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## Psychosocial needs of low-income people with cancer in Korea



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#### ABSTRACT

*Purpose:* The purpose of the study was to investigate significant psychosocial needs of low-income people with cancer in Korea and the extent to which these needs are unmet and which factors influence them

Methods: A descriptive study with a cross-sectional design was used. The data were collected by questionnaires from a convenience sample of 238 low-income people with cancer during 2009. A psychosocial needs inventory consisting of 7 categories with 48 items was used to identify significant psychosocial needs and unmet needs. Unmet psychosocial needs were defined to the needs that the participants reported as both important and unsatisfied. Influencing factors defined with multivariate regression analysis.

Results: "Health professionals" was the most important needs category, followed by "information. Among the 48 items, 37 were identified to be important or very important by more than 50% of the participants. All 37 important psychosocial needs were also identified to be unmet needs. "Emotional and spiritual" was the most unmet psychosocial needs category, followed by "practical matters" and "identity" categories. The most unmet need item was 'help with financial matters' (50.0%). The strongest influencing factor was 'no one to talk with'.

Conclusion: Low-income people with cancer experience high levels of unmet needs across a wide range of psychosocial needs. They need to be supported not only for practical matters but also for emotional and spiritual areas. The results provide a first step towards a development of interventions tailored to meet psychosocial needs and expectations of low-income people with cancer.

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#### Introduction

Cancer is a major disease, affecting millions of people world-wide. According to the World Health Organization (2014), about 32.6 million adult people diagnosed with cancer within the previous 5 years were living in 2012. Since the number of people living with cancer is expected to increase in the future with early diagnosis and improved treatment of cancer, oncology professionals need to pay attention not only to providing effective treatments but also to improving the quality of life of people with cancer.

Most people with cancer experience major changes in all aspects of their lives. In order for them to adjust to these changes, their psychosocial needs as well as physical needs must be accurately identified before they can be met. It is well known that psychosocial problems and distress are closely associated with cancer mortality (Hamer et al., 2009) and suicide; the suicide rate of people with cancer is twice that of the general population (Ahn et al., 2010; Misono et al., 2008). However, the overall prevalence rate of psychosocial distress was reported to be 35%–63% (Carlson et al., 2004; Mehnert and Koch, 2008; Kwon and Yi, 2012), indicating that at least one in three people with cancer suffers from psychosocial distress. Despite these negative consequences for quality of life and relatively high levels of psychosocial distress, only about 30% of people with cancer who are under psychosocial distress are recognized by oncology professionals (Fallowfield et al., 2001; Söllner et al., 2001).

To reduce the psychosocial distress of people with cancer, routine screening has been recommended (Carlson et al., 2010), and it has been associated with the satisfaction (Ong, Visser, Lammes, & de Haes, 2000; Walker et al., 2003) and quality of life of people with

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cancer (Ahn et al., 2010; Hamer et al., 2009; Misono et al., 2008). However, more information on psychosocial needs must be gathered to establish effective screening and intervention strategies. Psychosocial needs are affected by various factors such as the period of cancer treatment, type of cancer, gender and age, and religious belief. For example, the period during which the demand for psychosocial support is the greatest is after treatment (Barg et al., 2007; Harrison et al., 2009; Lee et al., 2010). Women and younger people with cancer tend to have greater needs than others (Barg et al., 2007; Ham et al., 2001; Mehnert and Koch, 2008; Thewes et al., 2004). Unmarried people tend to have more psychosocial needs (Barg et al., 2007; Ham et al., 2001), while religious belief is an inconsistent factor, having been found to be positive (Ham et al., 2001) and negative (McIllmurray et al., 2001). Therefore, people with cancer should not be dealt with as if they are a homogeneous group (Zabora et al., 2001).

The literature is consistent in reporting that low-income people with cancer have more psychosocial problems (Barg et al., 2007; Carlson et al., 2004; Park and Oh, 2010; Zabora et al., 2001). They are likely to have specific vulnerabilities in quality of life (Aziz and Rowland, 2002), resulting in lower survival rates than others (The Ministry of Health and Social Welfare (2006)). Indeed, low-income people with cancer experience the 'double suffering,' of poverty and cancer simultaneously (Yi et al., 2011). In addition, the distress of low-income people with cancer is less likely to be recognized by oncology professionals than that of higher-income counterparts (Söllner et al., 2001). Therefore, detailed information on the psychosocial needs of this vulnerable group of people with cancer is greatly needed (Moadel et al., 2006; Park and Oh, 2010; Steele and Fitch, 2008).

