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Into the Abyss: A Review of the Literature Related to the Spiritual Care of Family Caregivers In Community Hospice and Palliative Care

Donna Mann, MTS,

The recent rise in interest and occurrence of death at home has been welcomed by society and by the health care system for varying reasons. This has implications for pastors and congregations. Individuals have appreciated the opportunity to receive end-of-life care in the familiar and comfortable environment of their own homes rather than in an institutional setting. In a longitudinal study published in the *Journal of Palliative Care*, the authors found that “patients at home tended to be more satisfied with care than those in hospital or long-term care settings “(Heyland et al., 2009, p. 255). At the same time the government’s cost-saving agenda has precipitated restructuring measures by the health care system that aim to reduce more expensive forms of health care such as hospitalization for non-acute forms of medical care.

Family caregivers are the cornerstone of this movement from institutional care to home care. Community care cannot occur without their partnership. Caring for a family member with a life-limiting illness is an endeavour that requires physical, emotional and spiritual stamina and for which many are unprepared. At what cost are family caregivers supporting their loved ones in end of life care at home? What are the supports available to them and how effective are these supports? Northfield and Nebauer (2010) write, “This population (the dying) is functionally dependent on a family member who consequently makes personal sacrifices that directly influence his or her spiritual and mental health, psychosocial adjustments, and physical well- being. Selfless actions by caregivers may lead to a collapse in their provision of care” (p. 575).

The family is considered a care recipient in the model of palliative care provision endorsed by the Canadian Hospice Palliative Care Association (CHPCA, 2002). The physical, psychological, social, spiritual and practical needs of the dying and their family caregivers are to be assessed over the course of the hospice palliative care journey. In reflecting specifically on these spiritual needs we can recall with Thomas Moore the societal role of the parish priest in the *cura animarum* or “cure of souls.” It has historically fallen to the spiritual leader to “accompany and tend the soul in times of birth, illness, marriage, crisis, and death” (Moore, 1992, p.24). This article is based on a review of the literature that examined the body of research around the needs and the care of the caregivers as it relates to the question: How do the family caregivers of an individual with a life-limiting illness experience the participation of a spiritual care provider on a community hospice palliative care team?

Overview

There is a dearth of research focusing on spiritual care providers on community health care teams. This is primarily due to the fact that the presence of spiritual care providers as fully integrated members of community hospice palliative care teams is a relatively recent phenomenon. There is a wealth of related literature however, and it sheds light on the potential value of spiritual care provision to family caregivers providing end-of-life care. A fictitious case study will pull together the threads of the quantitative and qualitative research literature that relates to caring for the needs of the family caregiver.

Case Scenario

Susanna, an 80 year old widow, grew up in Europe and immigrated to Canada as a young married woman. She and her husband ran a successful bakery together for almost 40 years before retiring. Susanna has recently learned that she has a limited prognosis due to advanced ovarian cancer. Her only daughter, Helen, has moved in with Susanna to care for her with the support of the community hospice palliative care team.

Caregiver Burden

The author of a grounded theory research study described the role of the family caregiver as “jumping into the abyss of someone else’s dying” (Phillips & Reed, 2009, p.80). Family caregivers often experience emotions of sadness, anxiety, fear, a sense of helplessness and vulnerability, and even despair. The physical requirements of caregiving, the intense and distressing emotions and the financial strain can combine to result in a very high level of what has been termed ‘caregiver burden.’

In an article outlining the development and testing of a measurement tool called the Quality of Life in Life Threatening Illness – Family Carer Version (QOLLTI-F), researchers delineate the physical, mental and social costs of caregiving in the terminal phase. Cohen et al. (2006) state that “carers often report more psychological distress than do the patients” (p. 756) and the authors consider interventions to support family caregivers a societal obligation. This view is supported by a recent review of the psychosocial literature around family caregiving (Williams & McCorkle, 2011).

