Nursing and End of Life Issues: Choices, Decisions & Care for Our Patients and Ourselves

Are We Ready?

Caroline B. Burnett, ScD, RN, and Barak Wolfish, MPH

Emerging trends in end of life care and choices provide nurses with an opportunity to assume a major role in both educating and serving patients, their families, significant others, communities, and the nursing profession. In the next few editions of “The New Mexico Nurse” we will initially provide some historical background concerning end of life issues and identify how the health care system is responding. Next we’ll explain some of the basic legal understandings in end of life planning and care, describe approaches to help people clarify their values and successfully implement their end of life choices, and explore the critical roles to be played by nurses. Finally we’ll describe some of the specific end of life healthcare options that are evolving nationally and here in New Mexico. As is often said, “aging is not for sissies,” so buckle up and enjoy the ride...we all got there (if we are lucky enough).

Key Historical Developments

Historically, when more people tended to live in intergenerational extended family units and communities were smaller and tighter, dying was a more basic part of the fabric of life. Like childbirth, it was something that folks grew up with. Expectations for advanced medical treatments that could prolong or extend life were modest or simply just not available. People tended to die at home or in the local community hospital, often cared for by family, friends, and neighbors. End of life expectations changed dramatically as the health care system developed regional and tertiary referral centers with high tech ICUs, sophisticated medical specialties, advanced treatments, new pharmaceuticals and technologies, and a national system of insurance for senior citizens (Medicare).

While more people now live longer with greater access to these life saving technologies, others die further from home, in unfamiliar institutions, sometimes without proper regard for their wishes or the expense of such care to the individuals, families, or the system overall.

In response to the advancements in health care delivery, there have been several key developments to improve the effectiveness of our end of life system of care. First, is the increased availability of hospice care. Although the hospice movement has roots that go back to earlier centuries, in the United States it gained momentum in the 1970s and has grown dramatically with each ensuing decade, stimulated in 1982 when it was included as a benefit under the Medicare program. By 1995, hospice was a $2.8 billion industry, with $1.9 billion from Medicare alone, funding patients in 1,857 hospice programs with Medicare certification. By 1998, there were 3,200 hospices either in operation or under development throughout the United States according to the National Hospice and Palliative Care Organization (NHPCO). In 2013, hospice provided services to about 1.5 million patients.

According to the NHPCO, hospice is considered the model for quality compassionate care for people facing a life-limiting illness. Hospice provides expert medical and nursing care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s loved ones as well. Hospice focuses on care, not curing. In most cases, care is provided in the patient’s home but may also be provided in freestanding hospice centers, hospitals, nursing homes, and other long-term care facilities. Nursing has traditionally played a critical role in facilitating not just the care of patients at end of life, but providing them with the necessary emotional support to make difficult end of life decisions with a respect for persons across the life span and to do no harm.

A second response to help ensure that people receive appropriate care and eventually die the way they wish has been the development of advance directives to provide written instructions regarding their medical care preferences. State laws providing the legal basis for advance directives have been enacted in every state. Such laws guarantee patients’ rights regarding their healthcare choices and generally provide physicians who follow these directives with legal protection.

In 1990 the state of New Mexico’s Self-Determination Act formally required hospitals, nursing homes, home health agencies, hospice providers, health maintenance organizations and other health care institutions to check for and provide information about advance health care directives to all patients upon their admission to the facility.

In general, the goal of advance directives is to ensure that individuals receive care consistent with their personal goals and values and that their right to refuse, continue or discontinue treatment is fully respected. Specifically, advance directives enable an individual to provide written instructions concerning medical care preferences and identify a surrogate or proxy decision maker when the individual is unable to make his/her own health care decisions. It’s important to realize that advance directives are not just for the elderly. Rather, all individuals should consider their values and how they can inform their end of life choices and decisions.

Why Now?

As the "baby boomers" (those born between 1946 and 1964) come of age, the number and percent of older Americans confronting end of life issues will increase substantially and will be a daunting challenge for the health care system overall...and certainly that means for nursing as well. For the next 30 years there will be those born in the 1940s and 1950s dying at unprecedented numbers placing

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an extraordinary demand for both high-tech and high-touch health care and supportive services. Fortunately, there are some basic, well-established principles in nursing that provide clear guidance to practice ethically and to provide care “in a manner that preserves and protects healthcare consumer autonomy, dignity, rights, values, and beliefs” that will guide our journey through this challenge, including a commitment to patient self-determination and informed decision making.1

This year the “leading edge” baby boomers will be 65, well established on Medicare with many enjoying their Social Security retirement benefits. Some will be going through life-threatening crises right now, many will have experienced the passing of their parents, and most will have lost a number of their high school cohorts to “early” deaths. Believe it or not, nurses are getting older as well. According to a 2019 DHHS publication entitled “The Registered Nurse Population,” the age of nurses has been rising for the past two decades and by 2030, greater than 16% of RNs were 50 to 54 years old. The report indicates “This aging trend in the RN population has raised concerns that future retirements could substantially reduce the size of the U.S. nursing workforce at the same time the general population is growing and the proportion of elderly is increasing, raising demand for health care and nursing services.”

