

Concerns about cost of future medical care as a factor in advance care planning: Review and agenda for future research

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Abstract

This review explores the evidence for a relationship between healthcare related financial concerns and advance care planning. Large-scale surveys of public opinion in the US have found that people perceive the financial domain to be an important aspect of quality of life and a major concern regarding end-of-life care, and qualitative research has found that financial worries have been found to be a distinct domain of patients' self-perceived burden on their family. Concerns about being a burden on others have some influence on treatment decisions and advance care planning. Healthcare related financial concerns have some basis in fact, as consumers' out-of-pocket costs continue to escalate in some countries. Further research is warranted about healthcare related financial concern and its impact on motivation for engaging in advance care planning, and the content of those plans. A conceptual model of the relationship is proposed to guide further research. This includes three sets of variables: person characteristics such as health literacy, marital/family status and health state; the trait or state of healthcare related financial concern; and behavioral outcomes such as advance care planning and treatment decisions.

Despite the expansion of palliative care and hospice care, the dying experience in the United States and many other countries is still associated with high levels of suffering, some of which could have been avoided.¹⁻³ Death is a difficult outcome to accept, and patients and families as well as providers often pursue curative options, even when the efficacy of such pursuits is medically unlikely.^{4,5} The prevalent use of aggressive end of life interventions such as mechanical ventilation and resuscitation is associated with increased suffering for the patient as well as the bereaved family members.^{6,7} Advance care planning (ACP) may help to ensure that patients and families receive the care they really want and need toward the end of life.⁷⁻⁹ However, too few people have meaningful, comprehensive conversations with their families and healthcare providers about their values and preferences.

Given that many people are hesitant to talk about death and dying,^{4,10} it is possible that concerns about costs of care could provide an additional element of motivation to overcome the natural reluctance to discuss these topics. In some countries, families may be fully or partially responsible for the costs of healthcare. Out-of-pocket expenses are a serious consideration for patients considering certain treatments in some countries, and in diverse countries, people rate financial burdens as a one their top considerations regarding death and dying.^{11,12} In Australia, which has one of the highest out of pocket expenses per capita, 16% of adults reported cost as a barrier to health care access.^{13,14} This review explores the extent to which there is evidence that healthcare related financial concern motivates people to engage in ACP. A conceptual framework is then proposed to guide further research on this topic.

Advance Care Planning

ACP is the process of making decisions about the care you would want in the event a medical crisis renders you unable to speak for yourself.¹⁵ It is a process that should be undertaken by every individual over the age of 18, but many do not consider future medical decision-making until it is, unfortunately, too late.^{16,17} In an effort to shift these conversations away from the point of crisis, evidence-based programs such as Respecting Choices,¹⁸ The Conversation Project,¹⁹ and Vital Talk,²⁰ encourage healthy adults to reflect on these decisions earlier by normalising these conversations within the medical, community and familial contexts. Efforts to encourage lifelong ACP typically focus on the consideration of values and past care experiences, the careful selection of a healthcare agent or surrogate decision-maker, and affirmation of the agent's ability to honour the care decisions of the individual. This process may vary from a traditional legal process in that it can be lengthy, very personal, tailored to individual health and prognosis, and inclusive of the individual's spirituality and social support network.

The stages of ACP match an individual's life or disease progression. For healthy adults or those with manageable chronic illnesses, the Respecting Choices program encourages imagining various scenarios that result in the individual having 'little chance' of recovering the ability to know who you are or who you are with to consider goals of treatment.^{21,22} The individual is then asked to communicate care preferences to a surrogate decision-maker and complete an advance medical directive.

Individuals with a terminal diagnosis may extend ACP to include medical orders that support care preferences. Many states are evolving beyond the traditional Durable Do Not Resuscitate order to the POLST Paradigm.^{23,24} POLST (Physician Orders for Life Sustaining Treatment) is also a facilitated shared decision-making model wherein medical orders clearly specify treatments the patient would want and direct that treatment the patient does not want shall not be provided.

To identify prior research on healthcare related financial concerns in relation to advance care planning and treatment decisions, a semi-structured literature review was conducted using both peer-reviewed academic databases (PubMed & Web of Science), as well as grey-literature results from both Google and Google Scholar. Boolean constructs of multiple terms were created to cover the interaction of terms for finances (finan*, economy*, & cost*), healthcare (health*, treatment, & medical), and anxiety (worry, worries, anxi*, fear, concern*, & burden). Specific searches for 'medical bankruptcy' and 'surprise medical costs' were also conducted.

