



Medical decision making for older adults: an international perspective comparing the United States and India

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Abstract

There has been a significant decline in cardiovascular morbidity and mortality amidst pervasive advances in care, including percutaneous revascularization, mechanical circulatory support, and transcatheter valvular therapies. While advancing therapies may add significant longevity, they also bring about new end-of-life decision-making challenges for patients and their families who also must weigh the advantages of reduced mortality to the possibility of longer lives consisting of high morbidity, frailty, pain, and poor quality of living. Advance care entails options of withholding or withdrawing therapies, and has become a familiar part of cardiovascular care for older patients in Western countries. However, as advanced cardiovascular practices extend to developing countries, the interrelated concept of advance care is rarely straight forward as it is affected by local cultural traditions and mores, and can lead to very different inferences and use. This paper discusses the concepts of advance care planning, surrogate decision-making, orders for resuscitation and futility in patients with cardiac disease with comparisons of West to East, focusing particularly on the United States versus India.

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1 Introduction

The advent of modern cardiovascular therapies has significantly impacted survival and quality of life in patients with chronic cardiovascular diseases. There have been significant declines in cardiovascular morbidity and mortality in Western countries, in part due to technical advances in percutaneous revascularization, mechanical circulatory support, and transcatheter valvular therapies. As similar advances become more available in developing Eastern countries, comparable mortality and morbidity benefits are increasing. Nonetheless, coupled to the clinical benefits, advanced cardiovascular care brings about challenging end-of-life decisions. Potential benefits of increased longevity must be weighed against the possibility of a life pro-

longed but with poor quality and little pleasure. In Western countries it is generally thought that patients should be introduced to advance care planning in the outpatient setting.^[1] Patients and families are increasingly open to frank discussions and perspectives of care that are holistic and direct. However, this presumes access and openness that are rarely similar in developing countries.

In India, patients do not typically access healthcare until they are hospitalized with acute, life-threatening illnesses. Families are perceived to want to “save” the patient “at any cost” and physicians taking care of them typically subscribe to the cultural phenomenon termed the “technological imperative,” i.e., since technology exists to extend life, it must be utilized.^[2] Moreover, in the midst of such medical acuity, patients typically have very little impact on the decision-making process. Integrating concepts of withdrawing or withholding therapies in India will therefore imply shifts in both health care providers and public approaches to serious illness.

This review discusses the concepts of advance care planning, surrogate decision-making, orders for resuscitation and futility, and their application in patients with cardiac disease in Eastern countries like India.

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2 Advance care planning

Advance care planning entails dialogue between patients and families, and health care providers about future care.^[3] Advance planning is often focused on advance directives that identify wishes for medical care in the event that the patient can no longer make his or her own decisions (diminished decision-making capacity). Advance directives were first integrated into the legal structure in the United States approximately 35 years ago. Over the ensuing years, advance directive documents have been legislated in all 50 states.

Advance planning provides a systematized process for communication between health care providers, patients and their families about future care, as well as spiritual issues related to end-of-life care.^[4] Advance planning also includes identification of likely future decisions and beginning of alignment of patients' values with the choices that are made in their care.^[1] Advance planning is particularly important in the formulation of goals of care, or to plan for undesired events that occur in a given care path.

The concept of advance care planning remains predominantly unconnected from the "real-world" practice of medicine in most developing countries. In India, for example, a country with a population of over 1.2 billion, and a burgeoning cardiovascular disease burden, there is a poor provider: patient ratio and doctors may see up to 200 patients per day in their out-patient departments.^[5,6] According to the World Bank estimates, average visit duration is approximately 3.8 minutes.^[7] It is, therefore, impossible to engage patients in conversations about end-of-life care in such short duration.

