European Journal of Oncology Nursing 24 (2016) 79–86

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

The lived experience of patients in protective isolation during their hospital stay for allogeneic haematopoietic stem cell transplantation

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ARTICLE INFO

Article history:
Received 18 May 2016
Received in revised form
17 August 2016
Accepted 1 September 2016

Keywords:
Patient isolation
Loneliness
Social isolation
Haematopoietic stem cell transplantation
Phenomenology

ABSTRACT

Purpose: Patients undergoing allogeneic haematopoietic stem cell transplantation (HSCT) usually receive hospital care in protective isolation until full neutrophil recovery. Although the aim of protective isolation is to benefit patients' health by preventing risks of infection, it could have severe psychological implications. The aim of this study was to explore the lived experiences of protective isolation in adult patients who had been treated with allogeneic HSCT.

Method: A descriptive phenomenological inquiry based on Giorgi's approach was conducted in a university hospital in Italy. Ten patients (7 female and 3 male, age range 28–66), who had undergone allogeneic HSCT to treat a haematological malignancy, were interviewed about their hospital stay in protective isolation.

Results: A general meaning structure was identified as being isolated to achieve transformation. The revelatory themes were as follows: (1) the special place for transformation, (2) the experience of embodied transformation, and (3) light and shade from inside and outside. Participants experienced a transformation of themselves, of their relationships with loved ones, and of the environment.

Conclusions: Since patients may live the experience of being treated with allogeneic HSCT in protective isolation as a transformation process, health-care providers should monitor the psychosocial implications of the isolation practice.

1. Introduction

During the last few decades, there has been a growing tendency toward home care for patients with cancer, in order to lower hospital costs and improve patients' quality of life. This is, however, not always feasible when there is a need for high-technology systems, surgery interventions, high-dose chemotherapy, or total parental nutrition, or there are uncontrolled symptoms (Vaughn et al., 2016). In particular, patients who undergo allogeneic haematopoietic stem cell transplantation (HSCT) to treat their haematological malignancy become pancytopenic after myelosuppressive chemotherapy and infusion of donated stem cells. In order to lower their high risk of infection, they usually receive hospital care in protective isolation until full neutrophil recovery (Saria, 2011; Vokurka et al., 2013; Yokoe et al., 2009). The extent to which the isolation is implemented depends on the neutrophil count but varies drastically across centres and countries (Bevans et al., 2009; Hicheri et al., 2013; Lee et al., 2008). However, there is growing evidence showing its limited efficacy (Mank and van der Lelie, 2003; Russell et al., 2000), together with the clinical benefits for patients if cared for at home, such as lower incidence of acute graft-versus-host disease (GVHD), better nutritional status (Svahn et al., 2008), and also a higher survival rate (Bergkvist et al., 2013; Ringden et al., 2013). Thus, innovative models of outpatient care have been developed for selected transplant patients and the role of home care versus hospital care has been investigated by a growing number of studies (Cantú-Rodríguez et al., 2016; Faucher et al., 2012; Fernández-Avilés et al., 2006; Paul et al., 2015; Schlesinger

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http://dx.doi.org/10.1016/j.ejon.2016.09.001
1462-3889/

et al., 2009; Solomon et al., 2010). Findings show that the majority of patients were satisfied with being cared for at home following HSCT (Bergkvist et al., 2013; Mank et al., 2015; Schulmeister et al., 2005). In light of the possibility of caring for patients at home and thus considering a hospital stay in protective isolation as optional, patients' perceptions of being isolated should be taken into account.

In order to qualitatively investigate the psychosocial implications of hospital stay in isolation, the purpose of this study was to explore the lived experiences of protective isolation in adult patients who had been treated with allogeneic HSCT.

2. Background

HSCT patients have to face a long-lasting and difficult care pathway, including high-dose chemotherapy, drug toxicities, and HSCT complications. In particular, patients with indication for an allogeneic HSCT are in need of an HLA-matched donor. The infusion of allogeneic stem cells may in turn involve the onset of aggressive or lethal graft-versus-host disease (GVHD). Therefore, it is crucial for them to keep faith and meaning in their treatment, which is believed to increase the chances of a successful outcome (Coolbrandt and Grypdonck, 2010). In this context, the psychosocial adjustment to health-care procedures may represent for them a way to cope not only with the disease but also with their status as patients with cancer living with uncertainty (Dunn et al., 2016).

