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Religiously unaffiliated social workers in health care settings : working with religiously affiliated terminally ill cancer patients

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Ileana Sansano
Religiously Unaffiliated Social
Workers in Health Care Settings:
Working with Religiously Affiliated
Terminally Ill Cancer Patients

ABSTRACT

The purpose of this study was to explore how nonreligious social workers respond to religious terminally ill cancer patients within healthcare settings. There is limited research focused on the experience of the nonreligious social worker. Thus, a qualitative, exploratory study was chosen as an appropriate research design.

This qualitative study used a flexible interview format comprised of semi-structured open- and closed-ended questions presented to 5 nonreligious oncology social workers in the United States. The findings demonstrate that most or all of the oncology social workers had similar experiences: with a supervisor or work agency addressing how to work with patients that have a religious affiliation; with patients talking about their God and the role of that God in their illness or prognosis; with patients making religious requests from the social worker; with patients questioning their faith with the social worker; with providing chaplaincy services to patients; and with searching for religion-specific services or items. In addition, some of the oncology social workers had similar experiences with being asked what religion they ascribe to.

**RELIGIOUSLY UNAFFILIATED SOCIAL WORKERS IN HEALTH CARE
SETTINGS: WORKING WITH RELIGIOUSLY AFFILIATED TERMINALLY ILL
CANCER PATIENTS**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2012

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CHAPTER I

Introduction

Oncology social workers frequently work with dying patients. The issues of religion and spiritual practice often enter the room as the terminal patient anticipates death. How does a nonreligious social worker negotiate religious issues in this type of practice? How does a nonspiritual oncology social worker interact with her terminally ill cancer patients who actively incorporate spirituality into their experience and their method of coping? The purpose of this study is to explore the potential confusion, ambivalence, and difficulty that this situation may create for the nonreligious social worker.

The study's findings have implications for education, practice, and policy. This researcher was interested to learn, when does the topic of religion enter the room? How does a social worker respond to requests that are religiously affiliated (i.e., prayer, reading passages of religious script, etc.)? How does a social worker respond when a patient questions their own faith?

According to Hoyt (2008), there is a growing consensus that spirituality and the role of religion in a patient's life is an important part of a medical patient's experience and the existence of a spiritual or religious framework can potentially inform the likelihood of a positive outcome. However, Sahlein (2002) has pointed out that "there has been a trend of avoiding religious issues in social work education" (p. 381) and that there is little to no guidance in the existing literature for social workers. This results in "confusion, ambivalence, and anxiety among social workers regarding the management of religious material in treatment" (p.381). While social workers

struggle to negotiate religious material, Goldberg reminds us (as cited in Sahlein, 2002, p. 384) that such confusion on the part of the social worker creates “the very real possibility of short changing the patient.” Lomax, Karff, and McKenny (2002) share a few insights to how a social worker can interact with religious patients, such as appreciating the patient’s religious beliefs and practices, welcoming a patient’s faith, and consulting with clergy as a partner in healing.

Through this study, social workers will gain a better understanding of how nonreligious colleagues in the field of oncology social work are managing encounters with their religious patients. In the literature review, I will share information regarding the field of oncology social work, the role of religion within the healthcare setting, the role of religion in social work practice, and the social worker’s interaction with religious patients. Chapter three will discuss the methodology of this study. Following the methods and design, chapter four will present the findings of this researcher, and chapter five will be a discussion of the study and findings, and of the researcher’s bias. Chapter five will include recommendations for future research.

CHAPTER II

Literature Review

This chapter will review the literature on the practice of social work and the role of religion as it pertains to practice in general and terminal oncology patients in particular. The literature on the history of social work practice and religion will be reviewed, including current recommendations for social work education as it pertains to preparing social workers, and including current guidance for practitioners on issues of spirituality and religion. The literature on oncology social work practice will then be reviewed, followed by a brief review of the literature on how health care settings have incorporated patient's religious needs and practices.

Oncology Social Work

In hematology and oncology units and clinics, a team is typically made up of physicians, nurses, social workers, and support staff, with other support resources of the hospital accessed when needed, such as pastoral care. The social worker's role in oncology is to provide case management and emotional support to families, patients, and staff. Under this broad umbrella, the social worker will find herself engaged in many tasks: conducting psychosocial assessments; facilitating adjustments to illness; counseling through individual, family, and group therapy; discharge planning; making referrals; and advocacy (Lauria, Clark, Hermann, & Stearns, as cited in Zebrack, Walsh, Burg, & Maramaldi, 2008, p. 357). Taking care of oncology patients is complex and it is vital that there is a strong sense of interdisciplinary teamwork (Sell, Brief, & Schuler as cited in Supple-Diaz & Mattison, 1992, p. 114).

Social workers cope with a variety of stressors. Sze and Ivker (1986) reported that social workers who work in hospital settings perceive their environment as stressful as a result of extensive paperwork, heavy patient loads, insufficient training, limited authority and autonomy, restricted opportunities for advancement in pay and status, expectations of supervisors, low status in the organization and lack of adequate resources (as cited in Supple-Diaz & Mattison, 1992, p. 114-115). In addition, health professionals who work with dying patients and their families experience greater psychological stress (Supple-Diaz & Mattison, 1992).

The psychological distress that social workers experience in working with dying patients and their families can include helplessness, depression, boredom, apathy, guilt, displaced anger, work-related dreams, withdrawal from dying patients and questioning of the value of the work (Rohan & Bausch, 2009). Some of this distress comes from a social worker's own countertransference in working with this specific population. Countertransference can be defined as "an unconscious process involving the (social worker's) unresolved conflicts, both positive and negative" (Dunkel & Hatfield, 1986, p. 114). The countertransference experienced by social workers may be informed by feelings that the patient is experiencing himself or internal conflicts a social worker has over her own personal identity and past and present experiences.

