

Featured Innovation

Windows to the Heart: Creating an Acute Care Dementia Unit

An Interview with Jeffrey N. Nichols, MD

Cabrini Medical Center

In 1999, Dr. Jeffrey Nichols, chief of geriatrics at Cabrini Medical Center (CMC) in New York City, and medical director of the Cabrini Center for Nursing and Rehabilitation (CCNR), and his colleagues, received a grant from the United Hospital Fund to develop an eight-bed, family-centered acute care unit for patients with dementia at CMC, a 500-bed hospital. Because of their location in Lower Manhattan, these institutions serve an ethnically diverse population, including many non-English-speaking people of Hispanic and Asian origin, and they have a high proportion of elderly patients, including patients with dementia.

*This inpatient unit was created to address the widely recognized problem that when dementia patients are hospitalized, the experience is frequently highly stressful for both patients and family or non-kin caregivers. Patients with advanced Alzheimer's disease and other dementias often suffer a precipitous decline in function during and following hospitalization, which places additional burdens on both the patients and their caregivers (or "carers," as they are described in the United Kingdom). Following some focus group research with family caregivers of dementia patients, Dr. Nichols and his colleagues realized that it was not sufficient to "tweak this, tweak that" in the traditional system of care in the hospital in order to meet the identified needs; rather, they had to take a comprehensive, carefully orchestrated, and holistic approach to change – encompassing the physical, operational, and cultural environment of the institution. In the following interview with Innovations associate editor Karen S. Heller, Dr. Nichols describes the challenges he and his colleagues faced in starting this kind of unit in the acute care hospital setting and provides some preliminary evidence for its success. [Citation: Nichols J. Windows to the Heart: Creating an acute care dementia unit: An interview with Jeffrey Nichols, by KS Heller, *Innovations in End-of-Life Care*, 2001;3(2), www.edc.org/lastacts]*

Genesis of the Program

How did this project begin?

This project, which we call "Windows to the Heart," began three years ago, somewhat in response to the availability of a grant program launched by the United Hospital Fund to enable New York hospitals to look at ways that they could support family caregivers. Planning grants were given to more than 20 hospitals around the city to look at what they did, and come back with a proposal. Because Cabrini Medical Center has an extremely elderly patient population, we decided that we would target the family caregivers of patients with dementia because they represent a large portion of our patient population. Although we were not sure exactly what proportion of patients in our acute care hospital have dementia, we were fairly sure that it was a significant number of patients. Unfortunately, most hospitals don't do good screening, and hospital data systems don't capture the information because dementia is not usually the primary diagnosis. However, we have an affiliated nursing home where about 70 percent of the patients have dementia. This nursing home supplied a

portion, at least, of admissions to the hospital. Plus, we knew that there were a lot of patients with dementia in the community. So we decided to pull together some focus groups of family caregivers who had had relatives at Cabrini. Nursing staff identified patients that they could remember in the last few months whose care had involved family caregivers. We invited these family caregivers to come to some focus group meetings and share their experiences and suggestions with us.

Hospitalization—"Not Good" for Patients

The focus groups were run by professional focus group coordinators. We were expecting the family caregivers to tell us that they needed support groups, or more flexible visiting hours, perhaps better information about the disease, and better referrals for the time of discharge. We did hear those things. But even more loud and clear, people were saying that the hospital experience itself was *not* a good experience for the person that they loved, or for themselves. They told us that they felt ignored when they came to the hospital, and that they knew crucial things about what the patient needed, but there wasn't anybody to give that information to. They told us that we were relatively insensitive to the emotional stress that they were undergoing. And they said that what they really would like is for us to take better care of the patients.

The family caregivers were very straightforward with us that Cabrini Medical Center wasn't *worse* than other hospitals, but that *every* hospital was bad. Many of them had had their family members at other hospitals, as well. In New York, we happen to be located in a cluster of hospitals in Lower Manhattan which is known in the community as "Bedpan Alley" because there are literally thousands of hospital beds here within a couple of square miles. Manhattan is terribly over-bedded, and it is sometimes a matter of chance where an ambulance will take you.

In fact, when you look at the literature about hospitalization for patients with dementia, primarily with Alzheimer's disease, it tells you that patients suffer significant functional declines associated with acute hospital care.¹² This assumption of inevitable functional decline was the received wisdom in the field and has largely been taken for granted—this is simply something that has to happen because it's part of the disease. For many people with dementia, going into the hospital was always a disaster; they always wound up worse off than when they came in. Certainly, anyone who has worked in a nursing home will tell you that the patients always come back from the hospital in worse shape than when they left.

