European Journal of Oncology Nursing 18 (2014) 46–51

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

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

Jordanian cancer patients' information needs and information-seeking behaviour: A descriptive study

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Keywords:
Jordan
Cancer
Information
Needs
Adult
Chronic

ABSTRACT

Background: Cancer diagnosis can leave patients with uncertainty and anxiety that can be reduced by providing timely information and effective communication. Despite information provision being highly important in improving the quality of provided care, no study had been conducted to assess the information needs of Jordanian cancer patients.

Aim: To investigate the information needs of Jordanian cancer patients.

Methods: A quantitative research method and a descriptive cross-sectional survey design were used. The sample consisted of 182 Jordanian cancer patients. Participants were recruited from two hospitals; one of them was a university hospital and the second was governmental hospital.

Results: The mean age was 46.5 (SD 15.8 years); 52% of the sample were males. In addition, 38% of the patients had haematological tumours and 20% had gastro-intestinal tumours. The majority (157) wanted information about cancer. The results showed that patients would like to know everything about their disease (mean = 3.1, SD 0.9) and medical tests (mean = 3.0, SD 1.0). The results also revealed that younger patients, those who were working, and those with a high income had high information needs. However, patients who had reached the stage of palliative care seemed to require a lesser amount of information than those in the early stage of treatment.

Conclusions: Many factors may cause variations in patients' information-seeking behaviour. Therefore, a notational policy for information provision is needed to satisfy different patients' information needs. Healthcare providers should be aware that cancer patients' will continue to need information at all stages.

Introduction

Providing patients with information regarding their diagnosis, prognosis and treatment options is increasingly considered crucial (Ankem, 2006; Tsuchiya and Horn, 2009). Cancer patients are in need for ongoing information (diagnosis, treatment, post-treatment, re-occurrence, and end of life) (Rutten et al., 2005). This is because cancer patients' information needs vary in amount and type throughout cancer trajectory. For example in the early stages of diagnoses, patients sought information about disease, available treatment options and prognosis while in the late stages they are usually interested in more information about pain and other symptoms management (Matsuyama et al., 2012; Rutten et al., 2005). Cancer diagnosis can leave patients with uncertainty and anxiety that can be reduced by providing timely information and effective communication. Giving patients information is believed to help them in coping with cancer (Ankem, 2006; Tsuchiya and Horn, 2009). In addition, information provision for cancer patients would reduce mood disturbances, deterioration in their quality of life, and improve communication with their families (Arora et al., 2002; Rainey, 2006).

Previous researchers have indicated that patients wanted to know about their disease (Browall et al., 2004; Morrison et al., 2012; Tsuchiya and Horn, 2009). For example, a study was conducted in the US to evaluate cancer patients' information needs during the first months of their treatment (Matsuyama et al., 2012). The Toronto Informational Needs Questionnaire (TINQ) was used to survey 138 cancer patients. The study findings indicated that total information needs fluctuated during a nine-month period, although remaining high. In addition, most patients wanted to know "everything" about bad news (96%), side effects (96%), and bad prognosis (90%) (Matsuyama et al., 2012). A low percentage of

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http://dx.doi.org/10.1016/j.ejon.2013.09.007

participants chose the rating items “nothing” or “not very much” (3%). Finally, it was found that females, younger patients, patients with a low education level, and married patients had high information needs (Matsuyama et al., 2012).

A systematic review was conducted to summarize and evaluate research conducted in the area of cancer patients’ information needs (Rutten et al., 2005). The main aim of this review was to identify the type of information needed and the source of the received information. This review examined 112 studies that were published in the period from 1980 to 2003 (Rutten et al., 2005). It was found that patients mostly wanted information specific to their disease, treatment, side effects, prognosis and rehabilitation after treatment (Rutten et al., 2005). Further, the most frequently expressed information needs were related to cancer treatment (this was reported by 38% of the reviewed studies), followed by information related to specific cancer type. Five sources of information were recognized: healthcare providers, printed materials, media, organizational and scientific resources. Of these resources, healthcare providers, physicians (43%) and nurses (28%) were most frequently reported as the source of information, followed by printed materials (Rutten et al., 2005). This systemic review provided reliable evidence; it was comprehensive in its scope and was well conducted. However, more detailed information on research quality would be helpful, including the studies’ credibility and validity of their findings. Finally, this review recommended continuing the work in this area, conducting studies with a large and representative sample, and including patients with various types of cancer (Rutten et al., 2005). It also recommended paying more attention to the information needs of patients after treatment, relapse and at the end of life stage (Rutten et al., 2005).