Inclusion criteria for retaining results included direct relevance to the context of financial concern for individual costs of healthcare. Exclusion criteria included economic analysis of systemic or public finance, financial advice/analysis that focused exclusively on retirement, psychological or psychiatric definitions of 'anxiety' that did not include healthcare finances as a source, and in the case of grey literature, sources that demonstrated bias in their analysis towards an outcome that provided financial gain for the author or publisher. Studies were ranked by their impact and the limits of their generalisability by reviewing their sample size and citation counts. As some terms still yielded large amounts of results with widely heterogenous applicability to the contexts of this review, a secondary review applied filters for end of life and/or death-related decision-making to narrow the results. Finally, studies cited in relevant meta-analysis or further reviews were manually reviewed.

Findings

Costs of care for cancer and other diseases

As health economists have shown in numerous studies of cancer, there is often a spike in hospitalisations and costs of care in the final months of life,²⁵⁻²⁷ and end-of-life care that is of poor quality is often also quite expensive.²⁸ While most health economics studies in the US have focused on costs to payers and health systems, some financial burden hits the patients and families directly,²⁹⁻³² as well as indirectly via insurance plans and governments. The US has high rates of healthcare-related bankruptcy, medical debt and healthcare related financial anxiety.^{11,31-32} More than 15 million US Medicare recipients spend greater than 20% of their income on healthcare-related expenses, with lower income and chronically burdened patients being at the greatest risk.³³ There have been recent reports of patients foregoing targeted therapies for cancer because of out-of-pocket costs they cannot

afford, and clinician-researchers have begun to describe and study ‘financial toxicity’ as a side-effect of advanced cancer treatment.³⁴⁻³⁶

Numerous studies have shown the poor quality of life experienced by many patients and families toward the end of life.^{1,4,5} Most patients have a strong aversion to the scenario of ‘dying on a machine’, preferring instead to die at home with controlled symptoms being high priority.^{37,41} Despite this, the rates of hospitalisation and intensive care unit (ICU) admission in the last months of life have been increasing.³⁸⁻⁴⁰

Impact of ACP

ACP can help to ensure that one’s future care is concordant with one’s values and wishes, and help to ensure that family members and providers are all aware of those wishes to avoid disagreements and conflicts.^{7-9,42} While ACP is not limited to avoiding procedures and life support, several well-designed studies have found that patients who have engaged and documented their conversations about their goals for medical care have been shown to be less likely to be admitted to an ICU or pursue aggressive treatments at the end of their life. For example, a prospective observational study of patients with advanced cancer and their caregivers found those who had ACP conversations were less likely to have resuscitation, ventilation or ICU admission, and were enrolled in hospice earlier.⁶ A study of patients with advanced dementia found that those who had previously completed an ACP were less likely to be admitted to an ICU and to die in a hospital, and their healthcare cost less.⁴³ A large-scale study of US Medicare expenditures found that in high-spending regions, ACPs that specified limits in care were associated with higher probabilities of using hospice and lower probabilities of dying in hospital, as well as lower costs.⁴⁴ A randomised controlled trial in Canadian nursing homes found the ACP intervention arm led to fewer hospitalisations and lower costs.⁴⁵ A prospective study of patients with cancer found that those who had ACP conversations had one-third lower costs of care in the final week of life, and that lower costs were associated with higher quality of life.²⁸ Other studies have also shown a relationship between ACP and costs of care, but used questionable methods or measures, and a systematic review on this topic found that only half of 18 studies meeting review criteria found a positive relationship between ACP and costs.⁴⁶

Patient perceptions of burden

As patients face and prepare for their deaths, they often focus on how their lives and their final care will shape how they will be remembered by their loved ones. Interventions that focus on this sense of generativity or shaping a patient’s legacy with their family, have been shown to be effective in increasing a patient’s quality of life.⁴⁷ Conversely, there is often a strong desire among patients to avoid feeling like they are burdensome to others. Much research has been done on the topic of self-perceived burden (SPB), which has been found to be a salient concern across countries and cultures.⁴⁸ SPB appears to be rather prevalent, and to have considerable influence on the choices that patients make. Cohen-Mansfield,⁴⁹ studying hospitalised elderly persons, found that their concerns about burdening others were the most important factor in treatment decisions, findings that were echoed by later studies,⁵⁰⁻⁵² including decisions about CPR and dialysis.

