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Spiritual Issues of Family Members in a Pancreatic Cancer Chat Room

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Purpose/Objectives: To describe spiritual issues addressed by users of a pancreatic cancer informational Web site.

Design: Qualitative, descriptive.

Setting: The patient and family chat room of Johns Hopkins Hospital's pancreatic cancer Web site.

Sample: 600 postings on the pancreatic cancer Web site.

Methods: Identification of categories and themes in Web postings using the constant comparison method of content analysis.

Main Research Variables: Spirituality, relationship of the person posting a message (poster) to the person with cancer.

Findings: Relationship of the poster to the person with pancreatic cancer was explicit in 68% (n = 410) of the 600 postings, and 83% of those 410 postings indicated that the poster was a family member. Issues of spirituality appeared in 19% (n = 114) of the 600 postings and addressed four themes: spiritual convergence, reframing suffering, hope, and acceptance of the power of God and eternal life. Six percent of postings were by family members reporting on the death of their loved ones, suggesting that the site also served a bereavement function.

Conclusions: Family members of patients with pancreatic cancer sought and received spiritual comfort in a variety of forms in an Internet-based cancer chat room.

Implications for Nursing: Nurse developers of cancer information Web sites should periodically assess how the sites are being used and apply the information to the refinement of the sites to better meet user needs. Further study is needed to develop and evaluate cancer Web sites as an evolving medium for providing spiritual support to family members of patients with life-threatening forms of cancer.

Key Points . . .

- ➤ Pancreatic cancer is one of the most aggressive forms of cancer, and patients and their families need immediate access to information about its progression and treatment as well as ways to manage its accompanying distress.
- ➤ Johns Hopkins Hospital's pancreatic cancer Web site chat room is a source of spiritual support for many of its users, most of whom are family members of patients with pancreatic cancer.
- ➤ Further study is needed to determine the extent to which other cancer information chat rooms are used as sources of spiritual support and how Web sites might be refined to sustain this important function.

Pancreatic cancer is one of the most aggressive forms of cancer. Less than 24% of patients with the disease survive one year after diagnosis, and the overall five-year survival rate is only 15% (American Cancer Society, 2005; Li, Xie, Wolff, & Abbruzzese, 2004). High mortality rates and limited survival time provide patients and their families with little opportunity to gather information about the disease, its treatment, and ways to manage the distress of terminal illness. Many in such situations seek information on the Internet.

While evaluating the effect of a frequently-asked-questions (FAQs) educational module on users of Johns Hopkins Hospital's pancreatic cancer Web site (Coleman et al., 2005), the authors were surprised to find spiritual issues among the information being exchanged by users of the site's chat room (see Figure 1). Because the authors found only one other study in the literature that noted spirituality on a cancer information Web site, the purpose of the current study was to describe the spiritual issues discussed in those postings and consider how cancer information Web sites might be developed further to provide spiritual support to patients facing life-threatening forms of cancer. Although most messages were posted by family members, the few postings by patients with pancreatic

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Information	Support	Reporting status
Treatment type	Spiritual	Patient status
Symptoms	Social	Patient death
Other	Physical	

Figure 1. Types of Information in All 600 Postings

cancer also are described because they were relevant to family members' spiritual concerns.

Literature Review

Spirituality in Patients With Advanced Cancer

Spirituality is a broader concept than religion and is defined in this article as a person's beliefs and values regarding the search for transcendent meaning in life. Religion is a set of beliefs and practices that characterizes a faith community searching for transcendent meaning in a particular way (Sulmasy, 2002). In patients facing life-threatening illnesses, spirituality can be defined as the ability to transcend physical discomfort, accept death, surrender to the transcendent, and feel at peace (Stewart, Teno, Patrick, & Lynn, 1999).

Oncology nurses have recognized the importance of addressing the spirituality of patients with cancer and their families. In a review of research articles published from 1990–1999 in three major oncology nursing journals, 27% of qualitative studies and 14% of quantitative studies addressed religious and spiritual variables (Flannelly, Flannelly, & Weaver, 2002). Qualitative approaches to studying spirituality in patients with cancer have described the phenomenon in depth, providing healthcare professionals with a greater understanding of patients' spiritual beliefs and experiences. In a phenomenologic study of five women and two men with several types of cancer and heart failure, patients reported that their spirituality gave them the strength to face life-threatening illnesses. They described their trust in a higher power to see them through their journey and were grateful for the many blessings in their lives despite illness-related burdens (Albaugh, 2003). In another phenomenologic study, hope, as a component of spirituality at the end of life, was described by 23 patients with various cancers (Eliott & Olver, 2002). Hope was the wish for personally desired outcomes—subjective and objective, vulnerable and enduring.

