



Pain experiences of patients with advanced cancer: A qualitative descriptive study

Ozgul Erol^{a,*}, Serap Unsar^a, Lale Yacan^a, Meryem Pelin^b, Seda Kurt^a, Bülent Erdogan^c

^a Trakya University, Faculty of Health Sciences, Department of Medical Nursing, Edirne, Turkey

^b Sakarya University Faculty of Health Sciences, Sakarya, Turkey

^c Trakya University, Faculty of Medicine, Medical Oncology Clinic, Edirne, Turkey

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ABSTRACT

Purpose: Uncontrolled pain, especially in patients with advanced cancer, affects quality of life negatively and causes negative physical and psychological conditions. The aim of this study was to explore the pain experiences of patients with advanced cancer and how they manage with pain, and to present a view of pain management approaches of nurses from the perspectives of the patients.

Methods: This was a qualitative descriptive study of sixteen hospitalized patients with advanced cancer. Data were collected using semi-structured interviews with patients. Data were analysed by Colaizzi's phenomenological method.

Results: This study found that patients with advanced cancer who had pain experienced anxiety, helplessness, hopelessness and many restrictions in daily life as well as inability to manage with pain. Most of the patients with advanced cancer were not satisfied with their nursing care with regard to pain management. The themes that emerged were pain perception and experiences, effects of pain on daily life, pain management and management strategies and the patients' perspectives about nursing approaches to pain.

Conclusions: This study demonstrated the difficulties of patients with advanced cancer who experienced pain in their daily lives, yet lack pain management strategies. Furthermore, nurses' caring approaches to patients with advanced cancer who experienced pain was found inadequate. Oncology nurses should provide educational interventions in order to enhance knowledge and skills about pain assessment and non-pharmacologic and pharmacologic strategies used in pain management.

1. Introduction

Advanced cancer is described as a cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment (National Cancer Institute, 2015). Today, cancer patients live longer with the significant therapeutic effects of new cancer therapies. However, pain is still one of the most distressing and burdensome symptoms of cancer and cancer therapies, affecting all aspects of a patient's life (Haumann et al., 2017; Rustoen et al., 2009; Rustoen et al., 2013; Wengström et al., 2014).

The prevalence of pain is extremely high, especially in patients with advanced cancer. The International Association for the Study of Pain (IASP) estimated the prevalence of pain as 75% (IASP, 2009). A meta-analysis demonstrated that 64% of patients with metastatic/advanced cancer had pain (Van den Beuken-van Everdingen et al., 2007). Another study found that two-thirds of patients with end-stage cancer

experienced pain (Economou, 2009). A study conducted with patients receiving palliative care reported pain prevalence as 88.2% (Ozalp et al., 2017). Facing an advanced cancer diagnosis is by itself a difficult life experience for both the patient and the patient's family. The addition of pain to the advanced cancer diagnosis causes dramatic deterioration of a patient's quality of life in various ways (IASP, 2009). Having pain at the end of life results in many physical, psychological, social and economic problems that lead to serious limitations and worsened quality of life (Augustussen et al., 2017; Morss, 2010). It was reported that cancer patients had greater fear of dying while suffering from pain than dying (IASP, 2009).

Although cancer pain is an ancient problem, it is still a mismanaged and/or undertreated symptom around the world, needing much more attention by health care professionals (Eaton et al., 2015; Haumann et al., 2017; Jacobsen et al., 2009). Pain is a subjective experience; it is a symptom of whatever patients say and experience, so the primary

* Corresponding author.

E-mail addresses: ozgulerol@trakya.edu.tr (O. Erol), serapunsar@trakya.edu.tr (S. Unsar), laleyacan@hotmail.com (L. Yacan), meryemilmek@sakarya.edu.tr (M. Pelin), sedakurt81@gmail.com (S. Kurt), bulenterdogan@trakya.edu.tr (B. Erdogan).

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source is the patients themselves. Therefore, successful pain management requires much more attention to patients' pain perceptions, experiences and management strategies (Economou, 2009; Haumann et al., 2017). Today, although there are evidence-based guidelines for the management of cancer pain, nurses still do not assess and care for cancer pain properly (Eaton et al., 2015). Some studies have revealed that oncology nurses have little knowledge and inadequate attitudes and skills about cancer pain management (Alqahtani and Jones, 2015; Bernardi et al., 2007; Breivik et al., 2009; Yildirim et al., 2009). A study demonstrated that oncology nurses believe the benefits of evidence-based practices, but did not implement them frequently; rather, they continued to use the same conventional approaches in clinics (Eaton et al., 2015). Effective pain management needs a holistic care approach and effective team work by various health care professionals (Haumann et al., 2017).

