

Is It Time to Redesign Hospice?
End-of-Life Care at the User Interface

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Policy Brief

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Is It Time to Redesign Hospice? End-of-Life Care at the User Interface

Hospice is a system of end-of-life care that's not used to its full potential. That is, hospice is not used in the way that would benefit patients and families as much as it could. My argument is that this is an issue of usability, or ergonomics—the science of design. I illustrate how to take what we have learned from the science of usability to make hospice more accessible and approachable, and to increase hospice use among those who would benefit from it. Underneath this discussion, though, there is a more fundamental question: Can we make hospice more usable or do we need to think about redesigning hospice entirely?

What is Hospice?

Hospice is a system of care that is designed to support patients with serious illness and their families. There are currently over 3,500 hospice organizations nationwide and this number is increasing steadily. Most patients receive hospice care in their own homes or in a long-term care facility, but some receive at least some care in a hospital or dedicated hospice inpatient unit.

The standard hospice team, as defined by the Medicare Hospice Benefit includes a visiting nurse, physician, social worker, chaplain, home health aide and community volunteer. Hospice patients also receive respite care and short-term inpatient care, and medications, medical equipment, and medical supplies that are related to their admitting hospice diagnosis. Surviving family members also receive bereavement services following a patient's death. Medicare is the single largest purchaser of hospice

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services, (70%); the rest is funded by Medicaid (4%), private insurance (10%) and “other” sources, including community donations and grants (16%) (Hospice Association of America 2006).

Most hospice programs have two basic qualifications for admission that are defined by the Medicare Hospice Benefit:

- Participants must have a terminal illness with a prognosis of six months or less if their disease runs its usual course, as certified by two physicians, usually a referring primary physician as well as the hospice medical director, and
- They must also agree to give up access to most, if not all, aggressive treatment related to curing that illness.

About one-third of adults in the United States die while in hospice (Miller, Kinzbrunner et al. 2003), but this figure may be lower among ethnic minorities, rural patients, and other underserved populations (Greiner, Perera, and Ahluwalia 2003; Virnig et al. 2000, 2004). Most of the people who currently use hospice are elderly and white; about 60 percent of them are women (MedPAC 2006).

The goals of hospice are to help patients and their families cope with a terminal illness by providing support and services that include controlling symptoms, relieving pain, and working through the grieving process. Although there are few randomized controlled trial data to support hospice, there is strong evidence from case-control studies that hospice patients are more likely than non-hospice patients to be properly assessed for pain, to have their pain managed, and to receive appropriate pain medication. Their families may also be more likely to experience better bereavement outcomes (Miller et al. 2002; Miller, Mor, and Teno 2003; Connor et al. 2004; Casarett, Karlawish et al. 2005).

Hospice Is Underutilized and Utilized Improperly

Despite the benefits of hospice, most people who enroll in hospice do so very late in the course of their illness. For instance, the median length of stay is less than 4 weeks. One-quarter of patients enroll in the last week or less, and 10% enroll in the last 24 hours of life (MedPAC 2006, Figure 3-2).

Nobody can really agree on the ideal length of stay in hospice (Iwashyna and Christakis 1998; Kapo et al. 2005). A week? Ten days? Three months? If I had to pick an optimal length of stay I would say probably about two months, but there's no real science to that, it's just my guess. However, if a patient is referred to hospice in the last 24 hours of life, that's clearly not enough time for hospice to help that patient and family as much as they could have. Clearly those patients aren't getting access to all of the hospice care that might benefit them. Within the typical range of time that most people are in hospice—one day, one week, three weeks—longer within that range is certainly better. Hospice is an effective tool for end-of-life care, but it's not used to its full potential.

Increasing Hospice Usability

People have been trying to make hospice more useful by getting more people enrolled in hospice sooner, without much success. What's the solution?

One solution that I've been thinking about more and more lately, and which has started to inform my research, is that we're looking at the question of increasing hospice utilization through the wrong lens. We have been looking at hospice through a public health lens, an economic supply-and-demand lens, or maybe a medical lens. I think we need to start thinking in terms of a different paradigm, a paradigm of usability.

A typical definition of *usability* is “[t]hat quality of a system that makes it easy to learn, easy to use and encourages the user to

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regard the system as a positive help in getting the job done” (Georgetown 2006). The *usability paradigm* goes by different names—ergonomics, usability studies, human engineering, human factors science, and user interface design, among others. Nearly every product you use, the cell phone in your pocket, the computer on your desktop, has been designed with ergonomics or human factors design in mind to make it more usable, that is, used in the right way at the right time.