A recent study was conducted to explore the unmet needs of cancer patients (Morrison et al., 2012). The authors used self-reporting questionnaires containing 80 items thought to be relevant needs of cancer patients and 378 patients completed the questionnaire (Morrison et al., 2012). The findings revealed that informational needs about cancer, its treatment and side effects topped the list of unmet needs (Morrison et al., 2012). However, studies conducted since 2003 (Ankem, 2006; Cox et al., 2006; Galarce et al., 2011; Matsuyama et al., 2011; Morrison et al., 2012) to explore cancer information needs agreed with what was reported in Rutten et al. (2005). These studies show that cancer patients wanted to have detailed information about cancer, treatment, treatment side effects, prognosis, ability to work, and financial matters (Ankem, 2006; Cox et al., 2006; Galarce et al., 2011; Matsuyama et al., 2011; Morrison et al., 2012). Most were conducted in western countries (Ankem, 2006; Cox et al., 2006; Galarce et al., 2011; Matsuyama et al., 2011; Morrison et al., 2012) and a few in China (Lee et al., 2004) and Japan (Tsuchiya and Horn, 2009), but no study addressed this topic in Jordan.

Patients’ demographics and clinical characteristics could affect the amount and type of information needed by cancer patients (Ankem, 2006). This may help healthcare providers to predict patients with high informational needs and other who need lesser amount of information (Ankem, 2006). Thus, increasing patients satisfaction and avoid causing unnecessary anxiety and fear for those patients who need less or no information about their disease (Ankem, 2006; Cox et al., 2006). For example, there was a consensus among the studies that younger cancer patients wanted and sought more information than older patients (Ankem, 2006; Cox et al., 2006; Galarce et al., 2011; Jenkins et al., 2001). And patients with a high educational level tended to seek less information rather than those with a low educational level (Guidry et al., 1998; Matsuyama et al., 2012, 2011), although other studies reported contrary results regarding education level and information needs (Galarce et al., 2011; Mayer et al., 2007). In addition, it was reported that female cancer patients usually seek more information than males (Jenkins et al., 2001; Matsuyama et al., 2012; Mayer et al., 2007), Further, single patients required less information than married patients (Galarce et al., 2011; Matsuyama et al., 2012).

Most of the previous work utilized cross-sectional surveys or longitudinal research designs conducted either prospectively or retrospectively. In addition, authors used a wide range of sample sizes, and although larger samples are recommended, some studies used only a small number of cancer patients (Mallinger et al., 2005; Matsuyama et al., 2012; McGregor, 2003; Pinnock and Jones, 2003). This would limit the generalizability of the findings to the settings in which they were conducted. Furthermore, a large proportion of the studies used wide range of non-validated instruments, which would limit the utility of the comparison between different settings or even cultures (Western vs. Eastern) and would also add another threat to their internal validity.

Despite communication and information provision being highly important in improving the quality of provided care for cancer patients, the review of current literature revealed that no study had been conducted to assess the information needs of Jordanian cancer patients. Also, there is need for a study that includes cancer patients from different stages in the continuum of care (diagnosis, treatment, post-treatment, relapse and end of life) rather than only focussing on the first two stages. Further, patients with different types of cancer should be recruited to give a comprehensive understanding of their information needs. Therefore, this study aims to investigate the information needs of Jordanian cancer patients.

Methods

Objective

The main objective of this study is to investigate the information needs of Jordanian cancer patients, by answering the following specific research questions:

1 How much information do Jordanian cancer patients need?
2 What is the type of information needed by Jordanian cancer patients?
3 What are the sources of information provision for cancer patients in Jordan?
4 What are the predictors of high information needs among Jordanian cancer patients?
5 Are Jordanian cancer patients satisfied with the amount and type of information they have been given?

Design

A quantitative research method and a descriptive cross-sectional survey design were used. A survey design is useful when exploring attitudes, beliefs and knowledge-related topics, and a descriptive design is appropriate for this study because there is no intention to examine any cause-and-effect relationship (Gerrish and Lacey, 2010). In addition, it is useful when the researcher has limited financial resources (Gerrish and Lacey, 2010).

Sample

The sample consisted of 182 Jordanian cancer patients. Patients who met the inclusion criteria were invited to take part in this study. Hence, the researcher recruited only cancer patients who