

Résumé

**L'autodétermination :
analyse du concept et implications
sur la recherche dans le domaine
des soins palliatifs**

Marie A. Bakitas

Cet article analyse l'évolution, la définition, l'emploi courant et l'application du concept d'autodétermination dans le cadre de la recherche et de la pratique en soins palliatifs. L'analyse présentée vise à servir de base au développement du programme de recherche sur les soins palliatifs. L'auteure examine une littérature choisie portant sur les soins de santé aux adultes atteints d'une maladie chronique ou mortelle, notamment sur l'aspect historique, bioéthique, clinique, médical et infirmier. À partir d'une synthèse de la documentation, celle-ci propose une définition conceptuelle tout en identifiant des moyens d'intégrer le concept d'autodétermination dans la recherche portant sur les interventions palliatives.

Mots clés : autodétermination, soins palliatifs

Self-Determination: Analysis of the Concept and Implications for Research in Palliative Care

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This paper analyzes the evolution and the definition, current use, and application of the concept of self-determination in palliative care research and practice. Undertaken as a foundation for the development of a palliative care research program, the analysis considers selected historical, bioethical, legal, clinical, and relevant medical and nursing health-care literature on adults with chronic and terminal illness. Based on a synthesis of the literature, a conceptual definition is proposed and ways of integrating the concept of self-determination into palliative care intervention research are identified.

Keywords: self-determination, autonomy, concept analysis, integrative review, palliative care, Rodgers method

Introduction

The goal of palliative care is to improve the quality of living and dying of patients with life-limiting illness (World Health Organization, 1990). A tenet of palliative care philosophy is the determining, acknowledging, respecting, and honouring of patients' values and wishes as they approach the close of life (von Gunten, Ferris, Portenoy, & Glajchen, 2001). The concept of self-determination is embodied in this philosophy. Experts in palliative care see the enhancement or support of self-determination as one way of improving the quality of a patient's final days (American Geriatrics Society Ethics Committee, 1998; American Nurses Association [ANA], 2001; Ferris et al., 2002; National Hospice Organization, 1997). How can key aspects of self-determination best be integrated into palliative care practice and research? A concept with such a high degree of abstractness is not easily translated into everyday clinical practice. The task is further complicated if one attempts to identify, describe, measure, or design interventions that exemplify an amorphous concept to improve the care of persons with serious illness. A first step is to return to the literature in order to examine the evolution and current use of the concept (Rodgers, 2000). Self-determination has evolved from its societal origins as the right of a people to be free, independent, and protected

from oppression, to its application in health care through laws and bioethical principles. In 1991 the *Patient Self-Determination Act (PSDA)*, a milestone in the evolution of palliative care in the United States, decreed that health professionals have an obligation to recognize patient choice in health-care decision-making (*Omnibus Budget Reconciliation Act [OBRA] of 1990*, 1990). Since then, many attempts have been made to formally integrate principles of self-determination into palliative care practices, quality improvement activities, and research.

This paper analyzes the evolution and the definition, current use, and application of the concept of self-determination in palliative care research and practice. Undertaken as a foundation for the development of a palliative care research program, the analysis considers selected historical, bioethical, legal, clinical, and relevant medical and nursing health-care literature on adults with chronic and terminal illness. Based on a synthesis of the literature, a conceptual definition is proposed and suggestions for integrating the concept of self-determination into palliative care intervention research are identified.

Sample and Setting

A literature search was conducted to examine the concept of self-determination in palliative care using Rodgers's (2000) evolutionary method. The purpose of the search was to identify literature on the origin, definitions, attributes, antecedents, consequences, and exemplars of the concept. Computer searches for the years 1985 through 2003 using MEDLINE, the Cumulative Index to Nursing and Allied Health (CINAHL), and PsycINFO were conducted using the search terms self-determination, *Patient Self-Determination Act*, autonomy, advance care planning, and advance directives, which were then joined with the terms palliative care and terminal care. The original 516 cited titles and abstracts were then reviewed for relevance using the following criteria: historical background, focus on a cancer or palliative adult population, and use of the concept prior to and following the passage of the *PSDA*. Articles and reference lists were then reviewed for relevance. Pertinent articles from the reference lists were also examined.

One study (SUPPORT Principal Investigators, 1995) generated more than a hundred articles (some identified through the initial search and the remainder in reference lists). Only two of the most representative and relevant articles reporting study results (Covinsky et al., 2000; SUPPORT Principal Investigators, 1995) and three analyzing the meaning of the findings (Lynn et al., 2000; SUPPORT Principal Investigators, 1997; Teno, 1998) were included in the analysis.

A preponderance of the literature cited the *PSDA*, a US law; however, several international studies exploring the related concept of “family determination” were identified. This literature was retained and analyzed to assist in concept clarification.

Also reviewed were two Institute of Medicine reports on improving end-of-life care and palliative care in cancer (Field & Cassel, 1997; Foley & Gelband, 2001), literature on background ethics (e.g., *Code of Ethics for Nurses*) (ANA, 2001), historical and legal materials (including electronic sources), the National Hospice Organization’s (1997) *A Pathway for Patients and Families Facing Terminal Illness*, a chapter from a major palliative care text, and a study of the “concept analysis” of self-determination in a population of long-term psychiatric patients (Valimaki & Leino-Kilpi, 1998). A total of 65 references met the criteria for inclusion.

Concept Analysis Results

The results of the literature analysis are organized as follows: historical context, definitions and attributes, antecedents, consequences, and exemplars.