What do you do if you have a product or service that works well but you can’t get people to use it in the right way? How might we use some of the techniques that have been developed and tested in the last 20 or 30 years in these fields to try to make the hospice product better, more effective, and more usable?

Improve the User Interface or Redesign Hospice?

One lesson we’ve learned from years of research on usability is that there are really two ways to make a product more usable: we can improve the user interface through better instructions or education, or we can start from scratch and redesign the product entirely. So which approach should we consider for hospice? It’s helpful to consider a few examples.

Anybody who remembers a videocassette recorder (VCR) knows that they were almost impossible to use. You would go in to anybody’s house and you would find taped to the top or on the side of the television a little set of instructions that said: “1) do this; 2) do that; 3) do not, under any circumstances, do this, otherwise you’ll erase everything.” Yet despite the best instruction manuals, and despite the best do-it-yourself manuals, VCRs were really hard to use. Manufacturers tried to design the user interface to make them easier to use, but they really didn’t have much to work with. VCRs were never easy to use and they had no potential to be really user-friendly. VCRs didn’t have much of a future. It was time for a new product to perform the

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same function—and along came TiVo, DVD recorders, and a whole generation of much better products.

What does this have to do with hospice? Here's the point: If you consider difficulties of hospice access, and the challenges of using hospice in the way that would make it most effective, the TiVo solution may be the solution for hospice. In other words, we may need to give up and start over. But I still think there are a variety of different ways to improve the hospice user interface.

Observe the User's Experience

How do we improve the user interface for hospice? Two key principles come out of the user design literature. First, you have to observe the user's experience to figure out what's going on, why it is or is not usable. That means looking at, watching, and talking to people who are using that system. A good example of this is a driving simulator developed by Volvo, a Swedish car manufacturer known for designing safe cars. These driving simulators are rigged with microphones and multiple cameras so that designers can learn exactly how people respond in the setting of an accident or a near-accident. Where do their hands go? Where do their feet go? Where are they watching along the way? A lot of Volvo's success in redesigning cars for safety, and their safety reputation, comes not only from the structure of the car itself but from their understanding of the ergonomics of accidents and how people get into trouble.

In the course of our research, we've discovered that you can learn a lot about the hospice user interface through fairly simple methods. You don't need cameras and microphones, and you certainly don't need a driving simulator, although I suppose that's something to consider for future studies. Instead, the best way we have found, the easiest way, at least, to begin to explore the hospice enrollment process is to ask family members of patients who have received hospice care. There are some methodological

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limitations to this approach, but it turns out to be a very useful way to understand how we can make hospice more usable.

What We Already Know about the Hospice Interface

Let me take you through some things that we've learned about the user interface of the process of enrolling in hospice, or not enrolling in hospice as the case may be, and then give you some of the implications.

Who Initiates the Hospice Decision?

Before I embarked on this line of research I always assumed that physicians generally initiate discussions about hospice. At least that was my experience. I'd routinely sit down to meet with a patient and his or her family and I review the patient's situation and suggest hospice as an option. I was having these discussions all the time and I assumed that other physicians were as well. But apparently that's not true at least half the time (Casarett, Crowley, and Hirschman 2004). That means that for every physician who initiates a hospice discussion, there's another patient or a family who's thinking about hospice, but not discussing it with the patient's physician. This is surprising to me, but we've confirmed it in a number of studies since then.

The Timing of the Hospice Decision

The second thing we've learned about the hospice user interface is that a lot of patients and families think about hospice for quite a while before they actually discuss it with a physician. The result is long lag time between the time that patients or families start thinking about hospice and the time that they enroll. During that time many patients have goals and preferences that are consistent with hospice, but they just don't quite reach the decision point.

When they do reach the point of discussing hospice with the physician they often make what we call "snap" decisions. In fact, we've found that 85% of people enroll after a single discussion

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and usually they enroll that same day (Casarett, Crowley, and Hirschman 2004). That is not the kind of informed consent process that we would like to see for a major decision like this.

Instead, what I would like to see and what I try to do with my patients is to encourage them to start thinking about hospice before it's really an option. From my perspective, an ideal discussion might begin something like this: "Hospice is not an option for you right now. For instance, it's not consistent with your goals. However, hospice may be the best option for you at some point in the future. Let me tell you about hospice now so you can begin thinking about it. That way you'll be better able to decide for yourself if and when hospice is the right choice for you." And I continue to revisit the topic over the next couple of months. That's the gradual decision-making process I like to provide to my patients. Instead, all too often what I see is: "Hospice is the best option for you now. Do you want to call or should I?"

