



Dr. Kent Wilson, Medical Director, Honoring Choices Minnesota

Civic Caucus, 8301 Creekside Circle #920, Bloomington, MN 55437

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Present : Verne Johnson (chair), David Broden, Janis Clay (phone), Marianne Curry, Paul Gilje, Sallie Kemper, Tim McDonald, Wayne Popham (phone)

Summary of meeting: *The director of Honoring Choices Minnesota describes the development of a program, led by the Twin Cities Medical Society and providers, to help individuals decide and document their medical care and end of life preferences in case they are unable to participate in treatment decisions. He describes the inspiration for the program, the model in Wisconsin that they followed, and the progress already underway in Minnesota. Implications for cost savings and patient satisfaction are discussed, as well as the program's prospects for implementation.*

A. Welcome and introductions - During the July 15th Civic Caucus interview with Bud Hammes, director of Respecting Choices at Gundersen Lutheran in La Crosse, Wisconsin, Hammes cited a similar effort underway in the Twin Cities. Kent Wilson, MD, today's speaker, directs that project. See a report of the Civic Caucus meeting: <http://bit.ly/nrYmtM> .

Kent Wilson, MD, is Medical Director of Honoring Choices Minnesota (<http://tinyurl.com/3vbtasI>) and President of the East Metro Medical Society Foundation. He recently retired from his medical practice in otolaryngology. Dr. Wilson is a graduate of the University of Minnesota Medical School and a long-time resident of Saint Paul.

B. Discussion -

"I appreciate the invitation to come and chat," Wilson said. "I believe your organization could be very helpful in educating the community as to what we are trying to accomplish with Honoring Choices Minnesota."

Learning from the model in La Crosse, Wisconsin

A program at Gundersen Lutheran in La Crosse, WI has found significant improvements in medical care and savings when people make careful, conscious decisions in advance about the care they would like to have at the end of life.

He began with a chronology of their efforts.

In 2007, Wilson became president of the Ramsey County (now East Metro) Medical Society. A colleague had become familiar with the Gundersen Lutheran advance directives program in La Crosse, and thought the Society's foundation might be interested in pursuing a similar effort. Wilson, new to the foundation's board and interested in finding a project to work on, agreed to take on this effort. The foundation board authorized a site visit, so Wilson made the trip to La Crosse and spent a day observing the Respecting Choices program at Gundersen Lutheran.

There were a number of features that Wilson found appealing, particularly the effective communication and cooperation across hospitals and the record of success-90 percent of people that died in La Crosse had health care directives, and those directives were observed 99.5 percent of the time (published 2010).

Nationwide approximately 20 percent of people have a health care directive Wilson said, and of those 20 percent having directives, many keep their directive in an attorney's office or safety deposit box, not readily assessable by hospital staff.

To Wilson the numbers in La Crosse showed that the administrators had appropriate support structures and effective processes in place to sustain this program. "Having a carefully thought out health care directive had become the community standard. This is simply what you did, from the perspective of both the community's and the doctors' expectations."

As a result Gundersen experienced a reversal in the data regarding the location where people died. In the 1990's the majority of people that died in La Crosse County died in hospitals, Wilson reported. Yet over time this reversed, and a majority of people died in their homes.

"We looked at this and saw this was a model that could be used in the Twin Cities. Over the course of 20 years they had put together training materials to help train physicians, nurses, families, congregational leaders and lay people. We saw that we could do this as well."

Visit to the Twin Cities

After Wilson's visit to La Crosse, Bud Hammes, program director from Gundersen Lutheran, visited Minnesota to speak with the foundation directors and staff.

"He came to talk, and we asked the question of our medical foundation: Would the Twin Cities benefit from this type of program?" Yes, the members responded. They held another meeting with regional hospital administrators, and 27 out of 27 attending voted yes. One manager remarked to Wilson after the meeting that the foundation is the best place to undertake such an effort, "because there is no single hospital that could create a metro-wide program beyond the confines of their own hospital system."

