

The Use of Palliative Care to Promote Autonomy in Decision Making

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This article explores barriers to informed decision making in health care, and it proposes palliative care as one means of responding to the challenge of a widespread lack of autonomy in decision making. Through an exploration of research in the fields of autonomy and palliative care, the advantages of informed decision making and advance care planning by patients with advanced illness are discussed, and the implications for clinical practice and patient outcomes are described. Continuity, collaboration, and communication have a synergistic effect on autonomy. The expectation that the palliative care team will be in constant communication with the attending physician, nurses, and other specialists also promotes autonomous decision making. Patients who receive palliative care may have multiple advantages, including increased survival, improved quality of life, and opportunities for the exercise of autonomy.

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Healthcare delivery is structured with the expectation that recipients of that care will exercise autonomy in decision making. The reality of autonomous decision making remains elusive, however. Although control has ostensibly shifted to consumers, many who access health care have little or no preparation for making informed decisions that will allow them to exercise autonomy (Porter-O'Grady & Malloch, 2007). Autonomy has been described as one of the four major ethical principles (Beauchamp & Childress, 2001), and the principle of autonomy is widely accepted in the United States, as well as in other Western countries (Tong, 2007). Autonomy may be defined as the "right of a capable person to decide his/her own course of action" (Hospice and Palliative Nurses Association [HPNA], 2003, p. 236). An autonomous person possesses a set of values and goals, deliberates, arrives at a decision, and then communicates this decision to others (Tong, 2007). In this article, the authors will explore some barriers to the exercise of autonomy in health care today and propose palliative care as one means of addressing the challenge of a widespread lack of autonomy in decision making.

Palliative care is defined by the Center to Advance Palliative Care (CAPC) as an interdisciplinary approach to the care of patients diagnosed with a life-threatening illness, along with their families (Meier, Spragens, & Sutton, 2004). Goals of this comprehensive care are relief of symptoms and pain produced by serious illness, improvement in quality of life (CAPC, 2012), and promotion of self-determination (CAPC, 2009). Care is provided regardless of the stage of disease (National Consensus Project for Quality Palliative Care, 2004) and may be concurrent with curative treatment (American Academy of Hospice and Palliative Medicine, 2008). Palliative care also provides the assurance of continuity of care across delivery settings (Ferrell et al., 2007).

Among the chronically ill, the need for decision making is particularly salient. As the proportion of this group in the general population continues to increase, the challenge created by a failure to exercise autonomy will also increase. Palliative care addresses the needs of the chronically ill throughout the continuum of illness in a holistic manner: physically, intellectually, emotionally, socially, and spiritually. Major aspects of palliative care are the facilitation of patient autonomy, access

to information, and choice (HPNA, 2013a). Ideally, discussion of goals should occur at the outset of a serious diagnosis (Dawson, 2008). Early involvement of a multidisciplinary team can assist with patient-centered care and improve communications.

During this process, a palliative care approach views the patient holistically. Palliative care focuses not on the disease, but rather on the person and his or her illness experience. Eric Cassell, professor emeritus of public health at Cornell University, has published much about moral problems in medicine and care of the dying. In his seminal 1982 work, Cassell berated his colleagues for not considering the suffering of people in regard to their disease state and the sequelae of treatment. When healthcare professionals fail to engage the whole person and his or her illness experience, they also concomitantly fail to support autonomy. Palliative care treats the patient and family as the *unit of care*, or the person and his or her intimate community. With disease progression, the family may need to act on behalf of the ill person. Therefore, a mutual benefit accrues when the patient and his or her family are included in advance care planning and ongoing discussions.

Background

Before delving into barriers to the exercise of autonomy, changes in treatment approaches should be understood. The movement of health care and care of the seriously and terminally ill to institutions has created a lack of experience among the public with the usual progression of disease and death. In addition, individuals with chronic illnesses are living longer—a change for which neither the public nor the healthcare system was prepared (Meier et al., 2004). These changes have not only altered the manner in which health care is delivered and where it is delivered, but, more critical to the exercise of autonomy, they also have increased the need for advance and progressive planning. Today, death may be viewed as a failure of medical care by both the public and clinicians (Kiernan, 2007). Many Americans unfortunately believe that medical science can offer a cure to any patient for any disease state (Malloy, Virani, Kelly, Harrington-Jacobs, & Ferrell, 2008). Palliative care can help to clarify misconceptions and to provide information about diagnosis and prognosis.

Overcoming Barriers to Autonomy

Four particularly cogent reasons for advance planning at the time of diagnosis exist. First, the timing avoids confusional states that can occur as disease advances (Melhado & Byers, 2011). Second, an early discussion allows for a less emotionally fraught alignment of goals among patient, family, and healthcare providers. Third, dissonance between patients and proxy decision makers in end-stage disease may be avoided or, at least, mitigated. Finally, compelling research by Temel et al. (2010) found that patients who are provided with palliative care in addition to active treatment at the time of diagnosis actually had longer median survival times than those who did not.