Now, in the focus groups, the families were telling us the exact same thing—that they brought patients in who were moderately functional, but had some acute problem. When they came out of the hospital, the acute problem was resolved, but their baseline functional status was dramatically worse. What's more, in the course of the hospitalization, both the family caregivers and the person they love went through some very humiliating experiences. Somewhat surprisingly, the hospital and its leadership were prepared to listen to this experience.

Levers for Change:

Foundation Focus, Administrators' Own Experience, Hospital Mission

What made your hospital administration receptive to this message?

I think a combination of things made us responsive to this message. The United Hospital Fund's Family Caregiver Initiative was an encouragement to the hospital to choose family caregivers' needs as an area to try to focus on in the short run. When foundations fund initiatives, they are able to bring attention to issues and to put those issues on an institution's agenda. For example, when The Robert Wood Johnson Foundation says they are interested in adult daycare or end-of-life care, it

directs people to *think* about those domains. You may decide to do it or not, but it puts it on your list of something to consider.

A second factor that really made a difference is that there were individuals in senior hospital administration who were, in fact, caregivers themselves, some of whom had had their loved ones in the hospital. So, the stories that came out of the focus groups had a certain resonance for them, which they might not necessarily have had for someone else. That's really not so surprising, however; given the statistics on the percentage of middle-aged people who are family caregivers, it would be expected that at practically every hospital there are some senior staff who are, in fact, also serving as family caregivers. We were fortunate that the people we invited to help us think about the project had these experiences, and, consequently supported the project.

Third, our facility is sponsored by a religious order, the Missionary Sisters of the Sacred Heart of Jesus, known to most people as the Cabrini Sisters. As such, our hospital takes some mission issues rather seriously. It is part of our mission to provide family-centered care, and to feel that we were involved in something slightly larger than just getting people in and out of a hospital. So, when we heard these difficult stories from family caregivers of our patients, we sat down and said, "How can all this be different?"

Changing the Culture of Care

We pulled together a group of senior administrative people from both the hospital and nursing home and said, "If this is what's broken, how does one go about fixing all this?" The more we talked about it, the clearer it became that we could not change this in a piecemeal fashion—tweak this, tweak that, and we can make everything all right. In fact, we really needed to change the whole culture of care, by this I mean, change the whole way we went about interacting with families, the whole way that we took care of patients suffering from dementia in the hospital setting. This change affected staff people's job descriptions, the nature of their work, and what was considered important and not important. We realized that the whole culture of care had to directly involve the family caregiver. We *couldn't* just see the family caregiver as one more problem in a very busy day, which, to a large extent, is the way they had been viewed. On a good day, you have some time to deal with *their* needs, too. But in the current hospital setting, it is a difficult process because, there are six billion things to do, and the family caregivers' needs just seem like one more thing on top of everything else. So we felt that care wouldn't change if we just put a patch on top of a bad situation—the patch being a little bit of extra time, especially if that extra time is being funded out of a grant.

Coincidentally, somewhat parallel to this effort in our institution, the National Alzheimer's Association had a retreat in which they concluded that hospital care of Alzheimer's patients was a major, unaddressed area that they wanted to try to become involved in. When they had gone on their retreat, they had imagined all the different things that would need to be changed in the hospital to make it work. They envisioned that they would fund a hospital-based project that would try to do one of those things. Then, they heard through their New York chapter that we already had started something, and they came here and discovered that we were trying to do *all* of the things they were envisioning! We had naively launched ourselves to try to fix them all at the same time. But I think, in a way, the way we did it *may* be the only way it actually could be done.

The intention was always to transform the care of the patients that we already took care of rather than seeking to increase referrals from outside the institution. When we went further along, attracting other patients became something that the unit staff identified as a potential index of our success. But that was never the hospital's original goal. Our goal was to do a better job taking care of a group of patients and their family caregivers whom we were already seeing.

Barriers to Change & Strategies for Overcoming Them

In your own institution, what barriers did you encounter to making the kind of wide changes you envisioned, given the pre-existing culture, and the way things were set up? Did you anticipate them and were you able to address them?

We thought that one barrier would certainly be the general belief that nothing could ever change, that the way things are, is somehow inevitable. We knew that we were going to have to have major buy-in from senior administration in the hospital because what we were doing was going to cut across many, many different boundaries, and was going to, potentially, at least, put people's noses out of joint. We wanted to make sure that everyone whose department was going to be affected had made a commitment in advance, had blessed the project so to speak, that the project was *all right*, or else that we were prepared to deal with the reality that it *wasn't* all right. We didn't want to find out we couldn't implement the project because it was being secretly, or not so secretly, undermined by people who had different priorities or needs. So, we tried very consciously to involve everybody in the senior administration, relatively early, to let them know what we were doing, to say openly, "These are things that are going to be different, is that all right with you? Is that going to represent a problem? Tell us what the problem is in advance." We tried to prepare for a wide variety of different contingencies, and for administrative opponents.

