Honoring Choices Minnesota: Preliminary Data from a Community-Wide Advance Care Planning Model

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Advance care planning (ACP) increases the likelihood that individuals who are dying receive the care that they prefer. It also reduces depression and anxiety in family members and increases family satisfaction with the process of care. Honoring Choices Minnesota is an ACP program based on the Respecting Choices model of La Crosse, Wisconsin. The objective of this report is to describe the process, which began in 2008, of implementing Honoring Choices Minnesota in a large, diverse metropolitan area. All eight large healthcare systems in the metropolitan area agreed to participate in the project, and as of April 30, 2013, the proportion of hospitalized individuals 65 and older with advance care directives in the electronic medical record was 12.1% to 65.6%. The proportion of outpatients aged 65 and older was 11.6% to 31.7%. Organizations that had sponsored recruitment initiatives had the highest proportions of records containing healthcare directives. It was concluded that it is possible to reduce redundancy by recruiting all healthcare systems in a metropolitan area to endorse the same ACP model, although significantly increasing the proportion of individuals with a healthcare directive in their medical record requires a campaign with recruitment of organizations and individuals. J Am Geriatr Soc 62:2420-2425, 2014.

Key words: end-of-life care; advance care planning; healthcare systems; organizational innovation

The care that people receive at the end of life often does not fulfill their wishes. ¹⁻⁴ For example, although 70% of people say that they would prefer to die at home,

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DOI: 10.1111/jgs.13136

nearly 76% die in an institution, where they are likely to receive more-aggressive, more-invasive, poorer-quality care than they would have at home. ^{5,6} Because many others die soon after referral to hospice from an intensive care unit, ⁷ it has been suggested that the increasing availability of hospice and palliative care services has not shifted the focus from aggressive, curative care to that of the individuals wishes. ⁸ Even individuals with advanced illness, including metastatic cancer, may receive more-aggressive treatment than they want because they have not discussed their end-of-life care preferences with their doctor. ^{9,10}

A randomized trial of advance care planning (ACP) found that, for participants who died, end-of-life wishes were more likely to be known and followed in the intervention group, and family members of intervention group participants who died reported significantly less stress, anxiety, and depression. ACP also increases satisfaction with the care process. 12

In 1991, Gundersen Health System and Franciscan Skemp Healthcare (now Mayo Clinic Health System Franciscan Healthcare) in La Crosse, Wisconsin, implemented a model of ACP that subsequently became Respecting Choices (RC). From April 1995 to March 1996, 85% of La Crosse County adult residents who died (n = 540) had a written advance directive, and 96% of the advance directives had been entered into the medical record. Comparison of the national average of healthcare costs in the last 2 years of life with average costs during the same period for residents of La Crosse, Wisconsin, a community with high levels of ACP, suggests that ACP might also reduce healthcare costs near the end of life.

In 1999, Gundersen Health System developed the lessons learned from the La Crosse experience into a comprehensive curriculum: the Respecting Choices Organization and Community Advance Care Planning Course. Several healthcare systems in the United States (e.g., Kaiser Permanente Northern California) and abroad (e.g., Australia's national health service) have implemented RC. ¹⁵ Today, Gundersen Health System prompts all individuals nearing age 55 to share their preferences for end-of-life care with their physician.

Even though La Crosse is a small, homogeneous community, and the RC performance has not been replicated elsewhere, it was thought that a similar program could be organized in a larger, more-complex setting. Therefore, Honoring Choices Minnesota (HCM) was organized with the goal of recruiting all Minneapolis-St. Paul metropolitan area healthcare systems to adopt the RC model of ACP to increase, to the La Crosse level, the proportion of individuals with healthcare directives (HCDs) in their electronic medical record (EMR).¹⁷ This article describes the process used to implement HCM and early results of that effort.