Rohan and Bausch (2009) conducted 21 in-depth interviews with oncology teams (social workers, physicians, and nurses) from the Boston area. The interviews yielded a great deal of useful data including a discussion of coping strategies and the rewards of oncology work. These team members coped by "exercising, pursuing hobbies, taking vacations, reconnecting with nature, focusing on family, talking with family or friends, seeking refuge, engaging in spiritual practices and other rituals when patients die, adjusting their expectations of success, and perceiving their work differently over time" (p. 106). These members must find time and energy

to release and refocus their psychological distress. Self care is an essential important part of managing the distress that comes from working with an oncology population. The practitioners in this particular study had between 1.5 and 28 years of experience in oncology. Despite the number of years of experience in oncology, they developed coping strategies.

Although working with oncology patients can be exhausting and depleting, there are also rewards. These rewards included “being able to ease suffering, receiving gratitude from patients, having intimate emotional connections with patients, being inspired and awed by the human spirit, and gaining wisdom and perspective” (p. 108). Demographic data was not collected in this study, such as age, race, sexual orientation, and religious/spiritual affiliation. This information may have offered a glimpse to how certain identities are affected by work with this patient population. It may be useful to know if the study participants identified with a religion or not and whether these participants utilized spiritual rituals when a patient was dying.

Healthcare System and Religion

Social workers most often work with oncology patients within a healthcare system. Most healthcare systems are secular, although there are many that are affiliated with an organized religion. Regardless, it is this researcher’s experience that most hospitals offer some sort of patient support through religious professionals or religious services through public chapels or meditation spaces within the hospital. The existence of these religious and spiritual supports confirm that healthcare systems recognize the important role of religion for many patients. This section will focus on literature that explores the relationship between religion and the healthcare system.

Religion can be described as “a set of institutionalized behaviors, beliefs, and rituals shared by a community of individuals” (Larsen, 2011, p. 18). Knitter (2010) explains how

religion plays a role in how people “feel about themselves, view their world, and act in their world” (p. 259). Within the field of healthcare, approximately fifty percent of health professionals describe themselves as agnostic or atheist (Knitter, 2010). This is in comparison to the three percent of the American public that identifies as agnostic or atheist (Thoresen, as cited in Seybold & Hill, 2001, p. 24). What does this discrepancy mean for patients when so many of their medical providers do not seem to share the spiritual values of the patient?

Regardless of what era or decade they were trained in, Barnes (2006) and Puchalski and Larson (1998) found that physicians did not receive formal training about religion or spirituality in their medical educations (as cited in Cadge, Ecklund, & Short, 2009, p. 709). This would appear to suggest that medical education does not yet see this as an important aspect of patient care. Koenig, Hooten, Lindsay-Calkins, and Meador (2010) found information to the contrary. United States medical school deans were asked to fill out a questionnaire regarding spirituality and health (i.e., content in the curricula, student exposure to content, own attitudes, and attitudes of their faculty and students toward spirituality and health in the curriculum). It is important to note that this study primarily focused on “spirituality,” which the authors defined as “including all aspects of religion, religious practice, spirituality, and spiritual practice.” (p. 393). The study found that ninety percent of medical schools have courses or content on spirituality and health and only seven percent offered a required course dedicated to spirituality and health. Because only a few programs actually required these courses, health professionals may have limited knowledge about religion prior to interacting with patients. This creates a medical environment where health professionals may not be well prepared to address the religious aspects of their patients.

Cadge, Ecklund and Short (2009) interviewed pediatricians and pediatric oncologists about their interactions with patients and families and asked how the health professionals perceive religion and spirituality in relation to medical care. The physicians viewed religion and spirituality functionally, aiding in medical decision-making and end-of-life decisions. Religion and spirituality were also viewed as barriers when medical recommendations were in conflict with patient's religion and spirituality. A patient's religion and spirituality were also seen as a bridge when it assisted families in answering questions medicine could not. The authors also found that physicians described religion and spirituality as relevant in their work with patients that were receiving end-of-life care. Some pediatric oncologists found religion useful for patients and families making the shift from curative to palliative care. The literature in this area leaves many questions. We know the population at large frequently identifies as affiliated with a religion, but our health systems do not seem to have incorporated the significance of a patient's religious needs into training. This is similar to the limitations that exist in social work training. Social workers work with patients that have a religious affiliation, but they have received little training to guide their care of these patients.

Social Work Practice and Religion

Early American social work leaders, such as Jane Addams, were influenced by religious and spiritual practices. In the late 1800s, Jane Addams co-founded the first settlement home in Chicago. Between 1900-1920 Jewish Social Services, Catholic Charities, Lutheran Social Services and other religiously affiliated organizations were created to provide social work services (Bullis, 1996; Weick, 1992, as cited in Dwyer, 2010, p. 139). It is interesting to this researcher that social work has evolved so far from the early days of the field when religious groups organized the helping practice. Today, social work as a field seems very ambivalent about

the role of religion. Many link this disconnect to the introduction of psychoanalytic theory and the psychiatric viewpoint introduced in the years following World War I (Sahlein, 2002). As Freud (1961) declared spiritual concerns as childish (as cited in Dwyer, 2010, p. 140), science and strategy were emphasized. This evolving foundation appears to play a role in the minimal presence of religion in social work education today. Kvarfordt and Sheridan (2007) found that among a national sample of 283 social workers, 83.5% of respondents indicated that they had “never” or “rarely” received content on religious or spiritual issues in their training as social workers. In addition, Murdock (2005) found that among a random national survey of 299 gerontological social workers, 70% of respondents reported little or no preparation on spiritual issues during their schooling. Despite the absence of the role of religion in the medical education and social work education, it is incorporated into the language of social work standards of practice.

