



The need for social support provided by the non-profit cancer societies throughout different phases in the cancer trajectory and its integration into public healthcare



Tiina Yli-Uotila ^{a, *}, Marja Kaunonen ^{a, b}, Liisa Pylkkänen ^c, Tarja Suominen ^a

^a School of Health Sciences, Nursing Science, University of Tampere, FI-33014, Finland

^b Pirkanmaa Hospital District, Science Center, Finland

^c Cancer Society of Finland, Unioninkatu 22, 00130 Helsinki, Finland

ARTICLE INFO

Article history:

Received 21 January 2015

Received in revised form

27 April 2015

Accepted 3 February 2016

Keywords:

Patient with cancer

Cancer trajectory

Electronic social support

Non-profit cancer societies

ABSTRACT

Purpose: To describe the phases of the cancer trajectory when social support, in the form of electronic counselling services, as provided by the non-profit cancer societies, is needed, as well as how these services are integrated into the cancer care in public healthcare.

Methods: In this descriptive qualitative study a purposive sample of patients with cancer ($n = 12$) were interviewed. The data were content analysed inductively.

Results: Social support was needed when emotional well-being was weakened, when the body broke, when the care pathway induced unawareness, and when empowerment needed strengthening. There was no need for social support when well-being was considered in balance. The electronic counselling services were integrated into cancer care by supporting the patient with cancer emotionally, developing the informational expertise of the patient with cancer, expanding the opportunities for support, and supporting public healthcare. Integration required improvements to the actions of the patients and various actors involved in the healthcare system. There was no integration due to the health status of the patient and the sufficiency of the primary support sources. The received social support was not integrated into the actual cancer treatment process of the patient with cancer in the public healthcare system.

Conclusions: The phases of support needed in the cancer trajectory as defined by the patient differ from the traditional biomedical phases of treatment.

© 2016 Elsevier Ltd. All rights reserved.

1. Introduction

Cancer and its treatments may cause a wide range of physical, informational, emotional and social unmet needs in the cancer trajectory of patients (So et al., 2013). These needs may not be met by public healthcare and therefore, patients with cancer may need to turn to other sources of social support (Yli-Uotila et al., 2013). Social support needs are predominantly studied by the phases of disease treatment, leaving relatively little attention paid to how the patients define these phases (Fowler et al., 2013). When searching for social support the non-profit cancer societies play an important

role for patients, but the research on how the electronic counselling services (ECS) of the cancer societies, including telephone, email, and online chat counselling, are integrated into the cancer care in public healthcare are currently neglected.

During the cancer trajectory, cancer itself and its treatments raise many issues and may have profound implications on patients' lives. Patients with cancer may experience physical disabilities, severe fatigue, depression, changes in body image and sexual function, difficulties in adjusting to daily living and fear of recurrence (Mohamed et al., 2014; Peters et al., 2014; Simard et al., 2013). It is evident that in addition to medical care, patients need supportive care services in the cancer trajectory. While the medical care in Finland is performed mainly in the public healthcare system, supportive services are mostly offered by non-profit cancer societies. Social support, as resources given or received by other people, has proven to have either positive or negative effects on health

* Corresponding author.

E-mail addresses: yli-uotila.tiina.m@student.uta.fi (T. Yli-Uotila), marja.kaunonen@staff.uta.fi (M. Kaunonen), liisa.pylkkanen@cancer.fi (L. Pylkkänen), tarja.suominen@uta.fi (T. Suominen).

(Cohen and Syme, 1985). According to a study that evaluated the hospital-based cancer information and support centre, participants desired these kinds of services because they provided additional support to enhancing self-care capacity (Kinnane, 2012). It has also been shown that social support increases quality of life and decreases anxiety and depression (Pinar et al., 2012). Alternatively, social support can also be inadequate in nature, leading to anxiety and distress (Yli-Uotila et al., 2014). Social support can also vary during the trajectory, depending on what kinds of problems patients are confronting, as well as on the sources of support that are available to them and the nature and form of the support they are receiving (Pearlin, 1985). For example, in the study of Thompson et al. (2013), it was found that breast cancer patients experienced a high level of perceived social support at the time of diagnosis. However, two years after diagnosis, some patients showed declines related to the social supports that were associated with higher level of depressive symptoms, suggesting the patients continued to benefit from high levels of social support (Thompson et al., 2013).

The studies of social support needs usually focus on a certain phase of disease treatment. For example, a study among breast cancer patients revealed five themes of social support needs between diagnosis and surgery: available support, information and advice, care, having confidants and balancing distance and closeness (Drageset et al., 2012). In another study, the aim was to identify the trajectories of illness intrusiveness over the first two years after a breast cancer diagnosis, resulting in a high percentage of participants experiencing low intrusiveness. However, the results also suggested the effects of breast cancer on some participants' lives might have been specific to certain areas (Sohl et al., 2014). In a systematic review, the fear of cancer recurrence was reported to remain stable over the survivorship trajectory (Simard et al., 2013).

