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Martha Wiebe MSW

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## **Social Work, Religion, and Palliative Care**

MARTHA WIEBE, MSW

*Carleton University, Ottawa, Ontario, Canada*

*The profession of social work has deep roots in organized religion. While courses on spirituality have recently been on the curriculum in some schools of social work, religion is not incorporated into social work programs. In spite of a decline in church attendance in Canada, religion continues to be a salient force in the lives of many people particularly when they are nearing the end of life. Social workers working in palliative care need to be knowledgeable of religion and have sensitivity to religious practices. This requires a familiarity with religious language and skills in supporting people who look to religion for answers to the meaning and purpose in their lives and their deaths. It is frequently in times of crisis and uncertainty that people's faith becomes central. Social workers need the skills to support them on the end of life journey.*

*KEYWORDS hospice, religion, palliative care, spirituality, Christianity, dying, death*

Spirituality has received considerable attention in social work literature over the past two decades (Callahan, 2009; Canda, 1998; Coates, Graham, Swartzentruber, & Quелlette, 2007; Furman, Benson, Grimwood, & Candu, 2004; Graham, Coholic, & Coates, 2006). Religion, however, has been largely avoided or overlooked. Religious institutions have been viewed with suspicion and writing on spirituality has been careful to differentiate spirituality from religion and religious practices. While there is clearly overlap, spirituality can be seen as the comfort food for the religiously disengaged (Higgins & Burns, 2012).

Jacobs distinguishes religion and spirituality in this way: "Religion offers social forms or shared beliefs and rituals. Spirituality on the other hand,

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Address correspondence to Martha Wiebe, MSW, 495 Sunnyside Avenue, Ottawa, Ontario K1S 0S8, Canada. E-mail: [Martha\\_wiebe@carleton.ca](mailto:Martha_wiebe@carleton.ca)

provides personal experiences or themes of connectedness to others and the universe” (2004, p. 191). Spirituality can be seen as highly personal, focusing on a person’s internal life, while religion is inherently social. It involves worship, shared rituals, beliefs and practices (Callahan, 2009, p. 172), and sacred texts. Streets (2009) states, “A person is religious . . . when he or she believes in a deity and that belief is informed by a system of beliefs in and adherence to doctrines or dogmas” (p. 187). Both spirituality and religion help people to find meaning and purpose in life and both include some aspects of transcendence and transformation. While there is a distinction between the two, there is also blurring and one is not exclusive of the other.

In this article I will examine the place of religion, particularly Christianity, in social work with the dying. I will outline the training required, and the skills and sensitivity social workers need in working with this population. This article does not address the role of religion and spirituality across the lifespan but rather focuses on the role of religion at the end of life. Frequently this is with the population that is older.

The terms hospice and palliative care are used interchangeably with the recognition that hospice is a specific form of palliative care that generally takes place outside of a hospital. The World Health Organization (WHO) defines palliative care as the care of patients whose disease is not responsive to curative treatment, with the focus being on dealing with the patients’ physical comfort and their emotional and spiritual needs (WHO, 2002). In addition, the WHO has recently broadened its definition to include considerations of the health and well-being of family members and of caregivers (WHO, 2002; Sepulveda, Marlin, Yoshida, & Ullrich, 2002). My observations in this article are anchored in the literature as well as in my personal experience volunteering in a hospice. The case examples in this article do not represent any person, alive or dead, but rather are a composite of various people I met and became acquainted with in my 7 years of hospice work. No identifying information is included.

## SOCIAL WORK’S DISCOMFORT WITH RELIGION

The profession of social work has deep roots in organized Christian religion (Graham et al., 2006). Faith organizations have been an important component of the development of community social service organizations, particularly in the delivery of services to the poor and other marginalized groups. Many organizations delivering social services to the disadvantaged started in churches. Congregations saw unmet needs and found ways to provide services to the needy. Frequently church basements provided the venue for these services. Although governments today provide funding for many of these programs, faith communities continue to be an important part of the fabric of social services.