Social Work Standards and Guidelines

Social work associations create guidelines for social workers and educational institutions. The National Association of Social Work (NASW) was founded in 1955 in order “to establish and maintain professional standards of practice” (“NASW,” n.d.). One way this is accomplished is through the Code of Ethics. Within this Code, religion is mentioned four times. Under “Social Workers’ Ethical Responsibilities to Clients” in the section “Cultural Competence and Social Diversity,” social workers are asked to “obtain education about and seek to understand the nature of social diversity and oppression with respect to...religion.” Under the heading “Social Workers’ Ethical Responsibilities to Colleagues” in the section titled “Respect,” social workers are asked to “avoid unwarranted negative criticism of colleagues in communications with clients or with other professionals. Unwarranted negative criticism may include...religion.” Under

“Social Workers’ Ethical Responsibilities as Professionals” in the section “Discrimination,” social workers are asked “not (to) practice, condone, facilitate, or collaborate with any form of discrimination on the basis of...religion.” Finally, under “Social Workers’ Ethical Responsibilities to the Broader Society” in the section “Social and Political Action,” social workers are asked to “act to prevent and eliminate domination of, exploitation of, and discrimination against any person, group, or class on the basis of...religion.” Additionally, within NASW’s *Bereavement Practice Guidelines*, social workers are asked to offer spiritual help and to support and to respect religious rituals (as cited in Murdock, 2005, p. 134). Altogether, social workers are clearly encouraged to obtain education on religion, to understand religion, to avoid unwarranted negative religious criticism, to avoid discrimination on the basis of religion, and to prevent and eliminate discrimination against any person, group, or class on the basis of religion.

The Council on Social Work Education (CSWE) was created in 1952, a non-profit national association that serves as an accrediting agency for higher education institutions that wish to offer degrees in social work. Similar to the Code in NASW, this organization also emphasizes the spiritual aspect of patients. For example, the CSWE’s Gerontological Social Work Competencies “mandates respect for the older adult’s spiritual beliefs and call for gathering spiritual information in assessment and addressing spiritual needs” (as cited in Murdock, 2005, p. 134). The professional standards and guidelines of the field of social work encourage social workers to understand and respect religious and spiritual aspects of patients. These important national organizations have recognized the importance of religion and spirituality in the life of our clients. This researcher wonders why then there still seem to be gaps in training and practice.

Working with Religious Patients

Religion serves a variety of purposes for patients. Fosarelli (2008) describes how religion gives meaning to a patient's life and how it provides comfort when a patient's life is not going well. Koenig (2007) points to multiple studies that show a majority of medical patients want and do not mind if their physicians ask about their religious beliefs (as cited in Fosarelli, 2008, p. 837). Dobbins (2000) demonstrates that it is vital for social workers to acknowledge the importance of a patient's faith as an asset (as cited in Hodge, 2004, p. 255). When a social worker expresses her commitment to respecting this asset in her patient, Dobbins (2000) reports that this often enhances the therapeutic alliance (as cited in Hodge, 2004, p. 255). Knitter (2010) emphasizes the importance of not only understanding a patient's beliefs, but also engaging in their values and convictions. Thus, practitioners must demonstrate knowledge of, respect for, and engagement in a patient's belief systems.

The Social Worker's Role

This section will discuss the social worker's role in their interaction with a religious patient, from suggestions to what social workers have found to be appropriate and inappropriate spiritual interventions. Sheridan (2007) recommends that all social workers should take the time to examining their own values, beliefs, and biases concerning religion and spirituality. This way, the social worker will "work through any unresolved or negative feelings or experiences in this area that may adversely affect [their] work with (patients)" (Kvarfordt & Sheridan, 2007, p. 17-18). Social workers may passively or actively respond when they have not worked through their own unresolved or negative feelings or experiences towards religion- they may avoid discussion altogether. Peteet (1981) states that when therapists respond in this manner, they miss the ability to aid in a patient's ability to integrate their religious and emotional selves (as cited in Sevensky,

1984, p. 85). Furthermore, Lomax, Karff, and McKenny (2002) bluntly state that the therapist may not be able to treat a patient if a therapist is unable to relate empathetically to a patient's beliefs.

Murdock (2005) sought to explore gerontological social workers' attitudes about spirituality and the use of spiritual interventions in practice. The terms "spiritual" and "spirituality" were "used to convey the larger concept of the search for meaning and connectedness, within which all religions and many individual's beliefs fall" (p. 133). Murdock utilized a cross-sectional survey design and asked a random national sample. An exploratory survey was used- Sheridan's "The Role of Religion and Spirituality in Social Work Practice" Scale. What she found was striking- nearly 70% of respondents reported little or no preparation on spiritual issues during their schooling and only 24.5% reported satisfaction with their educational preparation on this topic. This finding was disappointing due to the fact that national social work associations have included this aspect within their standards and guidelines. This may create an environment where social workers are unable to agree on what is an appropriate or inappropriate spiritual intervention. The highest agreement for spiritual interventions included: reflecting on loss (99.3%); considering helpful spiritual supports (97.6%); gathering spiritual information (94.1%); and considering helpful spiritual beliefs (93.3%). The inappropriate spiritual interventions included: participating in patient rituals (67.4%) and touching for "healing" purposes (62.5%). In addition, the highest percentages of disagreement were found with recommending religious texts, sharing one's own belief, using religious language, and praying with the client. Altogether, even though many of the social workers were not prepared on spiritual issues during their schooling, there was still a consensus on what was an appropriate or inappropriate spiritual intervention.