Allowing a confused patient to engage in decision making may be a clear breach of informed consent (Melhado & Byers, 2011). Many patients on life support may be incompetent

because of medications or other variables. Zomorodi and Bowen (2010) reported that less than 10% of those in the intensive care unit are competent to make medical decisions.

Proxy decision makers are more likely to prolong treatment in the absence of a clear statement by the patient, fearing disapproval from other family members (Winter & Parks, 2008). Advance discussion of a patient's goals of care provides an opportunity for the patient to explore decisions with his or her family and healthcare provider in a frank, open exchange. Advance planning with the palliative care team and other healthcare providers enables clearer communication. The expectation is that discussions will continue and that patient-centered goals may be realigned as illness progresses.

A study of family discord and decision making (Winter & Parks, 2008) found that greater family discord in decision making was associated with stronger preferences for life-prolonging care. In addition, an association was found between lower family discord and preferences for palliative care. In another study, clinicians and proxy decision makers were frequently incorrect in predicting the medical decisions of a family member (Uhlmann, Pearlman, & Cain, 1988). These findings, and findings from others such as Melhado and Byers (2011), support the benefits of advance planning when autonomy can be exercised directly.

Fragmentation of care is another barrier to the exercise of autonomy. Patients with chronic illness or multiple comorbidities may have numerous specialists who provide care. This may cause fragmentation of care when communication among specialty and primary care providers is inadequate (Zomorodi & Bowen, 2010). Patients and families may have difficulty in understanding diagnosis and prognosis, particularly when conflicting messages from different specialties are received or perceived. Melhado and Byers (2011) reported that, in 76% of the studies they reviewed, poor communication and overly optimistic prognostication contributed to the continuation of life-prolonging treatments. Maltoni et al. (2005) found that better prognostication is a means to support patient autonomy because it aids in decision making and planning.

Although legislation to facilitate advance healthcare planning, or advance directives, has been present since 1991 with the passage of the Patient Self-Determination Act, public lack of understanding, apathy, and avoidance remain as barriers. Tong (2007) found that research shows that only 20% of adults have a living will. To complicate matters, many adults who do have a living will fail to communicate its contents to their families or their healthcare providers (Morrison, 2009). In the authors' experience, public education sessions on advance planning are often poorly attended, but efforts should continue because the subject is of critical importance.

Time constraints, concerns about misinterpretation, or fear of taking away hope often prevent discussion of advance planning in the context of physicians' daily practice. These discussions are also not billable under existing statutes. However, providers who do engage in these discussions have enhanced their relationships with their patients (Morrison, 2009). Palliative care providers, unlike other providers, are able to devote significant time to the discussion of patient goals. Although providers may be concerned about decreasing the patient's hope with early end-of-life planning, the alternative is a sudden discussion in the midst of a change in health status.

Promotion of Autonomy in Decision Making With Palliative Care

Discussions about goals of care when patients are critically ill may not be conducive to the exercise of autonomy. Palliative care, instituted early, provides a holistic approach, balancing psychosocial issues, care concerns, and prognostication. Palliative care can promote autonomous decision making at any point in the disease trajectory. However, the earlier the introduction of palliative care, the greater the opportunities for exercising autonomy and the better the patient outcomes (Temel et al., 2010).

The concept of palliative care is not well understood by many, including healthcare providers and the public at large. People often ask, “Isn’t palliative care the same as hospice?” All hospice is palliative care, but not all palliative care is hospice. Palliative care is broad in scope, and no specific treatment is excluded with palliative care (National Hospice and Palliative Care Organization [NHPCO], 2009), whereas hospice care is restricted to the pursuit of comfort care only. Educated providers do understand the breadth and benefits of palliative care, as they understand the value of other specialties. Palliative care creates mutual advantages for primary care providers and patients: Primary care providers receive assistance with complex cases, and patient autonomy is promoted.

Determination of patient goals during the palliative care process is an aspect particularly connected to autonomy. Doing so allows patients and families the opportunity to explore choices of the type, aggressiveness, and duration of medical treatment with the healthcare team. Palliative care also allows patients and families to learn about the alternatives to an all-or-nothing approach to health care. Palliative care providers can facilitate conversations in advance about the range and types of care that can be provided and under what circumstances. Once an understanding is accomplished, the patient and family then can discuss choices that are consistent with their values with the healthcare team. The result of this process will be the exercise of autonomy in decision making and advance planning, and the person in the midst of a disease, along with his or her quality of life, has become the focus.

Palliative care providers educate patients and their families about disease trajectories. Understanding trajectories is critical to the exercise of autonomy. For example, although the course of dementia tends to be long and gradual, patients with cancer tend to maintain functionality until about two months before death (Agency for Healthcare Research and Quality [AHRQ], 2003).

