European Journal of Oncology Nursing 17 (2013) 618–624

Contents lists available at SciVerse ScienceDirect

European Journal of Oncology Nursing

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

The significance of fellow patients for head and neck cancer patients in the radiation treatment period

Helen Egestad*

Department of Health and Care Sciences, Faculty of Health Sciences, University of Tromsø, N-9037 Tromsø, Norway

Keywords:
Head and neck cancer
Radiation therapy
Fellow patients
Support
Qualitative interviews

ABSTRACT

Purpose: Head and neck cancer patients undergoing radiation therapy feel anxiety, fear, and stress. The literature describes the importance of social support; however, there is a lack of research that describes what value fellow patients provide to cancer patients undergoing radiation treatment. The objective of this study was to explore how head and neck cancer patients are affected by their fellow patients in the radiation treatment period.

Method: This study was conducted via qualitative interviews, taking on a phenomenological, hermeneutic approach. Eleven head and neck cancer patients were interviewed.

Results: Contact with fellow patients can lead to less loneliness, reduction of uncertainty and negative feelings can be reduced. The feelings of having control can increase and self-esteem can be strengthened.

Conclusions: When head and neck cancer patients make relationship with fellow patients during radiation treatment, the contact can lead to a sense of emotional comfort or, sometimes, emotional distress. The relationship can result in increased knowledge and to a sense of feeling meaningful to fellow patients. This ensures better coping with treatment and side-effects.

Introduction

Head and neck cancer patients experience a high level of emotional distress in the treatment period (Chen et al., 2010). Treatment affects the patient through side effects and dysfunction (Eades et al., 2009; Mallack and Waldron, 2009). The experience also includes uncertainty due to concerns about the efficacy of treatment, about recurrence, and about the ability to manage daily living (Scharloo et al., 2010; Rose and Yates, 2001). Several studies have shown that patients undergoing radiation therapy have fears, anxieties, and stress related to the therapy (Andersen et al., 1984; Frith, 1991; Hinds and Moyer, 1997; Lamszus et al., 1994; Long, 2001; Poroch, 1995). Head and neck cancer patients' radiation treatment is complex. The illness and the treatment have an enormous impact on the patients' daily living (Feber, 2000; Myers et al., 1999). The malignancies affect the most visible area of the body, and may have a profound impact on the most fundamental activities of daily life, such as speech, breathing, eating, and drinking (Larsson and Hedelin, 2003; Wells and Kelly, 2008). Physical symptoms are dry mouth and throat, swallowing problems, and pain (Myers et al., 1999). Anxiety, depression, uncertainty, and hopelessness are the most frequently reported psychological problems (Larsson and Hedelin, 2003; Ledeboer et al., 2005; Myers et al., 1999; Wells and Kelly, 2008). Head and neck cancer patients have some of the highest documented rates of depressive symptoms for patients with any tumor type (Archer et al., 2008; Hamran, 2008). Aarstad (2008) focused on head and neck cancer patients' fear, the physical symptoms of the disease, and treatment viewed as demands on the patients. Semple et al. (2008) found that head and neck cancer patients have many challenges, such as physical changes, concerns about cancer, work and day-to-day tasks, interpersonal relationships, and social functioning.

The importance of social support for handling and coping with serious illness has frequently been discussed (Molassiotis et al., 1997; Sammarco, 2001; Van der Molen, 1999). Haisfield-Wolfe et al. (2012) performed a qualitative study where head and neck cancer patients receiving radiation treatment were interviewed. The study found that family and friend support was a common coping strategy used by patients, but the study says nothing about support from fellow patients. There is much literature describing how patients with the same disease can contribute comfort and support to cancer patients after treatment (Bottomley and Jones, 1997; Gregoire et al., 1997; Hitch et al., 1994; Korstjens et al., 2008; Sægrov and Halding, 2004). Support groups were found (by patients) to provide a unique sense of community, unconditional acceptance, and information about cancer and its treatment.

---

* Tel.: +47 77660637; fax: +47 77660612.
E-mail address: helen.egestad@uit.no.

1462-3889/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ejon.2013.01.001

Outside the group, patients felt isolated, rejected, and had a lesser knowledge about cancer (Ussher et al., 2006).

The benefits of support groups are well documented, but there is less research about the effect of unorganized patient-to-patient relationships in hospital wards (Isaksen Steen and Gjengedal, 2000). Isaksen Steen et al. (2003) found that many cancer patients had positive experiences with fellow patients, including, for instance, support and comfort. However, some patients had negative experiences, as they reported painful and sad feelings, and that contact with other patients had made them anxious (Isaksen Steen et al., 2003). Lamszus et al. (1994) found that many cancer patients wished to have more contact and conversations with fellow-patients when they were indoors patients.