Our feeling was, first of all, that we *could* change the culture of the whole hospital, but even to change one piece of it was going to require a major investment of time and willingness by all these other people. We thought that if we tried to create a unit that was separate and different, but not accepted by others, that, ultimately, it would be crushed. If it wasn't accepted, valued, and recognized from the beginning, that it couldn't possibly succeed. For this reason, we invested a great deal of time in planning and recruiting the interest or at least the understanding of other hospital personnel.

What senior administrators did you involve?

We involved the directors of medicine and nursing, excluding the director of surgery, because this was going to be a medical floor. In addition we recruited the heads of food service, pharmacy, housekeeping, security, social work, discharge planning, chaplaincy, senior nursing administration, and senior medical personnel. For example, if we planned to change visiting hours, we knew it would be important to involve the admitting office and security. We tried to include all sorts of different people who, potentially, were going to be affected by our efforts to change the culture of care.

Did these department leaders raise any concerns at the beginning?

They did. I would say, initially, there was a lot of concern. For example, the human resources leaders were worried that there might be objections from union personnel about anything that appeared to change job descriptions and reporting. We were fairly careful about how we went about making changes, and it turned to *not* really be an issue.

There were fewer problems than we anticipated. In any large bureaucracy, and hospitals are that on at least one level, people who haven't been consulted are inevitably going to have concerns that they're going to want to have addressed later on. Very often, however; if they are involved in solving the problem, or even framing the problem, they are going to be much more invested in the success

of the project. So, we were very concerned that hospital staff and senior staff would feel, at least to some extent, invested in the project, and willing to problem solve to make it happen. When they were asked to identify potential problems, in fact, they identified fewer problems, people were more agreeable about bending, more flexible, more understanding of what the needs were going to be like than we had originally expected.

How did you recruit the cooperation of these various departments?

We knew, for example, that we were going to need extra time from social service. So rather than scheduling the extra meetings we knew we were going to have to have, and then hearing from the director of social service, "My staff doesn't have to come to all these meetings. We've got other things to do," we started with her and said, "How much time can you commit from your staff to attend the extra meetings that we know are going to be necessary? We are not going to schedule more time than you think that they reasonably can provide." With this approach she actually gave us a larger number of hours than we probably would have asked for, originally. At that point, it became an accepted part of the social work staff's responsibility to attend these meetings and it was no longer a struggle as far as getting that time.

Did you involve quality assurance or risk management?

Quality assurance was *not* involved. And I'm not totally sure why that's true. It didn't really exist as a separate department here. We didn't involve risk management, either, which maybe reflected a lack of caution on our part because that's been an area that has been a problem. I mean, not that we've been sued, but subsequently they came back with a series of concerns that we had not really planned for. So, we should have involved them at the beginning, too.

Designing A New Acute Care Unit with Special Focus on Dementia Needs: Mindful Choices Create Coherent, Peaceful Atmosphere

Please describe what changes you made, briefly.

We designed and opened one eight-bed unit, on one medical floor of the acute care hospital. In designing the physical layout, we consulted with Lorraine Hiatt, probably the country's best known expert in dimension design. She is noted for her work in physical plant design, and has collaborated on a large number of nursing home dementia units and adult daycare programs. She spent a day with us and gave us some advice on how to make the space responsive to the needs of people with dementia, working within a limited budget.

We had what had been a stretch of rooms that went around the corner in a very large hospital unit. They were two-bedded rooms, and a corner four-bed room. We turned the corner four-bedded room into a caregiver and patient lounge. So, we removed the beds and the wall equipment, and put in couches, including a chair that turns into a day bed. We built a wheelchair accessible bathroom, and a family caregiver bathroom. We put in some shelves with patient education materials. We put in a lot of tables because dementia patients tend to eat better in a social setting. There are grab bars for the hallway. And we carpeted the lounge and the hallways, and made sure that the infection control people signed off on this beforehand. These changes turned out to be no issue whatsoever, although everybody told us they would be.

