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Campus Alberta Applied Psychology

Letter of Intent

Product Development for Palliative Care Program:

Addressing Psychosocial and Spiritual Needs of Clients and Families Choosing a Home Death

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## Product Development for Palliative Care:

### Addressing Psychosocial and Spiritual Needs of Clients and Families Choosing a Home Death

#### *Problem Statement*

The Fraser Health Authority (FHA) in British Columbia has implemented a hospice palliative care program for terminally ill clients who live in the region. The Burnaby Hospice Palliative Care Program (BHPCP) team provides services to clients in a hospital, hospices, and clients' homes. An information and communication book is provided to each client/family admitted to the palliative care program. Currently the book is comprised of five sections: 1) information about the program and the palliative care team; 2) care of the client at home; 3) checklists and guidelines for planning future care; 4) grief and bereavement; and, 5) communication worksheets to help manage medications and caregiver schedules. The BHPCP Team has identified the need to comprehensively develop Section 4 of the communication book: grief and bereavement (Leander, 2004, personal communication) to more adequately reflect the World Health Organization's (WHO) definition of palliative care; that is, care that addresses the psychological, social, and spiritual aspects of patient care as well as providing relief from pain and other distressing symptoms in efforts to enhance quality of life for clients and their caregiver families. The team leader, Adaire Leander, has identified the need to clarify the physical, social, psychological, and spiritual support available to the families through BHPCP. This final project will culminate in a product (i.e., the new grief and bereavement section) that will be added to the revised communication book.

#### *Rationale*

The literature in thanatology confirms that there is a growing trend in our western societies for persons with a terminally illness who express a preference for their place of death,

to choose, whenever possible, to be cared for in their own homes by their families (Karlsen & Addington-Hall, 1998; Kinsella, Cooper, Picton, & Murtagh, 2000; Koffman & Higginson, 2004; Stajduhar & Davies, 1998). A primary goal of palliative care in North America is that of supporting people “to die in the comfort of their own home” (Stajduhar et al., p. 8). Care in the home generally provides care recipients with a heightened quality of life as they continue to enjoy their privacy, their comfortable surroundings, and their family and social relationships (Kinsella, et al., 2000; Koffman & Higginson, 2004). Persons living with a terminal illness have a greater sense of their own value in an environment in which they have the freedom to continue to participate in various activities. Memories and cherished mementos of family members, friends, and celebrated events ensure that the person remains emotionally and physically connected (Vassallo, 2001).

How does the person with a terminally illness define “comfort”? One significant aspect of comfort is the relief from physical pain. Doyle and Jeffrey (2000) posed the question: “Why is it that doctors fail to control pain when effective analgesics exist?” In addressing their own query, Doyle and Jeffrey suggested that the failure to control pain may be a failure to consider all components of pain; that is, the social, psychological, and spiritual manifestations. Byock (1996) lends support to Doyle and Jeffrey’s suggestion in proposing that a conceptual model of medicine focused on illness, injury, cure, and rehabilitation is poorly suited for understanding the perspective of patients living with a terminal illness. The physical, spiritual and emotional manifestations of a person’s lived experience are interconnected; therefore, any one component may emerge out of the experience of another (Vassalo (2001).

Highfield and Carson (1983) identified the need for meaning and purpose, for giving and receiving love, and for hope and creativity as spiritual needs existing in all people, especially in

individuals in the terminal stage of life (as cited in Vassalo, 2001). These needs must be addressed in end-of-life care in ways that respect the clients' cultural values and spiritual beliefs (Komarony, 2004; Mazanec, 2004). In addressing the phenomenological nature of death, Byock emphasized the fundamentally personal experience of dying for the person and his or her family. In consideration of the influence of social, psychological, and spiritual components of pain, an underlying goal of this project is to explore interventions that have the potential for diminishing these dimensions of pain in a way that is culturally sensitive.

There is a considerable need in palliative care and hospices to support families as well as their loved one who is dying. Kubler-Ross (1970), whose work helped to bring the hospice movement into the mainstream in the United States, emphasized that supporting a client with a terminal illness includes helping and supporting the client's family. Kubler-Ross stressed the dynamic nature of the family's needs from the time the illness is diagnosed until after death of the client. Strang, Koop, and Peden (2002) remind us that caring for a dying loved one is "an emotionally intense, exhausting, and singular experience, set in a world apart from everyday life patterns" (p. 97), and Emanuel and Emanuel (1998) reported higher rates of physical and psychological illness in families of dying clients. According to Strang and colleagues informational, psychological, and spiritual needs ranked highest among family caregivers in their study; the caregivers they interviewed described their experience of preserving dignity and quality of life for their loved as one that "engulfed and overwhelmed them" (p. 102), seemingly crying out for their own needs for support and care to be met. The literature strongly supports the need to address the psychological, social, and spiritual needs of the family.

