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Meeting psychosocial and health information needs to ensure quality of cancer care in outpatients

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ABSTRACT

Purpose: The purpose of this study was to investigate patients' and caregivers' health needs for a re-orientation program based on principles of health promotion in an Oncology Department from an Italian University Hospital.
Method: A Cross-sectional design with qualitative and quantitative approaches was used. Participants included cancer patients and their caregivers. Information about disease concerns were collected using a survey form. Information about healthy lifestyle was obtained using motivational interviews. Information about perceived quality of oncology services was collected by a self-administered questionnaire.
Results: A total of 403 information requests were collected about patients' disease, 203 motivational interviews were carried out, and 219 questionnaires were collected. Overall, the results showed that patients and caregivers have healthy lifestyles even if meat consumption was high. Weak points were: poor physical space organization in the Service, long waiting times, and limited access to healthcare providers for patients.
Conclusions: This study revealed the need for an approach based on health-promotion principles, with a particular focus on patient wellbeing and quality of life. The study increases awareness about the influence that an environment has on patient health, thus suggesting that changes in culture, attitude, and health services re-organization are crucial to meet total needs of the individual as a whole process.

1. Introduction

Cancer is a life-threatening illness. Its diagnosis and treatment can have dramatic effects on the physical, psychological, and social wellbeing of cancer patients and their caregivers (Albert et al., 2004). The emotional stress caused by living with a diagnosis of cancer and its treatment, as well as the experience of living with physical problems can lead to psychological distress (i.e., depression, anxiety). Additionally, physical and psychological problems can lead individuals to experience considerable social problems such as inability to perform work or other normative social duties. Altogether, these problems may be difficult to manage for patients and their caregivers, and may result in a greater suffering and a weaker compliance with prescribed treatments (Adler and Page, 2008). In this sense, supportive communication about treatment and care for patients and their families/caregivers becomes central for quality of healthcare organizations.

The most common communication model is based on one-way information transfer, which places the patient as a passive receiver of information and the healthcare provider as the expert communicator (Kullberg et al., 2015). However, this kind of communication does not facilitate the understanding of the patient's psychosocial needs by healthcare professionals, who can fail to recognize depression and other stress symptoms, and can hinder the provisions of psychosocial support which is, instead, a necessary part for quality of cancer care. Therefore, a two-way information exchange in which both patients and healthcare providers contribute to ensure the understanding and quality of the information is needed (e.g., Kreps, 2009; Lee and Garvin, 2003). Studies have shown that a mutual exchange of information focused on cancer patients' needs results in increased patient satisfaction,

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participation, and safety (Alharbi et al., 2014; Zucca et al., 2014). Other studies have shown significant correlations between both patient satisfaction and adherence to treatment and high-quality communication between cancer patients and their healthcare providers (Bredart et al., 2005; Chow et al., 2009).

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). It is evident that in addition to medical care, care services support patients in the cancer trajectory. According to a previous study evaluating hospital-based cancer information and support center (e.g., Kinnane, 2012), participants desire these kinds of services because they enhance a patient's self-care capacity. Moreover, it has been shown that social support increases quality of life and decreases anxiety and depression (Pinar et al., 2012). In this sense, it is essential to understand the care process as a whole in order to meet psychosocial health needs of patients and their caregivers. In effect, studies have shown that patients' family members (i.e., husbands, wives, daughters, sons, and other caregivers) contribute directly to patient health. In fact, Segrin et al. (2005) found that partners' emotional distress positively correlated with anxiety, depression, and fatigue of women with breast cancer, and these effects were bidirectional. Other studies reported that high stress levels in caregivers interfered with their ability to provide adequate emotional and logistical support to cancer patients. These conditions can worsen patients' emotional stress and lead to more severe consequences, which can weaken motivation and decrease coping strategies (Adler and Page, 2008). Thus, a good way to satisfy patients' psychosocial health needs is to increase their self-efficacy—which is the belief that an individual is able to carry out a course of action to achieve a desired goal (Bandura, 1997)—by supporting them emotionally, by increasing their cancer information, and by lightening burdens in the relatives of cancer patients (Yli-Uotila et al., 2016).

