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Abstract

Based on a national survey, this study analyzes the roles and educational needs of hospice social workers regarding assessment and intervention in spirituality, religion, and diversity of their patients. Sixty-two social workers responded to the survey. Results suggest that spiritual care is shared among hospice team members and that most social workers feel comfortable in addressing these issues. However, role conflict and role ambiguity also exist. Respondents to the survey often felt ill-prepared to deal with some complex faith-based conflicts related to diversity. They saw themselves in need of assessment models and end-of-life decision-making interventions regarding assisted suicide and euthanasia. This study provides recommendations for social work practice, education, and research.

Key words: hospice, diversity, religion, spirituality, educational needs

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Introduction

Spiritual care is a growing function of social workers who work with terminal patients, their families, and their friends. Traditionally, clergy were considered responsible for spiritual care. However, all other caregivers, including social workers, can provide spiritual care to the dying.[1] Although the Joint Commission on Accreditation of Healthcare Organizations[2] mandates spiritual assessments in its standards, and the National Hospice and Palliative Care Organization (NHPCO)[3] supports interdisciplinary spiritual care, neither organization provides specific guidelines for social workers. Furthermore, Babler[4] states that no consensus in social work exists for definitions or standards of spiritual care, and little social work research exists on spiritual care with the terminally ill.

Babler argues that schools of social work and hospice agencies should increase training in spiritual care, because there are no common definitions or standards regarding spiritual care, few research studies on spiritual care in hospice, and little emphasis on spirituality, particularly in schools of social work. In a comparative study of spiritual care provision by different hospice professionals, he finds that social workers "have few tools with which to provide spiritual support and often struggle professionally as to what extent their role allows for provision of spiritual care."[4]

Recent social work literature suggests that social work curricula and continuing education programs need to increase their emphasis on assessment and intervention related to spirituality.[5-8] Hospice social workers themselves have expressed the need for more knowledge and skill in working with spiritual and religious issues presented by patients and families, including the need to become culturally competent for work with diverse religious traditions and spiritual practices.[9] Identifying the educational

needs of hospice social workers requires research. Hospice workers can use research data to improve educational curricula and agency practice.

This research project in this study surveyed a national sample of hospice social workers in regard to their roles, experiences with diverse client groups, and training needs in the areas of spiritual assessment and intervention.

Literature review

Role of spirituality in hospice social work

Social workers assisting with the problems of death, dying, and bereavement must be prepared to provide spiritual support to patients and their families.[4,10] Smith[11] concurs that spiritual and religious issues are very important to many terminal patients and must be addressed in a nonjudgmental manner. Reese and Brown[12] also support this view with findings that psychosocial and spiritual issues directly influence the quality of patient and family care. Kazanjian[13] asserts that spiritual and psychological strengths are necessary during loss to create a sense of wholeness, and that a peaceful death is more likely to occur when hospice workers effectively assess and provide appropriate interventions in the areas of emotional and spiritual resources.

Yet hospice professionals, including social workers, are continually reluctant to address the issue of spirituality or religion.[6,12,14,15] Millison and Dudley[15] find reticence among many hospice professionals to introduce spirituality unless it is initiated by the patient. Their reluctance may be the result of a perceived lack of objectivity, fear of proselytizing, value dilemmas, or role conflicts.[6]

Diversity and hospice social work

Cultural competence in human diversity requires an understanding of race, ethnicity, class, gender, sex, sexual orientation, family structure, marital status, religion, disability, and age. Canda and Furman[6] discuss the interrelationship of religion and other aspects of human diversity within and among diverse groups. For example, many variations based on religious and spiritual affiliations exist within a single ethnic group. A person who is African American and Southern Baptist may experience emotional altar calls and public expressions of personal forgiveness and healing; whereas a person who is African American and Episcopalian may experience more staid and communal expressions of faith and forgiveness. Likewise, sexual orientation and spirituality may be interrelated. A person who is gay may experience rejection by some denominations and acceptance by others.