Planning for end-of-life care is particularly challenging as it is typically regarded by many Indians as an inappropriate consideration in a discussion regarding caregiving. Even for the very elderly, the notion of death is rarely "accepted" as part of a rational concept of care. Instead, it is more common that families believe that every caregiving option

be utilized for life prolongation. Such presumptions are generally reinforced by the patterns of extended families living together in small domiciles, generating intense interpersonal linkages and even reverence for older adults. Thus, while there is nascent interest by a few in India to consider advance directives, this rarely has a substance impact on life and death management.^[8] While to some extent the innovative concept of advance planning helps patients contemplate preferences regarding recurrent hospitalizations and living with devices, management of acute illness almost always defaults back to the goal for a "cure" at any cost.^[9]

Physicians' capacity to encourage broader perspectives are limited by their limited understanding of palliative care, as well as fears regarding possible litigation in the absence of legal guidelines for end-of-life care.^[10]

3 Advance directives

Advance directives entail oral or written instructions about future medical care. The goal of advance directives is to bring the patient's preferences into the decision-making process in the event the patient loses decision-making capacity.^[11] In the US, there are two common advance directives: (1) the living will, and (2) the health care proxy (may also be called a durable power of attorney for health care) (Table 1). Patients may have both a living will and a health care proxy. Generally, advance directives require a legal statute to provide the authority supporting the directive, and to protect the clinicians who comply with directives.

The utility of advance directives to modify costs and improve outcomes in Western patients is well-established.^[12] A recent study among Western heart failure patients showed that patients who had advance directives were less likely to be transferred to an intensive care unit or to receive mechanical ventilation.^[13] Similarly, advance directives may be of immense value in limiting acute interventions during acute coronary syndromes, especially for patients who have

Table 1. Advance directives.

Living will	A document that states specific medical interventions and treatments the person would or would not want in the event she/he loses capacity and under specific circumstances (often in the event of life-threatening, terminal, or severely debilitating illness). Living wills often use boilerplate language that requires interpretation in light of real-time medical facts. For example, it may be difficult to interpret what was meant by "terminal illness." Similarly, when a person states not to ever be "placed on machines," it is not clear if this includes a trial of critical care in the event of an acute illness. Patients' oral statements may also state their preferences for future health care, in the event of loss of decision-making capacity.
Health care proxy	Also called durable power of attorney for health care, it designates a surrogate decision-maker to speak on behalf of the patient, when she/he can no longer make medical decisions. Designated health care agents work with the medical team to incorporate the patient's preferences, values, and goals to make decisions in real time. Clinicians should encourage patients to discuss their preferences, goals, and values with their designated health care agent.

lost the ability to participate in decisions.

Transferability of these benefits to Eastern countries is rarely straightforward. In India, for example, thrombolytic therapy remains the mainstay for achieving reperfusion in ST-elevation myocardial infarction.^[14] Percutaneous coronary intervention (PCI) is evolving as a superior alternate that may better facilitate increased longevity as well as gains in physical functional. While many assume that patients and/or health care proxies would naturally embrace this new therapeutic option, it is common for many patients and proxies to mistrust physicians and to misconstrue PCI as primarily a source for monetary gains by the providers. In addition to distrust,^[15] other barriers encumber advance care, i.e., provider-related, patient-related, and system-related barriers also complicate caregiving decisions.

Provider-related barriers indicate physicians' own cultural and ethnic backgrounds contribute to their apprehensions to discuss end-of-life with patients and their families and focus instead on "technological imperatives" of care. A general lack of knowledge, skills and confidence, as well as time constraints further impede aims to discuss goals of care.

Patient-related barriers mean insufficient of health literacy in India that contributes to cultural preferences to preserve life, and families' sense of obligation to "do whatever it takes" to restore health of their loved ones.^[16] In general, discussions oriented to end-of-life and/or withdrawing care are avoided.