Who Makes the Hospice Decision?

The third thing we've learned about the hospice user interface is that patients and families are both involved in the hospice enrollment decision. Earlier in my career, I wrote a grant proposal in which I said we were going to talk to patients about why they wanted to enroll in hospice. But the grant reviewers commented, "This is a great idea but patients don't make the decision to enroll in hospice. By the time they enroll in hospice they're too sick. It's the families who are making the decisions. You should really talk to the families." And my response was, "That's an interesting hypothesis, but I don't think it's true. Let's find out."

Since then we've done several studies that have looked at who makes the decision about hospice enrollment. In these studies, we've found that the reviewers were partly right; about a third of the time the patient is not involved in the decision at all. But for

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the most part the reviewers were wrong. Overall it tends to be a shared decision, and probably 15-20% of the time, patients make the decision by themselves (Casarett, Crowley, and Hirschman 2004; Casarett, Crowley, et al. 2005; Rickerson et al. 2005).

The key point here is that generalizations about who the user is aren't all that helpful. Patients and families are both involved, and we really can't ignore either of them. The bottom line is if you're thinking about improving the user interface, if you want to make hospice more usable, you really need to focus on both the patient and the family.

What Do Patients and Family Members Want to Know about Hospice?

The fourth thing we've learned about the hospice user interface is that patients and families have predictable questions about hospice care. When we interviewed prospective patients and their families at a hospice information visit to find out what they already knew about hospice, and what their information priorities were, we discovered that 40% of them knew nothing about hospice (Rickerson et al. 2005). But they also had questions that focused on three main issues:

- How often will hospice send someone out to visit?
- Who pays for hospice?
- What kinds of practical support and assistance does hospice provide?

Service Priorities

Finally, we've also learned that patients and families have predictable priorities for hospice services. These are the services that they say would be most useful to them. In a study of patients and families at the time of hospice enrollment, we found a variety of services that were important, including pain management, 24-hour care management, and practical help around the home.

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These sorts of things drive hospice enrollment. These are what people are looking for when they're thinking about enrolling in hospice.

However, we also found benefits of hospice that family members said they discovered during the hospice experience and wished they had learned about sooner. Emotional and spiritual support for patients and for family members themselves didn't seem to be important to families when they enrolled in hospice, but afterward they were much more important, maybe because they got those services and realized how valuable they actually were. Other things were very important to people at the time of enrollment but turned out not to be so valuable afterwards, such as pain management. Is that because they were afraid of having severe pain, but it never materialized, or did they get such good pain management they no longer thought of it as an issue? I don't know.

This raises an interesting question. What's important: what people say when they enroll, or afterwards? If you're thinking about the user interface and what sorts of benefits hospice offers, you should probably look at what people want at the time they're enrolling. But keep in mind that may not accurately reflect the total value of hospice, which is probably better measured by the benefits most valued by those who have been through the hospice experience.

Putting Information about Hospice in the Right Place

So we've learned a lot about the hospice user interface. But how do you reach all those people who really haven't thought about enrolling in hospice? How do you begin to tell them about it? This, I think, is the big challenge in designing the user interface.

We could probably write better instructions for hospice use, now that we have the data that I've described. For instance, we know what services are important to people, and what questions they

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have. That should allow us to explain hospice in a more effective, compelling way. But where should we put those instructions? Who do we address those pieces of information to? Who do we tell about those services, and how do we tell them? If you're talking about trying to improve the user interface for a VCR, you either put instructions on the front screen or in an instruction manual. But how do you do that for hospice?

In the Head or In the World?

Our usability colleagues would say you have a choice. You can either put knowledge in the head, meaning you can teach people, or you can put knowledge in the world, meaning put it around people so it's there when they need it. For example, let's compare two very different door opening devices, a door knob and an emergency pushbar.

Most of you recognize a door knob, but only because of your experience. There's nothing about that shape necessarily that tells you it's a door knob and exactly how to use it. If you're from a different culture, if you've never seen a door knob before, you wouldn't know what to do. Any knowledge about what to do with that door knob has to be in your head or you're not going to be able to open it. And even if that knowledge is in your head, you still need local knowledge: for instance, you need to know whether this knob is in a door that you push or that you pull.

Contrast that with the emergency pushbar door, such as the ones that are found on a fire exit door. Typically you don't need to know anything about how to open that door. All you have to do is walk up to it, and if you're panicked enough you push on it and it opens. There's no thinking about whether to turn or whether to slide or whether to push or pull, it simply works. It's worth mentioning, by the way, that this is actually an excellent test of good design. Products that are really well designed don't make you think—they're effortless.