Forming Honoring Choices Minnesota

Honoring Choices Minnesota is a collaborative association, Wilson said. The Twin Cities Medical Society, through its East Metro Foundation, is serving as the convener and coordinator of the initiative. No one on the roster of metro area health care organizations is missing from the group. As of this summer, all major providers have experienced this program at the pilot project level.

At the heart of the program is the effort to complete a health care directive through facilitated discussions with an individual and his or her family members. The family discussions revolve around the critical questions about treatment decisions that may have to be made at a point in time when the individual may be unable to participate in those decisions.

"The most crucial thing is that an individual would have a discussion with family, appoint an agent to act on his/her behalf, and express how the person's values and religious convictions should inform decisions-since you can't predict every specific question that may ultimately arise."

The program is underway in the Twin Cities. Fairview is training 18-26 facilitators per month. In the first seven months of the year, Park Nicollet entered 1,700 Health Care Directives (HCDs) into its information system. Allina is averaging approximately 1600 HCDs entered into their medical record per month, for January through June, 2011.

"We have seen at least at a pilot level that if the family has had the discussion and if the family has a document in their hands it will be followed. That's why having a culture open to advance care planning is so important. We're building an infrastructure for this process within the health care system. There is a long-term public education campaign that runs alongside the building of the medical infrastructure."

Upcoming coverage of the Minnesota effort

Twin Cities Public Television (TPT) came to us with an idea for a 2-3 year public engagement program. This public engagement program was similar in principle to the public engagement program carried out in La Crosse after medical infrastructure had been installed. We were generously supported by local foundations, non-profits, insurers and health care systems. This began in the summer of 2008 when the 'death panel' rhetoric was at its height.

"We wanted to get down to the levels of the individual, so we said: 'It's reasonable to have these discussions within your family, to have choices over how things will affect you.'"

The Citizens League helped in the effort by carrying out two-hour listening sessions on the topic with people across the state from various religious, ethnic, cultural and identity groups. "We felt modeling the types of conversations and controversies would be helpful. The League has completed those sessions and they will be writing us a report in 6-8 weeks with their conclusions."

The listening sessions revealed participants' notions about the quality of the end of life, Wilson said. "You'll see in the videos that people talked about the worst cases that tore families apart, and those that turned out well."

In one case he cited, the family knew the patient, a woman, had three months to live. She went first into home hospice care, then a hospice facility. Pain management was an issue in her care. The hospice staff over the first few days gave her a lot of medication that greatly inhibited her abilities. When her family had discussed this with her ahead of time, she said she wanted to be as wide-awake as possible so that she could visit with her grandchildren.

So the family sat down and had a conversation with hospice staff: 'We know this is your standard of care, but she just wants the top edge of her pain taken off, so that she can continue to interact.' The

hospice workers lessened the medication and the woman was then able to have the interaction with her grandchildren that she wanted before she died.

"TPT has developed a website with a toolkit of video clips, resources, and 'e-vites' to support and encourage family discussions. I think you'd all be interested in visiting www.honoringchoices.org. TPT Channel Two is making a series of six documentaries on advance care planning and end-of-life issues the program, to air over the next 18 months."

Strategy for growth: Keep it in the hospitals

To a question about Medicare, Wilson replied that, "We don't have a position on Medicare doing this type of program-this is being developed at the institutional level. It is good for the patients, their families and the system, and it turns out it is also less expensive, based on La Crosse figures. La Crosse is one of the lowest-cost cities in the nation for medical care during the final two years of life.

"Some areas have done this from the top-down; Singapore, British Columbia are examples of top-down directives being the creative impetus. Our strategy is fundamentally different. We want this to come through the collaboration of providers and patients and their families."