Other disease states—such as congestive heart failure, diabetes, or chronic obstructive pulmonary disease—exist where acute exacerbations with recovery occur, but each recovery is followed by a decline in overall health (AHRQ, 2003). Discussions about the probable trajectory will further prepare the patient and family to pursue individualized goals that allow for the exercise of autonomy.

Exercise of autonomy should occur along the entire trajectory of illness to the end of life. An ongoing relationship with the palliative care provider, in addition to other healthcare providers, creates trust, prevents the fear of abandonment, and provides care at the level of need, which tends to vary along

the disease trajectory. Palliative care providers will discuss and facilitate continuity of care, with settings and services that are required by patient and family. Murray, Fiset, Young, and Kryworuchko (2009) learned that assumptions should not be made—a preference for death at home is one example. Rather, care should be tailored to the individual and his or her stated goals. Follow-up care may be provided to family members during the bereavement period (NHPCO, n.d.). Knowing that the needs of loved ones will be supported after death may provide comfort to the ill person. Therefore, throughout the trajectory, decision making occurs in the presence of patient-specific information.

Palliative care has an interdisciplinary focus. A collegial, collaborative atmosphere pervades holistic care. Palliative care teams include some or all of the following: physician, advanced practice nurse, nurse, social worker, case manager, chaplain, dietitian, palliative rehabilitation therapist, pharmacist, and psychological counselor (National Consensus Project for Quality Palliative Care, 2004). Input from multiple disciplines with different perspectives informs decision making by patients and families.

The expectation that the team will be in constant communication with the attending physician and other specialists also promotes autonomous decision making. Multidirectional, patient-centered communication is essential to the provision of palliative care. Therefore, continuity, collaboration, and communication have a synergistic effect on autonomy.

Some may predict that early enrollment in a palliative care program might have a negative effect on patient outcomes. When comparing patients who received early-onset palliative care to those who received standard care, Temel et al. (2010) found that significantly fewer patients in the early-onset palliative care group received aggressive end-of-life care, but that they had longer median survival times.

In addition, patients receiving palliative care had improved quality of life and decreased rates of depressive symptoms (Temel et al., 2010). Temel et al. (2010) also determined that fewer patients in the standard care group had discussed resuscitation preferences in advance. Therefore, patients receiving palliative care in this study had multiple advantages: increased survival, improved quality of life, and more opportunities for the exercise of autonomy (Temel et al., 2010).

Caring Connections

www.caringinfo.org

Center to Advance Palliative Care

www.capc.org

End-of-Life Nursing Education Consortium

www.aacn.nche.edu/el nec

End of Life/Palliative Education Resource Center

www.eperc.mcv.edu

Hospice and Palliative Nurses Association

www.hpna.org

National Consensus Project for Quality Palliative Care

www.nationalconsensusproject.org

Relias Learning

www.reliaslearning.com

FIGURE 1. Additional Resources

Implications for Practice

- ▶ Understand that many patients have little or no preparation for making informed decisions that will allow them to exercise autonomy, although they are often expected to do so.
- ▶ Use position of trust and knowledge about the principles of palliative care to facilitate patient autonomy.
- ▶ Raise awareness that palliative care may be one way to promote autonomy in decision making.

Implications for Nursing

The need for education about palliative care among physicians, nurses, and other healthcare providers is becoming more evident because of the prevalence of chronic disease (Meier et al., 2004). Physicians should become familiar with the National Consensus Project for Quality Palliative Care, the National Quality Forum, and the CAPC (NHPCO, 2008). For nurses, the End-of-Life Nursing Education Consortium provides instruction in the principles of palliative care. The American Academy of Nursing (2013) and the HPNA (2013b) have published position statements on advance planning, stating that it is essential to providing care for those with life-limiting conditions. Healthcare providers who avail themselves of these documents will find high-quality, evidence-based information on the benefits of palliative care. Healthcare professionals must be educated about the principles of palliative care to empower their patients to facilitate autonomy (see Figure 1). A nursing commitment to public education about the need for advance planning must continue at the community level, beyond the institution. Nurses remain in a unique position as trusted healthcare professionals to educate the public about this topic.

Conclusion

NHPCO (2008) stated that palliative care is the right of every patient. The National Quality Forum (n.d.) promotes effective communication for those with life-limiting illness. Such communication allows individuals to make informed decisions based on realistic prognostic information, receive timely and honest answers to questions, and be assured of a commitment that they will not be abandoned, regardless of their choices. Lavoie, Blondeau, and Picard-Morin (2011) demonstrated that those with advanced illness attach great importance to their providers' respect for autonomy. These statements demonstrate the critical nature of advance and continued planning, personal participation in decision making, and the right to comprehensive care. A stated goal of palliative care is to facilitate autonomy (HPNA, 2013b). Honoring that goal, healthcare providers may then be able to assist patients with life-limiting illness to make decisions and gain control of their lives (CAPC, 2009).

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