To better identify and meet the psychosocial needs of people with cancer, it is necessary to differentiate between the importance of psychosocial needs and the extent to which they are met. Knowledge on the unmet psychosocial needs of people with cancer is especially important in psychosocial intervention (Barg et al., 2007; Harrison et al., 2009) because it helps in identifying the gap between needs and interventions. Previous studies (Barg et al., 2007; Vivar and McQueen, 2005) reported that the unmet psychosocial needs are high among people with cancer. Barg et al. (2007) reported that twothirds of cancer patients have experienced at least one unmet psychosocial need. Among the types of psychosocial needs, practical needs were frequently unmet in the terminal phase, while emotional and spiritual needs were not met at the time of diagnosis (Park and Oh, 2010). In a systematic review study, Harrison et al. (2009) found that unmet needs are highest and most varied during treatment, but a greater number of people with cancer are likely to express an unmet need after treatment compared to any other time. Unmet needs are also related to demographic factors, such as age, gender, marital status, and income (Barg et al., 2007; Sanson-Fisher et al., 2000; Soothill et al., 2001). Therefore, it is necessary to identify and address the unmet psychosocial needs of people with cancer, including low-income people with cancer (Harrison et al., 2009; Moadel et al., 2006; Steele and Fitch, 2008). With detailed knowledge about the prevalence of psychosocial needs and unmet needs of this group, we would be able to redesign services that meet individual needs and enhance the resources available to them.

The purpose of this descriptive study was to identify important psychosocial needs and to identify the extent to which they are unmet for low-income people with cancer.

#### Method

#### Sample and setting

A descriptive cross-sectional research design was used. The study participants were recruited through Community Health Centers (CHCs), which are operated by the Ministry of Health and Welfare of Korea. The CHC home health care services were established in 1995 for low-income people with diseases, including cancer. Currently 252 CHCs operate nationwide. Inclusion criteria of the study were people with cancer with an income of less than 504,344 Korean won (€330 or US\$475) per person per month (Ministry of Health and Welfare (2010)) and those registered to receive home health care services from CHCs.

#### Data collection procedures

Data were collected from seven CHCs; three CHCs in Seoul, and one each in Busan, Daejeon, Kwangju, and Goryeng-gun, representing four major cities and one rural town in Korea. Each CHC recruited 20–40 participants. Home visiting nurses approached 350 potential participants during 2009, and 81 of them refused to participate because of illiteracy or concerns about privacy. A total of 269 participants took part in the study, with a response rate of 76.9%. Among the 269 questionnaires collected, 31 were excluded from the analysis for being incomplete, leaving 238 questionnaires for analysis.

#### Measures

The questionnaire we used consisted of two parts: demographic and illness-related information and a psychosocial needs inventory. The demographic measures included gender, age, religion, marital status, whether the patient was living with family, caregiver, having someone to talk, and employment. The illness-related measures consisted of type of cancer, years after diagnosis, other disease, and current medical status.

The Psychosocial Needs Inventory developed by Thomas et al. (2001) was used to obtain a comprehensive picture of participants' psychosocial needs. It has 48 items, covering a wide range of needs: those related to health professionals (9 items), information (5 items), support networks (5 items), emotional and spiritual (15 items), identity (5 items), and child care (1 item), along with practical needs (8 items). Each need item had two five-point scales assessing the importance of the need and the extent to which the need as being met. In the original study, the threshold for internal reliability of the importance of psychosocial needs was a Cronbach's alpha of above 0.7 for six categories. The psychosocial needs inventory was translated for this study by two bilingual researchers and then back-translated by two other scholars. The face validity of the instruments was checked by five oncology experts. The alpha reliability was 0.95, ranging from 0.77 to 0.91 for each category.

A significant psychosocial need in our study was defined as a need item marked by the participants as either 'important' or 'very important' in over 50% of the participants. A significant unmet need was defined as a need that participants identified as to be 'important' or 'very important' and the level of satisfaction of the participants that the need was being met was reported as 'unsatisfied' or 'very unsatisfied' (Soothill et al., 2001). A box 'does not apply to me' was used to check if the participants wanted to indicate that the need did not apply to them.

#### Ethical considerations

This study was approved by the Institutional Review Board of the primary investigator's institution. Home visiting nurses approached the potential participants during their visits. After all their work was finished, the nurses then explained the nature and purpose of the study and invited the patients to participate in the study. Once the patients voluntarily agreed to participate, the participants' right to participate and withdraw at any time of the

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