Historical Context

Self-determination has origins in societal, ethical, legal, and, more recently, health-care, contexts. Regardless of context, a pattern of protecting and promoting self-determined choice is seen most vividly in response to oppression of an individual or group. Historically, a period of oppression often resulted in the adoption of rules or laws protecting the rights of the oppressed group. An early example of self-determination in a societal context is the 1620 voyage of Separatist Puritans to North America aboard the *Mayflower* seeking freedom from religious oppression (Pilgrim.net, 2002). This concept essentially gave birth to the United States and is pervasive in common law, in the *Declaration of Independence* and the *US Constitution* (THOMAS Web-based historical documents, 2002).

The concept of self-determination in health care grew out of the need for individual (patients’) rights. Before the advent of medical discoveries related to the prevention or treatment of fatal diseases and conditions, patients with illnesses such as cancer experienced deterioration and death. The role of doctors and nurses was to provide comfort in the progression towards “natural death.” As more and more means of fighting disease or prolonging life became available (e.g., antibiotics, vaccines, chemotherapy, cardiopulmonary resuscitation), patients could no longer passively await death with a caring doctor or nurse standing by to offer comfort (Robinson & Mylott, 2001). Physicians employed the new tools

to postpone or prevent death. Death was the enemy, to be defeated at all costs.

Thus evolved the practice of medical care in which every possible therapy was used simply because it existed. This phase of health care was marked by a paternalistic approach whereby the physician determined which therapies would be applied (Gadow, 1989) based on anecdote, experience, and availability — there being a dearth of scientific evidence. Rarely were patients' treatment preferences considered (Gadow). Nurses and patients played a passive role. Nurses followed doctors' orders and provided care that was consistent with a "death-defeating" approach, while patients accepted the care and treatments provided without question. Patient self-determination or choice was in the background, if present at all.

A legal precedent in self-determination was set by a 1914 ruling by New York Supreme Court Justice Cordoza: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body and cannot be subjected to medical treatment without his consent" (*Schloendorff v. Society of New York Hospital*, 1914). Throughout the 1960s and 1970s more obvious applications of the concept of self-determination emerged in biomedical ethics (Beauchamp & Childress, 2001) and health-care legislation (Bradley & Rizzo, 1999; Meisel, 1998), in response to violations against vulnerable populations such as prisoners and the seriously ill. In research, self-determination was clearly transgressed in the use of unwilling, uninformed subjects (e.g., Nazi prisoner experimentation and the Tuskegee syphilis study) (Bradley & Rizzo; Department of Health, Education and Welfare, 1979). In the early years, scientific inquiry with human subjects placed a higher value on the knowledge to be gained than on the lives of subjects, resulting in many human rights violations (Katz, 1992).

In response to these events, efforts to protect basic human rights and autonomy and self-determination in health research were widely supported (Bradley & Rizzo, 1999). The 1979 Belmont Report set out ethical principles and guidelines for the protection of human research subjects (Department of Health, Education and Welfare, 1979). It defined autonomous decision-making (informed consent) and outlined protections for persons at risk for diminished autonomy (e.g., subjects of biomedical research) based on ethical principles such as the bioethical principle of respect for autonomy embodied in the value of self-determination and its related clinical ethical practices of truth-telling, information disclosure, and informed consent (Fan, 1997). Protection for health-care consumers came somewhat later.

In clinical practice, paternalism and indiscriminate use of life-saving technologies in health care was viewed by some as oppression (Gadow,

1989; Robinson & Mylott, 2001; Salem, 1999). As a result, basic human rights in medical care began to dominate public and health-care discourse. Concerns about the inappropriate use of life-sustaining treatments and the absence of patient self-determination in medical decision-making culminated in the US Supreme Court case *Cruzan v. Director, Missouri Department of Health and Human Services* (cited in Bradley & Rizzo, 1999). The decision in this case of a 25-year-old woman left in a permanent vegetative state after a car accident affirmed the importance of formally documenting one's treatment wishes in advance of a medical crisis. In 1989, months after the Cruzan decision, a bill was proposed (and ultimately passed under the federal Medicare/Medicaid-related *OBRA of 1990*) according responsibilities to institutional health-care providers with respect to advance directives (*OBRA of 1990*, 1990). These provisions grew out of an earlier (1989) version of the *PSDA*.

The central patient right addressed by this legislation was that of autonomy. The Act accorded patients the right to access information pertaining to decision-making about their care, to accept or refuse treatment, and to issue advance directives. As interpreted by Meisel (1998), "the *PSDA* does not apply solely to information about advance directives but rather applies to a patient's medical decision-making rights in general" (p. 52). Medical decision-making was later defined as inclusive of "consent to treatment, informed consent, and end-of-life decision-making" (p. 52). Appendix 1 summarizes key aspects of the *PSDA*.

In nursing, self-determination is grounded in the *Ethical Code for Nurses* of the American Nurses Association (ANA). In Canada both the *Code of Ethics for Registered Nurses* and the *Joint Statement on Advance Directives* uphold the "client's right to self-determination" (Canadian Nurses Association, 1994, 2002). In the United States the ANA originally generated its code in 1950 and revised it in 1960, 1968, 1976, 1985, and 2001 (Daly, 2002). The 1985 version was heavily influenced by aspects of self-determination and concepts directly applicable to end-of-life nursing care (Scanlon, 1996). Specifically, it encouraged nurses to assess patients' ability to make decisions about end-of-life care; defend patients' care wishes and promote their freedom to make end-of-life decisions; prevent and/or relieve suffering associated with dying; evaluate the benefits and drawbacks of treatment to the patient; and support decisions on the withdrawal or withholding of treatments (including cardiopulmonary resuscitation, artificial nutrition, and hydration) (Scanlon). These interpretations and ANA position statements in the 1990s were an attempt to protect the vulnerable population of dying patients with regard to issues that could greatly affect the quality of their living/dying (e.g., assisted suicide, withholding of food and fluids, provision of adequate pain relief).

