

Creating Person-Centered Care

An excerpt from “Having Your Own Say: Getting the Right Care When It Matters Most,” edited by Bernard J. Hammes, Respecting Choices

*“Our health care system routinely fails people facing the end of life.
But the authors of this book offer hope that this can change. More than that, they show how.
No one has been more effective in demonstrating how much better health care can be.”*

—**Atul Gawande**, New Yorker staff writer and author of *The Checklist Manifesto*

Chapter 2: Creating Person-Centered Care When It Matters Most: Lessons Learned at the Gundersen Health System

Let’s begin with a story. This story is neither a feel-good fairy tale nor an entertaining action-thriller. This story is a moral drama that has or will likely feature each of us.

The plot line is simple. Having lived with an advanced illness for several years, someone you love dearly is now seriously ill. There are options for treatment, but there is considerable uncertainty about the ending. None of the probable outcomes are attractive. There are serious risks and burdens from attempting the treatments. Even with treatment, your loved one’s death in the near future is highly probable. You are asked by the treating physician, “What would your loved one want us to do in this situation?” You realize in a moment of stark clarity that you don’t know the answer, but you also know you cannot avoid making a decision. Whatever you decide will have a profound, lasting effect on the person you love. You also realize that you will never know if you made the right decision.

This tragic story line is lived out in hundreds of health organizations in the United States every day. It is a story where the patient’s chronic illness gets worse and the loved ones suffer with the responsibility to decide. A few of these cases have been played out in our courts and news media, but almost all are faced privately, as bedside dramas, lived by families of all backgrounds, cultures, religious traditions, and races.

Just as modern medical technology is part of our life, so, too, is the moral burden of the decision in this story. It is an unavoidable part of the contemporary human experience, and we have struggled to create effective human and social responses to it.

The most widespread social response has been the creation of laws that permit adults to sign documents that specify their preferences for future healthcare decisions. These documents typically fall into two categories: living wills and powers of attorney for healthcare. Living wills are documents that provide only instructions, typically about stopping medical treatment when you have been determined to be either terminally ill (i.e., you will die soon regardless of any treatment) or when you are in a persistent vegetative state (i.e., you lack any awareness but still open your eyes at times and fall asleep at times). Powers of attorney for healthcare are documents that allow you to appoint another person (or series of persons) who would have authority to make your healthcare decisions if you became incapable to make them yourself. In the most recent versions of this type of legislation and effort, these two documents are often combined so that an individual can create a legal document that not only appoints someone to make his or her healthcare decisions when he or she is incapable but also provides instructions about how and what decisions to make. All of these documents are typically called advance directives (ADs).

A newer approach to documenting a care plan that is rapidly being adopted in the United States is the Physician Orders for Life-Sustaining Treatment (POLST) paradigm. This paradigm goes by different names in different states, including MOLST, POST, and MOST, as well as POLST. This approach uses a standardized set of medical orders on a single sheet of brightly colored paper that stays with a patient as he or she moves across healthcare settings.¹ The POLST paradigm is designed for those individuals who have advanced illness and whose death in the next 12 months would not be a surprise. The POLST form can be used to order treatments to be provided, not provided, or some combination of both. This POLST paradigm provides a powerful way of creating highly specific care plans that all health professionals caring for a patient can follow, even when that patient needs to be transported from one place to another.^{2,3} The POLST paradigm can be far more effective than ADs alone for this population of patients.

While the AD and POLST legislation and regulation have created important tools for documentation, by themselves they do not fully resolve the real, tragic moral dilemmas faced by so many families. These legal responses focus on questions like which form to use and how to fill out the form, rather than on the moral and human question, “How should we take good care of this person in these circumstances?” So, while we needed clarification on the legal boundaries and processes, these efforts alone are insufficient to fully address the moral/human problem that we face.

One community in La Crosse, Wisconsin, has developed a more comprehensive model to help individuals and their families create personal health plans for these morally complex healthcare decisions. This La Crosse model starts from the assumption that it is necessary to redesign the health system so that, as a matter of routine, it is focused on the person and knowing the values and goals of each person. This approach is often called “patient-centered” care. Being focused on the person is not inherently about individual autonomy or legal rights; rather, it is about understanding the views,

values, history, and relationships that a person finds important and how these realities should guide medical decisions about the benefits and burdens of medical treatment. The focus on knowing the patient as a person means that assisting patients in care planning starts not with legal documents or forms but, rather, with interactions and conversations. It means investing in interactions where persons can better understand what choices they need to consider, thoughtfully reflecting on those choices in light of their views, values, and relationships and, finally, discussing these ideas and plans with those whom they most love. It also means undertaking these conversations in a way and at a pace that is acceptable to the person.