Social Work, Terminal Illness, and Religion

Snow, Warner, and Zilberfein (2008) pointed out that medical advances result in an increasing number of treatment options available at the end of life. They emphasized the growing importance of social workers in helping patients and their families navigate the health care system. Furman, Benson, Grimwood, and Canda (2004) explored the religious and spiritual beliefs, practices and affiliations among a random sample of social workers linked to a British social work association. The results from the collected questionnaires revealed that social workers strongly approved raising the topic of religion and spirituality with clients when they were experiencing terminal illness or bereavement. What was striking in this study sample was that only forty-seven percent believed that including religion and spirituality in direct practice was compatible with social work's mission. This low percentage does not reflect British social work association guidelines, whereby "social workers have the duty to show respect for all persons, and respect service users' beliefs, values, culture, goals, needs, preferences, relationships and affiliations" (as cited in Gilligan & Furness, 2006, p. 4).

Perhaps the belief of lack of compatibility between religion, spirituality and direct practice is a display of difference in cultural contexts. Furman and Canda (2007) first distributed the survey instrument among US social workers in 1997, followed by UK social workers in 2000, and in Norway shortly afterwards (Zahl & Furman, 2005, as cited in Furman, 2007, p. 100). In comparing these three countries, social workers from the US agreed that it is appropriate to raise the topic of religion when dealing with a client who has a terminal illness and who is bereaved, 73.4% and 75.2% respectively. Following closely after US social workers were ones from the UK (66.2% and 66.6%) and Norway (43.3% and 41%). It appears that the US social workers are more comfortable with the topic of religion. Furman points to how this may evolve

in the UK and Norway due to “rapidly changing service populations, revised ethical guidelines, and legislation” (p. 102).

Summary

A review of the literature reveals that there are many factors that could contribute to the way a nonreligious social worker engages a religious oncology patient. It does not appear, however, that the medical field and specifically the social work discipline within the medical setting has decided how to adequately provide education and training around the role of religion in patient care. This researcher was able to identify literature that emphasized that a patient’s faith can enhance the therapeutic alliance, and that patients, in fact, want their providers to engage with them on the issue of faith. The literature also highlights the fact that the majority of Americans today identify with a religion, and that professional organizations guide social workers to acquire education and training in the areas of spirituality and religion. What the literature did not address was how a nonreligious oncology social worker might work with a religious terminally ill cancer patient.

CHAPTER III

Methodology

The overarching research question for this qualitative methods study is, “How do social workers who do not identify with a religion work with terminally ill cancer patients who do identify with a religion?” A review of the literature revealed that there is little research in this particular area. An exploratory study was conducted using a qualitative method of data collection in the form of semi-structured interviews of social workers. Interviews were chosen with the hope that they will provide descriptive data from social workers that may broaden our understanding of the role of religion in social work practice; attitudes of social workers who do not hold religious beliefs; the need to pay attention to the religious and spiritual needs of clients; and the need for attention to these issues in training

Sample

A qualitative, exploratory approach was chosen for this study. Flexible interviews were conducted with five oncology social workers. In order to qualify, participants had to meet the following selection criteria: 1.) a social worker at the Masters level, 2.) does not hold religious beliefs, 3.) resides in the United States, and 4.) works or has worked in a hospital, hospice care, or nursing home for at least one year working with terminal cancer patients, some who may hold religious beliefs. Original recruitment efforts were directed at social workers located only in New York hospitals. An amendment to the original recruitment plan expanded criteria to include

social workers in all of the United States, and social workers located in hospice centers, mental health centers, and nursing homes, in addition to hospitals.

The five study participants were individually interviewed by phone using a semi-structured interview method. The final sample included two social workers with more than 10 years experience and three with less than 10 years of experience. Three social workers were female and two were male. Two social workers lived in New York and three were from other states (i.e., California, North Carolina, and Utah). All participants identified as Caucasian. Participant ages ranged from 32 to 62.

Informed Consent Procedures

This research project was submitted to the Human Subjects Review Committee of the Smith College School for Social Work. The project was approved by this committee on March 14, 2012 (see Appendix A). The informed consent letter described the study and the participant criteria. It also outlined the risks and benefits of participating in the study (see Appendix B). The informed consent form was explained to participants before obtaining a written signature from all participants. Participants submitted electronically signed consent forms by email before the interview took place. All names and other identifying information were removed during transcription and participants were assigned code numbers to each digital file and transcript.

Data Collection

The informed consent letter described the study and participant criteria. It also outlined the risks and benefits of participating in the study. All informed consent forms were signed by participants and collected prior to any interviews taking place.

Prior to the interview, participants were given the opportunity to ask questions, review the Informed Consent letter again, and decide whether he or she wanted to participate in the

interview. Participants were reminded that they were being recorded. Demographic information was collected at the beginning of the interview (see Appendix C). The interviews were conducted over the telephone and recorded. Interviews lasted from 20 to 25 minutes. A list of questions guided the interview (see Appendix D). Clarifying questions were asked of some participants when necessary. All personal information was disguised during transcription.

Data Analysis

Data was coded by the researcher. Themes and participant quotes were coded by the researcher. This was done by cutting and pasting all responses to questions together onto a *Microsoft Excel* spreadsheet.

CHAPTER IV

Findings

This study pursued content and thematic information of the experiences of nonreligious social workers working with religious terminally ill cancer patients. Each section of this chapter is broken down by each of the eight interview questions. This section will detail interview content and participant demographic information. At the end of this chapter, this researcher will summarize her findings.

