Chapter 1: **About the Toolkit Project**

“They kind of turned us over to hospice...there should have been more overlap between the health care team and hospice...I called to tell (the doctor) that (the patient) hadn’t eaten in 24 hours... And (the patient) died two hours later. The doctor said hospice was in charge of his care... the hospice people didn’t even know us... we should have had more information about what would happen when we got home, both for symptoms and medical care.”

- Mrs. M. (a 31 year old wife), recalls with pain the dying experience of her husband who died from an infection following his third bone marrow transplant.

Dying, and the death of a family member or close friend, represent a sentinel time--one that truly tests a health care system’s ability to provide compassionate and coordinated medical care. Nearly a year after her husband’s death, Mrs. M. recalls with great sadness that she was abandoned by the health care system that had seen her husband and her family through two successful and one final yet failed bone marrow transplant. Her husband had stopped eating and drinking fluids – quite common in a dying person. Coordination of care, early referral to hospice, and education for Mrs. M. regarding what to expect while her husband was dying would have lessened the her burden. Her hope was to have made a “terrible time, tolerable.”

Dying has profoundly changed over the past century. The vast majority of persons now die of progressive chronic illness – i.e., heart disease, cancer, strokes, chronic obstructive lung disease, and other such illnesses. As in the case of Mrs. M.’s husband, each of these diseases involves a journey in which the patient either dies on active treatment or decides to stop treatment. Decisions about ending treatment arise when burdens of treatment outweigh the benefits, the patients’ quality of life is at an unacceptable level, and no further treatment options remain.

Although the proportion of people who die may seem small relative to all persons who receive medical care, the patients who die often are those with the most needs and who incur the highest costs. Key to quality medical care for the dying, for example, is shared decision-making. That is, medical decisions need to reflect the informed preferences of the patient and his/her family, if the patient chooses to involve them in decision making. In addition,
while the health care system is organized around episodes of care, the dying and seriously ill persons need competent, compassionate, and coordinated care across the nursing home, home care, and acute care hospital settings. A seriously ill person truly challenges a health care system to provide such health care.

We must be concerned with the quality of care for all patients, from the person undergoing a routine cholecystectomy to the person that dies in an acute care hospital. The assumption that the person undergoing cholecystectomy wants to maximize function is certainly correct nearly 100% of the time. Indeed, that person’s health related quality of life is defined by the same construct of maximizing function. For the dying, this focus on maximizing function does not hold true. While one is dying, things once ignored -- such as spirituality and life closure -- often become more important. Consequently, a statement that health related quality of life is defined by preserving or enhancing function may not hold for the dying person. Goals of care should be individualized for all patients, and this is especially true for the dying person.

A second essential difference is that the family and those who care for the patients assume an even more important role. The World Health Organization recognizes this in its definition of the goals of palliative care as providing the best quality of life possible for dying persons and their families. Indeed, an often neglected aspect of care is attending to the needs of the family after the death of the person. Increasingly, health care systems have embraced patient centered medical care. For the dying, we believe that this construct must be expanded to encompass the important role of family – that medical care for the dying must be patient focused and family centered. Patient focused care recognizes that the main emphasis of care must be on meeting the patient's needs and expectations, while family centered care recognizes the important role of the family in the dying person's life as well as the important needs of family members, including help in adjusting to life after the death of a loved one.
Overview of the TOOLKIT Project

The Toolkit of Instruments to Measure End of Life Care (i.e., the TOOLKIT project) is a research effort with the overarching goal of creating measurement tools to allow health care institutions to evaluate whether care is patient focused, family centered.\(^5\) The TOOLKIT includes both a prospective and retrospective interview tool which relies on both the dying person's and family's perspectives to examine the quality of care that health care providers and institutions provide. For each interview, separate domains and modules allow you to tailor the instrument to your needs.

Our fundamental premise is best stated by Demings: “If you don’t measure it, you won’t improve it.” Too often, health care institutions have not focused on the unique needs of the dying. This initial TOOLKIT will hopefully provide you, the reader, with the measurement tools, the knowledge, and the skills to apply the principles of quality improvement in order to change key processes of care so that medical care for dying persons is truly patient focused and family centered.

Despite the universality of death, much research has not focused on the unique needs of dying persons and their families. Those of us who care for and study the dying are often facing uncharted waters. As noted by Dame Cicely Saunders, we must be committed to sharing knowledge, open to challenging fundamental assumptions, and willing to recognize that the key to quality of medical care for the dying is the dying person's and his/her family's "own view on what they need."

In the spirit of words of Dame Cicely Saunders, we are providing the measurement tools and resource guide on the World Wide Web free of charge. The instruments are copyrighted only to keep the instrument in the domain of the public. These instruments would not exist without the generous support of the Robert Wood Johnson Foundation. We are especially thankful for the guidance of Dr. Seth Emont, Rosemary Gibson, and Victoria Weisfeld, as well as the attendees of three conferences on measuring the quality of end-of-life care. These conferences were held in Woods Hole, Massachusetts and focused on developing research agendas for measuring the quality of care and quality of life of dying persons and their families.
We hope that this is not a final version of the TOOLKIT. Rather, we encourage feedback from you, the reader, in the spirit of sharing your knowledge and the results that you were able to achieve in your institutions. Given that this document will live on the World Wide Web, we plan on updating it. Our first efforts at updating will focus on providing the reader with results from diverse health care institutions in order to provide more of an authoritative benchmark on which to judge the results from your institution.

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Reference List


