Loneliness, Depression, and Social Support of Patients With Cancer and Their Caregivers

Zümrüt Akgün Şahin, MSC, RN, and Mehtap Tan, PhD

Loneliness is a significant psychosocial concern for patients with cancer, and depression may be an antecedent to loneliness. To date, no studies have directly addressed the relationship of loneliness, depression, and social support among Turkish patients with cancer and their caregivers. The emotional responses that result from a cancer diagnosis vary and may include anxiety, anger, frustration, or depression. Because of the unexpected demands and emotions thrust on them, the caregivers of patients with cancer may be just as likely to experience loneliness or depression following a cancer diagnosis. As a result, this study sought to examine that relationship among a sample of 60 patients with cancer and 60 caregivers.

A cancer diagnosis is a traumatic event that has a significant impact on patients and their families and may cause responses of shock, uncertainty, hopelessness, anxiety, and depression (Nijboer, Triemstra, Tempelaar, Sanderman, & Van den Bos, 1999). Patients with cancer have multifaceted needs, and family caregivers must deal with many unfamiliar and unexpected demands that include monitoring disease and treatment, administering medication, assisting with personal care, and providing emotional support (Given, Given, & Kozachik, 2001). Patients may experience severe symptom distress that influences social and physical function, curtails patient-caregiver interaction, and leads to emotional responses of anxiety, anger, frustration, or depression in the caregiver (Kurtz, Kurtz, Stommel, Given, & Given, 2004). Research suggests that most caregivers of patients with cancer experience anxiety, depression, and burden (Nijboer, Tempelaar, Triemstra, Van den Bos, & Sanderman, 2001). The distress is related to the caregiving roles, has been shown to continue over time, and may be exacerbated by changes in the patient’s condition (Northouse, Mood, Templin, Mellon, & George, 2000).

Loneliness was identified as a cluster of thoughts, feelings, and behaviors (Perry, 1990), and was defined as the psychological situation resulting from the differences among the individual’s existing versus desired social relationships (Demir, 1989). Loneliness is caused by a lack of satisfaction regarding the quality of relationships and does not depend on the characteristics of the social environment or number of friends. In addition, individuals with high loneliness levels were unsatisfied with their familial relationships (Damsteegt, 1992; Samter, 1992). Individual factors and external effects of life events that cause stress also are important contributors to loneliness. Loneliness causes a weakening in a person’s social status, impaired interpersonal relationships such as those with family, friends, and relatives; an increase in negative behaviors; development of emotions such as distrustfulness and suspicion; and a reduction in self-trust. Loneliness causes stress and anxiety, which, in turn, engenders increased loneliness (Alkan & Sezgin, 1998).

Loneliness is one of the major psychosocial concerns for patients with cancer as many patients suffer from loneliness associated with illness or illness-related situations (Cuevas-Renaund, Sobrevilla-Calvo, & Almanza, 2000; Fox, Harper, Hyner, & Lyle, 1994; Perry, 1990). Loneliness is inversely related to the number of family and friends and the degree of satisfaction with them (Bondevik & Skogstad, 1998; Jylha & Jokela, 1990; Kim, 1999; Mahon, Yarcheski, & Yarcheski, 1998).

Depression may be an antecedent to loneliness. Depression occurs frequently among patients with cancer, but often is underdiagnosed (Aapro & Cull, 1999; Spiegel & Davis, 2003). In addition, the presence of depression has a negative impact on quality of life, which interferes with the patient’s ability to cope as well as with evolution of the disease (Spiegel & Davis, 2003).
Illness-linked conditions may strongly affect the perceived social support from family and friends. Among Turkish patients with cancer, few studies focused on the relationship between social support and coping (Tan, 2007) and the relationship between social support and hopelessness (Tan & Karabulutlu, 2005); however, none directly addressed loneliness, depression, and social support among Turkish patients with cancer and their spouses.

Describing the factors that affect family caregivers of patients with cancer is an essential step in designing interventions that may prevent or reduce caregivers’ distress. More information about the psychological reactions in patients with cancer will enable healthcare personnel or family to understand and help the patients. Therefore, the purpose of this study was to determine whether Turkish patients with cancer and their caregivers differed in feelings of loneliness and depression, and how those conditions may be related to their social support.

The study addressed two main questions. Do patients with cancer and their caregivers differ in loneliness, depression, and perceived social support? Are loneliness, depression, and perceived social support related among patients with cancer and their caregivers?