Interviews were conducted with five oncology social workers. Information about participant's age, sex, race, years of post-masters experience, spiritual affiliation, type of masters-level coursework related to religion and spirituality, post-masters training or certification programs, and years of experience working with terminally ill cancer patients was collected over the phone. The interview questions were organized around the following themes: work environment and/or training as it relates to religion; a social worker's experience to patient's religious inquiry and request; a social worker's experience with a patient's discussion of the role of religion and their illness or prognosis; a social worker's experience with a patient's own religious questioning; a social worker's experience with supporting a patient's religious needs; a social worker's suggestions for training to meet a patient's religious needs; and a social worker's input regarding how she manages when she encounter a patient with a belief system different from her own.

Three female social workers and two male social workers participated in the study. Geographic locations included California, New York, North Carolina, and Utah. The age range was between 32 and 62. All social workers identified as Caucasian. Two identified themselves as having a spiritual affiliation. None of the participants could identify coursework they took during their masters program that related to religion. Three social workers described post-masters training or certification, such as four-year psychoanalytic certification, end-of-life certification, palliative care certification, grief work training, and crisis management training. The participants had been in clinical practice ranging between 4 and 16 years. Two participants had 10 or more years of experience.

Participants reported working with individuals ranging from newborn to age 100. Three out of five social workers identified as working within pediatric oncology where they worked with patients from newborn to 25. Three participants stated that their clients were predominantly Caucasian (over seventy-five percent). Two participants stated that their client population was a mix of White, Latino, Black and Asian individuals. These study participants practiced in urban cities. Three worked with men and women in equal amounts, one worked primarily with men, and one primarily with women. Participants were asked about the religion of their clients. Three participants identified that they worked with a predominant religion: one participant stated Jewish; one participant stated Mormon, and one participant stated Christian. All participants stated that at least half of their clients identified with a spiritual affiliation. One participant mentioned hypnosis and meditation.

Religion in the Work Environment

Participants were asked whether their supervisor or their work agency addressed how to work with patients that have a religious affiliation. Four participants stated that their work

agency had addressed this aspect of their work. Three participants stated that the topic of religion was brought up at least once a year through ongoing professional development workshops, continuing education units, or in-service trainings. One participant mentioned that she has discussed this topic with the chaplain that is affiliated with the hospital that she works in. One participant shared that his supervisor and his agency declined to address how to work with patients with a religion affiliation:

I'm an older, uh experienced social worker um so I feel like I came into this job not really needing that guidance. Um, I think that if I were brand new and coming in out of school um I would've wanted that guidance. So I guess my feelings are that at this age and with my experience um, I'm also very comfortable with um the issue of death and dying and, and bringing it up, talking to people and asking about religion and spirituality so I didn't feel I needed that so my feelings about it, it was fine but it has a lot to do with my age and my experience.

Responding to a Patient's Religious Inquiry

Participants were asked if a patient had asked them what religion they, the social worker, ascribed to. Three participants stated that patients had asked them about their own religion. One participant mentioned that she was asked whether she believed in a God or in an afterlife. Two participants stated that patients had made assumptions about the religion of the social worker. For example, one participant stated that patients would make statements like "I don't know if you are Jewish," "I don't know if you are Catholic," and "You are Catholic so you don't understand this." In addition, one participant described how one patient "loves to tell me how stupid I am about Jewish issues," when, in fact, his father is Jewish, a fact that he later disclosed to her.

One participant discloses to her patients that she does not affiliate with a religion but was raised in the predominant religion of the neighboring community. Another participant believes she would disclose to an inquiring patient that she does not affiliate with a religion. Two

participants do not answer the patient inquiry but try to reassure the patients that they have a great deal of experience with the patient's diagnosis.

Responding to a Patient's Discussion of the Role of Religion and Their Illness or Prognosis

Participants were asked whether a patient had talked about their God and the role of that God in their illness or prognosis. All participants stated that patients discussed the role of religion in their illness or prognosis. One participant stated that the relationship is inevitable: "When you're dealing with existential issues of cancer brings up, it (religion) always becomes part of the dialogue."

The three pediatric oncology social workers discussed how they work with the religion of the parent or parents of the diagnosed or dying child. Two of these social workers talked about religion, as spoken by patients or the family unit, from a positive and negative aspect. One of the non-pediatric oncology social workers talked about how patients included positive talk of their religion. Positive talk of their religion consisted of talking about the diagnosis or illness as part of God's plan:

Participant 2: Um the main thing that I hear them say is that they know that there's life after death or they realize that um...there's been um some occasions when the plan was set before I came here so this is part of the plan. Um so almost...this would be in my words...so almost um I don't know want to say a justification or rationalization but I can't think of a better word about helping it fit into kind of why the diagnosis occurred. So kind of you know there's a bigger plan.

Participant 3: Some people talk about how you know they pray, how they go to church, how they, you know, ask God for guidance, how they're at peace with their religion or you know their diagnosis based on their religious beliefs.

Participant 4: Um and then you know more the positive of you know "This is God's will" and, and you know "I've trusted God all this time and I'm going to continue to trust Him"...And so people really kind of holding onto their faith and um and trying to make sense of it and, and so...And also people that just um almost been resigned that this is part of God's bigger plan or something like that.

In addition, all of the pediatric oncology social workers (n=3) talked about religion, as spoken by patients or the family unit, from a negative aspect:

Participant 2: I think a lot of parents initially feel a lot of guilt about what could've couldn't have done and so...

