



The lived experience of patients with non-Hodgkin's lymphoma undergoing chemotherapy

Daren Chircop^{a,*}, Josianne Scerri^{b,c}

^a Department of Nursing, Faculty of Health Sciences, University of Malta, Msida, MSD2080, Malta

^b Department of Mental Health, Faculty of Health Sciences, University of Malta, Msida, MSD2080, Malta

^c Kingston University and St George's, University of London, London, SW17 0RE, UK

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ABSTRACT

Purpose: Patients with non-Hodgkin's lymphoma face many challenges when undergoing chemotherapy. However, there is a dearth of literature targeting the experiences of this patient group. Hence, the aim of this study was to explore the lived experience of patients with non-Hodgkin's lymphoma during the initial stages of chemotherapy (i.e. from commencement to mid-treatment).

Method: This study adopted a qualitative research design. Semi-structured interviews were conducted with six adult patients having non-Hodgkin's lymphoma and undergoing chemotherapy. Data collection was undertaken between July 2016 and December 2016. The interviews were audio-recorded and transcribed verbatim. The data was analysed using Interpretative Phenomenological Analysis.

Results: Three themes emerged: 'Living an emotional rollercoaster', 'Becoming dependent on others' and 'Facing an uncertain future'. This study highlights that, whilst undergoing chemotherapy, the participants experienced a rollercoaster of emotions, such as fear, relief, acceptance and depression, in addition to physical dysfunction. Moreover, two participants described feeling so overwhelmed emotionally that they even considered committing suicide. Nevertheless, all the participants stated that they hoped that their life would revert back to normal on completion of their treatment.

Conclusions: The findings of this study may help guide the formulation of interventions that target the needs of patients undergoing chemotherapy for non-Hodgkin's lymphoma. Such interventions may include the introduction of community services where health care providers can provide domestic support to these patients. Additionally, the information generated can also inform hospital policies, such as the introduction of screening programs to monitor for psychological distress in this patient group during treatment.

1. Introduction

Non-Hodgkin's lymphoma (NHL) is the tenth most common cancer worldwide (Ferlay et al., 2013). In Europe, the incidence rates for NHL have more than doubled since the late 1970s (Adamson et al., 2007). In spite of this, there seems to be an under appreciation of the impact of NHL on the patient's quality of life (Cheung et al., 2009).

NHL is a cancer of the lymphatic system, which is a network of vessels and glands spread around the body. The lymphatic system contains white blood cells called lymphocytes. In NHL, the affected lymphocytes start to multiply in an abnormal way and begin to accumulate in certain parts of the lymphatic system, such as a lymph node. As a result, NHL patients often present with a painless swelling in a lymph node, usually in the neck, armpit or groin. Furthermore, the affected lymphocytes lose their infection-fighting properties and thus,

the individual becomes vulnerable to infections. There are two types of NHL, B-cell lymphoma and T-cell lymphoma, depending on which type of lymphocytes are affected. Treatment options for NHL patients may include chemotherapy, radiotherapy, immunotherapy or a combination of these treatments (National Health Service, 2015). Usually, NHL patients are treated on an outpatient basis. However, sometimes due to the aggressiveness of the disease, as well as increased complexity of the treatment, the patient may need to be admitted for a short period in hospital for treatment (Macmillan Cancer Support, 2018). The most common first line treatment for NHL is the chemotherapy regimen made up of Cyclophosphamide, Hydroxydoxorubicin, Vincristine (Oncovin[®]), and Prednisolone (CHOP) (Schulz et al., 2007).

A literature search was conducted in the databases CINAHL, Medline, PsycINFO, and Web of Science using the keywords 'non-Hodgkin's lymphoma', 'chemotherapy' and 'experience'. The literature

* Corresponding author. Visiting Lecturer, Department of Nursing, Faculty of Health Sciences, University of Malta, Msida, MSD2080, Malta.

E-mail addresses: daren.chircop.09@um.edu.mt (D. Chircop), josianne.scerri@um.edu.mt (J. Scerri).

search identified seven quantitative studies (Merli et al., 2004; Doorduijn et al., 2005; Pettengell et al., 2008; Cheung et al., 2009; Kim et al., 2010; Tholstrup et al., 2011; Bolukbas and Kutluturkan, 2014) and only two qualitative studies (Swash et al., 2016; Chircop and Scerri, 2017) which explored the experiences of NHL patients undergoing chemotherapy. The quantitative studies indicate that undergoing chemotherapy has a negative impact on the patients' physical and role functioning (Pettengell et al., 2008; Cheung et al., 2009; Tholstrup et al., 2011); psychological well-being (Pettengell et al., 2008) and in the symptoms experienced, such as fatigue (Bolukbas and Kutluturkan, 2014), nausea and vomiting (Doorduijn et al., 2005; Merli et al., 2004), peripheral neuropathy (Kim et al., 2010) and diarrhoea (Tholstrup et al., 2011). On the other hand, the qualitative studies found that NHL patients undergoing chemotherapy experience informational and supportive care needs, as well as express concerns for their family (Swash et al., 2016; Chircop and Scerri, 2017). Additionally, NHL patients feel different from other cancer patients (Swash et al., 2016). In fact, Swash et al. (2016) indicate that the experiences of NHL patients differ from that of patients with solid tumours, such as breast and colon cancers, as they require more frequent hospital admissions and more intensive treatments. Furthermore, there is a clear degree of separation between those services aimed at solid tumours and those aimed at NHL patients (National Institute for Health and Care Excellence, 2003).

