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Evolution of the Care of the Dying: From Paternalistic to Palliative Care

Dilip V. Jeste and Emily C. Edmonds

We feel privileged to write a commentary on an article of historic value written by Noyes and Clancy (1977) on the topic of the dying role and its relevance to patient care. Those visionary authors criticized then-prevalent paternalistic attitudes toward dying patients and recommended what is becoming the best practice now: palliative care, including hospice services for the terminally ill. In this commentary we discuss the importance of this topic in view of the aging of the population, followed by a consideration of the timeliness of discussing death and dying with terminally ill patients, as well as the related constructs of successful aging, successful dying (or “good death”), and age-associated wisdom. Finally, we describe the visionary role of that classic article in anticipating the modern philosophy of palliative care and hospice.

AGING OF THE POPULATION

The population of the United States is aging rapidly. Today, approximately one in every seven Americans is 65 years of age or older, according to the U.S. Department of Health and Human Services. By 2060, this proportion is expected to increase to one in every four to five Americans, and the total number of older adults will

increase from approximately 46 million today to 98 million (AoA 2015). While older adults are not the only group to experience sickness and death, they are certainly overrepresented in terminally ill populations. For example, the National Hospice and Palliative Care Organization reported that approximately 84% of patients in hospice care in 2014 were age 65 years or older. By comparison, pediatric and young adult populations represent less than 1% of those receiving hospice care (NHPCO 2015). Older adults also account for a majority of deaths in the United States. Mortality data from the Centers for Disease Control and Prevention show that 73% of those who died in 2013 (the most recent year for which data are available) were age 65 or older (J. Xu et al. 2016). Thus, Noyes and Clancy’s (1977) article “The Dying Role: Its Relevance to Improved Patient Care” and their discussion of the “sick role” and “dying role” are highly pertinent to older individuals. Given the aging of our society, an understanding of these roles and optimizing of the care for dying individuals has become critical. The authors were certainly far ahead of their time in their acknowledgment of these issues, with a call to action. This dialogue is one that is still ongoing nearly four decades later, and is even picking up pace in recent years.

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DISCUSSION OF THE DYING ROLE

Noyes and Clancy (1977) discussed open communication between health care providers and patients as being essential to establishment of the “dying role.” They stated that “the notion that dying persons may be overwhelmed by learning about their prognosis remains unsupported, and unilateral decisions to withhold information ignore a person’s right to it and the likelihood that he is already aware of it” (p. 44). This statement has been borne out by empirical data. Research has shown that 65% of elderly individuals, including those who would be considered “frail” (i.e., those with a disability) would want to discuss their prognosis if their doctor estimated they had less than five years to live, and 75% would want to discuss it if the estimated survival was less than one year (Ahalt et al., 2012). Participants in that study reported that information about their prognosis would allow them to appreciate the time they had left and to prepare for medical and personal end-of-life matters. Therefore, providing medical information to terminally ill older adults and including them in end-of-life arrangements continue to be two important points to consider in optimizing patient care.

At the time that Noyes and Clancy (1977) wrote their article, it was common for patients to receive little information about their illness from medical personnel. The times certainly are changing with regard to how much patients know about their medical conditions today. This is a consequence of our changing attitude about patient autonomy. Whereas the prevailing attitude in the past was a perceived need to “protect” patients from such information, we now believe that patients have a right to know about their condition and prognosis. In fact, to withhold vital information could be viewed as unethical in the field of medicine. Nonetheless, it is possible that medical professionals may experience anxiety, fear, or reluctance associated with discussing end-of-life matters with patients. Some

of this discomfort may stem from the issue of physician-assisted suicide or euthanasia. Physician-assisted suicide is a topic that has sparked ongoing debate, controversy, and legal issues. As society continues to understand and address problems related to the care for dying individuals, it will be critical to make a clear distinction between (a) a physician who engages in physician-assisted suicide by taking active measures to help patients end their life and (b) a physician who discusses the dying process with patients in an open and honest manner and who does not administer treatments that are unnecessary or inappropriate in view of the patient’s prognosis. These are two very different ways of interacting with patients, and it will be important to educate medical professionals, patients, and society about this distinction.