Participant 4: You know, negatively, just again I've heard from some parents, mostly around their children, is you know kind of "How could my God, of you know, my loving God, do this to us?" And, and more of a retribution, more of like um you know God getting back at them. Um God punishing them for some misdeed, some past misdeed that they might have done. I've just heard that a lot...people respond really angrily and, and reject that God.

Participant 5: For instance if they felt they were being punished or they were um um their faith wasn't strong enough, that kind of thing, we would, we would pursue that to see whether they felt that they were changing their behavior at all. ...It's, it's obviously very complicated and maybe these are things you're looking at but um if they're feeling guilty that they're being punished, we certainly would talk about what they felt um guilty...

Responding to a Patient's Religious Request

Participants were asked whether a patient made any religious requests to the social worker. All participants experienced a religious request from their patient. Some of the participants (n=3) mentioned the request from the patient to bring in a chaplain. Some of the participants (n=3) stated described how they were incorporated (voluntarily and involuntarily) into religious blessings or rites.

Participant 1: There have been times when I've been working in the inpatient unit (*inaudible*) sometimes pastoral care will come. They will pray with families and I kind of get molded into it.

Participant 2: ...so again back to when people actually ask to have blessings in the LDS religion, um, I've asked the families if they'd like me to stay during that time or leave and um most of the time they'll say "Will you please stay?" So I am not reading from anything but yea it's okay for you to be present as we have this laying on his hands. So most of the time if I helped facilitate that and I am still there when it's occurring, there's an invitation for me to, I would say probably ninety percent of the time, be present for that.

Participant 3: I've participated as an inpatient social worker in blessed rites with the patient and their family. I can tell you one time that I did that. It was a patient that I've

been working with very closely and the family. And I was, you know, obviously very close with the family and so the time that he was actively dying, they asked me, they called the chaplain, or the priest in, to do the blessed rites. So it just felt natural to stay, you know participate in that.

Two participants discussed how they would specifically respond to a patient's request for prayer, where they did not disclose their nonreligious affiliation. Instead, they offered to have the patient in their thoughts. One participant emphasized how when a patient asks for prayer, what they are essentially asking for is positive energy.

Participant 4: Um, you know or I will say I will keep you in my thoughts. Or you know I will you know I'm not going to say, "Well, actually I don't, you know, about prayer or I don't pray." I'm not going to get into that discussion with them and uh mostly I'm just going to offer support and say that um you know I will and I'll keep them in my thoughts.

Participant 5: Um, if they ask me to pray for them, I generally respond "I will certainly be thinking of them and sending them as many positive thoughts as I could." Um...trying to send them positive energy. I mean I certainly believe in that. I think the definition of prayer can be kind of broad and so I didn't need to get into any discussion about whether I was actually praying in the way that they um defined it. Um because I think what they're asking for is that positive energy. Um, not my link to their God because I never claimed to have a link to their God.

Responding to a Patient's Own Religious Questioning

Participants were asked whether a patient questioned their faith with the social worker. All participants stated that they had this experience with their patients. Three participants mentioned the option of including the assistance of a chaplain when a patient questioned their religion. They acknowledged their boundary when it came to a patient seeking religious or spiritual guidance. One participant mentioned that sometimes patients renew their faith in times of crises. Some of the participants (n=3) emphasized the need for the patient to explore their questioning, to feel witnessed, to have their feelings validated, to be listened to, to have their experience normalized.

Participant 2: Um, I usually just let them talk about it...Um so there is...so as they say that, I think what I've learned over the years is really they just need someone to listen to them. So I try and do that from a non...from a way without asking more specific questions and going back to so "What are the feelings around that?" You know? As opposed to trying to lead them to one direction or another about um...um kind of what that means um literally for them as more of on an existential level I guess.

Participant 3: I think you just bear witness to their experience. You know, say to them, if they have like a religious leader they want to connect to or talk to their, you know, struggles. Cause for me, it's not really my, you know, I am there to support them.

Participant 4: ...you know trying to kind take away their guilt and normalize the experience again of childhood cancer, as well as miscarriage. Of just you know "There's nothing that you did wrong. You did everything right. And these things happen and we don't know why they happen" and um kind of, kind of that. And I don't really...I don't stay in the kind of religious realm to talk about, other than...I mean I'm not going to stop them from, from that language and talking about God and being angry with God at all but I will um, I will just say you know "I have no idea about that but I do know that you know these diseases happen and they happen to good people and, and we don't know why they happen." So something like that.

Two participants emphasized and reminded a patient about their faith as a strength and coping mechanism they utilized in the past. One of these participant mentioned that she would refer back to a time when the patient relied on people with expertise. She would note to the patient that faith and science can work together and that "there's not necessarily a confliction."

Supporting the Religious Needs of Patients

Participants were asked how they support the religious needs of their patients during treatment. All participants stated that they support the religious needs of patients during treatment by providing patients with information about the chaplaincy services in the hospital. Outside of the realm of obtaining hospital-related chaplains, most of the participants (n=4) noted identifying religion-specific services or items for patients, such as finding Christian churches, connecting Jewish patients to Rabbis, connecting Catholic patients to priests, and locating religious artifacts. One participant emphasized the need to express the hospital's religious

limitations, such as burning incense. She also noted her role as the patient's advocate within the medical team, such as when a patient's religion does not permit blood transfusions:

Participant 5: Um and also to advocate for them and help the medical team understand that, um what religious beliefs. For instance, if, if blood transfusions are a problem or things like that, the medical team they go ahead, they may not be aware and so it sort of helps um with that communication. So I can advocate for them on behalf of their religious needs. I can also sort of intercede and mediate when there's a conflict. Letting the medical team what's important but also helping the patient understand what limitations there may be and how we can um uh do as much as we can but um sometimes, we can't let them burn incense for instance in a hospital room.