System-related barriers imply insufficient training underlies difficulties among physicians to implement discussions related to goals of care with patients or families. Palliative care is not readily available. Legal structures also do not support the validity of advance directives and health care proxies.^[17]

4 Surrogate decision-making

Advance directives constitute a process by which patients retain control over their own healthcare and end-of-life decisions. Unfortunately, relatively few patients in India have advance directives and even when they do, the instructions within the document may be overlooked when the need for critical decision arises.^[18–22]

It is often essential to have a surrogate decision-maker to assert such preferences on behalf of the patient, but this too is rarely straightforward. Ideally, the surrogate decision-maker (usually a family member or friend) is aware of a patient's preferences and tries to infer what the patient would have chosen based on knowledge of his or her beliefs and values. When the patient's wishes are not known and cannot

be conjectured, the surrogate makes decisions in the best interests of the patient, i.e., in respect to the diagnosis, prognosis, benefits and burdens of the proposed treatment course. Table 2 lists the best practices for communication between medical providers and surrogates. Establishing each patient's goals of care is a critical step in effective management.

In India, the role of the surrogate is usually assumed by the spouse or the elder son in the family, although in clinical practice, most decisions are made by a collective mandate from all family members. Family conflict negatively impacts surrogate decision making (Table 2),^[23,24] and whereas many deep-seated pressures are typical in families, stressful scenarios can be common.

Being a surrogate decision-maker is difficult.^[25–27] A systematic review of 40 studies showed that surrogates frequently experience anxiety and stress due to grief, bewilderment with the clinical situation, and uncertainty about their roles.^[25] The surrogate experience is positively impacted by previous medical decision-making experience, and strong social support.^[27]

A 2006 statute in India rendered the authority of surrogate decision-makers invalid,^[17] stating that "it creates complications."^[10] The statute recommends forming an expert panel or moving the court to make health care decisions, such as consenting to a "Do Not Resuscitate" (DNR) order or withholding/withdrawing life-sustaining treatment.^[17]

5 Resuscitation decisions

In the US, patients or their legally designated surrogates may choose to forgo (withdraw or withhold) any treatment. The decision is made based on the benefits and burdens of treatment in the context of patient's prognosis and goals of care. Life sustaining treatment may be declined if it serves mostly to prolong a life deemed less desirable than death. Clinicians often play a pivotal role in helping patients and

Table 2. Surrogate decision-making: best practices for communication between providers and surrogates.

Designate a skilled communicator from the medical team and establish the relationship before difficult topics arise (if possible).
Ask about what has been important to the patient in the past and what is likely to be important to the patient in the future.
Counsel surrogates that their role is to decide based on what the patient would want.
Define broad goals for care based on the patient's values.
Avoid presenting a menu of treatment decisions to the surrogate; rather focus on the goals of care.
Make specific care recommendations to achieve the goals.

families navigate through these complex decisions about life-sustaining therapies by clarifying treatment outcomes relative to the context of patients' goals. Understanding their likely health circumstances with or without an attempt at resuscitation may help patients and/or patient's providers identify their preferences, particularly as their preconceived notions of life prolongation may be highly distorted. Some patients or their surrogates may want to know the prognosis, however, it is not necessary that every patient be told the prognosis when discussing resuscitation preferences.

DNR orders began in the US in 1980s and are now broadly implemented throughout the US. Patients are assumed to want an attempt at resuscitation, unless a DNR order is explicitly stated. While a DNR order is only intended to govern decisions pertaining to cardiac or respiratory arrest, it often has an unintended effect on other health care choices when admission to an intensive care setting or eligibility for procedures is tacitly or directly deemed less useful for a patient who has a DNR. Many disagree with this interpretation of DNR, but the connotation remains imbedded. Therefore, many patients, surrogates, and families may opt to avoid DNR when they fear the best treatment options may be withheld if a DNR order is in place.