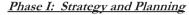
METHODS

Phase I: Strategy and Planning

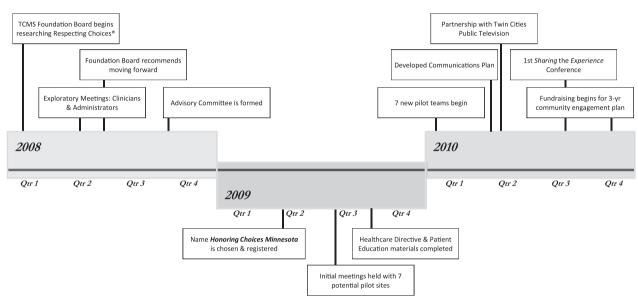
The strategy and planning phase was a 3-year process (Figure 1). In 2008, the Twin Cities Medical Society Foundation Board began researching and assessing community support for the implementation of a similar program in the Twin Cities. A site visit to RC in La Crosse suggested

Honoring Choices Minnesota: Developmental Milestones

Panel A



Phase II: Implementation



Honoring Choices Minnesota: Developmental Milestones

Panel B

Phase III: Refinement and Dissemination

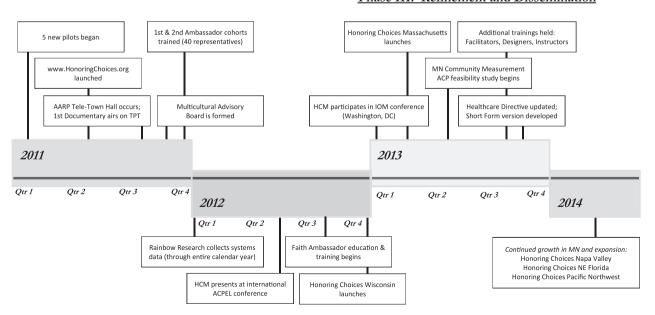


Figure 1. Honoring Choices Minnesota developmental milestones: (A) 2008-2010, (B) 2011-2014. TCMS = Twin Cities Medical Society; MN = Minnesota; ACP = advance care planning; HCM = Honoring Choices Minnesota.

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that the ACP model was feasible for the Twin Cities. After the site visit, the exploratory committee sought participation from two groups of healthcare system leaders: healthcare professionals who care for dying individuals (hospice and palliative care clinicians, geriatricians, long-term care providers, hospital chaplains, medical social workers) and health system and health plan chief executive officers, chief medical officers, and senior hospital and health plan administrators. HCM recruited participants through a series of face-to-face meetings between the physician director of HCM (KSW), the chief executive officer of the Twin Cities Medical Society (SS), the director of RC, and health system leaders. These exploratory meetings included a focus group of 42 healthcare clinicians and a meeting of 27 health system administrators.

As a result of these meetings, the Twin Cities Medical Society Foundation Board recommended moving forward in mid-2008. An advisory committee that comprised 18 representatives from healthcare systems, hospice programs, policy and regulatory agencies, and others with similar goals was organized to guide development of mission and vision statements, HCDs, and education materials. The advisory committee decided that building the healthcare infrastructure for ACP should come first, followed by a public engagement campaign. They named the program Honoring Choices Minnesota in 2009. In the second quarter of 2009, initial meetings were held with seven potential pilot sites, and later that year the HCD and education materials were completed. The definition of an HCD as defined according to Minnesota State Statute 145c is broad. The HCM HCD meets this definition.

For the first 2 years, the Twin Cities Medical Society paid the salaries of a part-time project director (Year 1, 0.1 full-time equivalent (FTE); Year 2, 0.25 FTE), administrative staff (Year 1, 0.1 FTE; Year 2, 0.25 FTE), and a medical director (Year 1, 0.1 FTE; Year 2, 0.1 FTE).

Phase II: Implementation

Implementation was a 3-year process that started in 2010 with the activation of seven new pilot teams. A critical component of the pilot activity was the training of facilitators in a 14-hour RC course. The role of the facilitator is to help individuals and families with ACP conversations using standard materials. Implementation also included development of a communications plan and engagement of Twin Cities Public Television (TPT) in the development of a public engagement program.

The objectives of the communications plan were to engage the public in discussions of end-of-life issues and to inspire Minnesotans to have family conversations about ACP and complete HCDs. The first communication activity was the creation of an e-mail distribution list of health system and health plan stakeholders, nonprofit foundations, nonprofit healthcare institutions, businesses, and social service agencies. Over the following 2 years, a Web site (www.honoringchoices.org), eight TPT broadcast documentaries, 700 video clips collected during 25 listening sessions, and an online newsletter were rolled out.