The two-bedded rooms stayed almost exactly as they had been before. They were re-painted to some more neutral colors, and we upgraded the lighting because shadows and odd lighting situations tend to induce paranoia and fear in patients suffering from Alzheimer's. One basic principle of

Alzheimer's design is to make things *look* as much like what they're supposed to be as possible. You want doors to look like doors, so outlining the door in color helps people recognize that the door is in fact a door. Things that you *don't* want people to pay attention to should be the same color as the background so that they do not stick out. We tried to follow those design principles, so the stairwell that goes down to the street is done in the same color as its background wall with no outlining. But all the other areas that we want people to go into are as carefully outlined as possible. Some of these patients will tend to wander—the general color and layout encourages people to wander in the direction of the caregiver room, which is where we want people to congregate.

We did something which seems like it's almost a violation of the patient bill of rights—we took the TV sets out of the patient rooms. There is a TV in the lounge, but we can control what's seen on that so you don't have the situation of people sitting around with TV sets blaring. Under normal circumstances, one watches what one wants. But, here we were quite conscious that confusing, repetitive, loud, hostile kinds of presentation of sound is very difficult for patients. As a result, the unit is extraordinarily quiet. *And* we play music. It's not boring, necessarily, but it is extraordinarily quiet.

There's no traffic through the unit because it is laid out on the far corner of the floor. The only reason to come out to the unit is because you want to be on the unit. No one is wandering through with squeaky carts, nobody's yelling to the other end, "Get seventeen out of bed. Have to go down to CAT scan." None of that goes on with a patient, not knowing whether he or she is number seventeen or not. There is no distracting overhead paging. So the only sounds patients hear are sounds that are *intended*. In addition, we try as much as possible to bring them into the day room where they can interact with other patients and their families in a somewhat more spacious setting because our two-bedded rooms are not really that big.

Staffing and Cost

What is the staffing of your eight-bed unit?

When we started the project, it was our intention that with one sole exception, there would be no difference in staffing between this unit and any other unit in the hospital. Part of the reason for that was purely practical—there's no point in setting up a unit that requires special funding, and then have it disappear after the grant money is gone. We had to come up with a plan that would be self-sustaining from the hospital's point of view. We are staffed primarily using our own in-house people reassigned from other units. The one difference in staffing between our unit and others in the hospital is that we have a pastoral care worker who is assigned almost exclusively to our unit. She is Latin American, bilingual, and has a lot of interaction with the Spanish-speaking patients and people from other ethnic groups who are Catholic.

We built an interdisciplinary team that looks at the patient and the caregiver as a unit, works with them and responds to the patient's behavior as meaningful behavior that needs to be understood. We understand that dementia patients have special needs. Using a team approach has allowed us to meet those needs in an acute care hospital.

Are staff exclusively assigned to this unit or do they rotate through it?

Cabrini Medical Center is a voluntary hospital, and most patients have private attendings of their own. Any doctor in the medicine department can admit a patient to this unit. We have the regular house staff, i.e., the interns and residents that any other unit in the hospital would have. Our unit has only eight beds, so it clearly doesn't have its own discrete house staff. In fact, it has been kind of a

funny process because the house staff recognize that the care here is different from other places in the hospital, and that they are expected to behave differently, and do different things. They observe that when patients in beds six through twenty-one get agitated, they can order restraints. But if patients in beds twenty-two through thirty become agitated, they are supposed to go see the patient and find out why he or she is upset. During teaching rounds we try to reinforce what some of the messages have been. The key message is twofold. First, the behavior of patients with dementia is meaningful. Second, caregivers can help us understand what those meanings might be. But because of rotating coverage, not every doctor who is on the house staff has necessarily been educated about the unit and our approach to patient care.

From a nursing point of view, our unit has essentially the same staffing as any other unit in the hospital. One of the reasons that we chose to have eight beds on the unit was that eight beds per nurse is the standard assignment for one registered nurse on the day shift. In general, seven of those beds are full at any given time. Family members had told us that one really difficult thing about the hospital was that they could never figure out who was taking care of their loved one. On most units, assignment sheets are not posted, nobody knows other people's names, and nametags are hard to read. So, family members would often spend long periods of time wandering through the floor trying to find somebody who knew whether their mother did or didn't have breakfast this morning. Did Mom go for a particular test? And if Mom went for the test, was it completed? Or was it canceled because she was too upset?

We wanted it to be relatively transparent for families to figure out who was involved in the patient's care. So if a family member walks onto the unit, which is physically separated off through its design, and sees a member of the staff, that staff member is taking care of his or her loved one. The only dietician who comes onto the unit is our dietician. The only social worker present is this unit's social worker. One of the things that the team decided in the course of the planning was that our slogan would be: "You can ask anybody because we're all involved in the care."

