



Contents lists available at ScienceDirect

European Journal of Oncology Nursing

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

How relatives of patients with head and neck cancer experience pain, disease progression and treatment: A qualitative interview study

Anne Schaller^{a,*}, Gunilla M. Liedberg^b, Britt Larsson^a

^a Rehabilitation Medicine, Department of Medical and Health Sciences, Faculty of Health Sciences, Linköping University and Pain and Rehabilitation Centre, County Council of Ostergotland, Linköping 58185, Sweden

^b Department of Social and Welfare Studies, Faculty of Health Sciences, Linköping University, Linköping, Sweden

A B S T R A C T

Keywords:

Head and neck cancer
Relatives
Pain
Qualitative content analysis
Interviews

Purpose: This study of relatives to patients with head and neck cancer (HNC) treated with radiotherapy describes how the relatives experienced the patient's situation, especially with respect to pain, and how the relatives themselves experienced the situation.

Methods: Semi-structured interviews of 21 relatives to HNC patients who suffered from pain were conducted, and a qualitative content analysis was performed.

Results: The relatives experienced that the patients suffered from physical, psychological, and social pain. A dark picture consisting of lack of participation and knowledge, psychological distress, and lack of support were reported. Thus, a main category: relatives struggle with loved one's pains related to head and neck cancer treatment and with their own demanding situation – was based on the following four categories: inability to relieve and comprehend the physical suffering of the patients; overwhelming emotions were experienced that affect the patients and the relatives themselves; in need of support from the health care service; and altered daily activities and family roles due to illness and treatment.

Conclusion: In patients physical, psychological, and social pain were prominent and in relatives psychological distress, lack of knowledge and support were experienced. Thus, to reduce pain and anxiety in patients and relatives, the health care professionals should provide relevant knowledge about pain management. The health care professionals should also provide educational interventions that address the psychological and social factors that impact pain for HNC patients and their relatives. Well-thought supporting care and easily accessible information about practical concerns should be offered to HNC patients and their relatives.

© 2014 Elsevier Ltd. All rights reserved.

Introduction

When people suffer from cancer, there is a risk that their family members' quality of life and everyday life will also be negatively affected (Northouse, 2005; Northouse et al., 2012). It has been reported (Juarez and Ferrell, 1996) that relatives may endure a great degree of suffering when their loved one is in pain. The extensive psychosocial impacts on head and neck cancer (HNC) patients are well known (Fischer et al., 2010; Kohda et al., 2005; Verdonck-de Leeuw et al., 2007). A prospective study of patients with HNC found that living with a spouse lowered the risk of adverse changes in quality of life (Fang et al., 2004). The importance of being

surrounded by family, of belonging, and of social support has been shown to contribute to good health and management of cancer diseases including HNC (Patterson et al., 2013; Pinquart and Duberstein, 2010).

Compared to population wide-levels relatives of HNC patients experience higher levels of psychological distress and lower levels of wellbeing (Ross et al., 2010). HNC patients require a considerable amount of care and support and it is difficult for their relatives to take care of them (Precious et al., 2012). To cope with this demanding situation, it may be necessary to provide psychological care for both patients and their relatives (Baghi et al., 2007). To date, however, few studies address the life situation of the relatives of HNC patients.

HNC often requires arduous treatment that causes severe adverse effects and sometimes the disease has a poor prognosis – the five-year survival for HNC is between 23% and 88%, depending on the type of HNC (Argiris et al., 2008). Painful oral mucositis (OM)

* Corresponding author. Tel.: +46 10 103 3970.

E-mail addresses: anne.schaller@liu.se, anne.schaller@lio.se (A. Schaller), gunilla.liedeberg@liu.se (G.M. Liedberg), britt.larsson@liu.se (B. Larsson).

is a common adverse effect of radiotherapy treatment (RT), the standard treatment for HNC. About 75% of patients with HNC experience physical pain despite pain relief treatment (Babin et al., 2008; Epstein et al., 2010).

A recent review (Longacre et al., 2012) did address several important aspects on care givers' to HNC patients situation but did not include care givers' experiences of the HNC patients' pain. This is also an issue which to our knowledge is sparsely studied and important to elucidate.

This qualitative interview study of relatives to patients with HNC treated with RT describes how the relatives perceived the experiences of the patient's situation, especially with respect to pain, and how the relatives themselves experienced the situation.