Furthermore, both genetic factors and external factors including environmental conditions (e.g., infections, pollution, and radiation) and lifestyles (e.g., diet, physical activity, and smoking) can be associated with cancer. High-quality communication should include patients' and caregivers' participation in the health care process by explaining and discussing safety risks and preventive interventions (Martin et al., 2013). In effect, more than 30% of cancer deaths may be avoidable by modifying risk factors such as unhealthy diets with low vegetable and fruit intake, poor physical activity, and tobacco and alcohol use (World Cancer Report, 2014). Such interventions would allow a timely recognition of the most common types of cancer—including breast, colorectal, and cervical cancer—increasing the chance of a cure.

Patients in remission have a greater risk of developing new cancers compared with people who have never had cancer before (Sunga et al., 2005; Ng and Travis, 2008). In this sense, several studies have documented that implementing good practices such as prevention and cessation of tobacco use (Johnston-Early et al., 1980), regular physical activity (Doyle et al., 2006), maintenance of a healthy weight (Whiteman et al., 2005), and routine consulting with healthcare providers about follow-up care after a cancer diagnosis (i.e., survivorship care plans) (Earle, 2006), can prevent new cancers or cancer recurrence, increase survival, and strengthen quality of life. Based on these findings, oncological care units should offer services to help patients and their families to prevent and manage the illness, as well as address the psychosocial aspects of cancer.

This study takes place within a re-orientation program based on health promotion principles in an Oncology Department from an Italian University Hospital. The main purpose of the study was to facilitate human conditions of reception and investigate patients' and caregivers' health needs for supplying information and orienting patients and caregivers towards specific social and health services. More specifically, our goals were the following:

- Investigating health information needs related to disease management by satisfying information requests about legal benefits, healthy lifestyles, and psychosocial healthcare needs;
- Investigating patients' and caregivers' satisfaction with information received by healthcare providers, structural and organizational aspects, and non-medical support services;
- Identifying aspects that need for specific improvements.

2. Methods

2.1. Study design

An observational cross-sectional study design was carried out from April 2014 to March 2015 in the outpatient unit at the Department of Oncology from an Italian University Hospital to identify health needs of cancer patients and caregivers and their perception on the quality of the offered service.

2.2. Inclusion criteria

Inclusion criteria for patients involved: (1) having a cancer diagnosis at any phase of the care trajectory (i.e., pre-treatment, undergoing treatment, or post-treatment in follow-up care); (2) being adults (≥18 years); (3) agreed to participate in the study. An exclusion criterion was to be healed from disease.

An inclusion criterion for recruiting caregivers was being an adult (≥18 years) individual identified by the cancer patients as a source of support (i.e., a family member, friend, or another significant person). Patients and their caregiver who met the inclusion criteria were considered suitable to take part in this study.

Clinics were not specific to different cancer types, thus we included people with any types of cancer.

2.3. Data collection process

During the day, patients and caregivers were approached in the waiting room at the time they arrived at the Department. Data were collected during 12 months with different instruments to investigate different information areas: (a) a survey form was used to collect information requests about disease, patient rights, and access to legal benefits; (b) structured interviews were carried out to examine health need and promote healthy lifestyles; (c) self-reported structured questionnaires were used to collect information about perceived quality of clinical practice, as well as structural and organizational aspects in the oncology unit.

The survey form was administered by the researchers in a first step. It included 20 items and was developed by the National Information Service in Oncology of the Italian Association of Cancer patients (AIMaC). Data were collected daily. Participants' responses were recorded in the form in which a response option (yes, no) for each item was marked by the researchers. In a second step, a structured interview—validated after a pilot test by a group of healthcare professionals—was performed. This occurred once a week and people were free to decide whether or not to take part in it after the first step. A total of 21 interview questions were used to investigate healthy lifestyles with counseling activity to orient patients and caregivers towards specific social and health services. The self-reported questionnaire—validated after a pilot study by a group of AIMaC volunteers—also was distributed weekly after the survey form and it could be completed at any time under one's own free will. The questionnaire included 21 items investigating