The worst that happens is you ask somebody and they don't know the answer, but they know who *does* know the answer. If the person who's delivering the tray doesn't know what the patient had for breakfast, he or she at least knows who would know, so the family member could be directed appropriately. And that has been a really positive aspect of the unit. It allows staff to have a much more meaningful interactions with family caregivers than the sort of milling around situation, which is unfortunately more common in acute care hospital settings.

Tell me about the cost of the project.

We had a phase I grant of \$30,000 and then a phase II grant to implement our ideas of \$175,000 from the United Hospital Fund. The hospital's capital contribution has been on the order of \$90,000. The project had to be something that other people would see and say, "We can do that." We had worked with the Alzheimer's Association and the New York City chapter wanted to be able to show that units like this could happen without a lot of extra funding. The grant covered the one additional pastoral care position and four consultants—an institutional change expert, the facilitator for the team planning meetings, the design consultant, and a research consultant who devised and implemented the satisfaction studies. The construction work was done at the hospital's expense. The only monies from the grant that went toward other staff cost, even during the training phase, were for overtime when we wanted to bring in staff from the other shifts so that we could have everybody together in the same room to plan together.

Extensive Training and Planning

Our goals required us to think both deeply and concretely about the needs of caregivers and of patients suffering from dementia. We really began with a very extended period of training, but training is almost the wrong word for it because it really was a very extended period of *planning*. What we did was to ask every member of the team that was going to be on the unit, from myself as the director of geriatrics through the housekeeping staff, to sit down and think through how their jobs would be different if, in fact, they were responding to the needs of both the caregiver and the patient.

We did have some family caregivers involved in the project, and they participated in these planning meetings as well. We considered many of the different tasks involved in daily care. For example, one of the tasks of an environmental aide is to deliver the meal trays. We asked, "What was going to be different about delivering the meal trays in the new unit from the old unit? If we were going to involve the caregiver and be supportive of the caregiver and the patient, what would we do differently from the way we do things now?"

Our patients require a long time to be fed. A very large number of them need to be assisted with eating, in some way or another—either hand fed or reminded to eat, cued, and so on. So, our dietician made an arrangement with the kitchen that our floor gets its food first, and the trays are picked up last. So, we actually have about an extra half an hour between food delivery and pickup. That logistical change gives us extra time to feed these patients, and it accommodates for the reality that we have limited staff at mealtimes.

Importance of Family-Centered Focus

We spent relatively little time actually training people about dementia, as such. In fact, over the course of almost a year of weekly meetings of an hour a week, we devoted only two hours to Alzheimer's disease, just so people would feel they knew something. The point is, most people in the hospital do not need to know much about the genetics of Alzheimer's disease unless they're going to do genetic counseling. But what they really *do* need is to be able to look at a patient suffering from dementia and respond to him or her as an individual; and to work with a caregiver who's telling them something and understand the importance of what that caregiver is saying.

One of the reasons we have had so much difficulty in taking care of dementia patients in the hospital is that they can't tell us a huge number of things about their daily care, and we've just sent home the person who had all the information! In fact, that person—the caregiver—is usually at the bedside, and knows how this patient usually acts, and how to interpret what that person's nonverbal behavior usually means. If the patient starts rubbing his stomach or pounding the table, it may mean "I need to go to the bathroom," or "I'm bored, I want something to do," or "I'm in pain," or "I'm only comfortable if I have a certain thing around." Before the patient came into the hospital, someone was feeding, dressing, and bathing this person everyday, and in most cases, responding to that person's needs remarkably well. In most hospitals, however, we have completely ignored caregivers' vast experience, and swept them aside, not realizing that we needed them desperately to help us provide the best quality care.

Did your history-taking change as a result of attending to what caregivers tell you? Do you document what they say?

Yes. That's one of the major differences in our unit. The first question nurses ask when patients come to the unit is, "Who is the caregiver?" We ask, "Who knows what this person could do before so that we have some idea of what function it is we are supposed to be preserving here? What seems reasonable to expect this patient to be able to do? And if we have a problem, whom should we be

calling to get more information?" These opening questions represent a completely new approach. Traditionally, nurses might be looking for the family member to ask, "Do you have the list of medications?"

In addition to approaching family members with new questions, when staff members get historical information from caregivers, they ask questions that show that they understand dementia and its effects. For example, if a family caregiver mentions a concern that the patient is someone who has a history of wandering, or who sometimes calls out at night or things like that, it isn't treated as something bizarre. Rather, staff members are familiar with the kinds of things that people with dementia usually do at home. So they won't just be eliciting problems from the caregivers, they'll also be eliciting what have been solutions that worked at home, and suggestions as to what should be done if a problem occurs in the hospital.