Methods

Participants

The study enrolled 60 patients with cancer, admitted to the Oncology and Hematology Department of Yakutiye Hospital from March 2008 to June 2008, and their 60 caregivers. A cross-sectional and descriptive correlational design was used.

To be eligible to participate in the study, patients had to be 18 years or older, with no known psychiatric or neurologic disorders that would interfere with the completion of the measures. In addition, they were at least four months past diagnosis, had never been in the terminal phase of the illness, and have been receiving cancer treatment in the hospital. All participants were literate in Turkish.

Permission to undertake this study was gained from the ethical committee at Atatürk University, and informed consent was obtained from each participant. The patients were informed of the purpose of the research and were assured of their right to refuse their participation or to withdraw from the study at any stage. The anonymity and confidentiality of participants were guaranteed.

Instruments

Participant data were collected using a demographic questionnaire, the Perceived Social Support From Family Scale (PSS-Fa), the University of California, Los Angeles, Loneliness Scale (UCLA-LS), and the Beck Depression Inventory (BDI). The research assistant contacted each patient and caregiver and verbally explained the study. If participant consent was obtained, a questionnaire was delivered to the hospital for both the patient and their caregiver. They were asked to independently complete the survey. If a patient was unable to complete his or her questionnaire, the researcher read the questionnaire items to the patients and recorded the answers. The questionnaires took approximately 30 minutes to complete.

Demographic questionnaire: The demographic questionnaire gathered the basic patient information, such as gender, age, marital status, education, and health insurance. Medical information regarding cancer stage, the time elapsed since diagnosis, treatment, and cancer recurrence, if any, were obtained from participants’ medical charts.

Perceived Social Support From Family Scale: The PSS-Fa, developed by Procidano and Heller (1983), aimed to measure the extent to which an individual perceives his or her need for support, information, and feedback fulfilled by family. The scale consists of 20 statements, to which the individual responds with “yes,” “no,” or “do not know.” For each item, the response indicative of perceived social support is scored as 1. Total scores ranged from 0 (no perceived social support) to 20 (maximum perceived social support) as provided by family. The “do not know” response was not evaluated. Eskin (1993) documented a test-retest reliability of 0.85 for the PSS-Fa. In this study, the alpha coefficients for patients and caregivers were found as 0.84 and 0.89, respectively.

Loneliness Scale: The UCLA-LS assesses the subjective feelings of loneliness or social isolation. Participants were asked to rate 20 statements as to how often they agreed with the description. The responses ranged from 1 (not at all) to 4 (often), with a total possible aggregate score range of 20–80. A higher score reflects the more loneliness a participant experienced. The UCLA-LS had an internal consistency of alpha that was equal to 0.94 (Russell et al., 1980). The validity and reliability of the Turkish version of the UCLA-LS have been confirmed (Eskin 1993). In addition, this instrument had an internal consistency of alpha that was equal to 0.96 for a Turkish population (Demir, 1989). In the current study, the alpha coefficients for patients and caregivers were 0.84 and 0.89, respectively.

Beck Depression Inventory: The BDI was developed by Beck, Ward, Mendelson, Mock, and Erbaugh (1961) and translated into Turkish by Hisli (1988). The BDI assesses depressive symptoms and is a 21-item, 4-point scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). The highest score is 63; 1–10 is considered normal, 11–16 indicates a mild mood disturbance, 17–20 indicates borderline clinical depression, 21–30 indicates moderate depression, 31–40 indicates severe depression, and more than 40 indicates extreme depression. The BDI has had high internal consistency, with alpha coefficients of 0.86 and 0.81 for psychiatric and non-psychiatric populations, respectively (Beck et al., 1961). Reported alpha coefficient for the BDI was 0.74 in a Turkish population (Hisli, 1988). In the author’s study, the alpha coefficients for patients and caregivers were 0.84 and 0.85, respectively.

Data Analysis

Descriptive statistics, means, standard deviations, and percentages were used to describe patients’ and caregivers’ characteristics. However, patients’ and caregivers’ loneliness, depression, and perceived social support were analyzed via Student t tests. Pearson correlation analyses were used to compare the differences among patients’ and caregivers’ loneliness, depression, and perceived social support. P values of less than 0.05 were accepted as statistically significant. All data management and statistical analyses were carried out using the pocket program of SPSS®, version 10.0, for Windows®.
Results

A total of 60 patients with cancer and 60 caregivers took part in this study. The mean ages of the patients and caregivers were 61.7 and 54.7 years, respectively. Of the patients, 85% were men, 62% were illiterate, and 72% were married. Of the caregivers, 82% were men, 67% were illiterate, and 80% were married. Most patients and caregivers reported a low income. Breast cancer was the most prevalent cancer type (77%), followed by lymphoma (69%). The average time elapsed since patients’ most recent cancer diagnosis was less than one year (1%), from 1–3 years (20%), and greater than four (79%). Patients were in active treatment.