Increasingly, social workers find themselves serving culturally diverse patients from different religious and spiritual backgrounds. However, poor understanding of cultural variables related to death and dying among predominantly white, middle-class hospice staff often leads to barriers to hospice access by minorities.[15] Furthermore, Irish, Lundquist, and Nelson[16] believe that the lack of culturally sensitive practice with dying people and grieving families may lead to increased litigation and negative publicity. Canda and Furman[6] assert that social workers must appreciate differences and commonality in diverse cultures to promote personal healing and social justice.

Education and training in spirituality

Cascio[14] cites the lack of knowledge concerning spirituality and its practice as the main reason for hospice social workers' reluctance to provide spiritual assessments and interventions. Irish, Lundquist, and Nelson[16] maintain that there is a need for more training in cultural differences and spiritual diversity for social workers who work with dying and bereaved patients and their families. Potter[17] advocates the exploration of nontraditional, non-Eurocentric views of religion and spirituality in social work education.

Methods

Research instrument

The research instrument for this study incorporated both closed and open-ended questions. Several of the questions regarding the role of social work in religion and spirituality were adapted from Cascio.[14] The instrument was pretested with a local hospice social work organization and revised based on pilot participant feedback.

The final research instrument included 31 closed and three open-ended narrative questions. The closed questions included demographic information including the description of hospice settings, roles of hospice social workers in spirituality and religion, and diversity issues in hospice social work. Closed questions also addressed the continuing education needs of social workers in religion, spirituality, and diversity. Two of the open-ended questions requested narratives from social workers, which described the most confusing and powerful experiences regarding spirituality and diversity encountered in the last six months. The third open-ended question asked the respondent for any additional information regarding spirituality, religion, diversity, social work, and hospice. The survey encouraged respondents to annotate the closed questions by writing in the margins of the questionnaire.

Sample

The study sample included all social work members of the NHPCO

located within the United States (169 potential respondents). The respondents were identified by code number only. The research instrument, a cover letter explaining the purposes of the research and a self-addressed postcard to request a copy of the survey results, was mailed to the social workers in May 2000. The final count of 62 respondents yielded a response rate of 37 percent.

Data analysis

The study included quantitative and qualitative data analysis. Researchers performed quantitative data analysis (frequencies and descriptive statistics) using SPSS for Windows 10.0.0, a statistical software package (SPSS, Inc., Chicago, IL). Researchers conducted qualitative data analysis on participant responses to two open-ended questions: 1) in the last six months of hospice work, what was the most perplexing or confusing experience; and 2) what was the most satisfying or powerful experience related to spirituality or religion? Qualitative data analysis involved preparing a typewritten set of narratives from all of the handwritten answers. The second author reviewed all transcripts and identified the main ideas in each paragraph of text. Based on the main ideas of the text, the second author defined a set of codes and definitions. The author reviewed the codes and definitions and revised them, as needed, to ensure that each code represented a separate idea. The other two authors used the set of codes and definitions to review the complete set of narratives and coded each narrative according to the coding scheme. Following the independent reviews of the other authors, the second author reviewed all three sets of coded transcripts to determine the degree to which the three authors agreed. The goal was to achieve at least 70 percent inter-coder reliability, which was defined as the number of agreements divided by the total number of agreements plus disagreements.[18] Inter-rater reliability for the first open-ended question (most perplexing or confusing experience) was 65 percent; inter-rater reliability for the second open-ended question (most satisfying or powerful experience) was 72 percent. After determining inter-rater reliability, codes were collapsed into categories representing the main themes in the data.

Results

Description of sample

Fifty-five of the 62 respondents were female; all but one respondent identified him or herself as Caucasian/European American. (One respondent identified him or herself as "human.") The mean age of the respondents was 47 years old. All but three respondents held professional degrees in social work. Six held a bachelor's degree in social work; fifty-two held a master's degree in social work (MSW); one respondent held a PhD or other doctorate in social work. Ten of the respondents held a degree or professional training in pastoral care or theology. The mean number of years in social work was 14 and the mean number of years of hospice social work was seven.