Methods

Participants

Relatives of curative HNC patients who had been treated with RT and were referred to the specialized pain care department at the University Hospital, Linköping in southern Sweden, north Europe participated in the study. The department is staffed by anesthesiologists and nurses specialized in pain care and treats inpatients and outpatients. Linköping is located in the county council of Östergötland. Catchment area of the University Hospital of Linköping is about one million people.

To be included, the family member had to be identified by the patient as the closest relative. The patients did not have to specify how they were related to the person they designated as their closest relative (i.e., the patients defined what was meant by closest relative).

Of the 26 relatives asked to participate in the study, 21 agreed to participate. Table 1 shows the demographic make-up (age, sex, relationship, etc.) of the relatives. The data were collected between

autumn 2010 and summer 2011 after the relative's patient (i.e., a HNC patient) had completed RT (Table 1). When the interviews were conducted the patients were still current for pain treatment as outpatients at the department. Relatives were provided written and oral information and signed a written consent before the interviews. The regional Ethical Review Board approved the study (2010-05-19).

Interviews and data analysis

All interviews were conducted by the first author (AS) either in the relative's home ($n = 11$), in the pain care department ($n = 9$), or in a workplace ($n = 1$). The semi-structured qualitative interviews were directed by an interview guide based on Kvale (1996) and Patton (2002). The interview guide, which included predetermined themes to answer the purpose, was developed by the authors to explore the relative's perspective of the patient's pain and of the relative's own situation. The opening question – “Can you describe your experiences during the period your patient underwent the RT treatment?” – gave rich information and often covered or initiated many of the themes. The time of posing the questions related to the predetermined themes varied, depending on how the conversation developed. The interview guide (Table 2) was used as a checklist to guarantee that all themes were discussed. The interviews were audiotaped and transcribed verbatim by an experienced secretary. AS read each transcript and checked them against the tape.

The interviews were analysed with qualitative content analysis as described by Elo and Kyngas (2008) and Krippendorff (2004). All three authors read the interviews to obtain a sense of the whole with an inductive approach. The interviews were reread systematically, by two of the authors (AS, BL), line by line to identify and underline the meaning units of text, relevant for the research aim. Descriptive notes were written in the margins of the transcripts, representing the start of the process called coding. To validate the result the meaning units and codes were compared and discussed by the authors to agreement was reached. A meaning unit consists of a sentence, several sentences, or a paragraph.

Then all interviews were organized in a computer program for qualitative methodology – Nvivo 9 (Edlund, 2011), and the meaning units were sorted into codes in the program. Further, these codes were sorted into subcategories that were used to develop categories. Based on the categories, a main category was created. This process was conducted by the first author (AS), who frequently consulted the others (BL, GL) regarding excerpts of the primary transcript data and the clustering of the data into subcategories and categories.

Table 1
Characteristics of the 21 relatives and their patients (HNC patients).

	Number
Sex	
Female	18
Male	3
Age	
20–39 years	6
40–59 years	6
60–89 years	9
Relationship to the HNC patient	
Spouse	12
Cohabitant	3
Child	6
Tumour site (patient)	
Oral cavity	8
Pharynx	6
Larynx	4
Others	3
Classification of malignant tumours according to TNM^a (patient)	
I	3
II	3
III	5
III	10
Time point^b of interview of relatives	
<2 months	9
2–4 months	8
>4 months	4

^a TNM = T relates to size and spread of primary tumour, N relates to spread in regional lymph nodes, and M relates to the occurrence of distant metastases.

^b After completion of patient's radiotherapy.

Table 2
Interview guide.

Can you describe your experiences during the period your relative (HNC patient) underwent the RT treatment?
<ul style="list-style-type: none"> ○ Pain ○ Symptoms ○ Health ○ Wellness ○ Family
How is the relationship between you and your closest relative (HNC patient)?
Can you describe if the relationship has been affected since the treatment or diagnosis?
<ul style="list-style-type: none"> ○ In what ways ○ Your role
What do you feel have helped your relative (HNC patient) during the treatment?
<ul style="list-style-type: none"> ○ What has been the most important? ○ What has been less good? ○ What support do you need as a relative?

Download English Version:

<https://daneshyari.com/en/article/5868448>

Download Persian Version:

<https://daneshyari.com/article/5868448>

[Daneshyari.com](https://daneshyari.com)