

Palliative Care and the Search for Value in Health Reform

Donald H. Taylor Jr.

Improving value in health care is of paramount importance, and doing so will require focus on both the costs and benefits of care. Palliative care addresses symptoms of disease regardless of prognosis, helps patients clarify their goals of care, and is key in improving value in the health care system.

The need to address health care costs was an oft-repeated rationale during the health reform discussion that culminated with the passage of the Affordable Care Act in March 2010. The pace of health care cost inflation in general and in the Medicare program in particular makes addressing program costs a key priority, since such costs are a major driver of the long-term federal budget deficit. And since it is well-known that the cost of care increases before death because of the burden of illness, and since 8 in 10 deaths annually involve Medicare beneficiaries, focusing policy efforts on addressing the cost of care for Medicare beneficiaries at the end of life seems like an obvious strategy [1].

While health care cost inflation represents a fiscal burden for the nation, focusing on cost alone, absent any information about quality or outcome, provides an incomplete picture. What is really needed is an increased focus on purchasing value in health care. Such a focus would be beneficial throughout the health care system, but the Medicare program is an obvious place to focus or begin such efforts, since it represents a large public expenditure of resources.

Any conception of value must consider the costs of health care alongside the benefits of health care. Benefits could be denominated in a variety of ways, but a simple approach would be to expect that health care should show benefits in terms of life extension and/or improvements in quality of life. Health care that does neither of these could be said to have no value to the patient and should not be performed. Of course, there are many uncertainties in the simple formulation I have stated. In a population, there would be an average effect, and some would receive high value from care, whereas others would receive little or even negative value (eg, a shortened life span or a worse quality of life), so any focus on value would have to allow for such uncertainty, as well as include mechanisms that allow updating in response to changes in the science. Leaving the difficulties in predicting the outcome of care provision aside, I pose the

following propositions, which I find to be uncontroversial: (1) health care that does not improve life span or enhance quality of life should not be performed, (2) health care that provides value makes patients better off, (3) there are finite resources with which to purchase value, (4) health care that provides more value per cost should be prioritized, and (5) individuals should be able to spend their own resources at their discretion.

Patient preferences are also key in assessing the value of health care because of both the uncertainty of the outcome achieved by receiving care and the cultural importance placed on autonomy and choice in our society. Of course, the current Medicare program elevates choice to the highest level by allowing patients to receive virtually any treatment so long as a provider (ie, physician or hospital) is willing to provide it, regardless of whether there is evidence of effectiveness or efficacy of the treatment for a given patient. At some point, it could become necessary to lessen or bracket the heretofore unlimited choice and autonomy that patients have in Medicare, as a way to address the program's fiscal imbalance. However, an intermediate step would be to provide patients with better information about the value of health care, with both benefits and costs as inputs to their care choices.

The Role of Palliative Care in Increasing Value

Palliative care is care that addresses the symptoms of disease regardless of patient prognosis, although palliative care is typically thought of as being relevant for persons facing advanced, life-limiting illness. Hospice is a subset of palliative care that is designed for persons who are believed to have a life expectancy of 6 months or less and focuses on relieving the burden of disease and improving the quality of life for such patients via an interdisciplinary, team-based approach. Past work has consistently demonstrated that hospice provides benefits to patients, with some work

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Address correspondence to Dr. Donald H. Taylor Jr., Duke Sanford School of Public Policy, Duke University, 112 Rubenstein Hall, Durham, NC (don.taylor@duke.edu).

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showing that it also reduces the cost of care to the Medicare program [2]. Increased access to palliative care among the Medicare population could be key for improving the value of care received by patients, since such care focuses on the goals of care and addressing symptoms among patients. In fact, recent work has shown that palliative care does indeed improve life span, improve quality of life, and reduce costs, at least in the case of individuals with stage IV lung cancer [3]. This makes increasing the “upstream” access to palliative care among Medicare beneficiaries a high priority. Such concurrent care has been shown in a sample of non-Medicare beneficiaries (ie, younger patients) to improve quality of life and reduce costs [4], and expanded access to palliative care in the Medicare program, signified by increased payment for such care, seems to be a high priority from a value perspective.

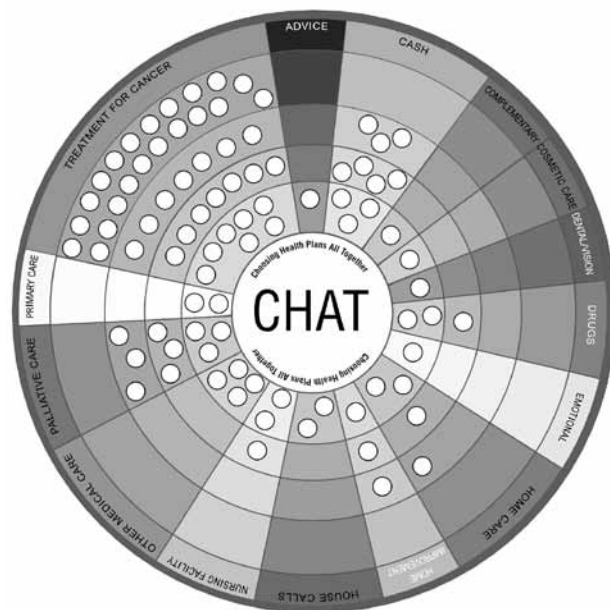
Choosing Health Plans All Together (CHAT)