There are various studies evaluating the pain experiences of cancer patients (Jacobsen et al., 2009; Korhan et al., 2013; Larsson and Wijk, 2007; McPherson et al., 2014; Schaller et al., 2015). However, few studies have investigated the oncology nurses' pain-related caring approaches through the eyes of patients with advanced cancer. The aim of this study was to explore the pain experiences of patients with advanced cancer and how they manage with pain, and to present a view of pain management approaches of nurses from the perspectives of the patients.

2. Methods

2.1. Patients and sampling

This qualitative descriptive study was conducted with sixteen patients with advanced cancer hospitalized in an oncology clinic of a university hospital in Edirne city, which is located in Trakya Region, Northwestern Turkey. This clinic has a 40-bed capacity for inpatients and an ambulatory chemotherapy unit for outpatients. Each room had one or two beds. Patients were generally residents of Edirne, close cities, towns and villages and even from Balkan countries. The data were collected between September and December 2015.

The sample used in the study was determined according to the aim of the study and by reviewing the qualitative studies in the literature (Burnard, 2004; Korhan et al., 2013; Sanders, 2003; Schaller et al., 2015). A purposeful sampling technique was used to identify the patients. Patients who were included in the study were those over the age of 18, within at least 6 months of diagnosis, without communication difficulties, who volunteered to participate in the study, a diagnosis of non-small cell lung cancer stage IIIB/IV, advanced gastric and colorectal cancer with stage III/IV, and with a Eastern Cooperative Oncology Group (ECOG) performance score of 3 (capable of only limited selfcare; confined to bed or chair more than 50% of waking hours), and 4 (completely disabled; cannot carry on any selfcare; totally confined to bed or chair).

2.2. Ethical considerations

This study was approved by the Ethical Committee of Trakya University Medical Faculty. Patients who were eligible to participate in the study were asked for verbal and written consent after being informed about the study's purpose and confidentiality issues.

2.3. Study design

The current study was a descriptive qualitative study. Data were collected using semi-structured interviews designed to obtain patients' pain experiences (Box 1). The semi-structured qualitative interviews were conducted with the guidance of Colaizzi (1978) and Speziale and Carpenter (2007). Interviews began with general questions related with patient's sociodemographic and disease related characteristics. As all

patients had advanced cancer, interviews took place at the bedside of the patients. Moreover, medication and caring activities were intense in the earlier hours of the day at the clinic. So, especially calm afternoon hours of the clinic were preferred for interviewing which were suitable for both patients and environmental conditions. Three researchers (OE, SU, and LY) recorded the interviews, which were digitally audiotaped, varied in length from 32 to 65 min; their mean duration was 44 min. Participants were encouraged to talk freely and to tell stories using their own words.

2.4. Data analysis

Data were analysed using Colaizzi's phenomenological method which helped to gain a sense of each participant's pain experience (Colaizzi, 1978; Speziale and Carpenter, 2007).

The following steps, presented in Fig. 1, were performed according to Colaizzi's process for phenomenological data analysis (Colaizzi, 1978).

Step 1. Three of the authors listened each recorded interview three times in order to gain a general sense and understand the patients' feelings about their pain experiences. Each interview was also transcribed, all expressions, thoughts and senses were written in a diary to assist in organising and identifying subthemes and themes by a researcher (MP).

Step 2. For each transcript, significant phrases and statements were extracted in order to understand what was said and the manner in which it was expressed. Three researchers (OE, SU, SK) checked the consistency of the extracted meanings and important statements. These statements were copied to a separate sheet, noting with their pages and line numbers by a researcher (MP).

Step 3. Significant statements were gleaned from general statements and they were formulated into meanings. Each significant statement related to pain experience was studied carefully in order to find a sense of its meaning. Subsequently, OE and SU assigned codes to the condensed meanings.

Step 4. Similar codes were grouped into more comprehensive subthemes and themes. All themes and subthemes were discussed with all researchers in case of disagreement.

Step 5. The findings of the study were integrated into a detailed description of pain and pain management strategies of patients with advanced cancer. Patients' pain experiences and perspectives about nursing approaches to pain and pain management were presented.

Step 6. The fundamental structure of the phenomenon was described. The meanings gathered from the previous steps of the analysis were described.

Step 7. Finally, the findings were validated by returning to the participants for an additional interview, to ensure the study represented their experiences. Six patients with advanced cancer were invited to examine the results and they approved the interpretations about their experiences.

To increase the reliability and trustworthiness seven steps given above were taken to verify the results. Semi-structured audio recorded interviews allowed for repeated listening of the data to check emerging themes and subthemes. Three researchers checked the consistency of the extracted meanings and important statements whether the final themes were true to participants' accounts. Emerging themes discussed with other researchers who had oncology research expertise in an open process till a consensus reached. Themes, subthemes and examples of patient narratives were given in Table 2. Participants invited to comment on the research findings and themes and approved the results. Patient narratives were translated into English in order to facilitate the readers' understanding the results.

3. Results

Patients' demographic and disease-related characteristics are

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