Neither the door knob nor the pushbar, I should point out, is necessarily a better door. While you probably don't want to live in an environment full of pushbar doors, on the other hand, you really don't want a fire door that opens with a door knob. You need to think about where to put the knowledge as a function of what you want that knowledge to do in the situation that it's required to act in. Here are a couple of rules of thumb.

- Put instructions in the head for common tasks. These are tasks that someone learns once and then uses for a lifetime. This works for cars, software that you use repeatedly, household appliances, and so on. You could put knowledge in the world for some of these things, but you really don't need to. You don't need to be reminded how to drive every time you get into a car. You learn it once, hopefully without too much damage, and you remember it.
- Put instructions in the world in situations when multiple users come through quickly, use a product once, and then move on. This would be the better strategy for products that are used in an emergency, or by a range of people with limited experience, or, I would argue, hospice decisions. For these sorts of situations, when you can't rely on people to know what do, you need to put knowledge in the world.

I'm not saying you can't improve the usability of hospice by teaching people—public service announcements and so on—but I'm not really optimistic that it's the best way. Nobody really wants to acknowledge that they're going to die, so it's difficult to begin to educate the public about a service such as hospice that (a) they may not need for many years, and (b) even though they may need it soon they don't want to admit it. For instance, public service announcements have been very effective, up to a limit, for seatbelt use. Chances are if I give you a message right now about seatbelt use, you'll probably be in a car at some point in the next 12 hours, so there's a much smaller lag time between the time that I give you that message and the time you have a chance to

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apply it. Contrast that with the hospice choice, where I might give you information about hospice today, and you might not be involved in a hospice decision for the next 12 years, in which case that message is not nearly as effective.

Putting Knowledge about Hospice in the World

This realization led us to think about how we could actually put knowledge about hospice in the world. How could we inform people about hospice at a time when they were actually appropriate for hospice? The short answer is that it's possible.

We designed a two-arm randomized controlled trial of 205 nursing home residents, half of whom randomized either to the intervention or usual care, in three nursing homes around the Philadelphia area (Casarett, Karlawish, et al. 2005). First we identified their goals—broadly focused on either aggressive life-sustaining treatment or comfort care. Then we determined whether their preferences were consistent with hospice. Finally we identified needs for palliative care—symptom management, and emotional and spiritual support, and so on—that hospice could meet. Using an algorithm, we notified the patient's physician and suggested hospice for those patients who were appropriate. In this intervention, we tried to tailor the hospice enrollment process and to identify people who might be appropriate for hospice. Here's what we found. The key result for me was that this simple, five-minute intervention, combined with whatever time it took to fax a brief summary to the primary care provider, increased enrollment in hospice, and also increased the length of stay for those patients who enrolled from 14 to 64 days. We also decreased acute care utilization. But what was really important to me was better family satisfaction near the end of life. Nobody's managed to improve family satisfaction in nursing homes, in particular, to this large a degree, but this fairly simple intervention managed to do just that.

What's Next?

While I've argued that you can improve the user interface, you can make hospice more usable, to get more people into hospice sooner, I'm not sure that's really the best answer.

There's actually an interesting usability analogy in seatbelt use. In 2005, the best estimates were that 82% seatbelt use prevented 15,632 deaths that year, but that optimal seatbelt use would have prevented an additional 5,328 deaths and thousands of injuries (NHTSA 2006). However, the rate of seatbelt use, although still increasing, was leveling off, and there was a lot of concern in the public health world that we're never going to get anywhere near 100% seatbelt use so we needed alternatives. And that's why we have airbags.

To some degree I think that's where we are with hospice. We're dealing with a system that restricts access based on a prognosis of six months or less and goals for care that emphasize comfort. Rates of hospice use have been gradually trending upward, but the length of stay in hospice has remained somewhere between two and four weeks. Remember the data I talked about earlier that suggest that the longer you're in hospice (up to a certain limit, which has yet to be defined) the better care you get. I'm convinced that without a major redesign we're not going to be able to get people into hospice any sooner.

Why might this be the case? Well, here's an analogy. The story goes, and may even be true, that the old Remington typewriters used to jam when people typed too fast. And so a consultant, as consultants even back then were, was brought in to try to fix the problem. The best solution he could come up with was, rather than improving the mechanism of the typewriter itself, to rearrange the keys so that commonly used keys were as widely spaced as possible, thereby slowing down people's typing speed (<http://en.wikipedia.org/wiki/QWERTY>).