Care planning needs to take into account the stage of health or illness of the persons and to plan for what is appropriate or possible at that stage of health. In the La Crosse model, we assist persons and their families in three distinct stages of health: (1) when people are healthy, we promote basic planning that typically creates a power of attorney for healthcare with specific instructions about if and when a severe, permanent brain injury or disease might change the goals of treatment from prolonging life to focusing on comfort; (2) when people have a progressive, advanced illness and begins to experience serious complications from that illness, we do disease-specific planning that provides specific instructions about when a devastating complication from the illness would alter the goals of care; and finally, (3) when we won't be surprised if the people die of their known illness in the next 12 months, we talk in more detail about specific treatment issues that are documented on the POLST form.

Such conversations take considerable time, and health professionals need to develop additional skills and competence to facilitate them well for each stage of the illness. In La Crosse, this reality led to the creation of a new role in healthcare: an ACP facilitator. These facilitators are typically staff who already have professional skills and who would have the time needed to devote to facilitating these conversations,

usually from 30 to 90 minutes. These facilitators work as part of a team that has the patient's physician as the central member.

To be successful, however, this new ACP system had to have more than facilitators. Other roles and responsibilities had to be considered and designed. These staff needed to be instructed on how to play these roles. So from the receptionist in the outpatient clinic to the medical records personnel, from the bedside nurse to the physician in the wellness clinic, each had a unique role to play in the ACP system. Each role needed to be carefully thought out, and staff needed to be trained and held accountable to play their roles.

In addition, the system needed standardized ways to document not only the interactions with patients, but also to document what plans were created. In the La Crosse community, the health organizations were not satisfied with the power of attorney for healthcare document created in state law, so they created a new state-law-compliant document that was easier to read, easier to fill out, and more comprehensive and clinically useful.⁴ This document was designed to complement the conversation process. In addition, the health organizations in La Crosse decided to implement the POLST paradigm. This program provided another specific tool to compliment the power of attorney for healthcare for those who were most likely to face serious medical problems. POLST has made an important contribution because it helped guide treatment even as a critically ill person was being transferred from, say, long-term care to an ambulance, to the emergency room, to a hospital bed. The POLST form made it possible for a highly individualized plan to be created and to be followed even in complex transitions of care, whether the plan was for all treatment, comfort care, or anything in between.

Medical record systems were also designed so that care plans were entered and maintained in a patient's medical records in a consistent manner and were always available to providers when needed. In the

beginning, care plans were stored in the paper medical record, but now are a part of the electronic medical record. Specific staff were made responsible for making sure that any ADs and/or POLST a patient had were (1) entered into his or her medical record, (2) updated over time, and (3) transferred from one facility to another so they were available to the patient's next physician.

Before these ACP systems were implemented, other local groups were engaged and included in the decision to implement the program. These groups included religious leaders, service groups, members of the county bar association, and public institutions, such as schools and libraries. This engagement was essential to establish trust and widespread support for this work.

To make the promotion of ACP easier and more effective, educational materials using a common name, logo, and messages, including print and video materials, were developed and used as a standard of care by the major health providers in all settings of care. Rather than promoting the mere completion of legal documents, these materials promoted discussions and conversations and provided guidance on when and how to have these conversations.

Finally, all these care planning systems were not only managed over time, but also subjected to quality improvement processes so that poorly functioning processes could be identified and improved.

This ACP program in La Crosse is known as Respecting Choices®.⁵ The systems described above were initially put into place in the La Crosse region from 1991 to 1993. The POLST program was introduced in La Crosse in 1997. Gundersen Health System, in collaboration with the other health organizations in La Crosse, has continued to monitor the outcomes of this system. The latest study data⁶ collected in 2007 and 2008 have demonstrated a very high prevalence of care plans for adults who die in health organizations in La Crosse County (90%), that almost all of these care plans are available in the medical record of the health

organization where people died (99.4%), and that the treatments provided are consistent with care plans almost all the time (99%). In addition, at the time of death, 67% of individuals also have a POLST form. These documents are almost always in the medical record and are consistently followed. In the 400 consecutive deaths reviewed in all settings of care in La Crosse County, 96% had some type of plan available at the health organization where the patient died.

This is what person-centered care could look like: a community-wide health system that organizes itself so that it makes a concerted, planned effort to talk with patients and those closest to them about their values and their healthcare goals, and these personal health plans are recorded and documented so that all health providers not only have access to them, but also know how to use them to provide the right treatment to each and every individual. The ultimate goal is to make sure that patients receive just the treatment they want based on truly informed decisions and to avoid over- or undertreatment.