Although historically social work and religion have walked hand in hand, the profession has largely steered away from religion in the past 50 years. The religious dimension is not included in social work studies, although spiritual issues have been incorporated into the curriculum of a number of schools of social work over the past decade or two (Graham et al., 2006). The impact of religion on current social work practice also has not received much attention in the literature. Quellette (2007) speculates that social work distanced itself from religion in “its efforts to be a credible and scientific profession,” (p. 89). Because religion is experiential and subjective it does not easily lend itself to scientific scrutiny, and for that reason seems to have been largely overlooked in the push for evidence-based social work practice.

A further reason for this disconnect might be the fact that organized religion in Canada has a checkered history. At times Christian churches certainly have been a destructive force, particularly with Aboriginal peoples, women, and sexual minorities. Abuses of power by church people who were in positions of authority have resulted in profound scars for many people. Rigid, intolerant dogma, and fear-based teachings have left many with a cynical perspective of organized religion.

To dismiss entirely the role of religion, however, is short-sighted (Wiebe, 2010). Not all religion is located in authoritative, patriarchal institutions intolerant of difference. Stereotypic notions of religion as ideologically manipulative and controlling should not and do not define all of Christianity. A narrow definition of religion as having an evangelical zeal for proselytizing would indeed run counter to social work values. This quite rightfully should be rejected in social work practice.

Rather than overlooking the significance of religion, it is important to examine it more carefully, recognizing its value and importance for many of the people social workers might encounter. While there are legitimate concerns about how religious dogma has had a negative influence, it is useful to sort out the good from the bad. In this article religion will largely refer to Christianity.

## RELIGION IN CANADA

Religion continues to play a significant role in the lives of people despite a precipitous decline in church attendance in Canada in the last number of decades (Bibby, 2011). According to recent Statistics Canada numbers, seven out of 10 Canadians continue to claim a religious affiliation (Focus Canada, 2011, p. 39). Further, one in four Canadians believes that religion is very important. This number increases substantially for Canadians who are 65 years and older. According to Bibby, 37% of people born before 1945 attend weekly church services (Bibby, 2011). Only one in four

Canadians reports no religious affiliation. While many people no longer attend church, eight in 10 people reported that they believed in God or a universal spirit (Focus Canada, 2011, p. 41). Again the statistics indicate that this belief is higher for those who are 45 years and older.

These numbers are important to consider when working in palliative care. Much of palliative care is with people age 45 years and older, many of them over the age of 65. My experience in a publically funded hospice is that many patients identify a religious affiliation on their admission form.

## FACING DEATH

The concept of death for most people is shrouded in fear, mystery, and uncertainty. When people are faced with a terminal illness diagnosis, questions emerge. Why is this happening to me? Why now? What is the meaning of my life? What is the meaning of my death? Is there life after death? Reflecting on these existential questions can be a deeply religious experience. Jacobs (2004) notes that death is a motivator for looking at spiritual issues.

It is because life is finite, that one strives to connect with the infinite. The knowledge that suffering occurs moves people to seek meaning and comfort. It is because sometimes neither life nor death makes sense that one strives to find and to conform to a belief system in which the contradictions of living and dying, joy and terror, order and absurdity are reconciled. (p. 191)

Emotional and spiritual needs tend to come into clearer focus on a person's death bed than they have earlier in life. Religion is frequently the scaffold on which people lean in trying to understand and come to grips with their imminent death. Religious beliefs can give significance to what they are experiencing and help to deal with the uncertainty they face.

## RELIGIOUS-SENSITIVE PALLIATIVE SOCIAL WORK PRACTICE

Social workers are uniquely positioned to work in palliative care and bereavement because the values that underpin the profession of social work align with the values of palliative care (Csikai, 2004). As in social work, palliative care places importance on dealing with the whole person. This holistic approach emphasizes that patients are more than their diagnosis or illness. Care rather than cure is the operative approach. In palliative care, as in social work, the emphasis is on caring for people regardless of their

class, ethnicity, religion, race, age, or sexual orientation (Berzoff & Silverman, 2004).