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Hospice, like the typewriter, is designed to be unusable, and historically that's actually how hospice got this design. The story goes that policymakers, particularly people at the Health Care Finance Administration (HCFA), now the Centers for Medicare and Medicaid Services (CMS), were concerned that there would be an enormous flood of people using hospice, the hospice benefit that CMS would be paying for, so they wanted to find some way to restrict the benefit. If that story is true, it turns out that they did that quite well, probably as well as the old Remington typewriter manufacturers. Now, though, we have an opportunity to think about redesigning the hospice Medicare benefit in a way that, I think, would cause a rebellion if we tried to reorganize the keyboards that we've all come to know and trust.

Redesigning Hospice

If you buy my argument that we've gotten about all of the usability that we're going to get from the hospice benefit as it stands now, there are two broad ways in which we can think about redesigning hospice.

Redesigning Hospice Services

One is redesigning hospice services, which is a subject for another presentation. But I think it's interesting to consider that the Medicare hospice benefit apparently was not the product of extensive market research, focus groups, or even data, but rather expert opinion. That's what gave us the hospice Medicare benefit that we've been living with for the last 30 years. No corporation would think about designing a product that way, at least no successful one. And yet we're all living with this product. We're doing a study now that uses those techniques of focus groups and conjoint analysis to figure out how you could design a better hospice Medicare benefit.

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Redesigning Hospice Eligibility Criteria

Redesigning something doesn't have to be complicated. If you're willing to take a step back and design from scratch, and to think about a problem of usability from multiple angles, you can often come up with a very simple solution that is very effective. For example, here's another story, which I think may be true (although it's such a good story it almost has to be fictional). Amsterdam is one of my favorite cities in the world, and the site of Schiphol Airport. The men's bathrooms at the airport were messy because of splash back, which frequently occurs when a man uses a urinal. This so offended the Dutch, who are a tidy nation, that they thought about ways to redesign urinals to try to make them less mess-inducing. Some brilliant industrial engineer had discovered that there's a sweet spot in the curve of a urinal which, when hit, sends the flow down the drain. And furthermore, there is something firmly embedded in the Y chromosome that causes men to automatically aim at a target if it's there. The solution they came up with was brilliantly simple: a target, an image of an insect (a fly) etched onto the sweet spot of the porcelain urinal. The logic was if you put a target on the sweet spot of the urinal, men will instinctively aim for it. And it works (Vicente 2004, 84-86)!

Let's focus on simple strategies for increasing hospice usability. One is to eliminate the restriction based on prognosis. The other is to eliminate the requirement that patients give up access to life-sustaining treatment. Let me briefly take you through some of the data we have to support either of these strategies.

Eliminating the Prognosis Requirement

One logical population to consider for hospice admission is nursing home residents. Almost all of them have needs for care that are consistent with hospice, so needs really aren't a realistic exclusionary criterion for hospice. Some of them have appropriate preferences for giving up life-sustaining treatment, but only a few. And a small minority, probably 10-12%, have a

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prognosis of six months or less. When you combine those two small groups—those with preferences that are appropriate for hospice and those with a prognosis that makes them appropriate for hospice—and you juxtapose them with the number of residents who have needs that hospice can meet, you wind up with a large population, most of whom are kept out of hospice because of one or the other of these eligibility criteria. At this point, you have to start thinking about where these eligibility criteria came from, and whether they're really doing us any good.

Is the six-month rule a barrier? I'll tell you as a clinician that prognosis is extremely difficult, and other doctors will back me up (e.g., Fox et al. 1999; Christakis 1999; Christakis and Lamont 2000). I see probably 5 to 10 people who are dying every week, and I still overestimate their prognosis. I've actually learned to take a best guess and to cut that best guess in half, which tends to be right more often than not. CMS has tried to encourage hospice enrollment by emphasizing that eligibility doesn't require a certainty that the patient will die in six months, but that really hasn't helped, especially since hospices risk not getting paid by CMS for patients who don't meet CMS criteria (Miller, Weitzen, and Kinzbrunner 2003).

Increasing the prognostic limit seems like an easy solution, but it is not the answer either. Some people would argue it should be twelve months instead of six months. We actually tried that in a bridge program at the University of Pennsylvania (Casarett and Abraham 2001). We found that the bridge patients lived longer and at six months they were almost twice as likely to still be alive (10% versus 5%). But that's not a large difference, in my view. In other words, if you make incremental increases in the prognostic limits, you get incremental increases in the number of people who benefit and the time that they benefit.