An additional historical trend in self-determination comes from social sciences research. Deci and Ryan (1985) propose a theory of intrinsic motivation and self-determination to explain human behaviour. According to this theory, human beings can be proactive and engaged or passive and alienated largely as a function of the social conditions under which they develop and survive. Autonomy, in addition to competence and relatedness, is postulated as an innate psychological need: when satisfied, it yields self-motivation and mental health; when unsatisfied, motivation and well-being are decreased. This theory has been applied to research in education, work, sport, religion, psychotherapy, and health care. In health care, self-determination theory has been applied to alcohol treatment, weight loss in morbidly obese patients, smoking cessation, glucose control, and medication adherence (Ryan & Deci, 2000; Williams, Rodin, Ryan, Grolnick, & Deci, 1998). No studies of self-determination theory in palliative or end-of-life care were found.

Definition and Attributes of Self-Determination

Self-determination is defined as “free choice of one’s own acts or states without external compulsion; determination by the people of a territorial unit of their own form of government, future political status, without coercion or outside influence” (Merriam-Webster OnLine, 2003). It generally refers to the rights of both a people and an individual and is broadly thought to include the principles of liberty, privacy, individual choice, free will, and being one’s own person (Beauchamp & Childress, 2001). Synonyms and related terms include autonomy, independence, choice, decision-making, empowerment, and freedom. The terms autonomy and self-determination are often used as surrogates (ANA, 2001). Autonomy comes from the Greek *autos*, or self, and *nomos*, rule or governance, whereas self-determination is the process of exercising one’s right to autonomy.

As concepts become more abstract, “their reality basis and their empiric indicators become less concrete and less directly measurable” (Chinn & Kramer, 1999, p. 55). Self-determination is relatively abstract as a concept, its definition broad and context-dependent. In Western bioethical principles, it is a “subjective conception of the good and promotes the value of individual independence” (Fan, 1997, p. 309). As a right of persons and patients, it is defined as a process related to expression of the ethical principle of respect for autonomy (Beauchamp & Childress, 2001). It is also defined as the opposite of paternalism (Gadow, 1989; Sutherland, Llewellyn-Thomas, Lockwood, Tritchler, & Till, 1989). In law, self-determination has a very specific definition. The OBRA regulations state that patients are entitled to be aware of and use advance directives when they enter a facility that accepts Medicare funding

(Meisel, 1998; *OBRA of 1990*, 1990). Additional aspects of the law are summarized in Appendix 1.

Nordgren and Fridlund (2001) interviewed 17 Swedish hospitalized medical and surgical patients in order to define self-determination from the patient's perspective. Responses to the question "How do you perceive that your right of self-determination finds expression in the context of care?" produced the themes of trust in the health-care team, acceptance of the care that is provided, and feelings of powerlessness. The patients did not feel empowered to participate in decision-making and lacked the information on treatment strategies necessary to do so. Hence, instead of supporting the attribute of self-determination, they identified characteristics of its absence.

Proponents of assisted suicide use the term "ultimate self-determination," defined as the patient's right to choose the time and place of death (Baginski, 1992; Folker et al., 1996; Swarte & Heintz, 1999). While assisted suicide is prohibited by law in most US states, some also question its ethical soundness and its consistency with the principles of self-determination, as it conflicts with the fundamental ethical principles of professional autonomy and non-maleficence (Burt, 2002; Low & Pang, 1999; Muller-Busch, 2001; Salem, 1999). Salem argues that instead of supporting autonomy, assisted suicide (which requires physician sanction and prescription of a lethal combination of medications) is actually an impediment to self-determination, its parameters returning "ultimate authority over this 'private and deeply personal' decision to medicine and society" (p. 30).

Four characteristics of self-determination were identified in the literature: personal (self-) appraisal, decision-making process, activities, and goals or outcomes (see Table 1). *Personal appraisal* requires the mental capacity, functional "strength," freedom, power, and information to evaluate one's values and preferences related to health-care decision-making. Koenig (1997) describes seven attributes of individual self-determination in Western culture (see Table 2). These can be summarized as the need for information, desire for control, freedom, openness, personal health beliefs about the future, religion, and family. They are quite specific and suggest that patients possess a relatively high level of sophistication, particularly with regard to Western cultural beliefs. Koenig challenges the notion that these attributes apply to patients of different cultural backgrounds and different value structures related to individual autonomy. Similarly, Fan (1997) proposes that an East Asian definition of autonomy requires family-determination, "an objective conception of good [that] upholds the value of harmonious dependence" (p. 309). Valimaki and Leino-Kilpi (1998) conducted a "concept analysis" of self-determination based on content analysis of qualitative interviews with 72 long-term

Table 1 *Attributes of Self-Determination in Various Sources*

Attribute	Ethical	Legal	Health Care
<p>Personal appraisal</p> <ul style="list-style-type: none"> • possessing physical and emotional strength • possessing power • possessing knowledge • possessing mental capacity • not controlled by others 	<p>ANA (1991); Department of Health, Education and Welfare (1979); Gadow (1989); Scanlon (1996); Sutherland et al. (1989)</p>	<p>Bradley & Rizzo (1999); Low & Pang (1999); Meisel (1998); Salem (1999)</p>	<p>Koenig (1997); Nordgren & Fridlund (2001); Valimaki & Leino-Kilpi (1998)</p>
<p>Decision-making process</p> <ul style="list-style-type: none"> • advance care planning for when capacity is diminished • refuse or accept care or treatment • rights of others not violated • continuity of providers 	<p>ANA (2001); Baginski (1992); Beauchamp & Childress (2001); Bradley & Rizzo (1999); Department of Health, Education and Welfare (1979); Fan (1997); Gadow (1989); Hern et al. (1998); Katz (1992); Koch et al. (1999); Koenig (1997); Quill (2002); Ruhnke et al. (2000); Scanlon (1996); Swarte & Heintz (1999)</p>	<p>Bradley & Rizzo (1999); Cerminara (1998); Engel et al. (1997); Haynor (1996); Meisel (1998); <i>OBRA of 1990</i> (1990); Ott (1999); Salem (1999)</p>	<p>Nordgren & Fridlund (2001); Valimaki & Leino-Kilpi (1998)</p>

