



The lived experience of Lebanese oncology patients receiving palliative care

Myrna A.A. Doumit*, Huda Abu-Saad Huijjer, Jane H. Kelley

School of Nursing, American University of Beirut, Beirut, Lebanon

KEYWORDS

Phenomenology;
Cancer;
Utrecht school;
Qualitative study;
Palliative care;
Dependency;
Communication;
Pain

Summary

The purpose of this study was to uncover the lived experience of Lebanese oncology patients receiving palliative care. The study design was based on the Utrecht School of Phenomenology based on the Dutch school of phenomenology. This study followed purposeful sampling in which ten participants, six women, and four men, with a mean age of 54.4 years were selected. In-depth semi-structured interviews along with observation field notes were used as the source for data collection. Data were analyzed using the hermeneutic phenomenological approach based on the Utrecht School of Phenomenology. The participants highlighted their distress from being dependent; their dislike for pity; their worry for the family and the worry about the family's worry; their reliance on God and divinity; their dislike of the hospital stay; their need to be productive; their fear of pain; and their need to communicate. Specific nursing actions related to the themes would include exploring patients' ideas, beliefs, and experiences regarding pain, and improved communication among patient, family, and the health care providers.

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Zusammenfassung

Das Ziel dieser Studie bestand darin, die gelebten Erfahrungen von palliativ behandelten libanesischen Krebspatienten zu evaluieren. Das Studiendesign basierte auf den Methoden der Utrechter Schule der Phänomenologie, die ihrerseits auf den Methoden der Niederländischen Schule der Phänomenologie beruhten. In dieser Studie fand eine zielgerichtete Stichprobenauswahl statt: Es wurden 10 Teilnehmer (6 Frauen und 4 Männer) rekrutiert, deren Durchschnittsalter 54,4 Jahre betrug. Als Quelle für die Datenerhebung dienten eingehende semistrukturierte Interviews sowie „observation field notes“. Die Datenanalyse erfolgte unter Verwendung der hermeneutischen phänomenologischen Methode der Schule der Phänomenologie in Utrecht. Die Probanden gaben an, unter ihrer Abhängigkeit von anderen Menschen zu leiden, eine Abneigung gegen jede Form von Mitleid zu verspüren, sich um ihre Familie sowie auch um die Sorgen der Familie zu sorgen, auf Gott zu vertrauen, unter ihrem Aufenthalt im Krankenhaus zu leiden, das Bedürfnis zu verspüren, produktiv zu sein, Angst vor Schmerzen zu haben sowie das Bedürfnis zu verspüren, mit anderen Menschen zu kommunizieren. Zu den spezifischen pflegerischen Maßnahmen in Zusammenhang mit diesen Themen zählen die Evaluation der

*Corresponding author. Mob.: +961 3 548623; fax: +961 1 744476.

E-mail addresses: ma12@aub.edu.lb (M.A.A. Doumit), hh35@aub.edu.lb (H. Abu-Saad Huijjer), jk33@aub.edu.lb (J.H. Kelley).

Ideen, Vorstellungen und Erfahrungen der Patienten im Hinblick auf den Schmerz sowie eine Verbesserung der Kommunikation zwischen Patient, Familie und Anbietern von Gesundheitsleistungen.

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Introduction

Cancer is now a major cause of mortality throughout the world, and in the developed world it is generally exceeded only by cardiovascular diseases (World Health Organization [WHO], 2003). It is estimated that the number of new cancer cases in Lebanon ranges between 3500 and 4000 yearly (Daher et al., 2002). There is no official number about Lebanese cancer cases receiving palliative care, but due to the early detection and enhanced methods of treatment, patients live longer with a diagnosis with disseminated cancer. Therefore, every health care worker caring for cancer patients might deal with patients who are in their palliative stage.

In the Lebanese society, cancer is believed to be a protracted illness causing great disability and suffering that finally leads to a painful death. The word cancer is not a preferred word to use, and euphemisms, such as "growth", "lump" and "that disease" have been developed as alternatives.

Palliative care is a new concept in the Lebanese health care sector and it is mainly linked with cancer disease. Compared to some western countries, Lebanon has not yet espoused palliative care as a practice specialty or as a clinical research field. Although palliative care is still not officially institutionalized, patients are financially covered by private insurance companies and the Ministry of Health to receive palliative care in hospitals. Chemotherapeutic drugs are dispensed free of charge by the Ministry of Health.

In Lebanon, health care professionals caring for patients with cancer are likely to highlight the survival rates associated with particular types of the disease or treatment, but they seldom document the quality of that survival (Shamseddine, 2004; Shamseddine et al., 2004). Patient survival is discussed and documented in studies as disease-free intervals, changes in tumor volume, toxicity of the treatment and, on occasions, patients' performance status.

Despite the fact that cancer is one of the leading causes of mortality in Lebanon, and that a majority of patients reach the palliative stage (Daher et al., 2002), very little is known about the lived experience of the Lebanese oncology patients receiving palliative care. One approach to capture the personal and social context of patients is to study their lived experience using a phenomenological approach.

In Lebanon, in parallel with the WHO (2002) definition, palliative care delivered to patients diagnosed with cancer is associated with low expectations for cure or remission. The palliative care definition used for this study is the WHO definition of this concept. It is worth noting that in Lebanon there are still no official written guidelines defining the provision of palliative care. Palliative care as it exists in Lebanon today is in line with international descriptions like

the WHO definition (A. Shamseddine and Z. Salem, personal communication, June 8, 2005).

An initial review of the literature indicated that a number of studies on the lived experience of cancer patients receiving palliative care have been conducted in several countries around the globe. Identified subcategories from the reviewed articles were: palliative care and cultures; palliative care and autonomy; palliative care and communication; and palliative care and pain. Studies conducted in different countries and cultures revealed that patients living in developed and developing countries have different and unique lived experiences of their illness (Appelin and Bertero, 2004; Astradsson et al., 2001; Osse et al., 2005; Harstad and Andershed, 2004). Culture was considered an important principle in comprehending individual perceptions of their lived experience, in terms of physical, psychological, social, and spiritual needs.

Studies on palliative care and autonomy related mainly to palliative care in end of life. Autonomy was believed to be a vital element in improving the quality of palliative care delivered to patients (Sahn et al., 2005; Tang, 2003; Koedoot et al., 2003).

Palliative care and communication studies revealed the important role that professionals need to play in order to facilitate communication through an open, trusting relationship with patients (Clayton et al., 2005; Kirk et al., 2004; Mok and Chiu, 2004). Results reported that building trusting relationships with patients helped the health care workers to exhibit a holistic approach to care.

While the goal for some patients may be to prolong life at any cost, reviewed studies on palliative care and pain indicated that the majority of seriously ill patients desire to obtain comfort from their pain and other symptoms, improve their quality of life, avoid being a burden to their family, have a closer relationship with loved ones, and preserve a sense of control (Bostrom et al., 2004; Dawson et al., 2005; Mystakidou et al., 2004; Coyle, 2004).

Although several studies have examined palliative care from the patients perspective (Appelin and Bertero, 2004; Osse et al., 2005; Proot et al., 2004; Tang, 2003), no studies focused on palliative care in Lebanon. This area constitutes a major gap in the literature.

Purpose of the study

The purpose of this study was to uncover the lived experience of Lebanese oncology patients receiving palliative care, and to obtain an increased understanding of the meaning and interpretation of their experience.

Methods

The study design was based on the Utrecht School of Phenomenology which combines characteristics of descriptive

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