I personally would recommend that hospice eligibility should be independent of prognosis. It's the only system of care that I'm aware of that actually waits until you have a certain prognosis,

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waits until you're dying, before giving you services. This doesn't really make logical sense to me, it surely doesn't make ethical sense, and it doesn't seem to be something that we should be designing into hospice. Eligibility based on some combination of needs and functional status would be better than this requirement of a prognosis of six months or less.

Patient Preferences

The requirement that patients focus on comfort goals may be a significant barrier for patients, who have to give up aggressive life-sustaining treatments and interventions. There's a strong feeling among physicians that this is a major barrier to hospice enrollment, that patients want to continue receiving aggressive life-sustaining treatment until there are no further treatment options left, and therefore they don't enroll in hospice. But nobody had actually tested that hypothesis, so we decided to try (Casarett, Van Ness, O'Leary, and Fried 2006). Terri Fried at Yale recruited about 200 seriously ill patients, age 60 or older with a limited life expectancy who required assistance with at least one instrumental activity of daily living (IADL), from several different care settings. She followed them for up to two years, and did serial interviews once every month to once every three months. This meant we had multiple at-risk periods; for each of these periods we could figure out whether their preferences for life-sustaining treatment at the beginning of each period predicted their subsequent enrollment in hospice during that period. So we could figure out during each of these periods, added up, whether people who wanted aggressive life-sustaining treatment were less likely to enroll in hospice and those people who wanted comfort care would be more likely to, which is what we expected. However, that's not what we actually found. Preferences really weren't a strong predictor of hospice enrollment.

Which is not to say that our model was useless. We found several other variables that were actually very strong predictors of hospice enrollment. For instance, people with worse functional

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status were more likely to enroll. Similarly, people with cancer, patients who knew that they were likely to die of their illness, and patients who were afraid of being a burden to their family were all more likely to enroll. So I think there are many factors that do predict these sorts of decisions about hospice enrollment. But I don't think preferences do. Or put somewhat differently, based on this I'm really not convinced that preferences are the barrier that a lot of physicians make them out to be.

But there's another way to cut this data. If you look at the people who were in the last six months of life who hadn't yet enrolled in hospice, that is, people whose prognosis, as near as we can tell retrospectively, would get them into hospice but who hadn't yet enrolled, we find two things. First of all, a small percentage of them had treatment preferences for hospice that are consistent with hospice, so you could look at them and think "They've got a prognosis of six months or less, and they've got goals that are clearly focused on comfort care. These patients should be in hospice, so why aren't they?" But that's only about 15% of the patient-days. On the other hand, the vast majority of patients who had not yet enrolled in hospice but were within six months of death, about 85% of patient-days, had preferences for treatment that would make them ineligible. They really wanted aggressive life-sustaining treatment. And for the most part their preferences for treatment were so strong that they would be unlikely to change.

Conclusion

In the short run, for the 15% of people in the last six months of life whose preferences make them appropriate for hospice but who don't enroll, that's a user interface problem. Those are the people you begin to identify through better communication, earlier conversations about hospice.

On the other hand, there's still that 85% of patient-days in the last six months of life who have strong preferences for life-sustaining

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treatment. And for those patients, we really need to think about a more fundamental redesign of hospice: that allows them to get hospice care, or something like it, while they continue to receive aggressive life-sustaining treatment.

Overall, I think hospice is effective, and we'll probably get more data as time goes on that hospice is effective, maybe even cost-effective. But hospice is definitely underutilized. I really do believe that it's a problem that we can think of in terms of usability. In the short run there are probably some gains to be made in improving the user interface, meaning better communication, better case finding, trying better to identify people who would benefit from hospice, who are interested in hospice, and getting them into hospice.

But I think fundamentally we're probably going to need much bigger changes in the way that hospice is designed, and specifically in the hospice Medicare benefit. Those changes will be in terms of both prognostic eligibility, ultimately dropping the prognostic criterion, as well as the requirement that people focus on goals for care that are comfort-oriented, because ultimately I think that will prove to be a significant barrier.

Bibliography

- ABCKeyboard.com. n.d. "How did we get stuck with QWERTY? More history...." Available from <http://abckeyboard.co.uk/qwerty.htm>.
- Born, W., K. Allen Greiner, E. Sylvia, J. Butler, and Jasjit S. Ahluwalia. 2004. "Knowledge, Attitudes, and Beliefs about End-of-Life Care among Inner-City African Americans and Latinos." *Journal of Palliative Medicine* 7 (2) (April): 247-256.
- Carter, Cindy L., Jane G. Zapka, Suzanne O'Neill, Susan DesHarnais, Winnie Hennessy, Jerome Kurent, and Rickey Carter. 2006. "Physician Perspectives on End-of-

Syracuse Seminar Series on Aging

Life Care: Factors of Race, Specialty, and Geography.”
Palliative and Supportive Care 4: 257-271.

