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26
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Social workers in palliative care

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Introduction

The profession of social work has its historic roots in religion. Much of the early work done by social workers was initiated and funded by churches caring for the poor, the disabled, the orphaned and other marginalised people in society (Cnaan et al. 2004; Crisp 2010; Graham et al. 2006; Schmidt 2008). As social work became more prominent and strived to become a respected, scientifically-based profession it moved away from religion. Things of the spirit defy scientific measurement and explanation. Evidence-based practice could not incorporate the immeasurable spiritual and religious dimensions and thus they were seen as incompatible with professionalism. Indeed social work made efforts to distance itself from its beginnings and particularly from religion (Gilligan and Furness 2006; Henery 2003; Sheridan and Amato-von Hemert 1999; Streets 2009). In part it was also the case that governments started taking a more active role in delivering many social services and churches thus had a less prominent role to play.

Over the past 20 years, however, there has been renewed interest in spirituality and its interface with social work (Callahan 2009; Canda 1998; Coates et al. 2007; Crisp 2010; Furman et al. 2004; Graham et al. 2006). In this chapter I will explore both the role and importance of spirituality and religion in end of life care. I will also make a case for the inclusion in social work curricula of topics that deal with spirituality and religious thought. In particular, I will point to the significance of religion particularly at the end of life and will draw on my experience as a volunteer working in a hospice setting. The case examples in this chapter do not represent any person, alive or dead but are composites of people I have encountered at the hospice. Names have been changed and no other identifying information is used.

This chapter is based on my experiences of working in Canada. Religion continues to play a significant role in the lives of many Canadians. A recent survey found that ‘a solid core of Canadians continue to embrace the Christian faith and other religious traditions’ (Angus Reid Institute 2015). Thirty per cent of Canadians surveyed embrace religion, and for people over the age of 55 this was slightly higher. Another 44 per cent indicated some ambivalence to religion but did not reject it. Of the people who indicated that they embraced religion, eight out of ten indicated that their faith strengthened them. Another finding in this survey was that ‘more than 70 per cent of Canadians today express belief in a “Supreme Being”’ and 66 per cent expressed a
belief in life after death. These are important findings when considering work in palliative care. To dismiss religion as irrelevant is problematic and perilous.

Definitions

While spirituality has saliency in recent social work literature, religion continues to be viewed with some suspicion and scepticism in many quarters of the profession (Cnaan et al. 2004). The literature on spirituality has dissociated itself from religion (Henery 2003). The concern about proselytising has discouraged social work from paying attention to the religious dimension as a part of many people’s lives. Proselytising would be in violation of the code of ethics and any attempt to evangelise is unethical; however, taking into account the role of religion in some people’s lives should be an important piece of an assessment (Furman et al. 2004). Of course, spirituality and religion are not two distinctive entities exclusive of one another; indeed, there is a great deal of overlap. A person who is religious adheres to a set of beliefs and doctrines generally shared in a community of other like-minded believers. Spirituality on the other hand is seen as a personal experience that does not necessarily subscribe to a community’s shared beliefs or rituals (Callahan 2009; Jacobs 2004; Streets 2009). In this chapter I will refer to both spirituality and religion.

Hospice care and palliative care will be used interchangeably. Palliative care is defined by the World Health Organization [WHO] as care of people when a cure is no longer available for their illness. The focus in palliative care is on physical comfort and in addressing spiritual and emotional needs (Sepulveda et al. 2002; WHO 2002). The objective is to provide comfort measures so that people can have the best quality of life possible in their remaining days or months. Hospice care is a subset of palliative care that tends to take place outside of a hospital, either in the home or in a community hospice facility.

End of life issues

When patients and their families receive the news that all treatment options have been exhausted and that palliative care is recommended, it can be devastating. Disbelief, hopelessness and anger are emotions that frequently surface. Staring into the abyss, the unknown, is daunting. The dying process is enveloped in mystery. Questions emerge: What will happen to me? How and when will the end come? What happens after that? Is there life after death? What is the meaning of my death? And what is the meaning of my life? Can there be meaning to my suffering and if so what is it? These existential questions raise profound issues that can be deeply spiritual whether or not people are religious. Callahan (2009: 169–70) has noted that ‘even when patients denied having religious beliefs, they expressed spiritual needs that included a desire for meaning, purpose and transcendence’.