Over time, we've tried a number of different ways of getting information from family caregivers. We always ask about feeding, dressing, ambulation, and continence. We tend to ask more open-ended questions than directive questions. Family caregivers don't come in neat packages. Sometimes the caregiver is present at the time of admission, and you can get all this information. Sometimes, however, people are cared for by two or three different caregivers, or there's a family member who supervises, but there's really a paid caregiver who is with the patient most of the day. So, you need to figure out what's actually happening with people.

We keep an independent, relatively informal log on all the patients in the unit, which is shared with the team. We preserve this log on the unit in case patients are readmitted so we don't have to ask all these questions all over again. It doesn't become part of their hospital chart.

What else is different for patients and their caregivers on your unit?

There are unlimited visiting hours on the unit. So if family members want to stay over, or feel that they need to stay over because the patient needs them for whatever reason, they don't need the special permission of a nursing supervisor to okay it in order to have it happen. It's an automatically accepted situation.

We have a caregiver room, which has fold-down beds in it, for people who want to stay over, and we have fold-out cots if you need to actually stay in the room itself. Because the units have two-bedded rooms, we discourage staying in the room itself if it is not absolutely necessary because, obviously, that affects someone else's privacy.

At the very beginning, large numbers of family members said that they were going to want to stay, but once they are actually comfortable that staff members know what they are doing, very few family members wind up staying. We were prepared for three or four different caregivers staying on the unit the same night. We didn't know how much capacity we should build in. It turns out that most of the people had been staying the night, basically, because they didn't trust the hospital to take care of their loved one. Once family members recognize that we are both well-intentioned and moderately knowledgeable, very few family members stay overnight.

Interestingly, there have been a remarkable number of relationships that developed among family caregivers. We professional care providers always tend to think it's all about *us*. The family members are coming to the hospital, they must want to see *us*. In fact, very often one of the benefits for family members of being on the unit is the opportunity to share experiences with other caregivers. Although we've attempted to provide some formal caregiver support, there are a lot of *informal* interactions that go on. For example, when people need assistance or reminders with feeding,

families sometimes will make arrangements with each other—"If you're here this morning to help with my dad, I'll be here this evening to help with your mother."

End-of-Life Care

What happens when a patient is really seriously ill or dying? Do you provide palliative care to the patient and family caregiver?

Most of the patients who have died on the unit have died unexpectedly, partially because Cabrini has a very large and quite well-known hospice. So, when we have patients who are recognized to be terminally ill, we encourage families to become part of the hospice program. The hospice unit is right upstairs from ours, and so, normally, patients would be transferred up there. Not so much because the clinical care is better or different, as because hospice includes better bereavement services than we have, which is particularly important. Usually end-stage dementia patients have very limited insight about what is happening to them. So, the biggest needs are usually the bereavement needs of the family. We have not done a lot with bereavement on the unit as such because we have had hospice here as a resource.

How is pain managed on your unit?

From my personal perspective, since I am board certified in palliative care as well as geriatrics, the biggest issue is getting staff to recognize that dementia patients have pain at all. Beyond that, very few end-stage, or even moderate-stage dementia patients have pain that requires an anesthesiologist kind of pain team, which is pretty much what the standard has been. Instead, what these patients really need is pain medication. We worked to educate staff that symptoms such as agitation, restlessness, sleeplessness, and so on are, in fact, common manifestations of pain in patients with dementia and that these symptoms need to be treated.

Another factor in this is that the doctor who takes care of the patient on this unit is the same doctor who would take care of them on any other unit. This means that we have relatively little control over what they choose to do or not do. Although most house staff and attendings are reasonably open to suggestions, not everybody is equally open-minded about this, so we don't have a guarantee that people will do what we suggest. We continue to do grand rounds, in-service training and continuing education on topics such as pain management in dementia and caregiver issues.

When you're considering moving a patient to the hospice unit, do family members ever feel concerned about a change in professional caregivers, during the last phase of a patient's life?

It hasn't come up much as an issue at all, probably because this is an acute inpatient unit, so most of the families really have not become that familiar with the staff. If it is obvious within a day or two of admission to the unit that the patient is dying, the family has only known the staff for a couple of days, so it isn't the same situation that you might face in a chronic care center. The second thing is that if the patient needs to transfer to hospice, the patient is only going from one floor to another, to an in-hospital hospice unit, and the patient would not be expected to give up his or her usual physician. Even if some doctors don't really *want* to take care of patients on the hospice unit, they still would go up and visit. So that piece of the common family abandonment concern really doesn't apply here.