Quantitative studies of spirituality in patients with cancer have helped to explain how variables such as spiritual well-being interact with other patient-related variables. Spiritual well-being has been described as the affirmation of life in a relationship to a higher being or God, self, community, and environment that nurtures the development of wholeness (Fernsler, Klemm, & Miller, 1999). In a survey of 160 patients in a palliative care hospital with a life expectancy of less than three months, spiritual well-being was inversely related to hopelessness, desire for hastened death, and suicidal ideation (McClain, Rosenfeld, & Breitbart, 2003). Laubmeier, Zakowski, and Bair (2004) found that spiritual well-being was associated with less distress and better quality of life in 95 patients with diverse cancers, regardless of their perceived life threat. Because of its association with reduced symptoms of distress in patients with cancer, further research is needed to evaluate the effect of interventions to promote spiritual well-being.

Prayer is one aspect of spirituality. It reflects a feeling of connectedness with God. Studies relating prayer to patient characteristics in people with cancer have been mixed. Meraviglia (2002) surveyed 32 individuals with a variety of cancers and found that prayer activity was associated with lowered functional status and the presence of metastasis at diagnosis. In contrast, in a later study by Meraviglia (2004) of 60 adults diagnosed primarily with non-small cell lung cancer, greater prayer activity was associated with higher psychological well-being scores and lower symptom distress scores. Longitudinal studies are needed to determine the extent to which the relationship between prayer and well-being changes over time.

Spirituality also has been shown to be important to caregivers of patients with cancer. In a survey of 55 caregivers of patients with a variety of cancers, information and spiritual categories were rated as most important (Harrington, Lackey, & Gates, 1996). In a qualitative study of 28 patients with a variety of cancers and their caregivers, seven categories of spiritual needs were identified as present in patients and caregivers. These were the needs to relate to an Ultimate Other, have hope and gratitude, give and receive love, review beliefs, have meaning, and have needs met related to religiosity and preparation for death (Taylor, 2003). Spirituality continues to be important to caregivers after the death of their loved ones. Higher-than-average levels of depression and high levels of spirituality were observed in 124 bereaved caregivers of patients with cancer and other illnesses (Wyatt, Friedman, Given, & Given, 1999).

Several limitations of the literature on spirituality and cancer are evident. Studies such as those cited previously included patients with diverse cancers and prognoses. Even in studies that have included patients with the same type of cancer, many did not control for disease stage, which likely differentiates the spiritual needs of those with terminal illnesses from the needs of those with curable illnesses. Further study is needed on the spiritual needs of patients with terminal cancer and their families. Also, few intervention studies have evaluated methods for providing spiritual support to patients with cancer and their families. In a comprehensive review of the healthcare literature on religious or spiritual factors, only 10% of the studies were intervention studies (Worthington, Kurusu, McCullough, & Sandage, 1996).

Internet-Based Cancer Discussion and Support Groups

Although Internet-based cancer support groups and the use of chat rooms by patients with cancer and their families have been studied, little has been written about the extent to which users of these sites address spiritual issues. In a content analysis of 252 postings on the University of Texas M.D. Anderson Cancer Center's Life After Cancer Care Web site discussion board, investigators found that postings addressed eight major themes: treatment, support, diagnosis, alternative treatments, long-term effects, nutrition, genetic issues, and miscellaneous. Sixty percent of the postings were by patients with cancer, and 40% were by family or friends. Spiritual issues were not identified (Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2003). Klemm and Hardie (2002) compared patients with different types of cancer who self-selected to a face-to-face or online support group. Participants in the online support group had higher levels of depression than those in the face-to-face support group. Again, spirituality was not discussed. In contrast,

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spiritual support through prayer was reported by Klemm, Reppert, and Visich (1998) in an analysis of 300 Internet messages on a dedicated cancer support group Web site. The investigators reported eight categories of information in the postings: information giving and seeking, personal opinions, encouragement and support, personal experience, thanks, humor, prayer, and miscellaneous. Given the limited information on spirituality and cancer Internet sites, the purpose of this study was to describe the spiritual issues addressed in the patient and family chat room of a pancreatic cancer Web site.