Recommendations for Social Work Training

Participants were asked about training they thought social workers needed in terms of training to meet the needs of clients for whom religious beliefs are significant. Some participants (n=3) believed that training would need to involve information about different religions. One of these participants felt that if she had had "more of that training at the beginning [, it] would have helped (her) have more insight quicker." Although another one of these participants acknowledged the need for social workers to obtain a "general understanding of all faiths," she also realizes that masters programs are general. She then states that "...even you learn about religion or spirituality, it may not be in the context of end-of-life, which is pretty specific." In addition, two participants pictured a training to meet the religious needs of patients during treatment to model itself among diversity training, as well as to be included in diversity courses in graduate school.

Notably, one participant believed that the topic of religion and spirituality "should be always used in supervision." Another participant believed that "a mandatory class for other disciplines...would be incredibly beneficial."

Encountering Patients with Belief Systems Different from Their Own

Participants were asked about other ways that social workers may encounter patients with belief systems different from their own. Some (n=3) participants were able to answer these questions. I believe the way the question was structured was confusing. In addition, after attempting to clarify the question for study participants, it became clear that the question was misunderstood. One participant described his work with a cancer survivor. Unfortunately, it was difficult to hear parts of this interview, as it was my first interview. The first interview was recorded in a way that made it hard to hear parts of the interview. This participant went on to describe his own work with the patient and how he did not agree with the way she was utilizing a vegetarian diet and meditation as a way to avoid cancer as a base for her spiritual beliefs. He furthered his disagreement by stating "...it doesn't help you treat it...There was no fighting it." Another participant described how she identified the religious needs of the patient and the family. She went on to state that religion comes up within end-of-life care eighty percent of the time. Two participants described that working with patients with belief systems different from their own is part of their work as social workers. Two participants specifically named working in substance abuse treatment and domestic violence. One participant mentioned working with patients with an HIV diagnosis.

Summary

This chapter has presented the findings from twelve demographic items and eight interview questions asked to five nonreligious, oncology social workers who work with religious terminal cancer patients. Most or all of the oncology social workers had similar experiences: with a supervisor or work agency addressing how to work with patients that have a religious affiliation; with patients talking about their God and the role of that God in their illness or

prognosis; with patients making religious requests from the social worker; with patients questioning their faith with the social worker; with providing chaplaincy services to patients; and with searching for religion-specific services or items. Some of the oncology social workers had similar experiences with being asked what religion they ascribe to.

One major theme surfaced during the interviews. This theme related to social workers working within their own professional boundaries. Sub themes included not disclosing their nonreligious status, integrating chaplain services for religious and spiritual assistance and providing space for a client-centered approach.

The next chapter will include a discussion of the research, observations of the interviews, the bias of the researcher, and suggestions for future research.

CHAPTER V

Discussion

This study sought to understand how nonreligious oncology social workers managed encounters with patients that identified as religious. This chapter will include a discussion of the observations of the social workers' reactions and responses, bias of the researcher, future research suggestions, and conclusion.

Observations of the Interviews

In general, this researcher observed that it was easy for participants to recall specific encounters with patients. These social workers were aware of the presence of religion with their oncology patients. These social workers are pushed to self reflect about their own personal issues with religion. Sahlein's (2002) statement about social workers' confusion, ambivalence or anxiety did not ring true among these study participants.

As a social work intern, I felt unprepared and confused about how to respond authentically to dying patients who invoked a God to help them cope when I did not believe in that God. Because these events did not make any of these five social workers uncomfortable, maybe my insecurity is informed solely by my lack of experience. Maybe as I develop as a social worker, these types of encounters will be as challenging and manageable as many other types of encounters.

Sahlein's (2002) statement of "a trend of avoiding religious issues in social work education" (p. 381) was evident when I asked the demographic questions at the beginning of the

interview, as none of the study participants had completed coursework that focused on religion or spirituality during their social work education. I believe that this area of practice deserves more attention during graduate training. My graduate level social work courses have covered a wide range of identities and potential bias and countertransference reaction, but none that addressed this particular constellation of variables. These research results and my own personal experience highlights the gap within education and confirms the literature. As a reminder, Kvarfordt and Sheridan (2007) found that 83.5% of their national survey of social workers had “never” or “rarely” received content on religious or spiritual issues in their training as a social worker. In addition, Murdock (2005) found that 70% of her national survey of gerontological social workers reported little or no preparation on spiritual issues during schooling.

Bias of the Researcher

I have struggled with these very encounters. As an intern, I wanted more guidance. I tried not to let my own ideas and experiences shape this research, but my own bias has affected the study. I have particular work experiences that impacted how my research question was formulated. First, I have background in working with patients with HIV as an Intern and patients with metastatic thyroid cancer as a Clinical Research Coordinator. My work with patients affected by HIV and cancer drives my energy to explore this specific kind of work. Second, I have been working within health care settings for almost ten years as a volunteer, an intern and a Clinical Research Coordinator. I feel comfortable approaching these settings and I also feel comfortable in being able to navigate the hospital systems. Third, during my social work field placement I ran a short-term, three-month group in regards to bereavement, mourning and grieving. In addition, I ran a short-term, two-month group in regards to goals among men with HIV. As a person who does not identify with spirituality or religion, I have felt uncomfortable

and “stuck” when patients talked about their feelings around their spirituality and religion. In addition, these group sessions challenged my beliefs about death and dying.