<p>Activities</p> <ul style="list-style-type: none"> • completing values history • provider- or patient-initiated discussions; family conferences • making a living will or appointing a proxy (durable power of attorney for health care) • completing “do not resuscitate” order • choosing “comfort measures” • completing unfinished business (relationships, finances, funeral) 	<p>American Geriatrics Society Ethics Committee (1998); ANA (2001); Candib (2002); Cantor (1998); Cerminara (1998); Engel et al. (1997); Havens (2000); Haynor (1996); Johnston et al. (1995); Miller (1991); Murphy et al. (2000); Ott (1999); Ruhnke et al. (2000); Scanlon (1996)</p>	<p>Bradley & Rizzo (1999); Cerminara (1998); Engel et al. (1997); Haynor (1996); Meisel (1998); <i>OBRA of 1990</i> (1990); Ott (1999); Salem (1999)</p>	<p>Havens (2000); Haynor (1996); Robinson & Mylott (2001); SUPPORT Principal Investigators (1997)</p>
<p>Goal/outcome</p> <ul style="list-style-type: none"> • self-determined life closure • peaceful death 	<p>ANA (2001)</p>		<p>National Hospice Organization (1997)</p>

Table 2 *Attributes of a Self-Determined Patient:
The Western Perspective*

- a clear understanding of the illness, prognosis, and treatment options, which is shared with the members of the health-care team
- a temporal orientation to the future and a desire to maintain control into that future
- the perception of freedom of choice
- a willingness to openly discuss the prospect of death and dying
- a balance between fatalism and belief in human agency that favours the latter
- a religious orientation that minimizes the likelihood of divine intervention (or other “miracles”)
- an assumption that the individual, rather than the family or any other social group, is the appropriate decision-maker

Source: Koenig (1997).

psychiatric patients; the patients’ personal appraisal focused on the importance of freedom of choice, access to power, and having the active support of others in pursuing their goals.

The characteristic of *decision-making process* is central in the *PDSA*. It is clearly specified as well in the ANA’s (2001) *Ethical Code for Nurses*, which also speaks to the role of nurses in enhancing the patient’s right to self-determination in terms of accepting, declining, or terminating treatment without “deceit, undue influence, duress, coercion, or penalty” (Provision 1, Section 1.4, “The right to self-determination”). Nurses are obliged to provide support throughout the decision-making process. The *Ethical Code for Nurses* speaks specifically to the patient’s right to elicit the support and advice of family members, partners, and nurses and other health professionals (Valimaki and Leino-Kilpi, 1998). More recent sources identify the role of the patient-appointed proxy in decision-making when the patient no longer possesses the ability to make decisions (Sullivan, 2002). The proxy, whether informal (family) or formal (health professional), must possess sufficient knowledge of the patient’s values and preferences to determine what care the patient would choose or refuse (Meisel, 1998). The standard is one of “substituted judgement” (recreating the patient’s choice), in contrast to “best interest” (doing what the proxy’s believes to be in the patient’s best interest) (Sullivan).

The third attribute, *activities*, refers to the many manifestations of self-determination, most notably the issuing of advance directives (Cantor, 1998; Cerminara, 1998; Engel et al., 1997; Havens, 2000; Ott, 1999;

SUPPORT Principal Investigators, 1997) but also issuing “do not resuscitate” orders, requesting “comfort care,” and attending to unfinished business (National Hospice Organization, 1997; Robinson & Mylott, 2001). Fear of over-treatment and desire for control are characteristic of persons who engage in these activities (Eisemann & Richter, 1999), an important legal aspect of which is the fact that self-determination supersedes the patient’s ability to state treatment preferences and allows for the appointment of a proxy (durable power of attorney for health care).

Lastly, *goals or outcomes* refers to the wishes that a patient hopes to fulfil as a result of self-determination, primarily with regard to dying on his or her own terms (Fan, 1997; Nordgren & Fridlund, 2001; Silveira, DiPiero, Gerrity, & Feudtner, 2000; Tulsky, Fischer, Rose, & Arnold, 1998). The goal of hospice care, as identified by an expert panel of the National Hospice Organization, is “self-determined life closure”: “Anticipating death, mentally competent patients will have full autonomy to make decisions about how the remainder of their life is spent within the allowances of law” (National Hospice Organization, 1997, p. 5).

In summary, self-determination is defined in the palliative care literature as an ethical principle, a right, a law, a care process, and an outcome of expert palliative care (ANA, 2001; Beauchamp & Childress, 2001; Koenig, 1997; Meisel, 1998; National Hospice Organization, 1997; *OBRA of 1990*, 1990). Its attributes include personal appraisal of individual rights, power, freedom of choice, decision-making process, activities, and outcomes. Following passage of the *PDSA*, activities of self-determination became more formalized through the use of a living will and/or the appointment of a health-care proxy (Bradley & Rizzo, 1999; Eisemann & Richter, 1999; Havens, 2000; Meisel; Rodgers, 2000; SUPPORT Principal Investigators, 1995). Palliative care professionals have contributed “self-determined life closure” as an outcome of palliative care. These attributes suggest the following revised definition of self-determination in palliative care: a process of decision-making that includes personal appraisal, the support and advice of others (family, health-care professionals), and activities that result in successful life closure and peaceful death.