The average loneliness score for patients was more than caregivers’ scores (see Table 1). More patients (n = 42, 70%) reported a high level of loneliness than that of caregivers (n = 38, 63%). Ten patients (17%) had no depressive symptoms; however, serious depressive symptoms were experienced by 34 patients (57%). As for caregivers, five (8%) had no depressive symptoms, whereas 42 caregivers (71%) experienced serious depressive symptoms.

Levels of perceived social support from family differed between patients and caregivers with a mean of 6.25 (SD = 3.3) for patients and 5.67 (SD = 3.36) for caregivers, respectively (p < 0.001). Score averages for the patients’ and caregivers’ perceived social support were above the mean score (10–20).

Both groups showed a strong inverse relationship between loneliness and perceived social support from family (see Table 2). A significant inverse relationship existed between perceived social support and depression scores for the patients and caregivers. In other words, the higher the score for social support, the lower the score for loneliness and depression.

Discussion

The current study was conducted to examine the loneliness, depression, and perceived social support of Turkish patients with cancer and their caregivers. Previous studies indicated that patients and caregivers are likely to be lonely because of social isolation associated with illness-related factors (Friedman, Florian, & Zernitsky-Shurka, 1989; Kele-Card, Foxall, & Baron, 1993). In the current study, 70% of patients and 63% of caregivers had high levels of loneliness. Family members and other relatives have a significant effect on patient well-being and quality of life through their help and support. However, occasionally the behavior of significant others may not be perceived as positive by patients; instead, behaviors may be perceived as overprotective or oversolicitous. In addition, the relatives of patients often will experience the cancer diagnosis as a great strain and also may be in need of help and support. Receiving that help and support may enable them to be more supportive to the patient.

The connection among patient depressive symptoms and caregiver depressive symptoms reported in other studies (Kurtz, Kurtz, Given, & Given, 1995, 2004) also was observed in the current study. The finding that caregiver depression was equal to or greater than that of the patient (Nijboer et al., 2001; Weitzner, McMillan, & Jacobsen, 1999) was supported in the current study, suggesting that unmet needs exist and early psychological assessment and potential intervention for caregivers and patients are recommended (Kelly et al., 1999; Mystakidou, Tsilika, Parpa, Galanos, & Vlahos, 2007).

The two groups were significantly different in perceived social support from family. Although the perceived social support from family of both groups was larger than the mean score, the perceived social support from family was greater than that of the caregivers. However, Turkish family structure and cultural characteristics, as well as demographic characteristics of participants, might influence this, in that all subjects have lived with their spouses, children, or parents.

An inverse relationship was seen between perceived social support from family of patients and caregivers with their reported levels of loneliness. Therefore dissatisfaction with social relationships may contribute to more feelings of loneliness and depression. Another study found that patients with high social support use coping strategies more efficiently and can better adjust to their illness (Tomaka, Thompson, & Palacios, 2006). Support and assistance from family members are beneficial in helping the patient cope with the stress from disease and treatment, and social support has been found to be the most important coping strategy and resource (Hilton, 1996; Lugton, 1997; Nichols, 1995; Tan, 2007).

Results of the current study are not generalized to patients with cancer and caregivers beyond the sample. It reflects only one geographic area of Turkey. In addition, future studies should include larger samples from different regions.
Clinical Implications

Patients felt loneliness in greater rates than caregivers, and depression scores for patients were lower than that for caregivers; the difference between them being statistically significant. Although the perceived social support from family of both groups was above the mean score, scores for the perceived social support from family of the patients was higher than that of the caregivers.

Nurses should know and identify the signs and symptoms of loneliness and depression, and intervene appropriately to alleviate the conditions by practicing effective communication techniques, providing psychological support, and helping them to use their support systems (e.g., family, friends), which are extremely important for both patients and caregivers. Nurses must know the psychological reactions patients and caregivers experience in order to assist them with adapting and coping with changes in their lives.

References


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