As a social work graduate student with experience in working with patients in cancer research in a previous job, interning at a medical center with patients with HIV and various forms of cancer, starting a short-term bereavement group, and co-facilitating a short-term goals-oriented group for adults with HIV, I had expectations about the study. I expected to find strong participant responses of countertransference around work with terminally ill patients. I expected deep feelings of sadness, guilt, and/or relief (from having to witness a patient’s struggle with their terminal illness). I expected a special kind of closeness, or even distancing, from the religious, terminally ill cancer patient. I expected that by working with terminally ill cancer patients, social workers are allowed the space to question or reaffirm their beliefs around religion.

Future Research

As I found it difficult to recruit a study sample of oncology social workers, I would be curious to know about the ease of recruiting a study sample of masters-level nonreligious social workers. In this regard, this sample would capture a wider range of populations that social workers interact with. It is also hoped that in recruiting from a larger sample, more diversity in gender and race would be present.

Conclusion

The experiences of nonreligious social workers who work with religious patients at the end of life have received minimal attention in the literature. While this study was limited in scope, it confirms the lack of social worker education around working with the religion of a patient.

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Appendix A: Human Subjects Review Committee Approval Letter



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

March 14, 2012

Ileana Sansano

Dear Ileana,

Very nice and thoughtful job on your HSR revisions! Thank you for your careful attention to detail. Your project is now officially approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Best of luck on a very interesting project that has a truly different approach the subject matter!

Sincerely,

A handwritten signature in black ink that reads 'David L. Burton'. The signature is fluid and cursive, with a long horizontal line extending from the end.

David L. Burton, M.S.W., Ph.D.
Chair, Human Subjects Review Committee

CC: Quincy McLaughlin, Research Advisor

Appendix B: Consent Form

Dear Interview Participant,

I am a Master of Social Work student at Smith College School for Social Work. I am conducting a study exploring how nonreligious social workers work with religious terminally ill cancer patients. Nonreligious social workers may identify as atheist, agnostic, or those who identify as not practicing a religion. This study will help me to examine how nonreligious social workers respond to the needs of their religious clients. The data from this study will be used in my Master of Social Work thesis and may result in professional publications and presentations on this topic.

You are being asked to participate in an interview because you are a masters-level social worker that does not hold religious beliefs, and have at least one year's experience working in a hospital, hospice care center, nursing home, or mental health center with terminal cancer patients, some who may hold religious beliefs. You are also being asked to participate because you are able to speak, read, and understand English. Individuals with no experience or knowledge about this topic were not invited to participate in this study. This interview will last for about an hour. The sessions will be audio recorded. After the interview, I will type up what you have said.

Personal data that will be collected includes age, sex, race, years of post-masters experience, spiritual affiliation, type of masters-level coursework related to religion and spirituality, type of training or certification programs, and years of experience working with terminally ill patients. Patient demographic information includes age range, race, gender, religious affiliation, and spiritual affiliation.

Minimal risk from participation is anticipated. You may experience distress when reflecting about your experiences treating dying cancer patients. Please let me know if you experience such distress and we can skip the question(s) or stop the interview.

Participants will be making a contribution to the field and sharing their experiences with other social workers whom encounter similar circumstances. Their experience participating in this study may offer them a chance to reflect on their own practices.

You will not receive compensation for your participation in this study.

This interview will be audio recorded. The audio recording will be listened to and transcribed by me. The transcription will be used to analyze the interview information across all participants. If I use a quote, your identity will be disguised. I will listen to the tape in private to protect your confidentiality. I will be working with my research advisor. My research advisor will review the data after identifying information has been removed. Confidentiality will also be protected by presenting the data in the aggregate in professional publications, without reference to identifying information or characteristics. Finally, all data, audiotape, notes and consent forms will be kept secure in a locked cabinet in my home for a period of three years as stipulated by federal guidelines after which time they can be destroyed or continued to be maintained securely or when materials are no longer needed.

Your participation in this study is voluntary. You may withdraw before the study begins. You may skip any questions. You may stop your participation in the interview at any point. There is no penalty for withdrawal from the study. If you choose to withdraw from the study, please contact me via email or phonenumber XXX-XXX-XXXX by May 31, 2012. I will have completed and submitted by thesis by this time. You may also contact me at the email or phone number listed below for questions or concerns about this study, before, or after the interview.

If you have any questions about your rights or any aspects of this study, please call the Chair of Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTOOD THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Signature of Participant: _____ Date: _____

Signature of Researcher: _____ Date: _____

Please print two copies of this form. One copy you should keep for your records. The second copy will be mailed or faxed to me.

Thank you for your time and for your cooperation in this study.

Researcher's Contact:

Ileana Sansano

Appendix C: Demographic Information

Participant Information	
Age:	
Race/Ethnicity:	
Gender:	
Spiritual Affiliation:	

Work Information	
Masters Coursework Related to Religion and Spirituality:	
Post-Masters Training/Certification:	
Years of Experience Working with Current Population:	

Study Participant's Patient Information	
Age Range:	
Race/Ethnicity:	
Gender:	
Religious Affiliation:	
Spiritual Affiliation:	

Appendix D: Interview Questions

1. Has a supervisor or anyone in your hospital ever addressed how to work with patients that have a religious affiliation?
2. Has a patient ever asked you what religion you ascribe to?
 - a. How do you respond?
3. Have you ever had a patient talk about their God and the role of that God in their illness or prognosis?
 - a. If so, how did you respond or engage the patient on this topic?
4. Have patients made any religious requests from you?
 - a. How do you respond to religious requests from your patients?
5. Have patients questioned their faith with you?
 - a. How do you respond to their faith questioning?
6. How do you support patient's religious needs during treatment?
7. What do you think social workers need in terms of training to meet the needs of clients for whom religious beliefs are significant?
8. What are other ways social workers may encounter clients with belief systems different from their own?