Contextual Basis of Self-Determination

According to Rodgers (2000), clarification of a concept involves exploration of the contextual aspects (temporal [antecedents and consequences], socio-cultural, and disciplinary contexts, and exemplars) to gain an understanding of the situations in which the concept is apparent.

Table 3 gives a temporal perspective of self-determination.

Table 3 Temporal Context of Self-Determination

Antecedents	Attributes	Consequences
<ul style="list-style-type: none"> • healthy person with awareness of mortality • “becoming ill”: diagnosed with serious illness; worsening of chronic illness; admission to hospital, ICU, nursing home • reasonable functional status • mental capacity (or DPOA-HC appointment) • cultural/religious orientation • age — frequently older • relationship with health-care provider — primary care, palliative care (assessment or provider-initiated discussion) • information about condition/prognosis • family discussions • education about PDSA 	<p>Personal appraisal</p> <ul style="list-style-type: none"> • possessing physical and emotional strength • possessing power • possessing knowledge • possessing mental capacity • not controlled by others <p>Decision-making process</p> <ul style="list-style-type: none"> • advance care planning for when capacity is diminished • refuse or accept care or treatment • rights of others not violated • continuity of providers <p>Activities</p> <ul style="list-style-type: none"> • completing values history • provider- or patient-initiated discussions; family conferences • making living will or appointing a proxy (durable power of attorney for health care) • completing “do not resuscitate” orders • choosing “comfort measures” • completing unfinished business (relationships, finances, funeral) <p>Goal/outcome</p> <ul style="list-style-type: none"> • self-determined life closure • peaceful death 	<p>Consequences</p> <ul style="list-style-type: none"> • discussions with family, physicians, social workers, lawyers • completion of AD • peaceful death • dying and death not consistent with patient’s wishes • less aggressive care at time of death than desired • family- or physician-determined circumstances around death <p>Organizational consequences</p> <ul style="list-style-type: none"> • increased ethics consultations and moral dilemmas • increased AD documentation compliance • increased patient requests for information • increased patient and professional education about AD • increased workload and role redundancy (MD, MSW, RN, APRN) • increased family conferences

Antecedents

The literature suggests various antecedents to the concept of self-determination. The first and most obvious one is becoming ill. This could occur in conjunction with the diagnosis or awareness of a life-threatening or terminal illness, a sudden worsening of a chronic illness, or admission to hospital or transfer to an intensive care unit (SUPPORT Principal Investigators, 1995). The latter was the context of the *PDSA* (Bradley & Rizzo, 1999; Haynor, 1996; *OBRA of 1990*, 1990). However, the expression of self-determined choices and values is not necessarily associated with illness. In fact, healthy people are often encouraged to complete advance directives (Havens, 2000; Johnston, Pfeifer, & McNutt, 1995; Silveira et al., 2000). This trend was evident following publication of results showing that patients' expressed wishes (as stated in advance directives in hospital medical charts) had not been incorporated into the plan of care at the time of death (Covinsky et al., 2000; Lynn et al., 2000; SUPPORT Principal Investigators, 1997).

Mental competency or capacity is an antecedent to self-determination in many contexts (Valimaki & Leino-Kilpi, 1998), but appointment of a proxy could ensure durability of preferences in the case of incapacity. Other antecedents are functional status, age (Johnston et al., 1995), and cultural or religious orientation (Koenig, 1997; Ruhnke et al., 2000). There are conflicting views between patients and providers regarding age and functional or health status. Patients generally say they prefer to have discussions with physicians when they are young and healthy, during preventative medical visits (Havens, 2000; Johnston et al., 1995; Silveira et al., 2000), whereas physicians tend to state that they initiate such conversations with older, sick, hospitalized patients (Hesse, 1995; Johnston et al.; Tulsky et al., 1998). One review cites the lack of physician payment for discussions about advance care planning as a barrier to its increased frequency in an office setting (Cerminara, 1998).

Other antecedents include the need for relevant information about a condition and about available therapies (Tulsky et al., 1998), family discussions and appointment of a proxy (Hesse, 1995; Tulsky et al.), knowledge about end-of-life legal issues (refusal/withdrawal of treatment, assisted suicide, euthanasia, double effect) (Silveira et al., 2000), and factors related to physicians and the health-care system. Physician factors include assessment of patients' knowledge about their prognosis in order to clear up misconceptions (Silveira et al.), patients' values (Tulsky et al.), patients' desired level of participation in decision-making (Barry & Henderson, 1996; Havens, 2000; Sutherland et al., 1989), and physicians' personal beliefs about futility or, based on prior conversations, about the patient's wishes (Haynor, 1996; Hesse). The main antecedent to self-

determination in the health-care system is passage of the *PDSA* (Bradley & Rizzo, 1999; Haynor; Meisel, 1998; *OBRA of 1990*, 1990). Although one intervention study found that knowledge about advance directives increased compliance (Murphy, Sweeney, & Chiriboga, 2000), this did not translate into self-determined choices (in the form of advance directives) regarding end-of-life care (Covinsky et al., 2000; SUPPORT Principal Investigators, 1995, 1997). Contact with clinicians experienced in palliative care has been identified as an antecedent to “self-determined life closure” and peaceful death (Ferris et al., 2002; Field & Cassel, 1997; Foley & Gelband, 2001; National Hospice Organization, 1997).