Measuring the Success of the Unit

How have you measured your success?

In the original grant proposal, we said that we were going to measure success based on, essentially, a *before* and *after* satisfaction study of caregivers and unit staff. We have done the *before* part, but we're just beginning to collect the *after* questionnaires now, so in about 4–6 months, I may have that information.

In terms of other measures, we had involved the staff on the unit in identifying what they thought were the measures that would make *them* know that we were a success. These included a variety of different things, some which are very straightforward. Occupancy and length of stay are two such simple measures. Our sense is that quality care can shorten length of stay, and that if we were doing a good job, our unit would be full or close to full most of the time. On average, our length of stay is 10-11 days, and 7 of the 8 beds are occupied. I believe our length of stay is shorter than for comparable patients at other hospitals. Another measure of success our staff thought would be telling is the hospital administration's commitment to the unit after the grant ends. For example, the administration might be inclined to keep the unit if they got a number of letters praising the unit, or did not experience any new headaches from it. We weren't quite sure what administrators would be looking for. Since the project began, we've had a massive turnover in the hospital administration (including the CEO, assistant to the president, VP for nursing and VP for medical care); however, we are gratified that the new administration has formally committed itself to maintaining the unit after the grant is completed, as part of how it sees the future of the hospital.

One measure that the staff on the unit believed would show whether we've accomplished something was if outside experts in the field came and looked at the unit, and said, "Yes, this looks like the kind of thing we think ought to happen." Certainly, on that measure we've been extremely successful. People from both the New York City chapter and the national Alzheimer's Association, and chapters around the country, have visited at the unit. Other visitors have included people from other hospitals, nursing homes, experts in dementia care, dementia design, and dementia clothing. It's hard to measure culture, but many people from the outside who have toured the unit have commented, "Yes, the culture of this unit *feels* like, *smells* like, *looks* like, therefore must *be* the kind of thing that we think is needed." So that recognition been a very gratifying thing for us. It is not the most objective measure, but still, we felt and still do feel it is quite significant.

Another measure was kind of a process measure, e.g., do we use fewer restraints? And we also are looking at patient outcomes: e.g., do our patients have less weight loss? Do we have, essentially, better outcomes than other units do with patients like this? As yet, I don't have the most solid data to support this, but it would *appear* that we have actually accomplished what we set out to do; there's a great deal less functional loss in our patients than occurs elsewhere in the hospital. For example, if they came into the hospital continent, our patients are much more likely to leave the hospital continent.

Although we have been tracking these kinds of indicators of functional outcome, the reason I'm saying it's not very scientific is that we have not compared our outcomes to a good set of matched controls. We keep track of what *we* do, but since the rest of the hospital isn't necessarily measuring things the same way, and also aren't taking care of the same patients, we are not sure exactly how to compare our outcomes.

We would like to do a more careful job of measuring the impact of the unit on outcomes. Currently, we just have a *sense* of how things are going. We have what families tell us, which is certainly extremely favorable. We don't yet have the formal data that would be useful for a better understanding of what units like this are about. We're in the course of applying to a New York foundation do a much more formal outcome analysis with real case controls, real functional

outcome data, and some better cost data to know, in fact, how much all this really costs.

Challenges Ahead: Continuity of Care & Appropriate Referral

What other challenges are you trying to address now?

Ensuring continuity of care for these patients across our hospital units and appropriate referral to our unit from the emergency department remain unresolved problems. There are no formalized ways of providing this continuity now. Sometimes the family will tell other hospital personnel, "My Dad was on this dementia unit before, the staff there seemed to know how to deal with his behavior." But there's no formal mechanism to ensure that kind of continuity.

We had originally planned to involve the emergency room in our planning because we were pretty sure, and families had told us, that emergency care for patients with dementia was a problem area in the hospital, and that was consistent with experience in other hospitals. So, we were expecting that to be a major intervention area for us. Unfortunately, all of the emergency room staff that we had originally intended to work with in the project wound up leaving. For much of the planning period, they were without a director, and were very short-staffed administratively. So, they were never able to attend our meetings. Ultimately, their not being involved in the planning process hurt us in a variety of different ways, not the least of which was that without them we have still not been able to have a really effective set of communications with the emergency room. They're still not doing a good job identifying patients appropriate to be admitted to the unit.