The dearth of literature and the differences that exist between patients with solid tumours and NHL patients suggest that there is a need to specifically explore the experiences of NHL patients. A thorough understanding of these patient experiences can help health care professionals to effectively implement interventions specifically for this patient group. Hence, the present study aims to explore the experiences of patients diagnosed specifically with NHL during the initial stages of chemotherapy (i.e., from commencement to mid-treatment) and their perceptions in relation to the remaining cycles of treatment.

2. Methods

2.1. Design

The design used in the present study was Interpretative Phenomenological Analysis (IPA) as it focuses on a deep understanding of the patients' lived experience of events (e.g., undergoing chemotherapy), as interpreted from the patients' own point of view (Smith et al., 2009). IPA is based on three major theoretical underpinnings which are phenomenology, hermeneutics and idiography. IPA is connected to phenomenology through allowing the participants to recount their experiences from their own perspective and hence, producing a subjective account of the experiences. Hermeneutics considers the interpretative process in which the researcher interprets the hidden or underlying meaning behind the subjective experiences of the participants. On the other hand, IPA is idiographic because it aims for an in-depth focus on the participants' experiences. The fundamental principle behind the idiographic approach is that the researcher conducts a detailed examination of each case. When all cases have been examined, the researcher conducts cross-case analysis for similarities and differences between the cases. This idiographic approach allows the researcher to identify emergent themes from the data and at the same time, see the particular intricacies of individual cases (Smith et al., 2009).

2.2. Participants

Since IPA is idiographic, it is conducted using small sample sizes as the detailed analysis of each case is time-consuming (Smith et al., 2009). Hence, a purposive sample consisting of four males and two females was recruited. The age of the participants ranged from 44 to 81 years. The participants had to be over the age of 18 years, diagnosed with NHL and were midway through their CHOP chemotherapy

regimen. Although the inclusion criteria did not specify the type of NHL (i.e. aggressive/non-aggressive), all the participants were diagnosed with aggressive NHL. As a result, all the participants had been admitted to the haematology ward at the local oncology centre in Malta to undergo their first two cycles of chemotherapy. Four of the participants were in retirement, one participant was a housewife, while the other participant was employed but was on extended sick leave. All the participants were in stable long-term relationships. Although data saturation is not critical to IPA studies (Smith et al., 2009), participants were recruited until no additional new knowledge was obtained from the interviews.

2.3. Ethical considerations

Ethical approval for the study was obtained from the relevant institutional research ethics committee. To reduce the risk of coercion, potential participants were recruited by an intermediary, who provided potential participants with an information letter. The information letter included a description of the study and outlined the participant's right to withdraw from the study at any time. Those participants who wished to participate in the study were required to provide their contact details to the intermediary. Once these contact details were received, the first author (DC) contacted those participants who indicated their willingness to participate by phone and any further queries were clarified. If the participants expressed their willingness to proceed, a time and place to meet up for further discussion was agreed. During this meeting, a time and place for the interview was agreed and the participants signed a consent form to indicate their voluntary participation in the study. Moreover, the confidentiality of the study participants was safeguarded by the allocation of pseudonyms and all transcripts and audio recordings were stored in a locked cabinet.

2.4. Data collection

Semi-structured interviews were used for data collection as they provide a detailed picture of the participants' lived experience (Smith et al., 2009). Each participant was interviewed midway through their treatment, that is, five weeks from the commencement of their chemotherapy treatment but before the commencement of the third cycle of chemotherapy. The interviews were conducted in a setting selected by the participants. Five participants chose to have their interviews conducted at home, while one participant selected the hospital setting. The interviews lasted between 60 and 90 min and were audio-recorded. The audio-recorded interviews were then transcribed verbatim. Data collection was undertaken between July 2016 and December 2016.

The interviews were conducted by the first author (DC). The first author (DC) used an interview schedule. Open-ended questions were used to encourage the participants to talk and elaborate on their experiences thus, enabling a rich account of the experiences (Smith et al., 2009). One question asked was: "Can you describe your first chemotherapy session?" This question was usually followed by prompts to facilitate a deeper reflection, such as "Can you describe any emotions that you felt?" or "What thoughts crossed your mind?"

2.5. Data analysis

Data analysis was based on the principles of IPA. Smith et al. (2009) describes a systematic process, based on thematic analysis for analysing the data collected. This process is guided by an attitude of openness and a willingness to dwell in the data in order to extract the meanings attributed to the participants' experiences. As suggested by Smith et al. (2009), firstly, the interview transcripts were re-read several times while also listening to the original recordings so as to become familiar with the participants' accounts. Then a line-by-line analysis (i.e., coding) of the experiential claims, concerns and understandings of each participant on their experience of undergoing chemotherapy was

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