Consequences

The consequences of self-determination, for patients (including healthy individuals), organizations, and health-care providers, are evident. Those found in studies with healthy individuals include discussions with physicians and family member about treatment preferences in the event of terminal illness, and, for some, use of a living will and/or durable power of attorney for health care (Eisemann & Richter, 1999; Havens, 2000; Johnston et al., 1995; Murphy et al., 2000; Ruhnke et al., 2000). Despite attempts to educate patients in the use of advance directives, understanding and use of advance directives did not always increase (Havens; Hesse, 1995; Nordgren & Fridlund, 2001; Ott, 1999; Sutherland et al., 1989).

For ill patients, self-determination does not necessarily result in a death experience that is consistent with their values and preferences (Covinsky et al., 2000; Hesse, 1995; SUPPORT Principal Investigators, 1997). Various strategies consistent with a patient’s wish for limited life-sustaining treatment and for comfort care may be integrated — for example, advance directives, actions regarding life closure, use of comfort measures, “do not resuscitate” or “no code” orders, referral to hospice or palliative care, and symptom management, including pain relief — but this cannot be attributed directly to the presence of an advance directive. Some patients receive *less* aggressive care than they have expressed a desire for (Covinsky et al.; Hesse; Ott, 1999; SUPPORT Principal Investigators, 1995, 1997).

An unexpected finding of the analysis is patient reliance on or desire for more family or physician involvement in end-of-life decision-making, which is apparent in more recent studies and studies with patients from non-Western cultures (Candib, 2002; Covinsky et al., 2000; Fan, 1997; Hern, Koenig, Moore, & Marshall, 1998; Murphy et al., 2000; Ott, 1999; Quill, 2002; Ruhnke et al., 2000; Sutherland et al., 1989).

One study (Haynor, 1996) and one review (Ott, 1999) summarize organizational consequences following passage of the *PDSA*. Haynor describes an increase in the complexity and volume of ethics committee

cases, in professional moral dilemmas, in compliance with advance directives, in patient requests for information, and in patient and professional education. Professional consequences were increased workload (for social workers and advanced practice nurses) and role redundancy in clarification of patient preferences (for physicians, nurses, social workers, and admitting clerks). Professionals also reported increased responsibilities related to patient and family discussions, family conferences, and clarification of the term “no heroics” (Haynor). Ott describes inconsistent consequences related to utilization rates and discussion of advance directives with providers and family proxies, effectiveness of interventions to increase the use of advance directives, patients’ understanding of and ability to complete advance directives, choices and application of treatment in the event of an advance directive, and cost issues.

Exemplars

Two published palliative care cases, those of an anesthesiologist with pancreatic cancer (Whedon, 2001) and a patient with breast cancer (Groopman, 2002), are presented as exemplars of self-determination.

In the first case the patient makes choices from diagnosis to death. He chooses symptom-relief methods that are consistent with his own beliefs and preferences:

Fred was admitted for uncontrolled pain for the third time in a week. He signed himself out against medical advice the day before. From the outset Fred was plagued by abdominal pain, nausea, fatigue, and weight loss. He declined a recommended celiac plexus block for pain management, nausea strategies, and nutritional advice. Rather than continuous analgesics by oral, subcutaneous, or transdermal routes for chronic pain, he chose intermittent intravenous injections via peripheral intravenous catheters inserted for his weekly chemotherapy. (In locations carefully selected so they would not interfere with his golf swing.) He chose smoking pot over other antiemetic regimens. He chose a diet of calorie and protein rich gourmet meals accompanied by an appropriate bottle of wine from his cellar. He altered his treatment schedules and traditional oncology appointment times to undergo Reiki treatments through which he found comfort and strength. He accepted Hospice home care only to alleviate the financial consequences of the treatment and symptom management. He did his utmost to maintain the same lifestyle post-diagnosis as he had pre-diagnosis. As it became clear that he was dying a long-standing relationship with the palliative care team allowed for frank discussions. Reconciliation, family gathering, communication, and planning for his death marked his final days. In a quote from his wife’s letter after his death she said, “he respected your knowledge and experience regarding the pain meds he needed. Let me assure you how much of a coup this was for you. And to your credit, you were able to back off when necessary and let him do things his way.” (Whedon, 2001, p. 32)

In the second case a physician describes a conversation with a patient newly diagnosed with advanced-stage breast cancer in which he solicits (and documents) her choices in the event of progression of the disease:

“We talked about the best-case scenario. But we also have to acknowledge that there is a worst-case scenario.”

I had found that this part of the discussion was best completed rapidly, as if removing an adhesive bandage.

“The worst-case scenario is that ultimately the cancer becomes resistant to all the treatments we have, and even experimental therapies are no use. Most people say that if they reach a point in the illness when their brain is impaired, and there is no likelihood of improving their quality of life, then nothing should be done to keep them artificially alive, through machines like respirators. It’s essential, Maxine, that I know what you want done if we reach that point.”

“I — I don’t think I would want that,” she said, haltingly.

“You mean that you would want only comfort measures to alleviate pain, and nothing done to prolong your life, like a respirator or cardiac resuscitation?”

“Yes, I think so,” Maxine whispered.

I nodded. This was her “end-of-life directive.” I would put it in writing in her medical chart.

“We have a plan of therapy and an understanding. Now let’s look on the positive side,” I said, trying to spark some of the determination she would need in order to endure the months of chemotherapy ahead. “You are young, your organ function is excellent — despite the deposits of tumor, your liver is still working well, and your blood counts are fine — so there is every reason to think that you will tolerate the drugs and we will make real progress.” (Groopman, 2002, p. 62)

Both cases contain attributes (personal appraisal, decision-making process, activities, and outcomes) that help to clarify self-determination as it exists in expert palliative care situations. In both cases the health-care providers demonstrate respect for autonomy. They share information that will be of value to the patients in making self-determined choices consistent with their values and preferences throughout the dying process. Family is an integral part of the decision-making process. Both cases show evidence of preparation for future dependence, while the patient still has mental capacity, including documentation of wishes and provider continuity throughout the illness trajectory. Opportunities for other means of ensuring “self-determined life closure” are evident, given the preparation for the possibility of a future marked by continued deterioration and death. Both patients experience the desired consequences of a peaceful death.