Rather than considering religion a peripheral relic from the past, social workers need to recognize the role religion continues to play in the lives of people, particularly in times of crisis and despair. The existential meaning of life becomes an integral component of the work in palliative care (Dane, 2004). It is essential that people who are working with the dying have an understanding and degree of comfort addressing both spiritual and religious questions.

Those who come to social workers for help do so as whole persons who are trying to give meaning to what they are experiencing. Their interpretation of what they are going through affects how their body functions and their sense of purpose. (Streets, 2009, p. 194)

Too often in health care settings the patient's spiritual quest is seen as the purview only of chaplains or other religious individuals. An individual's spiritual struggles, however, can surface at any time; they do not arise just at prescribed times when the chaplain is close at hand. While in an earlier age, people in crisis would tend to turn to the church minister or priest, now many may prefer to talk to the social worker (McKernan, 2007). Some patients might consider it easier to discuss religious matters with a social worker because the worker is not identified as representing the church. Social workers need to have skills to support people in a meaningful way in their spiritual and religious quests. It is imperative that social workers learn "to honour the spiritual issues woven into the concerns clients bring to us" (McKernan, 2007, p. 94).

### Practice Skills for Working with the Dying

Schools of social work have been remiss in teaching students how best to support people in their spiritual and religious journeys at the end of life (Bosma et al., 2010; Christ & Sormanti, 1999; Csikai & Raymer, 2005). While the value basis of social work and palliative care is similar, social workers are frequently ill prepared to work with the dying. Their own family backgrounds and their understanding of religion and spirituality might be rooted in unpleasant childhood memories of church and they might feel deep discomfort when the topics of faith or God emerge. Todd (2007) suggests a need to critically analyze how personal histories with religion might shape and distort workers' practice with the people and communities they wish to help. By not re-examining personal biases social workers may overlook the importance of religion and thus forego the opportunity to connect in a deep and meaningful way with the people they are serving.

While religion and spirituality are too important to be left solely to clergy, social workers have a lot to learn about healing and support from those trained in religion. Major religious organizations have existed for a long time, have a great deal of experience, and “have been refining their grasp of the cosmos and human healing for millennia. We cannot ignore the richness that this can add to current social work practice” (McKernan, 2007, pp. 94–95). Social work is a relatively recent profession and to dismiss other knowledge and experience is perilous.

There are several fundamental skills in working in palliative care. A caring attitude coupled with skills of attentive listening, engaging in life reviews, appreciating rituals and religious practices, validating feeling, and encouraging community support are essential in working with the dying and their families. These skills are outlined in more detail below with accompanying examples from my practice.

#### ACTIVE LISTENING

Good listening skills, as in all social work practice, are essential for work in palliative care. This is the ability to listen intently to people’s inner struggles, to hear their fears and anxieties, to pay attention to their silences, and to walk with them as they try to find meaning to what is happening to them. It is the ability to hear people talk about their faith and their religious beliefs and to recognize how these may be an anchor for them in their end of life journey. This might include being present in meditation and prayer with the patient. The role of the helper is to try to understand the person who is dying. While we will never be able to understand fully what that person is experiencing, the importance is in listening, and attempting to understand. What is required of the social workers is a listening ear, an invitation to talk, and an ability to support people. Sometimes it requires simply remaining quiet, being there to accompany a person in their last hours, holding a hand, being a presence. There is a fragile human element to this encounter. Nolan (2011) suggests that it may mean staying “. . . with the authenticity of the patient’s experience, often in a place beyond where words are effective” (p. 24). While it is essential to listen, it is fundamentally important that the workers not impose their religious or spiritual beliefs on patients.

*Case example.* Tom grew up in a religious family but moved away from the church and religion many years ago. Now as he confronts his own mortality he is searching for meaning and is reviewing his earlier religious beliefs and trying to make sense of what is happening to him. I listened attentively to Tom encouraging him to express his concerns, doubts, and fears. At one point he asks if I would be prepared to read to him from the Bible lying on his bedside table and to be with him as he prayed.

Social workers should be versed in spirituality and religion, including religious language, and have some level of comfort in meeting people in

these spaces. Understanding the language and narratives that fit people's experience is critical in building relationships of trust and support.