But the value of this approach isn't only about the value of respecting or honoring a patient's values and goals. There are other benefits. These other benefits include (1) avoiding treatments the patient considers burdensome, thus avoiding unnecessary suffering and indignity; (2) being better able to provide care where the person would want it; and (3) diminishing or eliminating the moral distress and its lasting effects experienced by family members who must make healthcare decisions when they do not know what their loved one would want.^{7,8}

Finally, there is a potential positive side effect of such care planning that has a benefit for everyone: lowering the cost of care. While neither the aim nor the goal of good care planning, cost savings have been noted in many places where effective care planning has been implemented.⁹ Savings come not as a result of denying treatment to any person; rather, savings occur because we know that, from the person's perspective, certain medical interventions are no longer of value to them. The vast majority of Americans are very clear about

one value: "I don't want to die hooked up to machines." If a person holds this value and documents it in a care plan, and if we can honor it almost all of the time, we can eliminate the high cost of medical intervention at the very end AND we can focus our care on the relief of physical, emotional, and spiritual suffering.

In summary, an effective care planning system benefits everyone. It's a more person-centered system of care, so not only can we more thoughtfully tailor medical treatments to the person, but we can also avoid unnecessary suffering for that person. We can help relieve families of the nearly impossible moral burden of making difficult healthcare decisions for someone they deeply care about. For the health system, we can bring to bear the vast array of medical services in a way that best carries out the professional responsibility to act in the patient's best interest and to minimize unnecessary suffering. For the payment system, we can avoid using extensive services by making sure that patients receive only those services they desire.

So, if this can be done in La Crosse, why isn't it done everywhere? In some of the chapters that follow, other authors will describe how it is being done elsewhere. But in our current US health system, there are enormous barriers to creating effective care planning systems that are truly person-centered.

Perhaps the biggest barrier is the disparity between the costs of implementing and maintaining the care planning system compared with what our current system pays health professionals to provide. Establishing an effective care planning system incurs real costs. Health administrators need to budget for the time to create a care planning system, for the staff to be retrained to play new roles, for medical records processes to be reorganized, and for staff to be provided the time to facilitate the conversation with patients and their families. But in our current payment system, there is little or no reimbursement for all this work. Given this reality, it is understandable why the prevalence of effective care plans remains low and the moral distress described in the opening story line remains common.

Perhaps the second biggest barrier stems from the fact that creating such a person-centered health system requires a huge shift in how we provide health services. Like all human systems or processes, healthcare tends to do what it has done. We have had decades of experience of treating acute medical problems in high-tech facilities like emergency departments and intensive care units. As a system, we are very good at providing this care and treatment, and this is exactly the care and treatment that many patients need and desire. Clearly, we do not want to undermine this capacity! But as we have gotten better and better at managing progressive, chronic illness and prolonging survival despite incurable illness, at some point in the progression of an illness, this model of acute care is not the right model. The point at which the potential benefits of the acute care treatment model are outweighed by its burdens and/or lack of clear benefits is as individual as the person who lives with the illness. The best service model for healthcare would allow individualization of health services, particularly for persons who have advanced illness, so that each person gets the care that matters to him or her the most. Unfortunately, in our current healthcare delivery model, patients seriously ill with a progressive illness are all too often presented with an either/or choice when it comes to planning for care. That is, either they stay in the current acute care model and get all that high-tech medicine can deliver, or they give up the acute care model and focus exclusively on the goal of comfort. So, to actually improve care planning, not only do we need to make care planning part of the routine process of healthcare, but for those individuals who have advanced illness, we need to be able to create a more flexible health delivery system so that each person can make individualized care plans that take advantage of all the medical treatment that might improve survival and function, but effectively refuse those treatments that come with too much burden, too low a probability of benefit, or loss of dignity.

It is exactly this simultaneous change of providing planning conversations and the flexibility of options that has been created in La Crosse. In La Crosse,

patients are provided the opportunity to create personal health plans about future medical care. Most, but not all, accept that opportunity at some point. The plans that are created are not about giving up treatment; rather, they are about tailoring treatment according to the values, goals, and illnesses of each person. Some patients have reasons to continue to push for all treatment. Others see diminishing returns for treatment and want to focus more on comfort and relationships. Still others may want to continue to try some treatments but forgo others. In each and every case, these are decisions a person makes with those they consider family. In this way, each family can focus on the support of this loved one and not get caught in arguments or anguish.

To put this in human terms, the typical story line in La Crosse is different from the one described at the beginning of this chapter. The story line in La Crosse is now that we know what the patient wants, and we know what choices to make. This, of course, does not take away the sadness and grief of loss and death, but it does bring comfort knowing that our decisions represented the values and goals of the person we loved, and that our own actions were both respectful and loving.

Put simply, this is just better healthcare... healthcare that every American deserves to have. And unlike most other improvements in healthcare, the evidence suggests that this approach, in the overall picture, will reduce the waste that is making healthcare unaffordable for us all. This is the care model we should each want for our own families and for ourselves. This is one change in the healthcare system that we cannot afford to allow divisive politics to derail. If we do, we and our families will all suffer for it.

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