Discussion

This literature review demonstrates that the concept of self-determination, a relatively abstract, complex idea, has been actualized in many different ways in various health-care settings. As described by Rodgers (2000), concepts are dynamic, constantly changing and evolving contextually and over time. This is certainly true for the concept of self-determination. Societal, legal, ethical, cultural, and palliative care practice and research influences have contributed to the evolution of definitions and attributes. Historically, in periods of oppression of vulnerable groups the focus of self-determination was freedom and self-governance. Bioethical, legal (specifically, the *PDSA*), and palliative care practice and research attempted to guarantee self-determined choice to vulnerable groups, such as hospital patients, through the documentation of treatment preferences and appointment of a proxy to ensure that the patient's plan of care was respected. Self-determination was often conceptualized as the completion of an advance directive, an attempt to reduce the entire process of decision-making on end-of-life care to a single act.

However, it became apparent that completion of a simple form could not ensure that complex patient choices, which are often situation-dependent, will be effectively captured and consistently applied within complex health-care systems. This view, which has been expressed by many health-care researchers, is summarized by Teno (1998) in a comment by Mencken: "For every human problem, there is a solution, which is simple, neat, and wrong" (p. 1170). Clarification of self-determination as a complex process is an important step in concept development.

Many studies focus on self-determination as a basic human right without considering the fact that an individual's personal appraisal of self-determination is shaped by a host of multidimensional individual factors (e.g., ethnicity, age, health status). The ethicist Renée Fox (1990) describes this lack of cultural perspective: "There is a sense in which bioethics has taken its American (Western) societal and cultural attributes for granted, ignoring them in ways that imply that its conception of ethics, its value systems, and its mode of reasoning transcend social and cultural particularities" (p. 207). Several recent studies eliciting the views of patients, especially those from non-Western cultures, on self-determination add to our understanding of self-determination in health-care decision-making. Despite the fundamental nature of self-determination, some patients do not feel empowered to make choices (Nordgren & Fridlund, 2001; Valimaki & Leino-Kilpi, 1998), while others prefer to turn decision-making functions over to family members or health-care providers because of underlying cultural beliefs (Baker, 2002; Candib, 2002;

Fan, 1997; Hern et al., 1998; Koch, Braun, & Pietsch, 1999; Koenig, 1997; Quill, 2002; Ruhnke et al., 2000; Shapiro & Bowles, 2002) or in times of serious illness (Barry & Henderson, 1996; Covinsky et al., 2000; Haynor, 1996; Prendergast, 2001; Tulsky et al., 1998).

Patients' views concerning their own level of involvement and that of others in the decisions about their care highlight the need for partnerships among patients, family members, and providers prior to serious illness. This approach is evident in the World Health Organization's (1990) definition of palliative care, which focuses on holistic care from the perspective of the patient and family. It places the patient's values and preferences at the foundation of care over the entire illness continuum, beginning with diagnosis (and emphasizing the importance of self-determination as a process).

Although health professionals have expressed a firm belief in self-determination, often affirming patients' rights in their professional codes and position statements (American Geriatrics Society Ethics Committee, 1998; ANA, 2001; Cain & Hammes, 1994; Cerminara, 1998; Department of Health, Education and Welfare, 1979; Engel et al., 1997; Ferris et al., 2002; Haynor, 1996; Scanlon, 1996; World Health Organization, 1990), they are still uncomfortable with advance care planning and lack the ability to manage it skilfully (Baker, 2002; Jezewski, Meeker, & Schrader, 2003; Prendergast, 2001; Shapiro & Bowles, 2002). Interventions to improve communication (Johnston et al., 1995; Murphy et al., 2000; Tulsky et al., 1998), increase the use of advance directives (Havens, 2000), and increase patient access to information (Barry & Henderson, 1996; Bradley & Rizzo, 1999; Eisemann & Richter, 1999; Silveira et al., 2000) often fall short of actualizing self-determined choices in end-of-life care (Covinsky et al., 2000; SUPPORT Principal Investigators, 1995, 1997). Improved provider understanding of individual patient factors to be assessed, including their desired level of involvement, fears, misconceptions, cultural beliefs, and values, might be more effective in matching providers' desires with patient outcomes.

The health-care system appears unprepared to consistently accommodate individual choices regarding end-of-life care. This is graphically illustrated in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), which found that thousands of patients in leading academic medical centres suffered needless pain and discomfort in an effort to prolong life rather than to provide comfort (SUPPORT Principal Investigators, 1995). The SUPPORT intervention, conducted by advanced practice nurses trained in communications and armed with state-of-the-art prognosis predictions, failed to achieve the desired outcomes. A vast literature has been generated in

attempting to identify the reasons for this failure (Bookbinder, Rutledge, Donaldson, & Pravikoff, 2001; Rutledge, Bookbinder, Donaldson, & Pravikoff, 2001; Rutledge & Donaldson, 2001; Rutledge, Donaldson, & Pravikoff, 2001). Canada has no corollary legislation to the *PDSA* and its focus is broader, with professional, institutional, and regional efforts being made to improve patient and family involvement in decision-making (Bowman & Richard, 2004; Canadian Nurses Association, 1994, 2002; Davidson & Degner, 1998; Singer et al., 2001; Singer, Martin, & Kelner, 1999).