However, few studies have addressed head and neck cancer patients' coping in the context of fellow patients. The purpose of this study was to explore how daily life of head and neck cancer patients are affected by fellow patients in the radiation treatment period. Daily life includes all of the varied activities that persons conduct and participate in Borg (2003).

A phenomenological hermeneutic approach may contribute to a broader understanding of head and neck cancer patients' experiences with fellow patients in the radiation treatment period.

Method

Design

A phenomenological hermeneutic approach involving in-depth interviews was used in this study (Dahlberg et al., 2001; Gadamer, 1999; Lindseth and Nordberg, 2004; Van Manen, 1997). Because the purpose of this study was to explore the lived experience of head and neck cancer patients undergoing radiotherapy, the study designed utilized a phenomenological hermeneutic approach. The approach seeks to understand phenomena in the everyday treatment world from the individual's perspective by describing and exploring their reality. A phenomenological hermeneutic approach is well suited to obtaining rich descriptions from participants understanding daily experiences, and the goal is to understand a phenomenon by recognizing its meaning (Van der Zalm and Bergum, 2000). The focus of each interview was on understanding the patients' perspective during the treatment period. An open, curious, and sensitive attitude is emphasized to encourage an open-minded analysis of the data (Dahlberg et al., 2001; Gadamer, 1999). The experiences must be understood in a human context and related to the person, because in hermeneutic phenomenology one believes that the important reality is what people perceive (Ricoeur, 1976). The interviews were based on an interview guide and were constructed in interaction between an interviewee and an interviewer. The focus of each interview was on the patient's needs. The interviews were tape-recorded and later, fully transcribed. The approach sought to understand what the encounters with fellow patients meant for the patients when they were receiving radiation treatment, from the individual's own perspective, by describing and exploring their reality. The focus was on the understandable meaning of these experiences, rather than the expression of something "factual" that need explanation (Lindseth and Nordberg, 2004). The method is based on text interpretation presented by Ricoeur (1976).

The data for this study were collected as part of a wider project using both quantitative and qualitative approaches. The primary purpose of the project is to focus on head and neck cancer patients' quality of life while they undergo radiation treatment. This article concentrates on the findings revealed by the in-depth interviews only.

Ethics

The study was approved by the Regional Committee for Medical Research Ethics (P REK NORD, 200900504-3KST017/400) and the Norwegian Social Science Data Services (21831).

Participants

Patients were recruited through the radiotherapy department at the University Hospital in the north of Norway. All patients with head and neck cancer, referred to the oncology center for radiotherapy, were approached. Patients were eligible for the study if they had been diagnosed with head and neck cancer and were going to receive radiotherapy. Patients were ineligible if they had metastasis or if they were unable to speak and understand Norwegian. The participants received a letter that broadly explained the purpose and the methods of the study and the level of commitment required to participate in the project. In the letter, patients were informed that they could be asked to participate in an in-depth interview after treatment. Every third patient who participated in the study was asked about the interview. Twelve cancer patients were invited to participate in the interview, but one declined because the patient was too ill to talk for 2 h.

Interview procedure

The interviews took place in the patients' homes about one month post radiation therapy. The interview consisted of open questions about their thoughts and feelings when they received radiotherapy. Every interview began with 'Please tell me about your experiences of the treatment'. The follow-up questions related to the participants narratives and focused on how the contact with fellow patients affected everyday life in the treatment period. The purpose was to obtain knowledge of how patients experienced contact with fellow patients. Each interview lasted for approximately one and one-half hours, recorded with a tape recorder. The interviews were transcribed shortly thereafter. The collection of data was carried out during 2010 and the spring of 2011.

Data analysis

The interview transcripts were analyzed within a phenomenological hermeneutic framework that was inspired by Gadamer (1999) and presented as a stepwise research method by Fleming et al. (2003) and Van Manen (1997). The analysis consisted of three phases: naïve reading; structural analyses; and comprehensive understanding. During the naïve reading phase, the researcher completes a naïve assessment of the meaning of the text. The text is read several times and a surface understanding is achieved (Fleming et al., 2003). In the structural analysis, the meaningful units, including sentences, key statements, paragraphs and metaphors, were marked (Howritz et al., 2002). Meaningful information from all the interviews was compared and analyzed to identify patterns, similarities, and variations in the data. The themes and subthemes emerged through a process of asking questions about the text and constantly moving between the marked meaningful units and the entire text (making a hermeneutic circle) (Fleming et al., 2003; Gadamer, 1999). In the final phase, the text is read again as a whole, the naïve understanding and the themes are reflected on in relation to the literature, and a comprehensive understanding is formulated. This process was not a strict step-by-step procedure, but required movement back and forth between the phases in a process, moving from understanding to explanation and from explanation to comprehension (Ricoeur, 1976). The researcher sought to identify meanings in the