One of the strongest voices in the literature related to caregiver burden is that of Peter L. Hudson. He and other representatives of the *European Association for Palliative Care’s International Palliative Care Family Caregiver Research Collaboration and Family Carer Taskforce* undertook a review of the tools used to assess the caregiver experience in palliative care (Hudson et al., 2010). Hudson and his colleagues have carried out many

quantitative studies involving family caregivers. In a self-report questionnaire incorporating numerous instruments administered to 302 caregivers in Melbourne, Australia, nearly half (44%) of the caregivers had a “probable anxiety and/or depressive disorder” (Hudson, Thomas, Trauer, Remedios, & Clarke, 2011, p. 522). The results of this study underscore the need for psychosocial support interventions for family caregivers. Hudson and Payne (2011) reviewed the literature of the past decade and write that “Families expect that their relative’s symptoms should be managed, that they will be offered emotional, social and **spiritual support** [bolding added], that treatment decisions will be respected, that they will have access to respite care and bereavement support, and that preference for site of death will be supported” (p. 867). In summary, the authors conclude that “unless there are substantial and sustained commitments to improve services and resources for family caregivers, by governments, health authorities, and research councils, palliative care will fail to deliver upon its core functions of adequately supporting the patient along with the family” (p. 867).

After two months of caring for her mother’s needs and coordinating the visits of the health care providers, Helen is becoming increasingly exhausted, both physically and emotionally. Susanna is having difficulty accepting her loss in functioning and voices concerns about being a burden on her daughter. Helen’s spouse comes to stay on weekends and notices that Helen is growing more anxious as the weeks unfold. He gently expresses his belief that another arrangement for Susanna’s care might be better for everyone. Helen refuses to even consider this, stating that she has always felt some emotional distance from her mother and that she sees this time as her final opportunity to have a closer relationship with her mother. She does agree to ask the homecare nurse if there is someone she can talk to about her feelings of anxiety.

Interventions to Reduce Caregiver Burden

A second and closely related theme in the research literature is that of the actual interventions formulated to reduce family caregiver burden. A number of Randomized Controlled Trials (RCTs) have been undertaken in the past decade to test specific interventions and have produced mixed results.

The Cochrane Collaboration is an international network committed to promoting evidence-based health care through their reviews which are published online. In the Cochrane Library there is an in-depth evaluation of RCTs that were conducted to test interventions for family caregiver support in the terminal phase of illness (Candy, Jones, Drake, Leurent, & King, 2011). Only Randomized Controlled Trials (RCTs) were eligible for this review and 11 were included. These involved a total of 1836 caregivers. Nine interventions supported caregivers directly and two supported patients and thereby their

caregivers indirectly. “The review found that interventions that directly support the family and/or friends help them to cope emotionally, and may help them to cope with their role in caring and improve their quality of life” (p. 2). The QOL findings were not statistically significant. The authors of the review state that “emotional support and information on managing the care of their loved one were common features of the interventions that were found to help buffer against psychological distress” (p. 25).

One wonders if quantitative research is the most appropriate methodology for investigating the effectiveness of caregiver interventions. This query is supported by Edwards, Pang, Shiu & Chan (2010) who believe that qualitative research is optimal in “sensitive multi- faceted areas” (p. 754). As Heyse-Moore poignantly states, “Spiritual distress is a phenomenon that can be studied just like any other process. A purely quantitative approach would, however, not be enough. It would be like trying to measure sadness by the volume of tears produced. To engage with soul pain, we must enter the world of the qualitative and of the subjective, of stories, particularly of people’s personal life-experiences, of intuition and of feeling.”(Heyse-Moore, 1996, p. 298).

As an example, in a phenomenological study of 22 bereaved family caregivers who had received hospice home care, the concept of “being present” emerged as the most crucial element of support in times of suffering (Clukey, 2007). In his article “Just Be There” Clukey writes that the “act of being present is a skill” (p. 153) that is vitally important in the effective support of patients and their family caregivers.