So, How Are We Doing?

In spite of this progress it is probably a surprise to no one that we have a long way to go to ensure everyone has a “good death” — receiving the level and kind of care that is wished, free from pain and suffering, with caring support and attention, while maintaining respect and dignity throughout the decision-making process at the end of life. In reality, there is a huge gap between what people say they want and what actually ends up happening.

According to a 2005 study by the Centers for Disease Control and Prevention (CDC) more than 70% say they would like to die at home, yet only about 30% do so. Similarly, a survey by the California Health Care Foundation in 2012 showed that although 80% of those surveyed indicate that they would like to talk with their doctor about end of life care, only about 7% have had that conversation. In that same survey 82% and that putting their end of life wishes in writing was important, but only 23% had done so.

In conclusion, we have work to do. It is a challenge to know when, where and how to start these important conversations, reach very personal understandings, and then translate them into proper documents so that one’s wishes can be honored when the time comes. Nurses, just like the rest of the population, will benefit from thinking through their own values and opinions regarding end of life choices and understanding how they can help ensure that they and their loved ones will have the kind of care that they want at the end of life. Whether a young nurse in training with aging grandparents, a mid career nurse with elderly parents, or a tenure nurse looking ahead towards retirement, this end of life discussion becomes very personal very quickly when events turn in that direction. By knowing and being clear on personal values, nurses are better equipped to engage their patients in these very critical discussions and offer support at the end of life.

So, this homework in understanding end of life choices and processes is critical on both a professional level to best serve our patients and for ourselves. The good news is that there are many resources now available to assist in this undertaking with suggestions, questionnaires, legal forms and encouragement, some of which are identified below.

References:
http://theconversationproject.org/
http://www.campaignfordeadlengaging.org/
http://www.agingwithdignity.org/live-wishes.php
http://dca.umn.edu/third/Decs/advance-directive.pdf

Footnotes:

5. From the Conversation Project website: http://theconversationproject.org/

Brief Bio:

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Part 2: Nursing and Advanced Care Planning – How It’s All Supposed to Work and the Critical Roles for Nurses

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In Part 1 last July we explored key historical developments that led to the current situation concerning end of life processes and care including: our aging population, increased expectations for life saving and life extending medical care, the evolution, and expansion of hospice services, and the legal recognition of patients’ rights to decide about their end of life care directly or through advance directives. However, there is still a large gap between how people indicate they wish to die (mostly at home with family and friends near by and without suffering), compared to the vast majority who actually die in institutions, too often with advanced/aggressive medical care that they do not fully understand, may not want, and which often does not improve the quality or even the longevity of their remaining life.

So how do we improve the system to help ensure that people of all ages understand their rights and options, think through and legally document their personal preferences for end of life care, discuss these choices with loved ones and their health care providers, and interact with a responsive and compassionate health care system to ultimately have the kind of death they are seeking? This can best be accomplished through system improvements at the individual level to encourage and support people to take thoughtful action regarding end of life choices throughout their lifespan and the training of clinicians and institutions to engage with patients about these issues at every appropriate opportunity. A recently released Institute of Medicine (IOM) report on “Dying in America” has studied these issues extensively and makes a series of far reaching policy recommendations for action at all levels.

This article will briefly describe the basic documents that help individuals legally declare their wishes for end of life care. It will then identify the key roles that nurses play in helping patients and their families understand the importance of advanced care planning and helping to ensure that their choices are honored to help ensure that effective advance care planning becomes the societal norm and not the exception.

Advanced Care Planning Primer

In its most basic terms, advance care planning involves learning about the types of medical decisions that might need to be made in the future, considering those choices ahead of time, letting others know about personal preferences, and identifying someone to make those decisions if he or she is no longer able. The National Institute of Aging points out that advance care planning is not just about old age. At any age, a medical crisis or traumatic injury can leave someone too ill and/or incapacitated to make his or her own healthcare decisions. To ensure that care is consistent with the individual’s desires, everyone is encouraged to put their values and choices into an Advance Directive, a legal document that goes into effect when the patient is unable to speak for himself/herself. It helps others (family members, friends, or healthcare providers) know what type of medical care they want and what kind they don’t want. (2)

Values Clarification: Ultimately the choices that an individual makes about end of life care are based upon their values — what makes sense to them, what feels “right,” and what would be ideal. There are no right or wrong answers when it comes to these personal values. Efforts to assist people think about them need to be neutral and accepting; Everyone is entitled to their own values regarding end of life choices and care.

