith, 1996).

A sample of interview transcripts will also be analysed by a second researcher to ensure reliability of the analysis from the interview transcripts. The second researcher has no direct experience with this patient group and no personal experience of critical care.

Justification of sample size

Power calculations are not appropriate in qualitative research as sample size is not predetermined. This study will aim to recruit between four and ten participants since this is consistent with the recommended sample size for IPA studies conducted at doctorate level (Smith et al, 2009).

Settings and equipment

Interviews will take place in a clinic room within the BWoSCC. Necessary equipment will include a digital voice recorder and a computer for transcription. In the event of participants who live a far distance away being recruited to the study or participants being too physically unwell to attend, it may be necessary to conduct interviews using telephone-recording equipment, which the researcher will obtain. In the case of telephone interviews, the researcher would use a telephone in a private office in the Academic Unit of Mental Health and Wellbeing in Gartnavel Royal Hospital.

Health and Safety Issues

Researcher safety issues

All interviews will take place at the BWoSCC. The researcher will only collect data during working hours when there are other staff members in the building. For participants who decide to take part in a telephone interview, the researcher will use a telephone in a private office.

Participant safety issues

As this research involves participants who have undergone an aggressive medical treatment for their cancer, their physical health may be compromised. As a result, the researcher will endeavour to provide a comfortable setting for participants and will be alert to the participants' wellbeing during research interviews. It is recognised that this study will involve participants discussing potentially distressing subjects and therefore, emotional support may be required. Should a participant become distressed during an interview, their distress would be addressed in a supportive manner and they will be reminded of their right to discontinue participation. Should participants wish to receive psychological support, they will be advised of the process to appropriate referral.

Ethical issues

Ethical approval from the relevant sources will be sought before data collection begins. Application to the West of Scotland Ethics committee and the BWSCC Ethics committee will be submitted. Participation in the study will be voluntary and participants will be free to withdraw from the study at any time.

Financial issues

A voice recorder and foot pedal to record and transcribe interviews, will be borrowed from the University. There will be costs of posting information sheets to participants.

Timetable

April 2012 – Submit major research proposal to course

August 2012 – Submit application to ethics committee

November 2012 – Begin data collection

November 2012 – March 2013 – Ongoing data collection and analysis

April 2013 – June 2013 – Write up

July 2013 – Submit major research paper to course

Practical applications

The practical applications of this study could be considerable especially if the study identifies themes that indicate potential reasons for increased incidences of psychological difficulties following cancer patients' admission to critical care. In addition, the results of the study will provide an in-depth understanding of what it is like for cancer patients to be admitted to critical care. Further to this, insight into the unique experiences of cancer patients in critical

care can be compared with other categories of patients admitted to CCU to determine similarities and differences between the separate groups and the reason for any differences identified. Insight into this experience can be used to inform clinical practice and can provide the rationale for further research and clinical intervention.

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