In Minneapolis and St. Paul the average cost of care for the final two years of life is a bit below the national average. The numbers are tending to improve. "But I think that the primary argument for this kind of program is that it's simply better medical care, better for families and better for medical teams. If we duplicate the effect of Gundersen there will be a positive economic effect as well."

The worst thing, Wilson said, would be a revival of the "death panels" rhetoric. So they are hoping to avoid having this end up in legislation. "Keep it at a family conversation level," he said. "Honoring Choices Minnesota - It's about the conversation." Consequently they are reaching out to many groups across the area, including faith, cultural and ethnic groups to build understanding and commitment.

Question and Answer

Q: Isn't there a strong financial disincentive for this kind of treatment limit?

A: It seems that there would be, Wilson said, but in practice the hospitals frequently lose money on long-term care at the end of life. There is a hospital reimbursement system for Medicare that pays a set amount for each particular defined medical event. There's a payment methodology so that if you go into a hospital with a particular medical condition there is a corresponding reimbursement maximum. The problem for the hospital arises if, when the condition calls for 5 days of treatment, it actually ends up taking 10 days; then the hospital has 5 days of unreimbursed service.

In the absence of a clear directive limiting the measures to be taken, the default of the medical community is to do everything possible to keep the patient alive. If it takes a family two weeks to come to a decision about what to do while the patient is in an intensive care facility, that's a very expensive situation.

"Most hospital administrators, I think, would say that both the health care system and the patient are best served when the patient is in the most appropriate medical setting for the acuity of the disorder, whether that be acute care hospital, transitional care facility or long term care facility.

The most important thing for everybody in health care, he stressed, is that the patient is getting the care that is appropriate for him or her at the time.

Q: What is the incentive for the individual to do this?

A: An important incentive is the peace of mind resulting from having control, as best one can, over decision-making about one's care when and if it will be needed. There is incentive for the family because an agent is appointed who will make decisions if the patient can't. It is better for the agent and health care team who know in advance the wishes of the patient, and smoother for the process when well-informed decisions can be made without family controversy.

We've had a number of discussions about putting financial incentives for health care directives into government programs, and we have steered quickly away from that approach. In health care if you put in place financial incentives there will immediately arise an industry to take advantage of those incentives. We went to the people at the department putting together health care homes and asked about offering a \$10 incentive for completing a health care directive. They asked in turn if we were crazy. 'We don't want to create a cottage industry of paper mills turning out rubber stamp health care directives for \$10,' they said. Neither do we. It is about the conversation with family that results in a useful, helpful family consensus and document.

Q: How do you know what all the options are for treatments before they happen-aren't there too many?

A: That's why these conversations have to be considered as moving targets. What you consider varies depending on where you are at a point in your life. If your situation changes-if you go on dialysis, for example, and so are more prone to kidney problems-all you have to do is make out a new one.

Allina has developed not only basic advance care planning, but also disease-specific advance care planning, as well as more particular questions for specific conditions. In the latter program the family and physician are able to get a pretty good sense of possible future issues that a particular medical condition, such as renal failure or congestive heart failure.

At Allina this year in the first six months they've done 1,450 of these 90-minute extensive discussions that got the family talking about disease-specific treatment plans, medication preferences and so forth. This is significant progress when you consider that it's taken Gundersen 20 years to get where they are today.

Q: When do you anticipate seeing results?

A: At Gundersen it was 10-15 years before the results started to become apparent. They have a few hundred people facilitating these conversations. We're moving in that direction and are on track to get there.

Conclusion

In the coming year, Honoring Choices' pilot programs in Twin Cities hospitals will continue and the public engagement efforts in collaboration with TPT will attempt to build support and encourage participation. One of the major barriers to fulfilling the long-term vision, Wilson pointed out, is that electronic medical records systems do not at present include end-of-life directive records that are readily available and transferable. Going forward the program will continue to work toward making advance care planning the standard of care for all adults and assuring that patients' choices are both clearly defined and conscientiously respected. He is optimistic about the program's future.

Thanks all around for the visit today.