There are several excellent tools to help people think through their values. The UNM Institute for Ethics has a comprehensive and open-ended downloadable “Values History” form to assist individuals in making health care choices in accordance with their personal values (http://form.unm.edu/ethics/docs/values-history.pdf). Compassion & Choices, a national nonprofit that is committed to helping everyone have the best death possible provides a variety of online resources including an easy-to-use values worksheet that can be accessed at https://www.compassionandchoices.org/userfiles/Values-Worksheet.pdf

Advance Directive: In New Mexico, the Uniform Health Care Decisions Act (24-7A-1-18 NMSA 1978) is the legal basis for advance directives. This law can be accessed at http://form.unm.edu/ethics/docs/uniform-healthcare-decisions-act.pdf. It specifies the right of any adult or emancipated minor, while having capacity, to make his or her own health-care decisions and make an individual instruction to tell medical providers how they want to be treated if he or she is dying, unconscious, or demented and can not articulate decisions about emergency care or other treatments. These may include decisions about CPR, resuscitation, or artificial nutrition and hydration. Several websites that provide these state specific forms are listed in the reference section. (3)

Power of Attorney for Health Care: This is a legal document to name a healthcare agent (sometimes called a “proxy”) to make medical decisions for the patient when he or she has lost capacity and is no longer able. The designated Health Care Decision Maker should be familiar with the patient’s wishes, values and choices as reflected in their Advance Directive, if available, but if not, then the patient’s family, friends, and/or healthcare providers. The law states that a person is to be presumed to have capacity to make decisions about any medical treatment for which he or she has not already executed a directive, unless it is otherwise apparent from the circumstances that the individual is not currently able to make decisions about the treatment. In the absence of any specific statement by the patient, the health care provider may act upon reasonable belief that the best interests of the patient would be served by such treatment. The nullity of any order for emergency medical treatment issued without the patient’s consent shall relieve the person issuing the order from civil or criminal liability for such treatment. (4)

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Nursing Roles in Advance Care Planning

Historically, nursing has a long and respected tradition of caring for patients and their families throughout the lifespan. Nurses are relied on to be at the bedside to assist patients assimilate information about their health, understand treatment options and offer supportive and comfort care when active treatment is no longer in the best interest of the patient.

Over the past several decades, providing this level of care has become increasingly difficult as a result of increased acuity of hospitalized patients, increased complexity of care, decreased length of hospital stays, increase in age of population and many other factors. These challenges require nurses to draw on their own values to inform approaches to clinical practice.

According to the ANA Code of Ethics for Nurses... "nurses have strong ethical responsibilities...this code of ethics makes explicit the primary goals, values and obligations of the profession." It highlights the need for nurses to incorporate the principles of autonomy (right to self determination), beneficence, non-malevolence and justice in their practice and care of patients. In order to accomplish this, we suggest that nurses must first decide on and accept their own set of values.

Further, an appreciation for values and human dignity is a prerequisite to assisting patients with complex, often difficult, end of life decisions. Some of this knowledge comes from one's own personal history, culture, religion, family and education. Nurses, in their professional education, often receive training in ethics and values that guide them in their emerging professionalism. However, a recent study by Brady et al. found that far fewer nurses than might be expected actually have exposure to training in ethics and values. Similar to findings reported by Brady et al., a study conducted by one of these authors (CB and colleague) also found that nurses reported exclusion as to what an advance directive actually is, the means of assuring it is a current and valid document and who had primary responsibility for talking with patients about end-of-life issues and securing a valid advance directive.

Findings such as these underscore the need for ensuring that nurses are well prepared through formal, graduate or continuing education to assume roles in assisting patients with their advance care planning. Further, nurses must understand and acknowledge patient values and be able to communicate with patients and other decision makers.

While the focus with NM MOST and other efforts for ensuring that Advance Directives are properly completed and accomplished directed towards the end of life when patients are already in a health care facility, this may be too limiting to approach increasing the overall proportion of individuals who have advance directives. Current research continues to show that a very small percent of the population (5%) have advance directives in place. Some questions that should be addressed include: 1) why is it that 2) what approaches are needed to change these low statistics and 3) how/where best to hold such discussions earlier with those who are more healthy? We suggest that the point of emphasis needs to be moved towards primary care settings and further into the community for maximum impact.

The Gunderson Health System in LaCrosse, Wisconsin has done just that. Through their program, "Respecting Choices – Advance Care Planning" and through education and civic engagement, they are encouraging conversations among individuals in the community concerning end of life wishes and facilitating completion of appropriate documents all before entering a hospital. http://www.gundersonhealth.org/respecting-choices

This discussion is not limited to the elderly or those with life threatening illnesses, but focuses on approaches to include all individuals across the life span. As a result of this comprehensive and diverse approach, it is reported that 98% of individuals have advance directives at the time of death. Promising efforts such as this should be able to be adopted in other communities.

In summary, we recommend that these end of life discussions not be centered only in end of life conversations, must engage a wide array of individuals of all ages, cultures, ethnicities, ages and socioeconomic backgrounds. Further, we recommend that basic nursing programs, continuing education offerings and advance practice education integrate values clarification, ethics and ethical theory and their application to clinical practice. Nurses, in collaboration with other disciplines, have the background, communication skills and holistic approach to care necessary to assist patients and their families with these challenging decisions.

References:
- http://www.gundersonhealth.org/respecting-choices

Briefly:
Caroline Burnett, ScD, RN, is retired from Georgetown University where she is an adjunct Professor of Nursing and Oncology. While on faculty she taught nursing and ethics, served on the ethics consult team, conducted research and published in the areas of patient information-seeking and decision-making behaviors.

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