Twenty-four percent of respondents identified themselves as Roman Catholic, 12 percent Lutheran, 38 percent other mainstream Protestant, 10 percent Jewish, 14 percent other religions, and one "no organized religion/believe in God." The majority of the respondents (85.5 percent) stated that their personal religion or spiritual orientation was very or extremely important.

Description of hospice settings

The geographic locations of the hospices were Midwest (42 percent), South (24 percent), Pacific (17 percent), Northwest (14 percent), and West (3 percent). Geographic locations were grouped by state using the schema from the *World Almanac Book of Facts*.[19] Most of the hospices were nonproprietary (93.5 percent), and 82 percent had no religious affiliation. Three hospices were linked to home health agencies, one was linked to a nursing home, and another was located in a correctional institution.

Most hospices (88 percent) employed at least one full-time social worker. The mean number of full-time social workers per hospice was five. Thirty-two respondents indicated that their hospices employed at least one part-time social worker. The mean number of part-time social workers per hospice was 1.5. Twenty hospices employed PRN social workers, as needed.

Sixty percent stated that their hospices employed at least one full-time chaplain. The mean number of full-time chaplains per hospice was one. Twenty-five respondents stated that their hospice employed at least one part-time chaplain. The mean number of part-time chaplains was .65. Only five of the 60 respondents reported using PRN chaplains in their hospices, although 12 reported using volunteer chaplains. One hospice had no chaplain.

Hospice social work roles in spirituality and religion

Eighty-three percent of the respondents stated that religion and spirituality were extremely or very important to their clients; 17 percent stated that religion and spirituality were somewhat important to their clients. Eighty-seven percent of respondents stated that they were very or somewhat comfortable providing for the spiritual needs of their patients and their significant others. The remaining 13 percent stated that they were either somewhat or very uncomfortable providing for the spiritual needs of their patients, and cited the following reasons for their discomfort: lack of knowledge

and skill, instructed that chaplains were responsible for providing spiritual and religious care in the hospice, instructed not to push religion on people, and belief that social work should not provide for this need.

Most respondents (92 percent) stated that they sought information on religion or spirituality in assessments of patients and their significant others. The respondents described their use of spiritual assessment and intervention skills. The most utilized types of intervention included listening to patients and their significant others talk about God or spiritual issues (93 percent), linking them to clergy (91 percent), and exploring the meaning of events in their lives (84 percent). The respondents noted praying for their patients (68 percent), praying with them as they prayed (60 percent), and, less frequently, leading them in prayer (25 percent). The respondents reported discussing spiritual issues regarding extraordinary care (59 percent), suicide (56 percent), euthanasia (51 percent), and assisted suicide (51 percent). Other less frequent interventions included discussing spiritual rituals (41 percent), using religiously based guided imagery (22 percent), teaching spiritual meditation (14 percent), and using spiritual genograms (five percent). Twenty-five percent of the respondents reported taking spiritual histories.

Diversity issues in hospice social work

The respondents described their hospice work in the areas of spiritual diversity. Ninety percent or more respondents reported working with patients who were Roman Catholics, Methodists, Baptists, Presbyterians, and Lutherans. Respondents worked less frequently with patients who were Episcopalians (77 percent), Jehovah's Witnesses (72 percent), Orthodox or Conservative Jews (58 percent), and Unitarian Universalists (55 percent).

Half of the respondents worked with Buddhists or Mormons. Less than half of the respondents worked with Orthodox Christians, Quakers, Muslims, Nazarenes, Hindus, or Mennonites.