People working in palliative care must be skilled in responding to existential questions and issues. The directive in palliative care is to consider the physical, emotional, social and spiritual needs of the person. The holistic approach of social work parallels that of palliative care. The emphasis is on caring for the person regardless of their social class, ethnicity, race, sexual orientation, gender or religion (Berzoff and Silverman 2004; Csikai 2004; Gilligan and Furness 2006).

While social work purports to view the whole person, most social workers have limited or no training in addressing religious and spiritual questions and frequently lack confidence in dealing with these issues when they arise (Hegarty et al. 2010). Canadian social workers in a recent study indicated that they felt unprepared for working with dying people and their families (Bosma et al. 2010). Similarly an American study found that workers were trained and competent in
Social workers in palliative care

preparing advanced health directives but felt inadequate in addressing cultural differences and
religious and spiritual issues (Csikai and Raymer 2005). Many expressed discomfort in dealing
with questions related to God, the soul and life after death. These were seen as the purview of
the chaplain. While the chaplain may be at ease in addressing these concerns, in many facilities
chaplains are present only periodically. When these issues arise it is important that the helper
in the room, whether it is a nurse, doctor or social worker, be able to respond in a caring and
appropriate manner.

In many respects social workers should be well positioned to work in the area of terminal/
palliative care in that they have a family focus and are familiar with helping people deal with loss
(Clausen et al. 2005; Gwyther et al. 2005). Lloyd (1997: 175) identified that ‘working with loss
and grief has long been identified as integral to core social work skills, social workers recogniz-
ing the pervasive and cumulative effects of loss on so many of their clients’. Social workers are
familiar with supporting people when they experience the loss of employment, the apprehen-
sion of children, the loss of their health or of their home. The distinguishing characteristic of
working with the dying and the bereaved is the spiritual or religious dimension of the work.

Lloyd found that:

when focusing on the experiences of dying or bereaved persons, a total of 82 per cent of
the social workers thought that spiritual pain was always, most times or sometimes present;
77 per cent also felt that philosophical questioning was always, most time or sometimes present.
(Lloyd 1997: 184)

Skills for working in palliative care

The requisite social work skills of listening, supporting and empowering are fundamental to
working in palliative care. However, when people are dying, many of them will seek religious
and spiritual support to help them cope with their terminal illness (Callahan 2009). The skills
already incorporated into the social worker’s tool kit require additional honing to take into
account the importance of faith.

A social worker’s childhood and personal experience with religious institutions may have left
them feeling disenchanted and possibly hostile toward religion. To work in palliative care it is
important that workers critically analyse how their view of religion may be shaping and distort-
ing their practice with people who are struggling with existential questions as they near the end
of their life (Todd 2007). Consequently, ‘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’ (Wiebe 2014: 343).

Open communications

Workers need to be open to hearing people’s stories and listening to their feelings of doubt,
anxiety and fear, and accompanying them in their attempts to find meaning in their suffering.

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 under-
stand fully 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.
(Wiebe 2014: 344)
It is imperative that workers are not dismissive of the spiritual dimension and recognise in a respectful way the importance of religious beliefs and personal faith. When the worker has a level of comfort with and an understanding and appreciation of the patient’s religion, it can form the basis of a trusting, genuine relationship between them.