Sinclair (2012) in a study of cancer patients found that prayer was the single most utilized coping method. Streets (2009) discovered that even in the 21st century many people still practice some form of prayer and meditation. Social workers are not called "to solve spiritual problems or concerns but to create a secure environment to nurture and support the client's exploration" (Jacobs, 2004, p. 193).

#### LIFE REVIEW

At the end of life there is often an interest in looking inward. Social workers can help by being a compassionate presence in this life review. Looking inward and looking back is a departure from what people tend to do in life which is to look forward, planning the future. During the dying process there is an inclination to reflect on the past. Engaging with people in doing this life review is one of the tasks of the social worker and it can be a particularly meaningful process.

*Case example.* Monty and I had a lengthy conversation in the hospice kitchen while he enjoyed the supper I had prepared for him. He was a friendly, outgoing 68-year-old Caucasian man who was particularly loquacious this evening. He had arrived a few days earlier and indicated that he was pleased to be at the hospice. Unlike most of the other patients, Monty was not suffering from cancer but rather had kidney failure. He was interested in telling me about how he arrived at the decision to discontinue dialysis, knowing that this would result in his imminent death, likely within a week. He spoke candidly about his decision. I invited him to tell me about what this meant to him. He started by reflecting on his life, the things he had been involved in, and his passion for the outdoors. He had spent many years working in eastern Canada and in the north, and had particularly fond memories of camping with his friends. He spoke about what was important to him and what true friendship meant. He also reflected on mistakes he had made. He spoke about how meaningless the last year or two had been with a routine of going for dialysis every other day, coming home feeling miserable, and then returning to hospital for another round of dialysis. He said he'd had a full life and he was ready for whatever lay ahead. He did not wish to look at a future of ongoing dialysis. He talked about meeting God either in heaven or in hell. Then in quite a spontaneous moment he blurted out that he felt he was half way to heaven when he arrived at the hospice. I listened and invited him to say more. He spoke about the mystery of the unknown and the uncertainty but also that he was ready for the next stage. Again he assured me that he'd had a full and enjoyable life. These were statements of acceptance. It was important for him to talk and for someone to be there to listen. This brief review of his life appeared to calm him. The

following day he talked with his sons for the first time about his imminent death. He died peacefully several days later.

Moments of reflection and coming to terms with the mystery that lies ahead are important. In a recent study at the Toronto Princess Margaret Hospital, patients reported that it was very useful to have a safe nonjudgmental space where they were invited to reflect on their cancer diagnosis and on their life (Nissim et al., 2011, p. 716). The researchers write “participants highlighted the importance of the therapist ‘steering me to go deeper’ and asking ‘concrete and relevant questions’ while still being ‘gentle, ‘not intrusive’ and ‘[not] trying to take me down any paths that I don’t want to go’” (p. 716). The authors go on to say that “. . . participants found the opportunity to discuss mortality-related concerns . . . to be uniquely valuable and relieving, and that it facilitated subsequent conversations with family members” (p. 719).

Helping the dying search for meaning and purpose in their lives is a role the social worker can play. Viktor Frankl (1963), who spent several years in a concentration camp during World War II, writes “if there is a meaning in life at all, then there must be meaning in suffering. Suffering is an in eradicable part of life, even as fate and death. Without suffering and death human life cannot be complete” (p. 70). Finding meaning in suffering may not take away the sting, but it can make the suffering more tolerable and can promote wholeness and quality of life for terminally ill patients and their families (Chidwick, 1988, p. 32).

#### APPRECIATING RITUALS

Part of helping people in their religious and spiritual quest is for social workers to have an appreciation and understanding of the importance of rituals and social practices. “The use of rituals, prayer, meditation, or scripture may elicit feelings of joy, comfort and peace . . .” (Jacobs, 2004, p. 192). Rituals are an integral part of the expression of faith in many religions and can be a tremendous comfort and support to some patients. These can become especially important during crisis times. Paying attention to the spiritual and religious beliefs and understandings of patients is an important component of hospice care. Social workers can support patients and family members in observing any rituals that are meaningful to them, before or after the death of a loved one.