The respondents were asked to indicate the ethnic and cultural identity of patients and their significant others with whom they worked in their hospices. All respondents reported working with Caucasian/Euro-Americans. The majority of respondents worked with African Americans (85 percent); gay, lesbian, bisexual, or transgender persons (73 percent); Asian Americans/Pacific Islanders (72 percent); Latinos/Hispanic Americans (72 percent); and biracial or multiracial persons (53 percent). Only 37 percent reported working with Native Americans/Alaskan Natives. Respondents noted working with patients who had developmental disabilities and those who were recent immigrants from every imaginable place, some of whom have not been here long enough to qualify as hyphenated Americans.

Continuing education needs in hospice social work

The survey asked respondents to identify their needs for continuing education in spiritual assessment and intervention. Sixty-eight percent requested more education in assessment skills concerning spiritual issues, spiritual histories (53 percent), spiritual genograms (47 percent), and discussing or assisting with spiritual rituals (54 percent). At least half identified the need for information regarding discussion of spiritual issues in extraordinary care, suicide, euthanasia, and assisted suicide.

The survey asked respondents to indicate their continuing education needs regarding religion or spiritual orientation. Fifty percent or more of the respondents requested more information regarding the following religions or spiritual orientations: Islam,

Hinduism, Muslim, and Buddhism. More than half of the respondents also requested education in working with Latinos/Hispanic Americans; Native Americans/Alaskan Natives; Asian Americans/Pacific Islanders. Twenty percent requested education on working with Caucasians/Euro-Americans.

Social worker narratives

Respondents described their most perplexing or confusing experience and their most satisfying or powerful experience related to spiritual or religious issues in the last six months. Qualitative analyses are as follows.

Most perplexing or confusing experience. Thirty-two of the 62 total respondents answered this question. The study identified two themes: challenges of diversity, and challenges and conflicts in decision making. For challenges of diversity, respondents described situations where they felt inadequate to meet the needs of patients whose ethnic, religious, or spiritual traditions were unfamiliar to them, including patients who had no religious background or who were self-described atheists.

Working with a Hmong family . . . had gone to an all-day workshop related to this ethnicity, yet felt quite inept with identifying needed social work intervention. I had been fascinated with information/education/ demonstration, etc., in the workshop, but hardly prepared to actually 'relate' and 'do good work.' It really takes practice and [our region] has pockets of diverse populations, but my locale is 99.9 percent Caucasian! We are given some literature, but after highlighting, there needs to be 'real people' to work with. Not sure this will ever work until/ unless [city name] is integrated.

Thirty-one of the 32 respondents addressed this particular issue. A secondary focus was that respondents felt ill-prepared to work with the needs of children, persons with developmental disabilities or incarcerated persons.

For challenges and conflicts in decision making, respondents described situations where patients and families may have been in conflict with the social worker or each other over end-of-life choices, including denial of the need to make a choice. In addition, the narratives elaborated on the decision-making process of the respondents, the process of deciding how much to disclose about themselves, and the degree to which personal and professional values may have been in conflict.

> On a regular basis, I am perplexed with regard to how to integrate the patient's spiritual beliefs into my social work interventions. I am often at a total loss as how to respond to a patient's anger toward God or despair that God has forsaken them. As a social worker, I am very aware of the problems of either presenting my own perspective on these issues or merely supplying pat answers. I try to enter the patient's world, but often, I do not know enough to do this effectively . . . I was thrilled to receive this survey, as a great deal more education with regard to matters of spirituality/ religion and diversity is sorely needed. Although social workers have usually not received any training in the area of spirituality and traditionally, have been instructed not to 'go there,' we do our clients a disservice if we cannot address these issues as they arise. As hospice workers, we in fact have to understand the patient's spiritual landscape, for without this knowledge and the ability to integrate the spiritual with the psychosocial, our interventions will be less effective.

Most satisfying or powerful experience. Twenty-five of the total 62 respondents answered this question. Researchers identified two themes—watching faith and watching death. Watching faith identified narratives where respondents communicated their profound respect and admiration for the courage and creativity with which patients faced death and found a sense of acceptance and freedom. They conveyed a sense of awe and honor that the patients and families would share their most private and intimate experiences with a stranger. Respondents felt that they learned as much from these patients and families as they provided in service.