Recent studies found that the number of depressed patients increased more than twofold one (El-Jawahri et al., 2015) and two weeks after transplant in isolated hospitalisation (Tecchio et al., 2013). However, the extent to which the increase in psychological distress is related to the protective isolation, or merely to the disease and its treatment, remains unclear. Protective isolation involves a rigorous physical restriction that could result in social isolation (Lee et al., 2011), severe limitation, or loss of self-determination and autonomy (Vottero and Rittenmeyer, 2012). Being isolated during such a threatening time may impair patients' coping abilities by increasing feelings of powerless and lack of support. Although patients may suffer from being isolated (because they feel lonely, imprisoned, and powerless), they do have the possibility of keeping the metaphorical door to the outside world ajar, and of adapting to isolation by relating with themselves (Biagioli et al., 2016). Since many changes have occurred in communication technologies, permitting patients to keep in touch with their loved ones through virtual means, such as smartphones or Skype, patients may also adjust to isolation more easily. In light of the upcoming possibility of managing HSCT recipients at home, patients' experiences of being in protective isolation during their hospital stay for allogeneic HSCT need to be explored further to better evaluate the psychosocial implications of this procedure.

3. Methods

3.1. Design

As the aim of this study was descriptive, it followed the phenomenological approach of Husserl (Streubert and Carpenter, 2011) to gain experience-based knowledge of the phenomenon of being isolated for allogeneic HSCT. Phenomenology addresses the totality of the lived experience from the participant's perspective by focussing on how objects and situations are perceived by and appear to the participant. We used Giorgi's (1997) descriptive phenomenological approach to develop knowledge capable of informing clinical practice.

3.2. Participants and setting

The participants were patients with haematological malignancies requiring allogeneic HSCT. Purposive sampling of patients who had been cared for in protective isolation during their hospital stay was conducted. The adult patients were recruited from the haematological service of a university hospital in Rome. Patients younger than 18 years old, not able to speak and understand Italian, with cognitive or speech impairment, or pathological conditions that could prevent active participation in the study were excluded.

The haematological ward, where the patients were isolated to undergo allogeneic HSCT, comprised eight single-bed rooms with en suite bathroom and a high-efficiency particulate air (HEPA) filtration system. The windows looked out on a corridor where visitors could come to see the patient and talk with him/her via a phone. Visitors were also allowed to enter the patient's room to visit, one at a time, for one hour after lunch (1 p.m.–2 p.m.) and one hour after dinner (7 p.m.–8 p.m.). Protective isolation implies that patients cannot get out of their hospital room during the neutropenic phase – neutrophil count below $0.5 \times 10^9/L$ – which usually lasts for between two and six weeks. The workload of the haematological service included approximately 50 allogeneic HSCTs per year, with costs completely covered by the National Health Service.

3.3. Ethics

Ethical approval was gained through the ethics committee of the university where the study was designed [protocol number 11.1 (15_TS).15 ComEt-CBM]. Participants were verbally informed about the study and were provided with an information sheet together with a consent form. It was made clear that their participation was completely voluntary and that data would be collected, analysed, and reported in the strictest confidence. Participants were also reminded that they were free to withdraw from the study at any time. Willing patients gave their signed consent to participate in the study.

3.4. Data collection

During October 2015, the nurse ward manager identified as potential participants those allogeneic HSCT recipients who met the inclusion study criteria using maximum variation, based on time since HSCT, length of hospital stay, diagnosis, and type of donor. Ten patients, who were in the haematological unit for their clinical check-up, were recruited and interviewed in a private and quiet room by two nurse researchers, who were not involved in the patients' care. Participants were asked about their hospital stay in isolation using open-ended and unstructured questions, such as ‘How did you feel during your hospital stay in protective isolation?’ or ‘What did it mean for you being isolated?’ When participants seemed to have nothing further to say, the interviewers encouraged additional narration or explanation to give participants sufficient opportunities to express their views extensively. In order to facilitate participants' description of their experiences, the interviewers adopted a welcoming attitude together with sensitivity, reassurance, and cordiality. No attempt was made to guide participants' narration or opinions. The interviews were audio-recorded and faithfully transcribed verbatim. The recordings were listened to several times in order to achieve a greater meaning of the participants' experiences and to ensure the accuracy of the transcripts.

3.5. Data analysis

Data were analysed following Giorgi's descriptive method