Methods

Sample and Procedures

The sample for this study consisted of 600 Internet postings downloaded in November 2004 from the patient and family chat room of Johns Hopkins Hospital's pancreatic cancer Web site (http://pathology.jhu.edu/pancreas). The postings were collected as part of a larger study to evaluate the effect of an FAQs module added to the site. The number of postings selected was guided by the number of postings needed to exhaust unique themes in a study of a cancer Web site by Klemm et al. (1998). Data that could reveal the identity of posters, such as names and e-mail addresses, were not recorded in the downloaded postings.

Approval from the Johns Hopkins Medicine Institutional Review Board was obtained prior to collecting data. The study was designated as meeting the U.S. Department of Health and Human Service's (2001) criteria for exempt research that addressed research involving the collection or study of existing data, documents, records, pathologic specimens, or diagnostic specimens, if the sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified. Because no identifying data was recorded in the study database, informed consent was not required. Individuals may have posted more than one message. Therefore, the postings, not the site users, are the unit of measure. An important ethical consideration in the study was that investigators are the developers and owner of the site and therefore have a responsibility to evaluate its impact on users.

Data Analysis

The primary author read all 600 postings and, using a qualitative description method defined by Sandelowski (2000), conducted the first level of content analysis involving the constant comparison method. In that method, the text first was coded into categories with words or phrases used by the subjects (Morse & Field, 1995). Sandelowski explained that qualitative description is a basic or fundamental type of qualitative method that is more interpretive than quantitative description but less interpretive than other qualitative methods such as phenomenology and grounded theory. In qualitative description, investigators remain closer to the data, often choosing words that subjects used to describe the target phenomenon. The initial phase of analysis produced 15 categories describing issues that fell within the authors' definition of spirituality—a person's beliefs and values regarding the transcendent meaning in life. When the posting stated the poster's gender or relationship to the person with pancreatic cancer, the information was recorded to describe the demographic characteristics of the posters.

In the second phase of the constant comparative analysis, four coauthors and the primary author reviewed the first 25 spirituality postings again to validate the categories assigned by the first author. They refined the categories and identified common themes across categories. In the third phase of analysis, the primary author and one coinvestigator from the second phase of analysis reviewed all 600 postings again and further refined the categories and themes of spirituality. No new categories or themes emerged after the first 300 postings, but all 600 postings were analyzed.

Findings

Nineteen percent of the 600 postings (n = 114) included content about spirituality. A summary of the characteristics of the people creating the postings is provided in Table 1. Sixty-eight percent of the postings indicated that the poster was a female, and family members of a person with pancreatic cancer created the majority of the postings. The two most frequently cited relationships were daughters and wives of the person with cancer. A schema describing the spirituality themes is presented in Figure 2. Further descriptive detail on each theme follows.

Spiritual Convergence

Promises of prayer and requests for prayer were some of the most common spiritual issues observed in the postings. The tone of those requests varied widely. One poster said that she was desperate when she asked for prayers for her loved one, whom she described as declining rapidly. Another pleaded for prayers for her loved one. Others simply concluded their postings with statements that their thoughts and prayers were with everyone on the site. Still others stated specifically what they were praying for (e.g., shrinkage of tumors after a course of chemotherapy). A number of posters acknowledged that their fellow chat room contributors may have diverse spiritual and religious practices by prefacing their request for prayers for a loved one with statements such as, "For those of you who pray."

Several posters shared with others the blessings for which they were thankful, such as a supportive friend, a helpful nurse, or being able to take time off work to be with their

Table 1. Demographic Data From Postings

Variable	n	%
Gender		
Female	410	68
Male	87	15
Unknown	103	17
Relationship to patient		
Unclear	194	32
Daughter	187	31
Wife	55	9
Other	51	8
Patient	45	7
Son	38	6
Friend	17	3
Sister	10	2
Husband	2	1
Mother	1	1

N = 600

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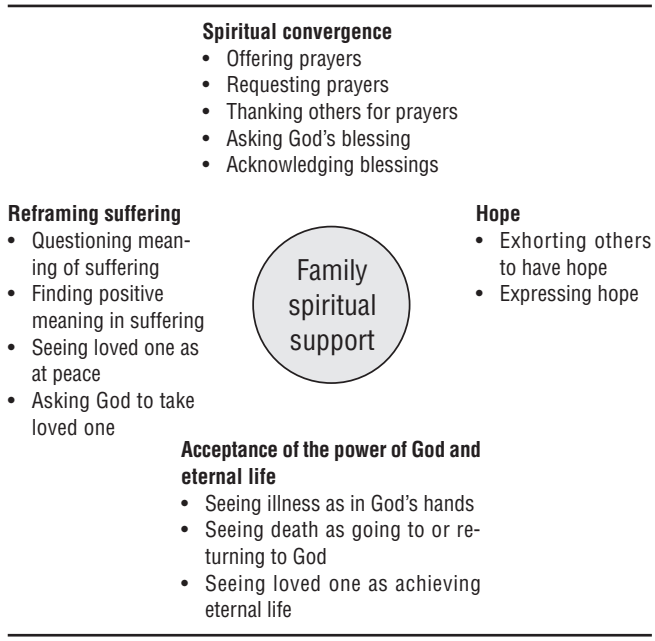

Figure 2. Themes of Family Spirituality in 600 Postings

loved ones. One poster explained that despite the difficult journey with managing pancreatic cancer, many gifts could be held on to throughout the experience.