Clarification of the concept of self-determination in the palliative care setting is hampered by three additional research issues. First, because of the many gaps in the scientific evidence on quality-of-life outcomes, it is difficult for health-care providers to determine what a patient can expect from different palliative therapies (Field & Cassel, 1997; Foley & Gelband, 2001), a key factor in patient self-determination. Second, the manner in which health-care providers communicate information to patients can influence the way in which patients receive and use that information (Johnston et al., 1995; SUPPORT Principal Investigators, 1997; Tulskey et al., 1998); patients can make self-determined choices reflecting their personal values and wishes only if they have access to the relevant information. Finally, informed patients and families who wish to take an active role in their health-care decisions — the essence of self-determination — cannot be accommodated without widespread changes to health-care systems.

Limitations of the Study

The choice of Rodgers's (2000) concept-analysis method seemed appropriate to the goal of identifying the evolution and current status of self-determination as a foundation for developing a program of palliative care research. However, this method has several limitations. Selection procedures for abstract ideas such as concept evolution, attributes, antecedents, consequences, and exemplars may exclude literature that examines conceptual meaning in other ways. As a literature-based form of inquiry, this method does not reflect the perspectives of patients, clinicians, or researchers, which could be captured through in-depth qualitative interviews. Further, instead of describing self-determination definitively, it provides a conceptual understanding based on a finite literature at a particular point in time (Rodgers). Interactive or participative methods, such as dimensional analysis, or critical methods may also be appropriate for a dynamic concept with this degree of abstractness (Rodgers & Knafelz, 2000).

Conclusion

The concept of self-determination requires clarification. It is an abstract, complex concept that is likely to change over time and within the multiple contexts in which it is actualized. Following passage of the *PDSA*, the lack of a clear definition of self-determination and its process hindered efforts to develop interventions to enhance it and hence to improve end-of-life care. This is illustrated in the negative results of the multimillion-dollar *SUPPORT* intervention, which failed to yield improved outcomes for thousands of seriously ill patients in five well-respected academic medical centres (*SUPPORT* Principal Investigators, 1995).

The implications of this concept analysis for palliative care research are summarized in Appendix 2. Future palliative care interventions should consider the complexity and evolutionary nature of self-determination. Research interventions and other strategies should consider the essential attributes of personal appraisal, decision-making process, activities, and outcomes. Such a comprehensive view takes into account the variety of patient (especially socio-cultural), provider, and health-system factors that might support or facilitate self-determination.

Fostering the broader idea of advance care planning rather than simply completing advance directives (Cantor, 1998), reimbursement of self-determination activities, especially in managed care environments (Cerminara, 1998), provider training in communication skills, and determining the influence of different cultural perspectives on views of self-determination are some of the areas of research suggested by the results of this analysis.

Future concept analysis could compare the actualization of self-determination research and policy in different countries. For instance, US research has been dominated by the *PDSA*, whereas Canada has favoured a non-legislative approach to self-determination, resulting in the development of policy and research focused on patient autonomy in decision-making (Bowman & Richard, 2004; Davidson & Degner, 1998; Singer et al., 2001). Comparison of the outcomes of these different approaches may serve to inform the development of best practices and palliative care research directions concerning self-determination.

The concept of self-determination has evolved from the notion of group self-governance to that of individual self-determination in health-care matters by means of advance directives. Another transition seems to be imminent: from the notion of self-determination as the completion of a form to that of a dynamic process of communicating health-care values and preferences among individuals, their families, and health-care providers (Agency for Healthcare Research and Quality, 2003; Brooks,

Hardy, Moseley, Myrick, & Jones, 2003; Lynn et al., 2000; Teno, 1998). The next step calls for health-care systems and health-care providers that are prepared to care for patients who exhibit all shades of self-determined decision-making.

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Appendix 1 *General Provisions of the PSDA*

- applicability: applies to hospitals, “skilled nursing facilities,” home-care agencies, hospices, and “prepaid” health-care organizations
- provision of written policies: describing patients’ right to make decisions concerning medical care, right to accept or refuse treatment, and right to issue advance directives
- provision of written information to adult patients at time of admission to medical facility
- documentation: must be provided in medical record on whether advance directive has been issued
- non-discrimination: health-care providers are forbidden to discriminate on the basis of whether a patient has issued an advance directive
- compliance with state law
- provider education about advance directives: staff and the community at large must be provided with education in advance directives
- conscientious objection: health-care providers need not implement the law if they object as “a matter of conscience”
- written description of state law: states must develop laws concerning advance directives (including medical decision-making — e.g., consent to treatment, informed consent, and end-of-life decision-making) that are distributed to patients by providers
- public education campaign: the Department of Health and Human Services is required to “develop and implement a national campaign to inform the public of the option to execute advance directives and of a patient’s right to participate and direct health care decisions”

Source: Adapted from Meisel (1998).

**Appendix 2 *Concept Analysis of Self-Determination:
Implications for Palliative Care Research***

- Consider the complexity and dynamic nature of self-determination in the development of palliative care interventions.
- Consider the nature of self-determination as a cultural, social, ethical, and legal construction.
- Recognize the importance of family; persons from non-Western cultures are more likely to view family and others as key participants in decision-making.
- Intervention research should consider opportunities for system change, as many health-care systems do not feature a patient-centred approach that encourages and supports individual choice in end-of-life decisions.
- A focus solely on increasing self-determination through the use of advance directives does not address the complexity of the process of communicating patients' values and preferences within complex health-care systems.
- Increasing the evidence base for palliative care practice (e.g., symptom control, communication skills) can serve to improve the quality of patient and family decision-making.
- Creative strategies and interventions are needed, to honour the wishes of those patients who tend to interact passively with clinicians and the health-care system.