Most often, patients with cancer desire cancer-related information (Li et al., 2011), which can enhance involvement in treatment decision-making (Davison and Breckon, 2012). Emotional support, in terms of availability and regardless of whether used or not, is needed, as well as practical tips on how to manage cancer in daily life (Drageset et al., 2012; Yli-Uotila et al., 2014).

It was concluded in previous studies that the health benefits depend on, for example, the source of social support. There may be cultural differences, as in a Chinese study, the preferred sources of support were family and society (You and Lu, 2014), whereas the preferred sources in the western world were hospital staff (Koutsopoulou et al., 2010; Park et al., 2014). Cancer societies, in general, are not utilised for support very often and they do not place the same importance on patients with cancer as they do the family (You and Lu, 2014). However, there is little research in this area globally.

In summary, patients with cancer experience a wide range of needs during the cancer trajectory, and social support is essential during the whole cancer trajectory. The phases of the cancer trajectory when social support is needed are usually determined by the phases of disease treatment. Therefore, the purpose of the present study is to investigate those phases as defined by the patients themselves. To our knowledge, there is no existing research on the integration of the ECS into the cancer care of patients in public healthcare, which is why our second purpose is to describe that area as well. Hence, the purposes of the present paper are, first, to describe from the patients' points of view the phases of the cancer trajectory when patients need to contact the ECS and, second, to describe how the ECS are integrated into the cancer care of patients in the public healthcare system.

2. Methods

This paper is part of a larger study that aims to describe the

experiences of the ECS of non-profit cancer societies, as reported by adult cancer patients and counselling nurses. In this cross-sectional descriptive qualitative study, we were especially interested in the perspectives of adult patients with cancer. In other papers we discuss the ECS as a source of social support for patients with cancer and how the counselling nurses in the ECS view the facilitators and barriers for social support of these patients.

2.1. Participants and data collection

A purposive sampling (Holloway and Wheeler, 2010) of adult patients with cancer ($n = 12$) was recruited from The Cancer Society of Finland and from two regional cancer societies from the western part of Finland. The Cancer Society of Finland comprises 12 regional cancer societies, five nationwide patient organisations, The Finnish Cancer Registry, Cancer Foundation and the Foundation for the Finnish Cancer Institute. Over 120,000 people are members of patient and regional organisations of The Cancer Society of Finland and it is one of the largest non-profit public health organisations in Finland (Cancer Society of Finland (2014)).

The participants were recruited by the counselling nurses (registered nurses and public health nurses) working in the ECS. They received written and oral instructions for the recruitment and written materials to be handed out to the participants from the researcher. The inclusion criteria were 1) a cancer diagnosis, 2) age ≥ 18 years, 3) pre-treatment, in-treatment or post-treatment phase of the disease, 4) contact in telephone, email or online chat counselling services, 5) able to be interviewed face-to-face within a two-hour drive from the researchers' university or by telephone nationwide and 6) willingness to participate in the study. Recruitment was carried out either face-to-face or in electronic counselling meetings with counselling nurses between May 2013 and May 2014. The aim was to recruit as heterogeneous a sample of patients with cancer as possible.

The interview guide (Table 1) was based on the literature and on the discussions with the representatives of the cancer societies when designing the study. The interview questions were pilot tested with two patients with cancer to ensure their feasibility. Based on the pilot interviews, the questions, as well as the way the researcher was performing the interviews were discussed and refined together with two advanced nurse researchers (Doody and Noonan, 2013). Pilot interviews were included in the data. The sociodemographic data were collected using a structured interview form (Holloway and Wheeler, 2010). Of the 12 interviews conducted by the first author, seven were conducted by telephone. Face-to-face interviews ($n = 5$) were conducted at the participant's home ($n = 2$), at the cancer society ($n = 2$) or at the participant's work place ($n = 1$). The interview time per participant was an average of 31 min, varying from 20 min to 55 min. The field notes of the interviews were utilised in the data analysis.

2.2. Data analysis

The data was analysed using an inductive content analysis (Elo and Kyngas, 2008). A content analysis in which data is categorised inductively is suitable for complex and sensitive nursing phenomena or if little is known about the phenomenon under study (Vaismoradi et al., 2013). The recorded interviews were transcribed verbatim by the researcher and downloaded to the qualitative data analysis software Atlas.ti (ATLAS.ti Scientific Software Development GmbH, Berlin) for organising the data. In the analysis process, the focus was on the manifest content of the data and the analysis was guided by the research questions (Vaismoradi et al., 2013). The interviews were read repeatedly in detail and the unit of analysis was identified. The unit of analysis

Download English Version:

<https://daneshyari.com/en/article/5868358>

Download Persian Version:

<https://daneshyari.com/article/5868358>

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