*Case example.* Angelica, a 75-year Italian woman, was admitted to the hospice suffering from a rare and aggressive form of cancer. She was emotionally fragile and at times quite weepy. She appeared to feel quite isolated, in part because of her limited ability to communicate in English. She was a deeply religious person who was struggling to find meaning in her suffering. One evening she asked me to retrieve her rosary which was hidden in the drawer of her bedside table. She mentioned that she was concerned that

staff would scorn at her if she wore the rosary around her neck. I assured her otherwise and encouraged her to wear the rosary. While at times she continued to be anxious, praying the rosary gave her a sense of calm and comfort. It was important to appreciate and recognize the significance of this ritual for her.

Streets (2009) notes that it is vital to show interest in clients' religious orientation and to have a nonjudgmental approach. Signalling interest gives patients permission to explore what is important to them: "social workers ask questions that encourage the client to reflect on how the client chooses to live his or her life and what the sources are that sustain and give him or her hope and meaning for living" (p. 191).

Religion can be a comfort and can provide a structure that promotes healing of the mind and soul. All cultures and religions have developed rituals and cultural practices to help people who are dying, to assist the bereaved through the grieving process, and to provide forms for remembering the deceased (Dane, 2004).

#### REFLECTION AND VALIDATION

Regrets are a common theme for people who are dying and for their loved ones. It is not unusual for people to lie in a hospice bed enumerating their many regrets. Social workers can help give expression to these regrets, encouraging patients not only to review their lives but also to gently help them find forgiveness, both of others, and of themselves. Modelling an accepting attitude toward the person and validating them can help move them toward forgiving themselves. Candu and Furman (1999) suggest that "it is perhaps this experience of being valued in the present in spite of the obvious shortcomings and failures in the past that provokes clients into forgiving their pasts and developing a more forgiving attitude in the present" (p. 307). Forgiveness is an important component in releasing people from their psychic pain and from feelings of anger and guilt; it helps them arrive at a level of acceptance and sense of peace.

*Case example.* During the admission process at the hospice Frank and his second wife mentioned that they wanted to ensure that his estranged son, Michael, was not allowed to visit, and that if he phoned the call should not be put through to Frank's room. Frank had not seen his son in nine years until he recently showed up at the hospital to see his father. Frank's wife noted that that visit had been upsetting for him.

After a few weeks in the hospice, one evening, Frank started talking about his son and the difficulties in their relationship. He talked about his frustration with his son's lifestyle and his drug use. He also noted that his son was hostile towards him when he remarried and refused to attend the church wedding. As he talked he started reflecting on how badly he handled his divorce. He stated "I should have been more open and patient with my

son and rather than be angry, I should have tried to understand why he didn't approve of my remarriage." Frank mentioned that he was far too critical of his son and regretted that he wasn't a better father. I noted that as parents we all make mistakes and suggested that his son seemed to want to make things right between them. A few evenings later he asked if I would dial his son's phone number. The following day his son visited and in the privacy of the room tears were shed and burdens lifted. Frank died peacefully a few weeks later with his wife and son at his side.

Family members and loved ones struggle with many of the same issues that the dying person is dealing with. The existential questions of life and death are issues for them, as they are for the patient. Confusion and a sense of uncertainty are common; after all no one has come back from the other side. Emotions of fear and anger are frequently evident. Conflicts that have not been resolved come to the fore, and feelings of regret and guilt are not unusual. Dealing with unfinished business is one of the fundamental issues that surfaces in palliative care. Social workers can support and assist family and loved ones in trying to deal with the unfinished issues they have with the dying person. In a recent article (Hagarty, Abernethy, Olver, & Currow, 2010), authors identify the need for spiritual support for caregivers.

#### COMMUNITY SUPPORT

Part of a social worker's role is to help identify communities of support and to enable and encourage these communities to extend comfort to the dying person. A religious community can be a source of great solace for patients and is frequently in the best position to provide comfort. The shared belief of transcendence can be particularly reassuring at the time of dying. Religious convictions can offer meaning to life and to death. "Many people find hope in religion or spirituality. One reason is that most religions and spiritual systems offer some explanation of what happens after death" (Ellor, Netting, & Thibault, 1999, p. 89). It is essential that those in positions of helping, understand and appreciate this dimension of people's lives. A social worker can be there to encourage and support that community in comforting the dying person.