In a review of the qualitative research and mixed method research from 1998-2008 on home-based family caregiving (Funk et al., 2010), the method of data collection was predominantly (89%) through open-ended interviews and focus groups (p. 596). The data were typically analyzed through constant comparative and theoretical coding drawn from grounded theory methodology (p. 597). The review yielded a rich synthesis of the facets of support which impact the experience of family caregivers: “Caregivers emphasize that trusting relationships, support networks and sharing caregiving tasks contribute to security, hope, reassurance, and enhanced ‘semblance of normality’ and comfort, a sense of ‘togetherness’ with others and trust, and manageability. Support can also mitigate anxiety, stress and uncertainty, vulnerability, and feelings of abandonment or isolation” (p. 500). These needs could be met by both formal and informal support systems, contributing to a more positive experience of caregiving at end of life. Five of the 105 studies reviewed specifically included the dimension of religious care, making mention of family caregivers “using faith and religious-based beliefs to help cope” (p. 601).

Perhaps one of the most promising avenues for supporting both the individual with a life- limiting illness and the family caregiver is that of “life review.” The practice of interviewing individuals near the end of life and supporting them as they make meaning of

life experiences has been receiving increasing attention. Chochinov and Cann (2005) view a particular form of life review, Dignity Therapy, as a spiritual intervention.

Chochinov et al. (2011) conducted a Randomized Controlled Trial of Dignity Therapy which was published in the journal *Lancet Oncology*. This is one of the most promising developments in life review intervention and indeed in the psychosocial-spiritual support of individuals at the end of life. Chochinov and his team of researchers, based at the University of Manitoba Palliative Care Research Unit conducted an RCT involving 441 patients with a life expectancy of less than 6 months. One group received standard palliative care, another group client-centred care and the third group a “dignity therapy” intervention, consisting of a specific form of life review “based on an empirical model of dignity in the terminally ill patient” (p. 1). An edited version of the patient’s audio recorded and transcribed words is given to patients to share with others as they choose. Patients were surveyed after the study and those who received the dignity therapy intervention were “significantly more likely to report benefits in terms of finding the treatment helpful, improving their quality of life, their sense of dignity, changing how their family saw or appreciated them, and helping their family than did those in the standard palliative care and client-centred groups” (p. 759). Although this intervention was carried out by trained psychologists, psychiatrists and palliative care nurses, it is not difficult to envision hospice spiritual care providers who are accustomed to engaging patients in meaning-making and exploring identity offering this intervention to individuals in their homes. Indeed Chochinov and Cann (2005) write that “the role of chaplains in spiritual care, and how they can best identify and meet the needs of their clientele, merits further investigation” (p. S-112).

The effect of Dignity Therapy on family caregivers is the aspect most central to this literature review. In a study by McClement et al. (2007), 60 bereaved family members of patients who had received the Dignity Therapy intervention prior to death were surveyed about its impact on their loved ones and on themselves. 95% of family caregivers reported that DT had helped the patient. 78% said that the generativity document helped them in their grief and 77% said that it would continue to be a source of comfort. 95% would recommend DT to other patients and family members facing a life-limiting illness.

The intersection of support for the patients, the family caregivers and their subsequent bereavement experience establishes Dignity Therapy as a potentially ideal spiritual care intervention for the community hospice palliative spiritual care provider to employ to support family caregivers.

A referral to the team’s spiritual care provider, Andrea, is made and both Susanna and Helen appreciate the opportunity to have someone they can trust to listen to their struggles. Susanne opens up about her early years in Europe and expresses

the wish that her daughter and grandchildren could understand how different her life was from theirs. Andrea introduces the concept of Dignity Therapy and Susanne agrees to share her stories and reflections on her life. Helen is able to verbalize her feelings of guilt about her relationship with her mother as well as her belief that caring for her mother was a form of “penance” that she deserved.

The Voice of the Family Caregiver

In a meta-study analysis and synthesis of the qualitative literature on spirituality and spiritual care, Edwards, Pang, Shiu, and Chan (2010) found that “the engagement of family caregivers in spiritual care appears underutilized” (p. 753) and that their “views and needs ... are also largely not addressed in current literature” (p. 767). In this section of the review our attention will now turn of the voice to the family caregiver in the available literature.