> The patient was in a close, involved family with multiple losses in a short time . . . the patient was able to maintain a daily dialogue with God: 'Oh, God, why? Well, what's happening here? Oh, God, I have such good memories of these people— thank you. You know, I am really ticked off, God!' She has absolute confidence in a relationship that allows her to state deep grief, sharp anger, touching joy with her God and not expect judgment or punishment, only 'God understands if I'm ticked off.' This has been a marvelous lesson about relationship ups and downs, based on acceptance and freedom.

Watching a patient die featured prominently in narratives that described the process of dying and the range of images and feelings that patients communicated. The respondent social workers were honored to be a part of the final days and, in some cases, final moments of the patient's life.

> I was present with a patient and family during his active phase of dying. I placed my hand on his arm, introduced myself as 'the hospice social worker.' I suggested to the patient that he was surrounded by the love of his family. Family members were crying softly around his bed. I told the patient that his family would always hold the memory of him close in their hearts. I then said, 'Jim, you can cross over to the other side, whenever you are comfortable doing that.' At that moment, the patient died. Every one of us around the bed knew he was gone. It was a powerful, moving, spiritual experience.

Discussion

Demographics

The majority of respondents were middle-aged Caucasian/Euro-American women. On average, they had approximately 14 years of social work experience and almost seven years of hospice social work experience. Most held an MSW degree. In sum, the majority of respondents had a high level of education and experience in hospice social work. Furthermore, the majority of respondents indicated a high degree of personal importance placed on religion and spirituality, including a denominational affiliation. This may have contributed to their degree of comfort in providing spiritual and religious assistance to hospice patients and families. Younger, less-experienced hospice social workers might have responded differently.

Most hospice organizations had at least one full- or part-time chaplain. However, the mean number of full-time social workers per hospice was 5.3. This indicated that social workers were more likely than chaplains to be called upon to address spiritual and religious issues, simply by virtue of their presence.

Social work in spirituality and religion

For effective implementation of social work in hospice, social workers must understand their comfort level with spiritual issues and the comfort level of their patients. In this sample, the majority of respondents saw spirituality and religion as very important to their clients, and the majority of respondents were very or somewhat comfortable in attending to their patients' spiritual and religious needs. This is consistent with respondents' personal attitudes toward religion and spirituality. However, these results contradict data from the literature which suggest that social workers tend to be uncomfortable with spirituality and religion in hospice care.[6,12,14,15] In the current study, only a minority of respondents expressed discomfort.

Not surprisingly, a high comfort level with discussing spiritual and religious issues leads to more frequent assessment of these issues. It is interesting to note that, while respondents assessed current issues related to spirituality and religion (such as patients' fears about death or conflicts with clergy), few completed a spiritual history. This indicates that respondents lack models or methods for taking spiritual histories, which is consistent with the literature.[5-7,14]

In regard to spiritual interventions, most consisted of active listening, providing access to clergy, and exploring the meaning of events in patients' lives. These are typical social work activities and may not necessarily reflect attention to spiritual and religious issues. Respondents reported specific religious issues that related to extraordinary care (e.g., tube feeding, ventilators), suicide, euthanasia, and assisted suicide. Arguably, these activities reflect problem-solving issues that relate to medical decision making and social policy, as much as they relate to spiritual care. Interventions, such as praying for and praying with patients, require little or no training; whereas interventions such as guided imagery and spiritual meditation require education specific to pastoral care of clergy rather than social workers.

Diversity issues in hospice social work

Respondents reported working with religious groups that ranged from Protestant and Roman Catholic traditions to Jehovah's Witnesses, Muslims, and Unitarians. In regard to ethnic and cultural diversity, most patients were Caucasian; however, 85 percent of respondents reported that they had worked with African American patients. Based on the data gathered, it is not clear how many ethnic or cultural minority patients comprise the average caseload of these social workers. Respondents may have worked with only one or two patients or with 100 patients. The number of respondents who worked with biracial patients was relatively low. This may be a result of self-identification: most people describe themselves as white, black, or Latino/a, rather than as biracial.