Casarett, David, and Janet L. Abrahm. 2001. “Patients with Cancer Referred to Hospice Versus a Bridge Program: Patient Characteristics, Needs for Care, and Survival.” *Journal of Clinical Oncology* 19 (7) (April 1): 2057-2063.

Casarett, David, Roxane Crowley, Carolyn Stevenson, Sharon Xie, and Joan Teno. 2005. “Making Difficult Decisions about Hospice Enrollment: What Do Patients and Families Want to Know?” *Journal of the American Geriatrics Society* 53 (2) (February): 249-254.

Casarett, David, Jason Karlawish, Knashjawn Morales, Roxane Crowley, Terre Mirsch, and David A. Asch. 2005. “Improving the Use of Hospice Services in Nursing Homes.” *Journal of the American Medical Association* 294 (2) (July 13): 211-217.

Casarett, David, Peter H. Van Ness, John R. O’Leary, and Terri R. Fried. 2006. “Are Patient Preferences for Life-Sustaining Treatment Really a Barrier to Hospice Enrollment for Older Adults with Serious Illness?” *Journal of the American Geriatrics Society* 54 (3) (March): 472-478.

Casarett, David J., ME Marenberg, and JH Karlawish. 2001. “Predictors of Withdrawal from Hospice.” *Journal of Palliative Medicine* 4 (4) (Winter): 491-497.

Casarett, David J., Karen B. Hirschman, and Michelle R. Henry. 2001. “Does Hospice Have a Role in Nursing Home Care at the End of Life?” *Journal of the American Geriatrics Society* 49 (11) (November): 1493-1498.

Casarett, David J., Karen B. Hirschman, Roxane Crowley, Linda D. Galbraith, and Melinda Leo. 2003. “Caregivers’ Satisfaction with Hospice Care in the Last 24 Hours of

David J. Casarett

Life." *American Journal of Hospice and Palliative Care* 20 (3) (May-June): 205-210.

- Casarett, David J., Roxane Crowley, and Karen B. Hirschman. 2003. "Surveys to Assess Satisfaction with End-of-Life Care: Does Timing Matter?" *Journal of Pain and Symptom Management* 25 (2) (February): 128-132.
- Casarett, David J., Roxane L. Crowley, and Karen B. Hirschman. 2004. "How Should Clinicians Describe Hospice to Patients and Families?" *Journal of the American Geriatrics Society* 52 (11) (November): 1923-1928.
- Christakis, N. A., and T. J. Iwashyna. 1998. "Attitude and Self-Reported Practice Regarding Prognostication in a National Sample of Internists." *Archives of Internal Medicine* 158 (21) (November 23): 2389-2395.
- Christakis, Nicholas A. 1999. *Death Foretold: Prophecy and Prognosis in Medical Care*. Chicago: University of Chicago Press.
- Christakis, Nicholas A., and Elizabeth T. Lamont. 2000. "Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients: Prospective Cohort Study." *British Medical Journal* 320 (February): 469-472.
- Connor, Stephen R., Martha Tecca, Judi Lund Person, and Joan Teno. 2004. "Measuring Hospice Care: The National Hospice and Palliative Care Organization National Hospice Data Set." *Journal of Pain and Symptom Management* 28 (4) (October): 316-328.
- Fox, E., K. Landrum-McNiff, Z. Zhong, N. V. Dawson, A. W. Wu, and J. Lynn. 1999. "Evaluation of Prognostic Criteria for Determining Hospice Eligibility in Patients with Advanced Lung, Heart, or Liver Ease." *Journal of the American Medical Association* 282 (17) (November 3): 1638-1645.