Financial worry is a domain identified in several qualitative studies of perceived burden.⁵³⁻⁵⁵ One study conducted in Kenya found that worry about being a financial burden on others was a significant aspect in quality of life near death.⁵⁵ Another study found that both healthy adults and those with chronic illness had concerns about being ‘an intolerable burden’ on others when asked to reflect on ‘states worse than death’, and that one of the five domains of this burden was financial.⁵³ A third study identified financial issues as one form of SBP among minority and non-minority persons.⁵⁴ Financial issues do not appear to have been specified in the quantitative studies of self-perceived burden.⁴⁸

As McPherson’s review points out,⁴⁸ there may be a significant difference between patient and caregiver (and provider) perceptions of burden; the only study in their review that compared both perspectives found a modest correlation. This is an important issue in advance care planning – if a patient is sensitive to SPB, they may want to avoid treatments or scenarios when they are most at risk for being burdensome. Conversely, their next of kin may be sensitive to avoiding feelings of guilt, and may want to engage in treatments and efforts at life support to avoid guilt at the time of death. This is the kind of discordance that is useful to unearth prior to a crisis, so that the patient selects an agent they can trust to be true to their own wishes, and the agent and family members can understand what decisions and wishes the patient has made, and why.

Large-scale surveys

Three recent public opinion surveys link financial concerns to quality of life at end of life and advance care planning. A statewide survey in California asked 1669 participants to rate the importance of 12 different factors at the end of life.⁵⁶ 'Being at home' was endorsed as 'extremely important' by 33%; 'Living as long as possible' by 36%; 'Having loved ones around me' by 60%; 'Being comfortable and without pain' by 66%; and 'Making sure family not burdened financially by my care' by 67%, the most of any factor. Similarly, in a cross-country survey of adults in the US, Italy, Japan and Brazil, both US and Japanese adults ranked 'making sure your family is not burdened financially by your care' as their top concern for end of life care.¹² Our survey of 600 adults in the Richmond Virginia area in 2014 focused on ACP issues,⁵⁷ asking what concerned participants the most about future healthcare treatment. Of those expressing any concern (474), 9% said 'That wishes are followed', 11% said 'Quality of healthcare' and 46% said 'Cost of treatments', the most of any factor.

These three surveys give some indication that healthcare related financial concern is a key factor in perceptions of quality of life and dying, and may potentially play a role in motivating people to engage in ACP. Further research could explore this issue more fully, particularly since the financial domain in self-perceived burden research has not been studied using quantitative approaches.

The path ahead

In some countries, a significant share of healthcare costs falls on patients and families,^{11-13,25-29} concerns about such costs and the potential for medical debt have prompted research on the 'financial toxicity' of cancer treatments.³⁴⁻³⁶ Qualitative research has revealed that healthcare related financial concern is a distinct domain of self-perceived burden,⁵³⁻⁵⁵ and SPB has been shown to be related to treatment decisions and advance care plans.⁴⁹⁻⁵² Large surveys suggest concerns about the costs of future treatments are salient for advance care planning, and are a key element of quality of life near the end of life.^{12,56,57}

The implication for healthcare practice is that clinicians or lay persons who are facilitating ACP conversations should be cognisant of these concerns and the role they may play in people's motives and choices. Further, ACP facilitators should be forewarned of potential discordance between the individual making an ACP, and their surrogates or agents, regarding the importance of financial costs that may be incurred from treatment decisions. Despite this, financial decision-making is not a central theme in ACP models such as Respecting Choices. While an individual may express concerns or identify financial-related stressors in a facilitated conversation, the current model does not actively seek this information from the individual.