Need for continuing education

As noted earlier, respondents gathered some basic information about spiritual issues, but they expressed a need for systematic methods for gathering, organizing, and interpreting the information. While approximately one-fourth of the sample indicated that they did take spiritual histories, more than half of the sample reported that they needed more specific information about how to do this. Similarly, while only five percent of respondents used spiritual genograms, 47 percent wanted to know more about this assessment tool. As hospice workers become more familiar with these tools, the use of these tools would increase. In regard to spiritual interventions, more than half of the sample wanted to know more about discussing or assisting with spiritual rituals. This may be related to their experiences working with diverse populations. In the open-ended narrative questions, some respondents discussed rituals related to body preparation and burial dress that were unfamiliar to them.

Respondents also requested more information regarding ways to discuss suicide, assisted suicide, and use of extraordinary means, such as feeding tubes and ventilators. They reported discussing these decision-making issues with patients and families. The ethical, legal, and emotional consequences for patients, families, and social workers, show a need for continuing education in this area.

In regard to ethnic and cultural diversity, respondents requested information about all categories, including Caucasian. Since all but one of the respondents identified themselves as Caucasian, this may reflect the view that Caucasians do not view themselves as a homogenous group. Perhaps the respondents were also aware of the need to confront cultural self-awareness issues such as one's own biases and societal privileges.[20] Two-thirds of respondents wanted to know more about Latinos and about Native American/Alaska Natives. Respondents may be interested in more information on these groups because they work with these populations infrequently and may not have advanced preparation for this work.

Limitations of the study

The sample may not represent all hospice social workers for several reasons. The NHPCO is a paid membership organization that may not be accessible to all social workers in hospice. Respondents were primarily white, middle-aged women. Because the NHPCO database does not record

the race or ethnicity of their members, there is no way to determine whether the sample represented hospice workers in general based on these demographic characteristics. Also, the return rate (37 percent) may have been higher had the survey been shorter. After reading 11 pages, potential respondents might have succumbed to the fatigue factor.

Conclusions and recommendations

Important lessons for social work practice and education include helping social workers reflect on and resolve role conflicts and ambiguities through frank discussions during agency inservices and staff meetings. Access to recent literature in social work can help practitioners and students understand the contemporary professional view of the role of social workers in spiritual care. Discussions among practitioners and students should address role conflict issues explicitly. In addition, agency policy should address role division as a reflection of the hospice organization's mission and philosophy.

Helping social workers to see themselves as learners when confronted with unfamiliar spiritual traditions can improve their cultural competence for work with diverse populations. Social workers, like chaplains, can listen to the distinct needs of dying patients and their families, who, in turn, communicate how they find meaning in their lives. Hospice organizations should encourage their social workers to use empathy and narrative treatment models that allow patients to tell their life stories. This approach respects both the uniqueness of the person and their culture.

Hospice organizations should develop a handbook of materials (including case studies and assessment models) so that social workers can access training information more readily. Agency inservices and local conferences can use these materials to address needs documented in this study to develop concrete methods for assessment. With a starter set of cases, hospice organizations could create their own cases that address local needs and issues, including diversity. They could develop pilot tests of interdisciplinary agency training formats that apply specific spiritual and religious assessment models to case studies for a particular region or community. These case studies can apply multiple professional perspectives to the common goal of understanding and responding effectively to patients and families coping with loss.

Recommendations for future research topics include: 1) repeating the study with a larger sample, focusing on factors contributing to social workers' discomfort with spirituality and religion in assessments and interventions; 2) researching hospice social workers' cultural self-awareness and how personal biases affect the helping relationship; and 3) researching interprofessional roles in spiritual care including the conflicts and ambiguities that make hospice social work a joy and a challenge.

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