Syracuse Seminar Series on Aging

- Georgetown University 2006. "Definition of Usability."
www.georgetown.edu/uis/ia/dw/GLOSSARY0816.html.
- Greiner, K. Allen, Subashan Perera, and Jasjit S. Ahluwalia. 2003. "Hospice Usage by Minorities in the Last Year of Life: Results from the National Mortality Followback Survey." *Journal of the American Geriatrics Society* 51 (7) (July): 970-978.
- Haupt, Barbara J. 2006. "Characteristics of Hospice Care Discharges and Their Length of Service: United States, 2000." *Vital Health Statistics* 13 (154. DHHS Publication No. (PHS) 2003-1725) (July)
http://www.cdc.gov/nchs/data/series/sr_13/sr13_154.pdf.
- Hospice Association of America. 2006. "Hospice Facts & Statistics." Accessed October 19, 2006. Last updated on March 2006. Available from
<http://nahc.org/hospicefs06.pdf>.
- Iwashyna, T. J., and N. A. Christakis. 1998. "Attitude and Self-Reported Practice Regarding Hospice Referral in a National Sample of Internists." *Journal of Palliative Medicine* 1 (3) (Fall): 241-248.
- Kapo, Jennifer, Holly Macmoran, and David Casarett. 2005. "'Lost to Follow-up': Ethnic Disparities in Continuity of Hospice Care at the End of Life." *Journal of Palliative Medicine* 8 (3) (June): 603-608.
- Kapo, Jennifer, Joan Harrold, Janet T. Carroll, Elizabeth Rickerson, and David Casarett. 2005. "Are We Referring Patients to Hospice Too Late? Patients' and Families' Opinions." *Journal of Palliative Medicine* 8 (3) (June): 521-527.
- Knowledge@Wharton. 2006. "The Business of Hospice Care." Philadelphia, PA: Wharton School of the University of

David J. Casarett

Pennsylvania. May 31. <http://knowledge.wharton.upenn.edu/index.cfm?fa=printArticle&ID=1493>.

- Medicare Payment Advisory Commission (MedPAC). 2006. "Report to the Congress: Increasing the Value of Medicare." Washington, DC: MedPAC. June. http://www.medpac.gov/publications/congressional_reports/Jun06_Ch03.pdf.
- Miller, Susan C., Vincent Mor, Ning Wu, Pedro Gozalo, and Kate Lapane. 2002. "Does Receipt of Hospice Care in Nursing Homes Improve the Management of Pain at the End of Life?" *Journal of the American Geriatrics Society* 50 (3) (March): 507-515.
- Miller, Susan C., S. Weitzen, and Barry Kinzbrunner. 2003. "Factors Associated with the High Prevalence of Short Hospice Stays." *Journal of Palliative Medicine* 6 (5) (October): 725-736.
- Miller, Susan C., Vincent Mor, and Joan Teno. 2003. "Hospice Enrollment and Pain Assessment and Management in Nursing Homes." *Journal of Pain and Symptom Management* 26 (3) (September): 791-799.
- Miller, Susan C., Barry Kinzbrunner, Peggy Pettit, and J. Richard Williams. 2003. "How Does the Timing of Hospice Referral Influence Hospice Care in the Last Days of Life?" *Journal of the American Geriatrics Society* 51 (6): 798-806.
- National Highway Traffic Safety Administration. 2006. "Traffic Safety Facts (2005 Data): Occupant Protection." DOT HS 810 621. Washington, DC: NHTSA. <http://www-nrd.nhtsa.dot.gov/pdf/nrd-30/NCSA/TSF2005/OccupantProtectionTSF05.pdf>.
- RAND Corporation. 2006. "Redefining and Reforming Health Care for the Last Years of Life." Research Highlights.

Syracuse Seminar Series on Aging

http://www.rand.org/pubs/research_briefs/2006/RAND_RB9178.pdf.

- Rickerson, Elizabeth, Joan Harrold, Jennifer Kapo, Janet T. Carroll, and David Casarett. 2005. "Timing of Hospice Referral and Families' Perceptions of Services: Are Earlier Hospice Referrals Better?" *Journal of the American Geriatrics Society* 53 (5) (May): 819-823.
- Teno, Joan M., Brian R. Clarridge, Virginia Casey, Lisa G. Welch, Terrie Wetle, Renee Shield, and Vincent Mor. 2004. "Family Perspectives on End-of-Life Care in the Last Place of Care." *Journal of the American Medical Association* 291 (1) (January 7): 88-93.
- Vicente, Kim. 2004. *The Human Factor: Revolutionizing the Way People Live with Technology*. New York: Routledge.
- Virnig, B. A., S. Kind, M. McBean, and E. Fisher. 2000. "Geographic Variation in Hospice Use prior to Death." *Journal of the American Geriatrics Society* 48 (9) (September): 1117-1125.
- Virnig, Beth A., Ira S. Moscovice, Sara B. Durham, and Michelle M. Casey. 2004. "Do Rural Elders Have Limited Access to Medicare Hospice Services?" *Journal of the American Geriatrics Society* 52 (5) (May): 731-735.