So, we've applied to the United Hospital Fund for a Phase 3 grant specifically to work with our emergency room because we still see that as a big, unresolved need. This has been something that has held us back all along -- since dementia is not usually a patient's primary diagnosis, clinicians don't write it as a diagnosis on charts. They don't think of our unit as one to admit patients to, when they are deciding where patients are going to go in the hospital. When the patient ultimately *is* admitted, the admitting office clerks don't do mental status evaluations on patients, so they can't identify appropriate patients. So, the vast majority of our admissions have come because a family member came and specifically said, "I want that unit I read about in the paper." Other patients may have been admitted to a different floor, and then within some period of time the patient was exhibiting problematic behavior, or sometimes staff simply recognized that this patient was appropriate for our unit and should be transferred to it.

One of our original ideas had been that we would be a source of reassurance and information for dementia patients and their caregivers from the moment of admission to the hospital. That piece has really not happened for a lot of patients. What happens is you have the first terrible day, when demented patients are agitated, pulling out their IVs, tied down in restraints, and all this stuff happens. And *then* somebody says, "This never happens with the patients who are down on the special unit for dementia patients, why don't we transfer this patient down there?" But, it would have been nicer if the patient never had to go through that whole experience to begin with. We're still not doing the job that I'd like to be doing in that area. I don't think this problem is unique to us; most specialized units in hospitals revolve around the patient's primary diagnosis. Because dementia is so often really a co-morbidity, it's very difficult to get these patients into the system. Most hospitals don't have good mechanisms in place to identify these patients early on, and so begin to provide them with the care that they're going to need at the time of admission.

Innovation: Bringing Knowledge of Best Dementia Care into the Hospital

Overall, what do you feel is most innovative about your unit and approach to the care of patients with dementia and their caregivers?

What the unit does is to bring into the acute hospital setting a lot of what's been known for some time about good dementia care in long-term care. It's hard to look at some of the individual things and see them as so remarkable if you are familiar with what good assisted-living programs, good adult daycare programs, good Alzheimer's units and skilled nursing facilities have been doing for years. We certainly didn't invent interdisciplinary care. Almost all of the behavioral approaches that we use are things that were known to people in other contexts. But insofar as hospitals are at the top of the care system, hospitals have not previously been prepared to listen to what people in rehabilitation settings or long-term care know, and incorporate that knowledge into the hospital's culture and systems of care. One of the big advantages that we had here at Cabrini is that we are a connected hospital and nursing home: for example, I'm the chief of geriatrics in the hospital as well as medical director of the nursing home. This dual role means that I'm able to go back and forth between two different worlds and say, "These challenges can be tackled." And people believe me. A lot of what we've talking about in terms of dementia care problem solving takes place on a daily basis in different settings. It just never has happened in hospitals before. In the long term, I think that is the most unique aspect about everything that we've done.

Do you see a spillover into the wider hospital culture, from your unit?

It certainly spread a little bit. We are, essentially, a sub-unit on a floor that has also other geriatrics patients and has oncology on it. As I said, our unit is a standard assignment for nurses, but most of the other staff, in fact, go from one part of the floor to the other, or some nights and evenings, one person might assigned both to our unit and to some patients on the rest of the floor. The head nurse for the unit feels very strongly that there's been a lot of positive carryover with other patients on the floor, in terms of conveying a whole different approach to patients and families. That's been extremely positive.

Parting Thoughts

Do you have any advice for others seeking to start a similar unit at their hospital?

One of the things that we've struggled against is the notion that there are prefabricated solutions for problems. For one thing, we have tried to persuade people that you have to actually go and see the patient, that you couldn't just "look it up" before prescribing or writing orders for care. You had to actually talk to the caregivers, rely on their expertise about the patient, and mutually find out how to solve a problem. So, our approach has been a problem-solving one, rather than coming up with a model we would want people to follow.

From the very beginning, I never expected that this unit was going to be *the* model that everybody else would use. Rather, we have taken a stab at addressing the many challenges to show what *could* be accomplished. I could imagine this unit looking very different, maybe even staffed differently, and functioning differently. As proud as I am of everything we've done, I certainly recognize a lot of the limitations of what we've done and that most of it we made up along the way. I think that it's actually the process, and not necessarily the model, that is the really important thing. The really vital

task is thinking through how to meet the needs of the patient within the context and culture of your institution, and not that the unit have eight beds or be set up a certain way. We made a lot of accommodations to the structure of the hospital. So, I'm not necessarily interested in persuading people to do it the way we did. I think that far more important than the solutions we reached is really the process of getting there, the careful needs assessment and planning, and that people shouldn't give up that process to mimic what we've done.

References

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