*Case example.* Nellie arrived at the hospice suffering from a cancerous tumor in her throat. She had been an active member in her church and sung in the choir for many years. She found comfort in music and particularly appreciated when her friends sang gospel songs to her. Nellie's community was a source of great support. It became clear that the singing was also a form of comfort to the singers, a way of them saying goodbye to their dear friend. I encouraged this support and made available a comfortable space where the patient and her friends could be together and sing their favorite gospel songs.

## Training for Social Workers

In a recent Canadian study, social workers report that they are inadequately prepared to work in palliative care and with bereaved families (Bosma et al., 2010). Csikai and Raymer (2005); in their survey of health care social workers in the United States, they found that the training workers receive in assisting people at the end of life seemed quite adequate regarding issues such as preparing advanced directives. But it was far from adequate in dealing with cultural differences and religious and spiritual issues (p. 63). It appears that when talk turns to God, the soul, or heaven, social workers tend to retreat. Many feel uncomfortable or inadequate to talk about these matters, so rather than exploring the person's religious beliefs, they may quickly change the topic. Yet spiritual care is the responsibility of all caregivers.

There is clearly a need to enhance the training social workers receive in dealing with spiritual and religious issues (Clausen et al., 2005). Some would contend that it is questionable whether one can credibly work in palliative care without coming to grips with the deeper aspects of life (Chidwick, 1988). Spiritual and religious support is an integral component of palliative care. Hagarty et al. (2010) note that “. . . health care professionals continue to report a lack of confidence, core competencies, and training in assessing and meeting clients' spiritual needs” (p. 267).

End of life work requires helpers to have an understanding and sensitivity to the meaning that patients ascribe to religion. A component of the training is for workers to gain sensitivity to their own spiritual needs. If workers are not attentive to their own spiritual being, how can they be respectful of the religion and spirituality of those with whom they work? Training in this area includes self-reflection and challenging students to think about their own philosophical meaning of life and death.

Reflecting on their own spirituality will allow workers to more genuinely respect and understand the spirituality and religion of those confronting death. While it may be intimidating, social workers should not shy away from having these deep and profound conversations. Chidwick (1988) suggests that mainly it requires openness, genuineness, and care.

. . . we should not be overcome by the prospect of entering the arena of spiritual care. We can provide spiritual support simply by our love and our actions. Since we are capable of loving and caring, we fulfil the basic criteria for engaging in spiritual growth. (p. 27)

Paying attention to religion in social work education will help refine social workers' practice skills by deepening their understanding of the role of faith, allowing for more profound encounters with people, particularly those at the end of life. The profession's taboo about religion must be confronted in order for dialogue on religion to occur. “Social work educators and practitioners

can aid the profession in contributing to the public conversation about religion by critically examining from various social work perspectives the role of religion in people's lives and as a social force" (Streets, 2009, p. 197).

Social workers must be prepared to hear what we may call God talk and to invite discussion of the role that religious faith has in the lives of the people with whom they are working. They must also develop a knowledge and respect for the rituals and religious practices that might bring comfort to the person.

## CONCLUSION

Religion continues to be an important factor in the lives of many people and frequently comes into clearer focus at the end of life. It is essential that social workers are versed in the language of religion, and appreciate the salience of religious and spiritual affiliations, beliefs, practices, and rituals in palliative care. It is time that the schools of social work recognize that religion continues to be a force in people's lives and that students need to be prepared to deal with such matters in their practice. Religious beliefs and practices are dimensions that should not be overlooked; there is a close connection between matters of religion, spirituality and caring for the terminally ill.

It is a privilege to walk beside those who are at the end of their life journey, and it is an opportunity to participate in a most profound experience. Social workers need to be prepared to engage in this journey of discovery with people, and in doing so find a meaningful place for religion and spirituality in the care for the dying.

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