A crucial element of end-of-life care is the need to remain hopeful. According to Herth (1990), the presence of hope is "extremely important for terminally ill patients, regardless of

physical limitation or proximity to death” (as cited in Wong-Wylie & Jevne, 1997, p. 33).

Beavers and Kaslow (1981) speak to the communal characteristic of hope in highlighting that, “Hope does not exist in a vacuum, but rather in shared experiences with others” (p. 125). Dufault and Martocchio (1985) note:

Hope is *reality-based* from the perspective of the hoping person. . . . Through the process of examining reality in relation to hope, hoping persons examine their own personal resources and limitations, and external factors as they and others perceive them. The external factors include the physical and social environment. (p. 384)

Beavers and Kaslow further posit that developing authentic hope in adults is contingent on “rediscover[ing] beliefs in values beyond one’s own being and one’s family, a relatedness to the larger universe and a feeling of harmony with (at least part of) it” (p. 122). The literature on hope strongly supports the need for addressing physical, social, psychological, and spiritual aspects of terminal illness.

#### *Description of the Method and Procedures*

A comprehensive literature review will be undertaken to familiarize myself with the challenges faced by persons with a terminally illness and their families from the time of diagnosis, through illness until death and bereavement. In keeping with the goals of the project, the review will focus on the psychological, social, and spiritual challenges facing persons who are dying and their caregivers. To locate relevant studies, computer searches (using Academic Search Premier) will be conducted including the search terms ‘home death’ ‘end of life care,’ ‘psychosocial challenges,’ and ‘spiritual challenges.’ Using the ancestry approach, reference lists of all articles will be searched for additional articles. Studies will be included if they are

published in English, between 1990 and 2005, and address various issues on burdens and interventions in the care of patients with a terminal illness and their families.

The second step will be to consult with different care providers of the BHPCP team (i.e., palliative care nurses, social workers, St. Michael's Hospice manager, chaplain, and others) and talk with them about experiences and ideas they might have about palliative care. No aggregate data of consultants will be collected or reported in any way within the final project; rather, the discussions with these consultants will be limited to very general and informal communications which will inform the researcher's views and assist in the development of the final product. These informal conversations will not extend beyond general conversation or consultation one would have with others in everyday situations. Currently, the researcher is neither an employee of the Fraser Health Authority, nor a member of the care team; the BHPCP team members are known to her through previous volunteer hospice work and counselling practicum involvement.

The third step of the project will involve recording the psychosocial and spiritual interventions in the literature and comparing and contrasting these with the interventions offered by the BHPCP team. The efficacy of the BHPCP team approach will be considered in light of the research findings. Insights that may result include: How best can the BHPCP address the challenges of lack of hope for clients in the program? How can the BHPCP ensure that psychosocial and spiritual interventions are appropriate and relevant to clients' cultural beliefs and values?

The final project will include the literature review, the results of comparing and contrasting the interventions proposed in the literature with those applied through the BHPCP, the recommendations for additions to social, psychological, and spiritual interventions, and the revised section of the communication book: The final project work will inform the creation of

the newly-revised grief and bereavement segment of the communication book. The new segment will be divided into sections addressing specific needs and relevant interventions: a description of each intervention will be followed by examples. For instance, a client experiencing increased anxiety and restlessness will easily identify the section dealing with anxiety in which interventions (e.g., support available through BHPCP, visualizations, relaxation, and so forth) will be explained. Where appropriate, scripts will be provided. If relevant, the section will also include recommended readings.

Throughout the development of the final project, I will consult with the Palliative Care Team leader, my final project supervisor, and my academic advisor to ensure that I am meeting the expectations of the palliative care program, the needs of the clients, and the academic requirements for the final project.

#### *Potential Implications*

Two main groups stand to benefit from the development and the addition to the grief and bereavement section of the communication book: First and foremost, the clients and their families will benefit from newly proposed interventions to help manage their considerable challenges throughout a very emotional, and often chaotic, period in their lives. Clients will have access to materials that provide them with a variety of alternatives for dealing with the very normal psychological reactions of anxiety, isolation, anger, despair, depression, and other emotions often experienced during the terminal phase of life and after the death. Clients will also have avenues for exploring existential issues that become particularly urgent for people confronting death (Emanuel et al., 1998).

Second, the BHPCP team will benefit through gaining new perspectives in the management of pain and suffering. The team members will be empowered and will empower

clients by sharing newly-learned interventions in addressing psychological and spiritual components of pain (Doyle & Jeffrey, 2000). It is hoped that these alternative approaches to caring for patients with terminal illnesses and their families will diminish suffering and restore hope in the lives of BHPCP clients. As a consequence, the demands for formal care in the control of pain may diminish, thereby, enabling more efficient support and medical services by those providing treatments to individuals living with a terminal illness.



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