There is sufficient cause to study healthcare related financial concern (HRFC) as a phenomenon that may be playing a role in advance care planning and treatment decisions. To help guide such efforts the following foundational questions and conceptual model are proposed:

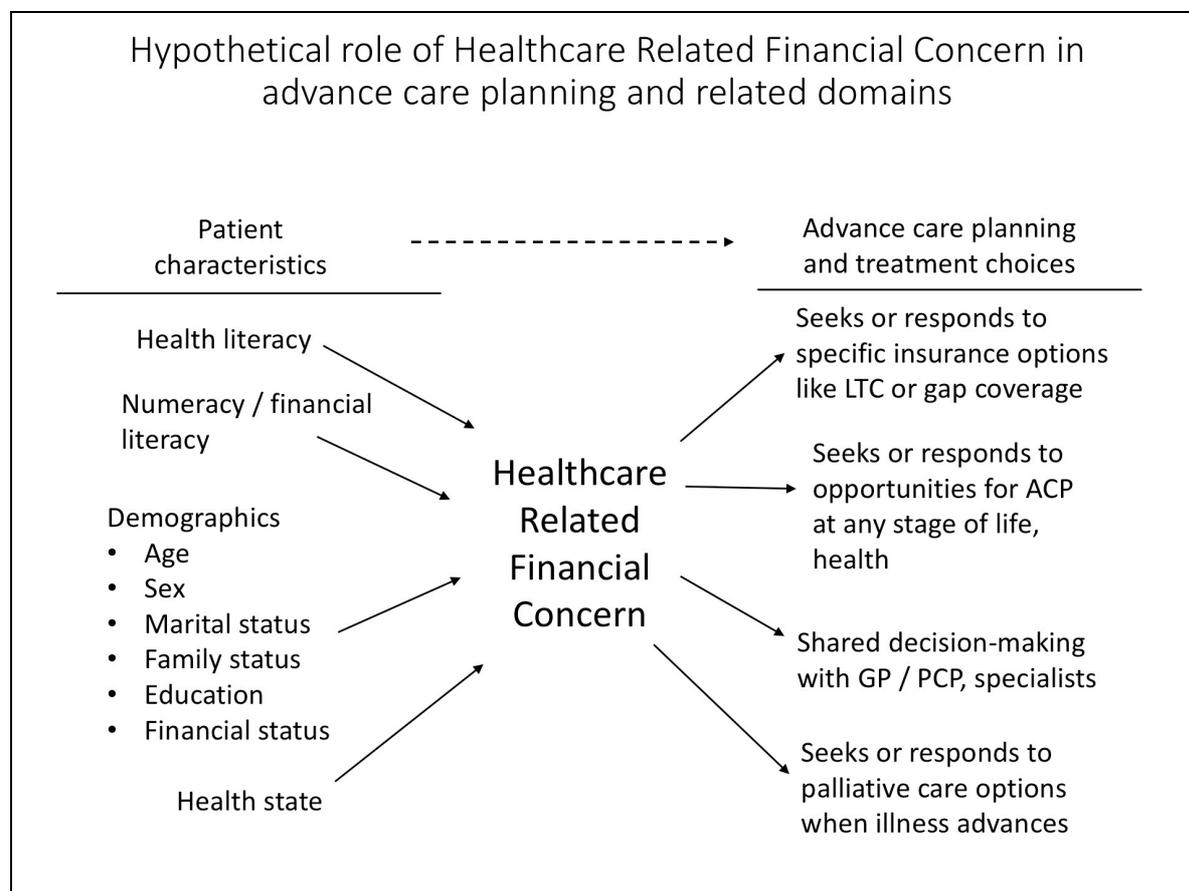
- Can the financial domain of SPB, as identified in qualitative research, be operationalised and measured in quantitative research?
- How much concordance is there between patient perceptions, care-giver perceptions and actual out-of-pocket costs for various treatment scenarios common in ACPs such as resuscitation? How does this differ by country, or within a country?
- Do financial concerns constitute a distinct motivation or reason for people to have ACP conversations and prepare advance directive documents? Do those concerns shape the kinds of decisions people make in their advance directives, such as avoiding hospitalisation or intensive care?

In the proposed model (figure 1), the patient and family characteristics are presumed to have both direct and indirect effects – via HRFC – on advance care planning and treatment choices. If HRFC itself can be primed or otherwise manipulated, then the effects could be readily measured. Research methods such as large-sample surveys could determine whether various demographic characteristics or capabilities (health literacy for example) are correlated with HRFC or the behavioral outcomes on the right side of the figure, while experiments could be conducted to manipulate levels of HRFC as a

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state to investigate its effects on behaviour. Research using this model could be initiated in any country and then expanded to others.

Figure 1: Conceptual model for guiding future research on this topic. LTC = long-term care (skilled nursing). GP / PCP = general practitioner / primary care provider.



Conclusion

Financial concerns seem to be a salient domain of quality of life and self-perceived burden among patients, and may motivate and shape advance care planning and treatment decisions.

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