In a qualitative descriptive study inspired by phenomenology, grounded theory and ethnography and entitled “The Modified Self,” Carlander, Sahlbery-Blom, Hellstrom, and Ternestedt (2011) studied caregivers’ self-image when caring for a dying family member at home. Caregivers’ experiences fell into three patterns: challenged ideals, stretched limits and interdependency. The challenges to their self-image were connected to ‘forbidden thoughts,’ intimacy and decreasing personal space. The authors concluded that it is important to provide the opportunity for family caregivers “to express thoughts and feelings ... [such as] ‘forbidden thoughts’ ” as a means of supporting them in the challenges to their self-image (p. 1097).

Bekelman et al. (2011), in a qualitative grounded theory study of 33 outpatients with chronic heart failure and 20 of their caregivers, found that participants appreciated early integration of palliative care services, particularly psychosocial support as well as symptom control. A sample quote from a caregiver is as follows: “The most helpful thing would be [to have] someone to talk to about this. Somebody to just kind of unload on sometimes. Cause you can’t unload on [patient]. And he can’t unload on me sometimes, too.” (p. 1320)

In an analysis of the theme of security from a prior study of coping by family caregivers at end of life, Funk et al. (2009) identified the dimension of “feeling secure in their own identity and self-worth as a caregiver and individual” (p. 435). The authors conceptualized this as a “type of psychological security” (p. 442). Affirmation of the care being provided by the family caregiver, normalization of a range of feelings, and encouragement of self-care are examples of interventions that increased their psychological security.

Hebert, Schulz, Copeland, and Arnold (2008) researched the questions that family caregivers want to discuss with health care providers. Ethnographic interviews and focus groups were the methodologies used to collect data from the caregivers (current and bereaved) of individuals at end of life. Among the questions participants wanted to ask and did not were religious/spiritual questions. These included: "Why is this happening? Why is God allowing this? Will my loved one go to heaven?" (p. 479). One bereaved daughter is quoted as saying, "I know you aren't supposed to – we just wonder why, but you're not supposed to question God. Why is this happening? But, who could answer this question?" (p. 479). The authors of this study associated questions that were not raised and therefore not answered with increased caregiver distress. They advocated a referral to clergy for caregivers wanting their spiritual questions addressed.

The spiritual needs of family caregivers are highlighted by Murray, Kendall, Boyd, Worth, and Benton (2004) in a prospective qualitative interview study of patients and caregivers. The study found that patients in their last year of life had significant spiritual needs including the maintenance of a sense of self-worth, the search for meaning and sometimes forgiveness (p. 44). Caregivers also expressed their spiritual needs that had been precipitated by suffering. The authors found that it was difficult for both patients and caregivers to express their spiritual needs to "busy" health care professionals, often actively trying to hide their distress. It was clear however that "adequate time and sensitive use of active listening skills such as empathy and open questioning, can create conditions where patients and carers feel able to discuss their hopes and fears if they wish." (p. 44)

A mixed methods study looking specifically at family caregivers' quality of life before and after patient palliative surgery interventions revealed that the "needs of family caregivers are multiple and complex" (Borneman et al., 2003, p. 997). One of the major themes emerging from the data was that of "spiritual needs" (p. 1000). The authors write that "family caregivers clearly disclosed heightened spiritual needs at this critical time of the illness" (p. 1000). Analysis of the interviews resulted in categories of Faith in God, Reluctant Faith and Search for Meaning. The need for spiritual care intervention was clearly indicated.

In a stratified random national survey of patients (340), bereaved family members (332), physicians (361), nurses, social workers, chaplains and hospice volunteers (429 in total), the patients rated religious/spiritual peace along with control of their pain as the factors that most impact their wellbeing at end of life (Steinhauser et al., 2000). Indeed the difference between patients' and families' ranking of these items was minimal. This, coupled with the reality that the majority of patients struggle with "spiritual concerns" at advanced stages of illness (Alcorn et al., 2010), puts great onus on hospice palliative care teams to address patients' and their family caregivers' spiritual needs at the end of life. The Steinhauser et al. study also reported that among the 332 bereaved family caregivers, 2 of

the most important factors at the end of life were to meet with a clergy member and to discuss personal fears. Currow and Hegarty (2006), in a poignant hermeneutical article, write of one whose “presence creates a safe space within which the person who suffers is supported in expressing and exploring the anguish, the paradoxes and the wisdom in the inner darkness, the deep questions with no easy answers, the interplay of hope, fear, denial, and acceptance” (p. 134).