POSITIVE ASPECTS OF AGING

The way in which dying older adults are cared for in our society may be a reflection of society’s larger view of older adults. In the Western world, old age is often viewed as the stage in life that is primarily characterized by negative outcomes, including declining physical and mental health, reduced functioning, diminished cognitive capacity, and increased dependence on others. This pessimistic view of aging was even more predominant when the authors wrote their piece in 1977, and it continues to reflect many people’s perception of the aging process. However, contrary to this notion is the growing interest in “successful aging” or “positive aging.” This area of research is focused on understanding how individuals continue to function well as they age, and attempting to identify potentially modifiable characteristics or interventions that may enhance older adults’ well-being and functioning (Depp, Harmell, & Jeste, 2014). At the Stein Institute for Research on Aging at the University of California, San Diego, we are conducting a longitudinal study of successful

aging, labeled the Successful Aging Evaluation (SAGE) study. In a sample of more than 1,000 community-dwelling adults enrolled in the SAGE study, aged 50 to 99 years, we examined participants' perception of whether they were aging successfully using a rating scale of 1 (lowest) to 10 (highest). Contrary to expectations, we found that older age was associated with higher self-ratings of successful aging, despite worsening physical and cognitive functioning (Jeste et al., 2013). Psychological characteristics that were most strongly associated with self-rated successful aging were a high level of resilience and a low level of depression. Furthermore, the effects of resilience and depression on self-rated successful aging seemed to be at least as strong as those of physical disability. These results suggest that interventions designed to modify one's level of resilience and depression in older individuals with terminal illnesses could be useful in enhancing subjective well-being.

AGING-ASSOCIATED WISDOM

Understanding of successful aging is related to the concept of wisdom. Wisdom is a complex idea consisting of cognitive, reflective, and affective processes (Ardelt, 2004). Although wisdom is an ancient concept, scientific investigations of wisdom have only recently gained interest. We reviewed the empirical literature on wisdom and identified 31 studies that had proposed a definition of this concept (Bangen, Meeks, & Jeste, 2013). By integrating similar conceptualizations of wisdom across the articles, we were able to identify nine specific subcomponents of wisdom: social decision making and general knowledge of life; prosocial attitudes and behaviors; reflection and self-understanding; acknowledgment of uncertainty; emotional regulation; value relativism and tolerance; openness to new experience; spirituality; and a sense of humor. Wisdom is thought to be associated with growing old, particularly in Eastern cultures (Jeste & Vahia, 2008). In support of this hypothesis, research has shown

that some components of wisdom seem to increase in late life, including social decision making, emotional regulation, and positivity (Jeste & Oswald, 2014; Lim & Yu, 2015). Findings on other components of wisdom are somewhat mixed, and more research is needed to establish how different aspects of wisdom change over the course of the life span (Lim & Yu, 2015).

In addition to the relationship with increasing age, certain life experiences may also play a role in enhancing one's level of wisdom. This may include the experience of having a terminal illness. Given that the end of life provides an opportunity for self-transcendence and self-reflection on life's full trajectory (Vachon, Fillion, & Achille, 2009), patients at this stage may have a unique perspective on the sick role and the dying role. In addition, one's perspective may change after being diagnosed with a terminal illness. As Noyes and Clancy (1977) describe, individuals in the sick role have a duty to want to get well. By contrast, those in the "dying role ... must relinquish unrealistic hope of recovery but must retain the will to live" (p. 42). This transition between roles, therefore, requires that one accept or come to terms with the terminal illness and approaching mortality. Thus, perhaps it may be the enhancement of wisdom that allows terminally ill individuals to move from the sick role to the dying role. If so, this suggests it may be possible to improve the well-being of dying individuals by fostering certain components of wisdom, such as acceptance, self-reflection, acknowledgment of uncertainty, and emotional regulation.