Reframing Suffering

Reframing suffering was done in negative and positive ways. Some postings described feelings of conflict between spiritual beliefs and the present experience of suffering but seemed to present the conflict to other posters in an open-minded or hopeful way. For example, one poster stated that she had reached her limit for tolerating stress but believed that God did not give a person more suffering than he or she could handle. Two posters questioned why God wanted their loved ones to suffer. One expressed concern that God was punishing her mother with this disease. Still another described his father's life as one in which he gave of himself to many of those around him but received little thanks in return. He concluded that the matter was for his father and God but welcomed comments from other posters.

The anguish of several posters nearly leapt off the page as parts of the postings were typed in all capital letters. Two posters personified pancreatic cancer as "the monster," one asking God why her loved one had to fight that monster. Another poster referred to the disease as "this beast" that was taking the life of her loved one. One poster described her family's experience with the disease as a nightmare and asked that God take her loved one so that he would no longer suffer. Two others also asked God to take their loved ones because they did not want to see them suffer any longer. Several posters cast the suffering of their loved ones in a more positive way, explaining that they had gotten to know their loved ones more intimately by helping them through the illness experience to death.

Hope

The postings contained many variations on hope. For some, hope seemed all encompassing (e.g., trying to have new hope each day). Several posters simply closed their message with statements such as "Keep the faith," or "There is hope out there." Other posters expressed more specific hopes that new treatments would be found to cure their loved ones before death. A few acknowledged that their loved ones were dying but hoped that their pain could be controlled during their last months of life. One poster stated that her mother hoped that she could be pain-free but remain alert enough to interact with her family. Only one posting mentioned the concept of "false hope." The poster was the friend of an older adult with pancreatic cancer whom she thought was receiving aggressive chemotherapy that served only to prolong her suffering. She stated that she thought that having hope was important but that her friend's physician was giving her false hope.

A poster with pancreatic cancer explained that although she was satisfied with the care she was receiving from her physicians, she believed that they could offer no hope because all they gave her was medical information. She described the chat room as her lifesaver because the other users brought her "loving" support and hope.

Acceptance of the Power of God and Eternal Life

Messages also included the acceptance of pancreatic cancer or impending death as being the will of God. One poster explained that her husband had complete trust in God and sought to follow God's will even as he suffered from his illness. Others echoed that sentiment. One poster explained that God would tell people how long to live.

Thirty-four postings reported the death of a loved one with pancreatic cancer. One poster reported her father's day of death as the day he was "born into eternal life." Another described her loved one's transition as a passing into the next world with the help of angels.

Discussion

Demographic Information

Several findings in the study were unexpected. One was that only 11% of the 600 postings were by individuals with cancer. The chat room was used largely by family members of patients with pancreatic cancer. That finding differs from the M.D. Anderson Cancer Center study in which 60% of the posters were people with cancer (Schultz et al., 2003). Perhaps because the M.D. Anderson Cancer Center site addressed a variety of types of cancer, many posters may have been in the early stages of cancer with mild symptoms or may have been experiencing cancers that were curable compared to patients with pancreatic cancer. The severity of symptoms that commonly accompany pancreatic cancer may have prevented many patients with the illness from participating in a chat room. Also, some patients may have been too overwhelmed with the information they were already receiving from their physician to seek out additional sources of information.

The finding that a majority (68%) of the postings were created by women was consistent with the M.D. Anderson Cancer Center study that reported that 75% of posters on that Web site were women. The finding can be explained only partially by the slightly higher prevalence of pancreatic cancer in men as compared to women; instead, it more likely reflects a cultural preference for women to serve as caregivers rather than men.

