

I. The Understanding of Health and Illness Underlying the Model

The model for delivering quality hospice palliative care is based on a broad understanding of how people experience health and illness, and how the healthcare system responds to them.

The Illness Experience

When people become ill, their lives change dramatically. They experience a disease, condition, or aging,ⁱ and a wide range of issues that are frequently part of their illness experience, including the manifestations of the disease process (e.g., symptoms, functional and psychological changes), and the predicament of how to adjust and continue living under these new circumstances. An illness often leads to changes in roles and relationships. It can result in a number of losses: of opportunity, income, and financial security.^{11,12} It can interfere with people participating in experiences that bring meaning and value and add quality to their lives. It can cause suffering and lead everyone to question what the future holds in life and in death.

Most people do not want the changes that come with illness. They perceive these changes to be a threat to their capacity for meaningful and valuable experiences, and to their future. For many, it is the first time they face the fact that they will die at some time in the future.

Health and Quality of Life

The World Health Organization defines **Health** as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”¹ The state of healthiness is a perception on the part of each individual. In the presence of health, people live their lives in ways that bring them meaning and value. Based on the issues, challenges and opportunities they face, they decide what they like to do, how they will live and run their lives. They decide what will bring them most meaning and value.

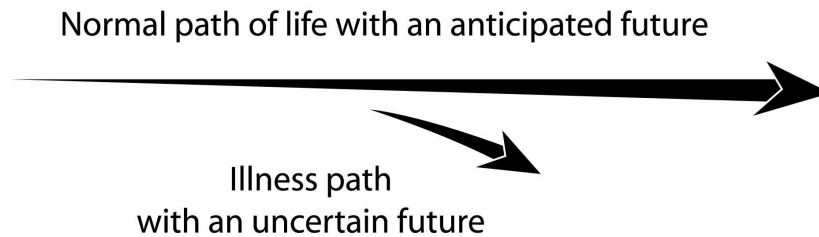
David Roy, at the Montréal Research Institute has suggested that **Quality of Life** is: “meaningful and valuable experiences” and “the capacity to have such experiences.”² The choices that each person makes and his/her experiences lead to a very personal sense of the quality in life. Quality of life is closely tied to autonomy, and the capacity and right to determine our own future.

¹ World Health Organization (WHO) Definition of Health, <http://www.who.int/about/who/en/definition.html>.

² Ferris FD, Flannery JS, McNeal HB, Morissette MR, Cameron R, Bally G. A Comprehensive Guide for the Care of Persons with HIV Disease. Module 4: Palliative Care. Mount Sinai Hospital & Casey House Hospice, Toronto, Ontario 1995.

ⁱ For simplicity, the term “disease” will be used to represent disease, conditions, or aging throughout the document.

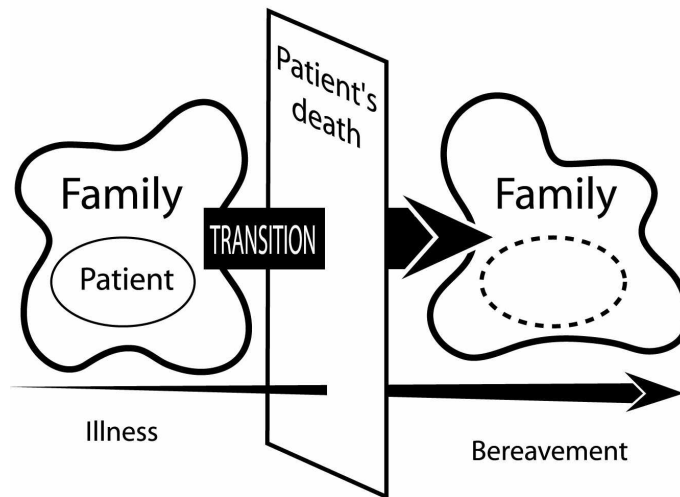
Figure #4: Divergence from the Path of Life



Who is Affected by the Illness?

While a disease affects an individual (the patient), the resulting illness also affects the patient's family (i.e., everyone close in knowledge, care and affection – see page 92), and anyone who lives or works with the patient, or provides care. During the process of an illness, family roles, leadership and group dynamics will be challenged, and even changed. As an advanced life-threatening illness evolves and the patient dies, the existing family group adjourns and a new group forms that will have different membership, roles, leadership and group dynamics. While the patient is no longer present in person, her/his memories and legacies live on and affect everyone.