**Empathy**

Empathy is the ability to feel along with a person, trying to step into the other person’s shoes and hear where that person is coming from. It is the ability to have a compassionate presence. A recent study of cancer patients in Toronto found that the ability of the therapist to respond in a caring and empathical manner was the most helpful attribute (Nissim et al. 2012). While I was at the hospice one evening I heard a woman calling out from her bed: ‘I can see the headline in the newspaper now; “woman dies and no one cares”.’ I walked into the room, sat with her and held her hand, reassuring her that I cared. She was feeling very anxious and fearful that she might die in the middle of the night when no one was in the room. I understood her anxiety and reassured her that the staff at the hospice were available 24 hours a day and that we tried very hard to ensure that no one died alone. Holding her hand seemed to calm her and she started verbalising her fear of dying. She mentioned that she used to believe in God but had stopped going to church some years ago and now felt abandoned by God. We spoke at some length about her family who had visited her earlier that evening and with whom she appeared to have a good relationship. I listened to her and reassured her that God’s love shone through other people and going to church was not God’s prerequisite. She smiled as I left the room and soon fell asleep.

It is important that workers are vigilant to recognise spiritual distress and be open to hearing people’s fears and anxieties. Plantive (2015) suggests that we be bold in the questions we ask and the discussion we invite with people in palliative care. Giving patients permission to have the difficult discussions also means allowing them to control the conversation (Gawande 2014).

**Reviewing the past**

Our daily lives are frequently marked by planning for the future – what we need to accomplish today or this week or in the coming months, where we plan to travel, what our short- and long-term career goals are and so on. Our view tends toward what lies ahead. At the end journey a somewhat different pattern emerges, that of looking back. This is a time when people look in the rear view mirror of what their lives have been. It can be a time to contemplate significant relationships and one’s accomplishments but also to consider the unfinished business in one’s personal life. Engaging with people in reviewing their lives is a therapeutic role the social worker can play.

A recent experience I had at the hospice was with a 65-year-old woman. When Matilda was admitted she expressed disappointment and anger at being referred to the hospice. She resisted the idea of palliative care but all treatment options had been exhausted. Her chart indicated that staff and volunteers should avoid using the term hospice or palliative care with Matilda – she did not want to face the fact that a cure was no longer an option for her. Matilda was a single woman with no family nearby. During her time at the hospice she had few visitors and indeed requested that a note be taped on her door asking visitors who came to restrict their visit to 15 minutes. Matilda appeared to be depressed. Nolan (2011) reminds us that when patients lose hope that recovery is possible they can fall into profound despair.

One evening after I had assisted her in eating her dinner I asked her about her work and learned that she had held a high level professional job in government. She spoke about the chal-
Social workers in palliative care

Challenges in her work but also how rewarding it was. I asked her about the things she was proudest of and she mentioned the many accolades she had received when she retired a year previously. She noted that when she looked back she felt privileged to have had such a full professional life. She was raised Catholic and although she didn’t attend church she indicated that she still had a belief in God. When I was ready to leave her bedside she took my hand and with a smile on her face said, ‘Thank you for this. It was so good to have a meaningful conversation’. When I returned a few days later I learned that Matilda had died peacefully the previous evening.

Providing opportunities for reconciliation

In looking back at one’s life, people sometimes focus on unresolved issues. There are regrets about disrupted relationships. When someone is admitted into the hospice we periodically receive information from the patient or the family that one or another of the family members is estranged from the dying person. Sometimes the patient does not wish to discuss this, but at other times they struggle with the estrangement and want to find ways of mending the relationship. Releasing a burden the dying person is carrying may happen through the simple act of listening without judgment and encouraging the patient to talk. Social workers can also try to facilitate reconciliation. If both parties to the estrangement are open to talking, a bridge can be built; however, this is not always an option. When Philip was admitted into the hospice, he had not had contact with his son for over 15 years and had no information about where he might be and no way to reach him. Indeed he did not even know whether his son was still alive. It was clear that there was a great deal of residual psychic pain around this fractured relationship. Although a reunion was not possible, I encouraged Philip to speak about the relationship. He spoke about what went wrong and how he wished he had reacted differently to his son. He mentioned that his son had a serious drug problem and how this caused Philip a great deal of worry, anger and pain. Then at some point he looked up from his pillow and said, ‘I forgive him and hope that he can forgive me’.