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Spirituality Themes

The current study's researchers were surprised that 19% of all postings addressed some aspect of spirituality because the site was developed to provide factual information about the disease and its treatment options. Instead, many posters were seeking the support of others facing the same experience. One patient poster explained that she obtained factual medical information from her medical team and hope and support from her fellow chat room users. Because patients with pancreatic cancer have little chance for a cure, hope may not be mentioned or encouraged early in the diagnostic phase of the disease. Postings from the study revealed, however, that hope can have many objectives other than a complete cure, such as remaining pain-free and able to interact with family as the disease progresses. Those findings are consistent with the report of Puchalski (2002), who found that, as the possibility of a cure becomes less likely, patients' hope shifts to important goals that can be achieved, such as living to see the birth of a child or attending a family member's wedding.

The spiritual convergence in 16% of postings, evidenced by statements such as those offering and requesting prayers, has not been described in other studies of chat rooms (Klemm & Hardie, 2002; Schultz et al., 2003). However, the importance of spirituality and social contacts to caregivers of patients at the end of life has been reported in other studies. In a study of 62 family caregivers of patients with end-stage Alzheimer disease or recurrent metastatic cancer, Rabins, Fitting, Eastham, and Zabora (1990) examined characteristics of family caregivers that predicted adaptation. Nearly 30% of the variance in positive adaptation was explained by the number of social contacts and another 13% by self-reported religious faith that is an expression of spirituality. Investigators concluded that a strong religious faith and frequent social contacts were the two best predictors of positive adaptation in caregivers. By supporting spiritual convergence, perhaps the chat room supported religious faith and provided social contacts that might have been otherwise challenging to find while caring for a loved one with pancreatic cancer.

That 34 (6%) of posters returned to the site after their loved ones died was a unique finding. No reports in the literature were found of family members in online cancer support groups returning to the site to report on the death of their loved ones. The chat room, therefore, also may serve as bereavement support. One poster with cancer specifically stated that she was introducing her husband to the chat room so that he could find support there after her death. In other cases, postings described the peaceful deaths of loved ones and the belief that they were with God.

The use of a chat room on a cancer information Web site for such intimate conversations with strangers about family members' hopes, fears, and spiritual issues that delve into the meaning of life has not been described previously in the literature. Discussing those issues without the eye contact, body language, and tone of voice that characterize face-to-face conversations would seem to be challenging. But perhaps the anonymity of this venue is freeing. Family members of patients with pancreatic cancer readily discussed their own suffering and fears as they cared for their loved ones at the end of life. Yet, the site was more than a method of catharsis for burdened caregivers. The attention of posters often was directed toward others, offering prayers for the loved ones of specific posters as well as for all posters as a group.

Implications for Nursing

The greatest number of postings that included spiritual issues in the current study involved requesting prayer or offering prayer for others. A similar valuing of prayer was reported in a nondenominational cancer program-sponsored spiritual event held in several churches in the community of a cancer center (Dann & Mertens, 2004). Ninety percent of the 209 interviewed found the spiritual event very helpful, and the majority of respondents favored the program's components of prayer, music, and scripture. Perhaps spiritual music and selections from scripture and other sacred literature could be added to cancer information Web sites as additional sources of spiritual support to be used by individuals who access the site or to be shared and reflected upon with others in the chat rooms of the sites that have this function. Different modules could be added to Web sites that would support users' spiritual interaction. For example, a separate prayer intention page could be set up on the site similar to prayer intention books in many churches that allow members of the faith community to join in praying for the needs of others in the community. The challenge is to be able to respect all of the many religious beliefs of the Web site's users, many of whom are international.

An online survey of users would be an efficient way to obtain data to guide the improvement of spiritual support information or the structure of the site. For example, users could be asked to identify spiritual readings, prayers, music, or art that they would find helpful to have on the Web site. Perhaps to complement the spiritual support they receive online, users also would like information on how to connect with a faith community near their homes if they are not part of one or would like encouragement on how to access spiritual support within their faith community if they already belong to one. Many churches provide respite care and bereavement support for members.

One change resulting from the study is that a separate chat room for bereavement has been established on the site and now is used widely by those who have been using the chat room during their loved ones' illnesses and those who have joined the site since the loss of their loved ones. Healthcare professionals who develop sites for people with life-threatening cancer and their families may wish to consider adding this option.

Conclusions

The study findings suggest that many individuals, particularly the family caregivers of patients with pancreatic cancer, are able to express their spirituality and find spiritual support in the chat room of a Web site devoted to the disease. Nurses and other healthcare professionals who develop and evaluate cancer information Web sites can take a more holistic view of users by supporting their spirituality along with providing information on disease diagnosis, management, and prognosis. Further study is needed to identify facets of cancer information Web sites that can provide spiritual support to individuals and facilitate the development of supportive cancer Web site communities.

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