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Patients' and healthcare providers' understandings of life-sustaining treatment: Are perceptions of goals shared or divergent?

Keri L. Rodriguez*, Amanda J. Young

VA Pittsburgh Healthcare System, Center for Health Equity Research and Promotion, University Drive C, Bldg. 28, Room 1A129, Pittsburgh, PA 15240 1000, USA

Abstract

In this cross-sectional qualitative study, researchers performed in-depth, semistructured interviews with 30 pairs of patients and their primary care providers in an outpatient clinic of a large, urban Veterans Affairs (VA) medical center in the United States. During audiotaped interviews to assess their understanding of advance directive concepts, participants were asked what "life-sustaining treatment" means to them and why they think of it in the way they do. The findings indicate that patients and providers in the United States tend to view and discuss life-sustaining treatment in terms of four goals for end-of-life care: (1) extending the length of life, (2) improving the quality of life, (3) maintaining or improving specific biological functions, and (4) assisting the body for a temporary period of time. Patients thought providers were more concerned with extending the length of life than with quality-based outcomes, and patients often discussed life-sustaining treatment as acceptable means for short-term but not long-term use. Many providers indicated that they struggle with conflicting quality-based and physiologic care goals. The findings highlight the importance of eliciting patient preferences not only for specific types of treatment, such as cardiopulmonary resuscitation, but also for end-of-life care goals or desired health-related outcomes, such as maximizing the quantity of life. The findings also suggest that advance directives and patient-provider discussions that focus on acceptable health states and valued life activities may be better suited to patients' end-of-life care goals than those that focus on specific medical interventions.
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Keywords: USA; End-of-life care; Life-sustaining treatment; Advance care planning; Healthcare preferences; Qualitative research; Veterans

Introduction

Despite an ethical and legal consensus regarding the rights of US citizens to refuse life-sustaining treatment, surveys show that patients in US hospitals frequently receive unwanted interventions (Fischer, Tulsky, Rose, Siminoff, & Arnold, 1998; Hanson, Danis, Garrett, & Mutran, 1996; Teno, Fisher, Hamel, Coppola, & Dawson, 2002). Part of the reason for this problem may be that life-sustaining treatment has a multiplicity of working definitions in the field of medicine and within US state and federal law, and part of the reason may be that legal documents and discussions

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*Corresponding author. Tel.: +14126886000/815734; fax: +1 412 688 6527.
E-mail address: keri.rodriguez@med.va.gov (K.L. Rodriguez).

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about life-sustaining treatment and end-of-life care tend to focus on specific medical interventions, such as cardiopulmonary resuscitation, rather than on health-related outcomes, such as maximizing the quantity or quality of life.

The Patient Self-Determination Act (US Congress, 1990) requires US hospitals, skilled nursing facilities, home health agencies, hospice programs, and health maintenance organizations to maintain written policies and procedures guaranteeing that every adult receiving medical care will be given written information concerning an advance directive for healthcare. The most common examples of an advance directive are a living will (a document in which a patient provides information about whether or not life-sustaining treatments should be instituted if, in the future, the patient suffers a life-threatening condition and is not able to communicate his or her preferences at that time) and a durable power of attorney for healthcare (a document in which a patient appoints another individual to make healthcare decisions if the patient is no longer able to make them).

Life-sustaining treatment can be a nebulous and confusing concept. While it can refer to dramatic measures such as organ transplantation, mechanical ventilation, and kidney dialysis, it also refers to less technically demanding measures, such as administration of drugs (e.g., antibiotics, insulin, or chemotherapy) or nutrition and hydration. In fact, within the Veterans Administration (VA) Healthcare System, which is the largest fully integrated healthcare system in the United States, life-sustaining treatment is defined as "any medical treatment that is used to delay the moment of death" (Department of Veterans Affairs, 1998, p. 2). The VA encourages use of its own advance directive form, which allows patients to designate a durable power of attorney for healthcare, to express their wishes about life-sustaining treatments, and to list other treatment preferences all in one document (Department of Veterans Affairs, 1998). Other medical systems, hospitals, and institutions make similar forms available to their patients or clients. Although there are exceptions, hospitals generally accept a variety of forms as long as the wording in the forms meets state requirements.

While there are myriad examples of life-sustaining treatments, there are three basic types of decision-making protocols in the United States, with the first type consisting solely of do-not-resuscitate orders, the second type specifying treatment objectives, and the third type outlining detailed treatment plans (U.S. Congress & Office Technology, 1988). As a result, life-sustaining treatments may be used to permit the initiation of standard or experimental treatment to achieve a specific medical outcome (e.g., the cure or alleviation of an underlying disorder) or to help the patient achieve a personal goal (e.g., seeing a loved one for the last time). The outcomes and goals should ideally be mutually acceptable to the patient and his or her substitute decision-makers, including family members and healthcare providers (Emanuel & Emanuel, 1992; Guadagnoli & Ward, 1998; Szasz & Hollender, 1956).

The aim of our study was to assess elderly patients' and primary care providers' understandings of four concepts related to advance directives: life-sustaining treatment, terminal condition, state of permanent unconsciousness, and decision-making capacity. We chose these concepts because they are standard in living wills and durable powers of attorney for healthcare and because patients should understand them before making choices about specific medical interventions. We performed qualitative interviews with a cross-sectional sample of elderly patients and primary care providers at a VA medical center in the United States. We chose outpatients and their primary care providers as the focus of our study because healthcare administrators and researchers have suggested that discussions about advance directives be conducted in the primary care setting when patients have time to think about their medical care preferences and discuss their wishes with their family or a proxy (Department of Veterans Affairs & Pittsburgh Healthcare, 2000; Duffield, 1998; Duffield & Podzamsky, 1996). In this article, we present interview data to explore and contrast the ways in which the patients and primary care providers expressed their understanding of life-sustaining treatment.

Methods

Setting and participants

With the approval of the VA Pittsburgh Healthcare System (VAPHS) and University of Pittsburgh Institutional Review Boards, we recruited study participants between April 2000 and October 2002 from a large, urban, outpatient primary care clinic in the VAPHS. Physicians, certified registered nurse practitioners, and physician assistants were eligible for participation if they were primary care providers at the clinic. Patients were eligible for participation if they were 60 yrs or older, ambulatory, able to speak and read English, residing in the community, receiving outpatient care from the VA, and not acutely ill (i.e., not hospitalized or in obvious distress).

The study investigators began by inviting all 45 primary care providers in the outpatient clinic to participate. The invitation was sent by interoffice mail, and a follow-up was sent by e-mail. The first 30 providers who responded were enrolled in the study. After each provider was interviewed, the research coordinator checked the VA's computerized patient record system to identify patients who met the study