At the hospice a common refrain in the dying chapters of someone’s life is dealing with 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’ (Wiebe 2014: 347). Dealing with unfinished business has particular urgency in a palliative care setting for both patients and their loved ones. It is important to validate the pain but also to point out and recognise that failure is human and we have all made mistakes. Trying to work through regrets and unfinished business to forgiveness will help the person find peace. Spiritual comfort and guidance can help people come to terms with past conflicts, feelings of guilt and regret and to see the divine hand in forgiveness.

Importance of rituals

Jacobs (2004: 192) suggests that ‘the use of rituals, prayer, meditation, or scripture may elicit feelings of joy, comfort and peace’. Rituals can be one of the significant comfort measures at the end of life. Prayer and meditation are commonly-used methods that hospice patients rely on (Callahan 2013; Jacobs 2004). Workers who are uncomfortable with this miss an opportunity for a profound encounter with the patient at a critical time in life. Social workers need to recognise and be at ease with prayer and with talking about God.

I have frequently observed the importance of religious rituals for the dying person as well as for those sitting at their bedside. Religious symbols are often in evidence; a crucifix hung over the doorway or the Torah on the bedside table. Some Muslims request that we position the
hospice bed so that the dying person faces toward the Holy Mosque in Mecca. For Catholics there is the request for the last rites and many find comfort in praying the rosary. Michel had lost much of his sight so he asked his family to tape a picture of Jesus on the railing of his bed so that when he woke up he could see it. Susan had a rosary on her bedside table and would pray the rosary when she woke up at night and felt fearful. She would also ask me to read to her from the Bible, particularly from the Psalms. All these measures can provide some degree of support and comfort to dying people and their loved ones.

**Social work education for end of life care**

Schools of social work for the most part do not have spirituality or religion as part of the core curricula (Canda and Furman 2010; Csikai and Raymer 2005; Oxhandler and Pargament 2014). This lack of training is particularly critical for those who will work with the dying and the bereaved. A recent US survey of clinical social workers reported a low level of integrating clients’ religion and spirituality in their clinical practice (Oxhandler et al. 2015). Yet in palliative care an appreciation and understanding of religion and spirituality is an important professional asset. Furness and Gilligan (2010: 2186) have argued that ‘those affected by ill health and life crisis may turn to religious or other belief systems as ways to support and comfort them in times of need, especially when conventional health treatment has failed to cure or aid recovery’. While some workers might feel uncomfortable with religious talk, they must be vigilant in recognising spiritual distress and be open to engaging sensitively with patients’ spiritual concerns.

In our highly secularised society, many students may have had very limited exposure to religious thought and faith. Curriculum content should include ‘models of spiritual development and religious traditions, content on understanding and accepting diversity in religious and spiritual values, and assessment and intervention skills related to religious and spiritually sensitive practice’ (Sheridan and Amato-von Hemert 1999: 127). Although they may not be religious, students need to develop an awareness of their own values and beliefs particularly regarding their own mortality and learn about the importance of faith. An exploration of this in the classroom could offer an opportunity for them to reflect on their own concepts regarding death. Thinking about their own spirituality can help workers guide patients in an exploration of their spiritual beliefs and needs. Students also need to broaden the frame and learn about religious values, beliefs and practices across different cultures and faiths. Inviting this discussion in the classroom must be done in such a way as not to imply a certain kind of answer or to evangelise. In the same way inviting this discussion at the bedside must be done sensitively:

> the prohibition on proselytizing should not be construed as a prohibition on asking patients about their spiritual or religious beliefs and practices. Skillful spiritual screening, history-taking, and assessments should not be threatening to patients or specific to one denomination, faith, tradition or philosophical orientation.

(Puchalski et al. 2009: 901)

**Conclusion**

Many Canadians in the twenty-first century believe in a God or Supreme Being. Faith can be an anchor in people’s lives and tends to have particular significance and poignancy toward the end of life’s journey. This dimension of people’s lives however has been ignored to a large extent in the training of social workers. While social work education provides students with the essential skills of helping people deal with pain and loss, the religious element has not been given
prominence. Recognising and undergirding the religious beliefs and faith that support people as they face death is an area in social work curricula that requires more attention. An appreciation of spirituality and religion can contribute to rich and meaningful relationships as people enter the final chapter of their lives.

References