Figure #5: Patient and Family



If the family group can deal with the multiple losses and changes associated with a death, and make the transition through their bereavement experience safely, the survivors will rebuild their lives successfully and reintegrate into society. If the transition is not successful, surviving family members may themselves become patients in the healthcare system, burdens on society, or ineffective employees.

For society, a family's suffering and the quality of their lives is a public health issue. By focusing on relieving suffering and improving quality of life, hospice palliative care aims to promote health – physical, psychological, social and spiritual well-being - in everyone who is affected by

illness and bereavement, including those who provide care. Our success will be a “determinant” of the health of our society in the 21st century.¹³

Multiple Complex Issues

To be effective at relieving suffering and improving quality of life, caregivers must be able to identify and respond to all the complex/multiple issues that patients and families may face.^{14,15,16,17,18,19,20} If one or more issues are missed, they can compound one on another. This can lead to increased distress and further complications.

The issues commonly faced by patients and families can be categorized into 8 domains, each of which is of equal importance (see figure #7 on the next page; **Note:** the issues in each domain are examples and not an exhaustive list).

Associated Expectations

Each issue identified by the patient and family also comes with expectations, needs, hopes and fears. For example: how will the illness affect my relationships with others? What can be done to change the experience and the way it will evolve? How can I restore or maintain my capacity for meaningful and valuable relationships with others for as long as possible?

While each of these issues and its associated expectations, needs, hopes and fears can be challenging and stressful, they can also present opportunities for growth.²¹ People may face personal issues they had not recognized before. They may find new approaches to activities of daily living and their roles and relationships. They may develop a new understanding of life, the future, death and dying. They may discover new experiences that are meaningful and valuable in their lives.

The Health Care System’s Response

As illness disrupts people’s anticipation of the future, they seek help from the healthcare system to assist them to restore their capacity to live to as close to “normal” as possible. Ultimately, with a combination of appropriate therapeutic interventions aimed at fighting their disease, relieving their suffering and improving the quality of their lives, a patient’s and family’s experience of illness and bereavement may be very different, and their future may be closer to what they anticipated.

