



# The Immediacy of Illness and Existential Crisis: Patients' lived experience of under-going allogeneic stem cell transplantation for haematological malignancy. A phenomenological study



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## ABSTRACT

**Purpose:** This paper reports a study exploring the lived experience of fifteen men and women treated with allogeneic stem cell transplant (SCT) for haematological malignancy.

**Method:** The study followed an interpretive phenomenological methodology using semi-structured interviews. Participants aged between 22 and 68 years were purposively recruited from two specialist treatment centres and were interviewed within three months to one year post SCT between April and September 2013. Data were then analysed using interpretive phenomenological analysis.

**Results:** An overarching theme that emerged from the data was: The Immediacy of Illness and Existential Crisis. The Immediacy of Illness and Existential Crisis developed from participants' experiences of critical events accompanied by enduring uncertainty continuing into the recovery period. Participants suffer major disruption to their lives physically, psychosocially and emotionally, including facing their own mortality, without a sense of when they may resume the normality of their former lives.

**Conclusions:** Ambiguity and uncertainty characterise the experiences of those with haematological malignancy. Whilst participants have access to specialist teams, there are opportunities for health and social care professionals to provide more support for individuals to come to terms with the critical events they have faced and to prepare them for their return home and to continue former lives and aspirations following prolonged hospitalisation.

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## 1. Introduction

Haematopoietic stem cell transplant is increasingly the treatment of choice for patients with a range of haematological cancers including leukaemia, non-Hodgkin lymphoma, Hodgkin lymphoma and myeloma (Rizzo et al., 2006). Globally, 10 000 patients are treated annually for haematological illness (Gratwohl et al., 2008). For those with malignant disease, treatment with stem cell transplant (SCT) follows intensive courses of chemotherapy and radiotherapy including total body irradiation in some cases. Significant morbidity and mortality are associated with the underlying illness and treatment including transplantation. Physical and psychosocial problems are known to continue well into the post-transplant recovery phase (Andrykowski et al., 2005; Lee et al., 2001). In

addition to complex physical and bodily changes, there are psychosocial and emotional issues to be faced (Cooke et al., 2009; Sherman et al., 2005; Hacker and Ferrans, 2003; Hacker et al., 2002; Hendricks and Schouten, 2002; Fife et al., 2000). This paper reports the findings from an interpretive phenomenological study which explored the lived experience of 15 people treated with allogeneic stem cell transplant (SCT) for haematological malignancy.

### 1.1. Background

Considerable attention has been dedicated to the assessment of quality of life (QoL) for patients undergoing SCT. In a review of QoL literature following SCT between 2002 and 2007, it was found that although physical, psychological and social aspects of QoL improved over time, survivors of SCT experience persistent anxiety and depressive symptoms, fatigue, sexual dysfunction and fertility concerns (Mosher et al 2009). Of thirty seven studies reviewed by

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Pidala et al. (2009) examining QoL after SCT greater impairments to QoL were found in those undergoing allogeneic SCT compared with autologous SCT. However acute and chronic Graft Versus Host Disease (GVHD) were found to pose threats to QoL in those receiving allogeneic SCT (Pidala et al., 2009), corroborating Lee et al.'s (2006) findings that those with chronic GVHD had worst QoL in those six months post transplantation.

Over recent years studies of patient experience have begun to highlight the challenges faced (Stephens, 2005; Jones and Chapman, 2000; Cohen and Ley, 2000), not least to try to make sense of the traumatic events both leading up to diagnosis and during treatment with SCT. In a study exploring the lived experience of 20 adults undergoing autologous SCT patients report being physically and emotionally unprepared for what they had to face (Cohen and Ley, 2000). In a study of 7 people receiving autologous SCT patients report dramatic changes in their appearance as well as severe weakness and report a determination to stay alive despite feeling near to death (Stephens, 2005). Adult survivors of autologous bone marrow transplantation report how the fear they experienced during treatment was balanced with hope for survival (Cohen and Ley, 2000). The psychological cost of SCT is reported in patient narratives and is linked to the invasiveness of the treatment with some participants expressing that you never recover completely from the transplant leaving an undetermined period of recovery (Stephens, 2005).