SUCCESSFUL DYING ("GOOD DEATH")

An important lesson that we have learned from hospice patients is that moving from the sick role to the dying role is not about "relinquishing hope," as Noyes and Clancy (1977) described. This was highlighted in a recent qualitative study by Kogan, Penido, and Enguidanos (2015) in which researchers

interviewed 12 seriously ill patients ($M_{\text{age}} = 64$ years). These investigators found that patients did not necessarily “lose hope” when confronted with a terminal illness. A terminal prognosis resulted in patients maintaining their sense of hope; however, patients did redefine their goals. For example, rather than hoping for a cure for their illness, they were hopeful about being in their preferred care setting, being free of pain and other symptoms, and being able to establish or solidify family connections (Kogan et al., 2015). These older patients have taught us that the dying role involves development of wisdom, acceptance, and shifting one’s hopes and goals.

Once one has gained the necessary information about her or his medical condition and has transitioned into the dying role, the final stage is the dying process itself. An extension of the area of successful aging is that of “successful dying.” The concept of successful dying or a good death has evolved over generations. In modern times, it is believed that attributes of a good death include pain and symptom management, awareness of death, patient dignity, family presence, family support, and communication among the patient, family, and health care providers (Granda-Cameron & Houldin, 2012). Taking steps to ensure a good death is critically important to improving care for and the well-being of terminally ill individuals. The setting where one receives care at the end of life may be one factor in determining a good death. A review of the literature by Gomez, Calanzani, Gysels, Hall, and Higginson (2013) identified 130 studies, 95 of which were published since 2000, that reported on individuals’ preferences for place of death. The investigators found evidence from 75% of the reviewed studies that the majority of adults would prefer to die at home. In addition, 10 studies reported that 80% of people did not change their preference for a home death as their illness progressed. Despite people’s desire to die at home, most individuals die in an institutional setting (Teno et al., 2013). There is also evidence that patients who die in hospitals often

have a poor quality of life. This may be related to invasive life-sustaining medical treatments that prolong death, inadequate pain management, and poor patient–physician communication (Granda-Cameron & Houldin, 2012; SUPPORT Principal Investigators, 1995). Therefore, future efforts are needed to assist older adults in having a comfortable home death whenever possible, or to at least keep them out of an acute hospital setting at the end of life.

PALLIATIVE CARE AND HOSPICE MOVEMENT

A significant improvement in the care of dying individuals since Noyes & Clancy’s (1977) paper has been the rapid growth of the field of palliative care, particularly within the past decade (Teno et al., 2013). Palliative care is a medical specialty focused on improving quality of life for patients with serious illness and their families. It involves an interdisciplinary team, including physicians, nurses, social workers, chaplains, and other professionals. In the United States, palliative care interventions are currently most often provided in an acute care hospital (Kelley & Morrison, 2015). Hospice is a related but separate term that describes care delivered to patients who are in the final six months of their life. Given most patients’ preference to die at home, there has been an increased focus on home-based models of hospice. According to Kelley and Morrison (2015), hospice care in the United States is most often provided in patients’ homes, in addition to settings such as assisted-living facilities, nursing homes, and residential hospice facilities. Data show that the percentage of older adults dying at home increased from 15% in 1989 to 24% in 2007 (Teno et al., 2013). This is certainly a step in the right direction. However, there is still much to be done to increase the utilization of palliative care and hospice services. For example, Teno and colleagues (2013) reported that referrals to hospice often occur late in the dying

process, resulting in very short hospice care (e.g., three days) following a lengthier stay in an acute hospital setting.

In sum, Noyes & Clancy's (1977) compelling paper on the sick role and the dying role in our society continues to be highly relevant to the care of older adults, a rapidly growing segment of our population. People are becoming more aware of the issues surrounding the care of dying individuals, and progress has been made with regard to the provision of palliative care services and home-based hospice care. The field of successful aging has shown us that there are positive aspects to growing old, including improvements in emotional health and aspects of wisdom. Interviews with patients who are terminally ill have also shed light on the importance of active

coping, acceptance, and maintaining hope; these factors may prove critical in helping one transition successfully from the sick role to the dying role. In addition, we are beginning to understand the qualities of a good death, including many people's desire for open communication regarding prognosis and their preference to die at home. However, there is considerable room for improvement, as evidence shows that patients often do not receive optimal care at the end of life (e.g., frequent death in acute hospital settings; late hospice referrals). Thus, conducting further research and providing more education to both health care professionals and the general public is vital in order to best implement a dying patient's wishes and to make the end of life as fulfilling as life itself.

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