Figure #6: Changing the Experience of Illness

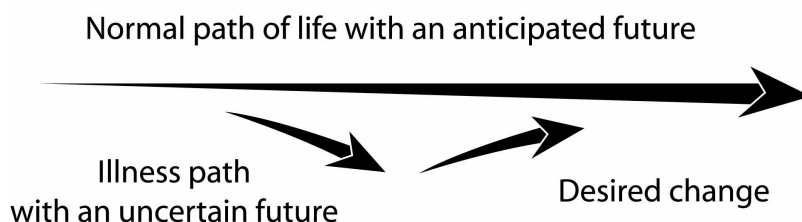
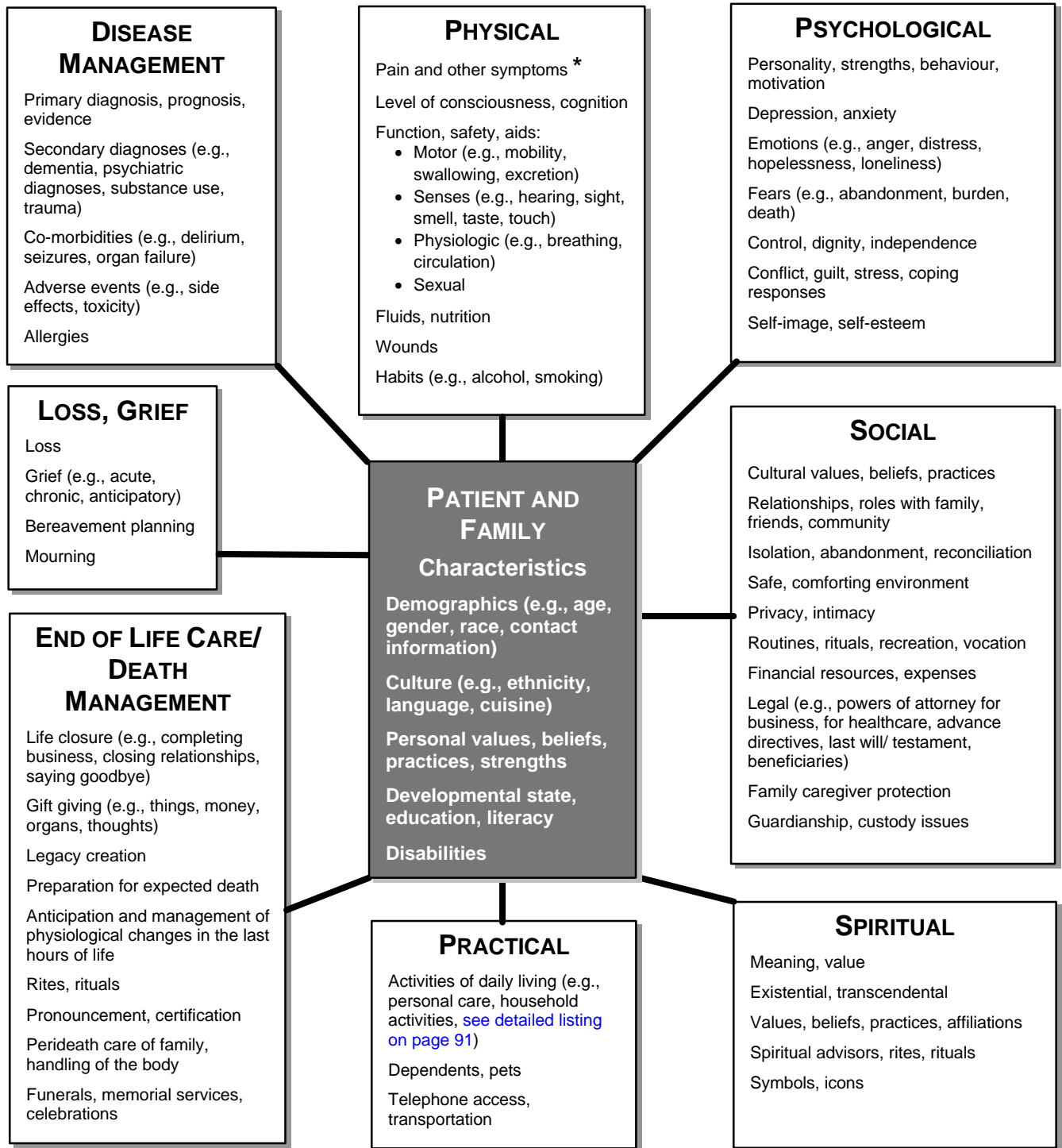


Figure #7: Domains of Issues Associated with Illness and Bereavement



* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

References

URLs were last updated August 2005.

- ¹¹ Covinsky KE, Goldman L, Cook EF, Oye R, Desbiens N, Reding D, Fulderson W, Connors AF Jr, Lynn J, Phillips RS. The impact of serious illness on patients' families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA* 1994; 272: 1839-44.
- ¹² Albert T, Williams G. The Economic Burden of HIV/AIDS in Canada. Ottawa, ON: Canadian Policy Research Networks Inc., Renouf Publishing Co. Ltd. 1998.
- ¹³ Lalonde M. A new perspective on the health of Canadians: a working document. Ottawa, ON: National Health and Welfare, 1974.
- ¹⁴ Emanuel LL, Alpert HR, Baldwin DC, Emanuel EJ. What Terminally Ill Patients Care About: Toward a validated construct of patients' perspectives. *Journal of Palliative Medicine*, 2000; 4(3): 419-431.
- ¹⁵ Emanuel EJ, Emanuel LL. The promise of a good death. *The Lancet*, 1998; 351: 21-29.
- ¹⁶ Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL (eds.). *Through the patient's eyes: understanding and promoting patient-centered care*. Jossey-Bass Publishers, San Francisco, 1993.
- ¹⁷ Singer PA, Martin DK, Kelner M. Quality End-of-Life Care: Patients' Perspectives. *JAMA*, 1999; 281(2): 163-168.
- ¹⁸ Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families and providers. *Annals of Internal Medicine*, 2000; 132(10): 825-832.
- ¹⁹ Steinhauser KE, Christakis NA, Clipp EC, McNeilly J, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA*, 2000; 284(19): 2476-2482.
- ²⁰ Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, Grambow S, Parker J, Tulsky JA. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage* 2001 Sep; 22(3):727-37.
- ²¹ Byock I. *Dying Well: The Prospect for Growth at the End of Life*. New York, NY: Putnam/Riverhead, 1997.