During the process of Dignity Therapy, Susanna reveals traumatic wartime events that took place when she was a child. Andrea supports her in working through these experiences. Susanna wonders how God could have allowed such atrocities to impact her life. Andrea’s willingness to enter into Susanna’s suffering opens up the opportunity for Susanna to unburden herself after so many years. The ability to tolerate another’s suffering without either running from it or drowning in it, is critical in the provision of effective spiritual care to dying persons and their loved ones.

Religious Struggle and Negative Religious Coping

Kenneth J. Pargament and colleagues have published seminal work in the area of religious coping in the psychology literature of recent decades. There is a growing body of literature addressing religious coping among the terminally ill and their caregivers, indicating that negative religious coping has a profound deleterious effect on caregiver well-being.

A 2006 quantitative study by Pearce, Singer and Prigerson examined the relationship between religious coping and the experience of caregiving in a sample of 162 informal caregivers of terminally ill cancer patients. “When the caregivers perceived God’s love and care, their burden of caring, though not lifted, became not only bearable, but was also deemed a positive and enriching experience” (p. 755). However, when negative religious coping was present, the effects on caregiver well-being and the caregiver experience were significant. “Caregivers who felt abandoned or punished by God or felt that God was powerless to help, were more likely to report greater burden and a poor quality of life, and to experience little caregiving satisfaction” (p. 755). These authors also recommend that such caregivers receive appropriate support from religious and healthcare professionals.

As published in the *Journal of Palliative Medicine* in April of 2013, Julie Exline and her colleagues conducted a survey of family members of home-care hospice patients. The sample of 134 revealed that 43% experienced some level of anger/disappointment toward God. This was associated with “more depressive symptoms, lower religiosity, more difficulty finding meaning and belief that the patient was experiencing greater pain” (p.

369). The authors concluded that anger toward God is an “important issue among family members of hospice patients” (p. 369) and one that these individuals may want to address with hospice team members. The importance of having a team member with the requisite skills for supporting individuals struggling with anger toward God is evident.

Based on this brief examination of the theme of religious coping in the literature, it seems that attending to the specifically religious struggles encountered by this population would have a significant positive impact on the burden of these family caregivers.

Conclusion

Over the course of Andrea’s involvement with Susanna and Helen she is able to facilitate a reconciliation between them on a deep level. Susanna achieves a greater measure of peace through sharing her Dignity Therapy document with her daughter and grandchildren. She is able to view her life from a greater perspective and affirm herself in how she was able to rise above the challenges she faced in her early years. Helen comes to understand some of the reasons for the emotional distance that has characterized her relationship with her mother and has a much deeper appreciation for the difficulties her mother has faced and surmounted.

It is evident from this review that the needs of family caregivers in palliative care are immense and that a wide range of interventions would be welcomed. Quantitative and qualitative research has begun to explore the value of various interventions, the efficacy of which has been difficult to measure. Hudson, Zordan, and Trauer (2011) have surveyed members of The International Palliative Care Family Carer Research Collaboration and have outlined priority research areas. These include: “intervention development and testing; under-researched caregiver groups; access to services; unmet needs; bereavement; experience and implications of the caregiver role; and development of assessment tools” (Hudson et al., 2011, p. 397).

Spiritual care has been identified as an integral dimension of palliative care. Priorities and concerns related to spiritual need and struggle have begun to emerge. The specialized role of the spiritual care provider has been highlighted in this review and the literature supports the practice of the care of the soul as a “sacred art” (Moore, 1992, p. xv)

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