The words "do everything" are often used when discussing the alternative to a DNR order. This language also creates much potential for misunderstanding as it provides little clarity. A more constructive thought process would begin with premise of clarifying each patient's goals of care, as well as considerations as to what is medically reasonable. It is, for example, possible to try to utilize state-of-the-art medications and procedures, but to still allow a patient to die a comfortable, natural death. These nuanced differences become particularly important for patients who are not likely to recover satisfactorily with a cardiac resuscitation.

Resuscitation discussions are challenging and personal, and require frank, clear language and often considerable time. Because frequent discussions about resuscitation can be a burden to patients and families, the content of the conversation should be tailored to the specific situation. For example, a full discussion of the benefits and burdens of resuscitation may be appropriate when there is a significant change in health status. However, even when there is no change in health status, it is often helpful to confirm patient preferences as part of routine care.

One tool designed to carry the resuscitation orders between sites of care is the Physician Order for Life-Sustaining Treatment (POLST). POLST originated in the state of Oregon in the US,^[28] and enables patients with advanced illnesses to specify preferences for their care in a portable and legal format. POLST has now spread to 32 states in the

US.^[29] It is a physician order form that has a distinct color, and is kept in the patient's home or in the patient's chart in a supervised setting. The POLST form is intended to travel with the patient across all care or living settings, and is a legal order that is followed by medical professionals across sites.^[30] POLST is a tool that can be used with or without existing directives.

In India, orders regarding resuscitation status for hospitalized patients are rare. This is attributable to a multitude of factors, including cultural sensitivities associated with dying, lack of patient autonomy and poor facilitation by physicians. An Indian physician's education lacks formal orientation to end-of-life and palliative care medicine.^[31] There is no legal infrastructure to support physicians who may want to guide withdrawing or withholding care.^[31] Data from intensive care units in New Delhi and Mumbai demonstrate low rates of withdrawing and withholding life-sustaining interventions preceding death.^[32,33] However, 80% physicians taking care of terminal patients in these intensive care units believe there is need for forgoing life-sustaining treatments.^[31]

6 Futility

Increasingly, cardiovascular clinicians are accepting that some treatments, though technically feasible, still fail to alter the patient's quality of life, function, or prognosis. Transcatheter aortic valve replacement may, for example, overcome aortic valve stenosis, but it does not necessarily improve geriatric syndromes such as frailty, sarcopenia, and cognitive impairment. Thus in certain patients, even successful transcatheter aortic valve replacement can do little to modify poor outcomes.^[34]

The concept of futility is often invoked in response to requests for treatment the medical team feels would not be beneficial to the patient. The concept of futility is defined in two ways in the health care context. Physiologic futility implies the treatment is ineffective at achieving a desired physiologic effect (e.g., antibiotics to treat a viral infection). Goal-defined futility implies treatment is ineffective at achieving the patient's goals (e.g., to restore previous level of function, survive to hospital discharge, or live independently).

The concept of goal-defined futility is particularly useful in describing the limits of what patients can expect from the health care team. Patients and families may misinterpret the term "futile" to mean the patient's condition is futile, but this is incorrect. The point is that futility implies that the treatment is not able to achieve the desired goals.^[35]

In India, intensivists have petitioned for guidelines to clarify futile intensive care for seriously ill or dying patients.

In particular, decisions regarding discontinuation of life-sustaining treatments remain controversial.^[10] However, this may also be interpreted as an opportunity for hospitals to partner with different religious groups and to initiate critical dialogue with surrogate decision makers and families on behalf of dying patients. This step can be crucial in changing the landscape of end-of-life care delivery in India, given the reverence that religious beliefs and customs hold in India.

7 Conclusions

Partnering with patients and their families is important for delivery of patient-centered care and shared decision-making. While cardiovascular therapies and technology can more effectively prolong patients' lives, it becomes increasingly important to integrate each patient's overall status and goals to medical feasibility. This is particularly important in developing countries like India, where advanced technologies are now suddenly juxtaposed to older beliefs and traditions. Advance care planning provides structure and standards to keep align patients and medical options aligned.

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