In the fall of 2010, Duke University began collecting data as part of the CHAT study. CHAT is a participatory, decision-making approach to developing consensus on topics, and it has been applied in a variety of health-related contexts [5, 6]. The goal of CHAT is to provide rational, patient-defined, evidence-based recommendations to inform a redesign of the Medicare benefit package for care at the end of life, as well as to inform the transition from the current hospice benefit to a more patient-centered palliative care model. The CHAT approach provides information to participants in a format that allows them to meaningfully provide their opinions and perspectives, in this case related to the types of care that should be a part of the Medicare benefit package. It also allows patients to interact with other patients and nonexperts in a way that encourages dialogue involving diverse perspectives.

The study is enrolling patients being treated at Duke University Medical Center and Duke Raleigh Hospital who have cancer that has been treated in the past year and are age-eligible Medicare beneficiaries. In addition, family caregivers (typically a spouse or an adult child) are also eligible for the study, regardless of the patient’s disease status or age. Initial attempts to enroll patients who had not only cancer but also a life expectancy of 6 months or less proved to be impractical for a variety of reasons.

Study participants attend CHAT sessions lasting 2-2.5 hours, during which they make decisions about what types of care should be covered by the Medicare program for patients with advanced cancer. Note that patients are not asked to answer what types of care they would prefer but, instead, are serving as informants for what type of care Medicare should cover for patients who are believed to be facing the final 6 months of life. Participants must identify benefits that represent what they believe to be most beneficial, given the constraint that they cannot choose everything (Figure 1). There are different types of care that are relevant for caring for patients with advanced cancer, and

FIGURE 1.
Choosing Health Plans All Together (CHAT) Wheel



Note. The CHAT wheel is co-owned by the National Institutes of Health and the US Public Health Service. ©2000 University of Michigan Board of Regents.

these were taken from the literature. The cost of items of care currently covered by Medicare were estimated, from Medicare sources, for patients who died of cancer, and the costs represent the mean costs for the final 6 months of life. Other types of care that are or could be used by patients in such a situation were identified from other sources, including items that are not presently covered by Medicare. Thus, the choices that are provided to patients are based on plausible economic costs.

The essence of the CHAT exercise is decision making under a resource constraint. Patients could choose from only a limited number of units of care (50 of 92 possible units, denoted by pegs in the CHAT wheel), so they could not choose everything. In that way, the goal of the exercise is to identify care that is viewed as being most important for persons with advanced cancer, as judged by persons with cancer (though not necessarily advanced) and their family caregivers.

The CHAT exercises were conducted as follows. Participants complete a prequestionnaire and then, 4 separate times, make decisions about care covered by Medicare. First, they make choices individually, without discussion with other members of the CHAT group (ideal size, 10-12 persons). Second, they make choices in small groups, in which they work to develop 1 consensus choice about what care to cover. Third, they make a full group consensus choice. Finally, they make another individual choice, without discussion with other CHAT members.

At different points in the CHAT exercise, respondents are provided with information about what could happen to

a patient with advanced cancer. The participants then look at the choice they made and decide whether this outcome is acceptable. This new information either confirms or helps change the perspective of participants with regard to the choices they have made. Participants conclude with a post-CHAT questionnaire that focuses on how hard the exercise was for them and whether they would be willing, on the basis of their membership in the group that made the decision, to abide by the choices of the large group even if they disagreed with the group's choices.

Policy Importance

There are a variety of ways in which the Medicare benefit package could, and probably should, be updated. Alteration of the hospice benefit, which has been largely unchanged since its inception in 1983, is one of the primary areas that is ripe for change. A movement toward a concurrent model of palliative care—whereby patients are provided earlier access to palliative care services, which are reimbursed in a manner to incentivize this care—is a change that would be consistent with moving toward a value focus in the program. One of the primary goals of the CHAT study is to look at the preferences of Medicare beneficiaries who have some experience with cancer, as well as those of their family and caregivers, as a way to inform discussions of altering Medicare policy in this manner. By identifying patient preferences under a resource constraint, the study will help to provide some insight into how a new palliative care benefit might be

structured. This is a small step toward improving the degree to which the Medicare program focuses on purchasing value for its beneficiaries. **NCMJ**


Donald H. Taylor Jr., PhD, MPA associate professor, Duke Sanford School of Public Policy, Duke University, and Duke Cancer Care Research Program, Duke University Health System, Durham, North Carolina.

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