As survival rates continue to improve researchers have begun to consider the wider context of the psychosocial and emotional impact of treatment and recovery for those with haematological malignancy receiving SCT. In this paper the theme of the Immediacy of Illness and Existential Crisis resulting from a diagnosis of haematological malignancy and treatment with allogeneic SCT is reported.

## 2. Aim

The aim of the study was to explore the lived experience of patients undergoing allogeneic SCT for haematological malignancy.

### 2.1. Design

The study followed an interpretive phenomenological methodology (Smith et al., 2009) to gain insights into participants lived experience leading up to and following allogeneic SCT. Smith et al. (2009) advocate a homogenous sample so that convergence and divergence of experiences can be examined in some detail. The participants in this study formed a homogenous sample by virtue of their treatment with allogeneic SCT whilst their experiences, personal characteristics and contexts were unique.

### 2.2. Setting and sample

A purposive sample of 15 participants aged between 22 and 68 years were recruited from two specialist treatment centres in the UK. The researcher was invited to join the multidisciplinary meetings in the out-patient departments where patients attended their follow up appointments post SCT. Clinical teams identified patients who met the inclusion and exclusion criteria for the study (Table 1). Patients were approached by the researcher, who explained the purpose of the study and provided a participant information sheet. Arrangements were made to contact potential participants over the following few days to elicit their willingness to take part in the study. Nine men and six women agreed to participate in the study (Table 2).

### 2.3. Ethical considerations

A favourable opinion was granted by a Committee of the National Research Ethics Service and the Faculty of Health and Medical Sciences Ethics Committee at the University of Surrey. Permission to conduct the research was granted by the Research and Development Departments at the two study sites. A significant ethical issue concerned the possibility of causing distress to a vulnerable group of people. The most important strategy put in place was preparedness to discontinue the interview in such circumstances. The participants' specialist teams and general practitioners were informed about the study and the participant information sheet stated that the researcher could make referrals for professional support should this be required. The researcher was not involved in providing clinical care for the participants. Voluntary written consent was obtained from participants before data collection.

### 2.4. Data collection

Participants were interviewed on one occasion in their homes or at the treatment centre between April and September 2013. Since the essence of phenomenological enquiry is to understand the experience through participant accounts (Smith and Osborne, 2007) the interview was non directive other than the opening question "Can you tell me about your experience of being treated with allogeneic SCT and what has it been like returning home?" This opening question was supported by probes and affirmations of understanding (Kvale and Brinkmann, 2009). The narrative style of interview enabled the participants to tell their story and to talk about experiences which were important to them in relation to the overall purpose of the study. Four participants asked for their husband or wife to be present. One participant attended with her mother. Permission to include family members' contributions to the interview was gained.

### 2.5. Data analysis

Interviews were recorded and transcribed by the primary researcher. Thematic analysis of the interview transcriptions was conducted using the procedural steps outlined by Colaizzi (1978) and Smith et al. (2009) as a guide. This process ensured a standard approach was taken with each interview transcript including reading and re reading the transcript and line by line coding. Common themes were subsequently identified and any exceptions across the data sets highlighted. Interpretive phenomenological methodology recognises and accepts that a researcher's previous knowledge and experience are included as part of the analysis (Colaizzi, 1978; Crist and Tanner, 2003; Smith et al., 2009).

### 2.6. Trustworthiness

The researcher is a nurse, experienced in eliciting patient's stories and a pilot interview served as valuable practice in narrative interview technique. The first author of this paper conducted the primary data analysis and the second two authors provided commentary on raw data and the emergent themes. This process in addition to reading relevant literature and maintaining a research log and field notes contributed to the overall trustworthiness of the study (Lincoln and Guba, 1986).

## 3. Findings

One of the overarching themes that emerged from the data was: The Immediacy of Illness and Existential Crisis. The sudden or

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