Strategic partnerships like the one developed with TPT in 2010 were crucial to the success of HCM. HCM also partnered with the Citizens League, a nonpartisan policy-

oriented nongovernmental organization (www.citizens-league.org), to conduct community focus groups that discussed ACP and end-of-life experiences and attitudes. AARP and other organizations also provided support and in-kind services.

Sharing the Experience, a daylong conference, was organized so that lessons learned could be shared, individuals could tell stories about their experience with HCM, and multicultural and interdenominational faith panels could present their perspectives on ACP.

Fund-raising efforts for a 3-year public engagement plan began in the fourth quarter of 2010. After identifying a corporate champion, HCM developed and presented the plan to the broader community of stakeholders.

Five additional pilot sites were initiated in 2011, the web site was launched, ACP documentaries were televised, and a multicultural advisory board was formed. Two ambassador cohorts were also trained in 2011. An ambassador is a volunteer (often a healthcare professional) who undergoes 2-hour quarterly training sessions and speaks to community groups, multicultural communities, and faith communities about ACP planning conversations. Ambassadors are supported with toolkits that include talking points, PowerPoint presentations, and videos.

In 2010, a budget of \$100,000 covered the salaries of a 0.25 FTE project director, a 0.5 FTE administrative staff, and a 0.25 FTE medical director. In 2011, a budget of \$300,000 covered the salaries of a 0.25 FTE project director, a 0.25 FTE medical director, a 0.5 FTE administrative staffer, and a 1.0 FTE community engagement director. Approximately \$350,000 was budgeted for the TPT project.

In 2012, Rainbow Research was engaged to develop a formal evaluation plan and to help analyze clinical and community data, interpret findings including factors contributing to unintended outcomes, and develop and revise pilot data collection instruments and protocols. In spring 2012, they surveyed program coordinators at 10 health plans. Other milestone activities in 2012 included multiple presentations, the development of the Faith Ambassador Program, translation of informational materials into the most common languages spoken in the Twin Cities, and the launch of Honoring Choices Wisconsin.

In 2012, a budget of \$300,000 covered a 0.25 FTE project director, a 0.25 FTE medical director, a 0.5 FTE administrative staffer, and a 1.0 FTE community engagement director. An additional \$400,000 was devoted to the TPT project.

Phase III: Refinement and Dissemination

Phase III was begun in 2013. While continuing local initiatives, HCM became known nationally through publications¹⁷ and conference appearances (e.g., an Institute of Medicine conference). In 2013, additional organizations in Wisconsin, Massachusetts, Napa Valley, northeastern Florida, Washington, and Oregon adopted the model. In 2013, HCM also revised the long-form HCD and introduced a short-form HCD. The \$350,000 budget in 2013 covered a 0.25 FTE project director, a 0.25 FTE medical director, a 0.5 FTE administrative staffer, and a 1.0 FTE community engagement director.

RESULTS

Building an ACP Infrastructure in the Healthcare Community

When approached, healthcare professionals who care for dying individuals overwhelmingly agreed that individuals would benefit from being better informed about their end-of-life choices. They also agreed that healthcare professionals would benefit from ACP skills training and that a standardized approach to eliciting individual preferences was desirable.

All of the chief executive officers that HCM approached agreed that participation would benefit their patients who wanted ACP services. Conditional on the Twin Cities Medical Society leading the effort, they also committed their organizations to help develop consistent training methods and materials. Finally, they agreed to commit money and staff to the project.

Eight large metro healthcare systems had adopted the HCM program as of April 2013: Allina Health, Health-Partners, Park Nicollet Health Services, the HealthEast Care System, North Memorial Health Care, Hennepin County Medical Center, Ridgeview Medical Center, and Fairview Health Services.

Building Community Partnerships

HCM has recruited more than 700 community partners. Approximately 90% of these partners are organizations; the rest are individuals. Forty-five trainers have trained 60 ambassadors and more than 1,000 healthcare system and community facilitators. From January 1, 2011 to December 31, 2013, more than 27,000 unique individuals visited the Web site, and the HCD form was downloaded more than 2,200 times. Working with and supported by the Bush Foundation, the Minnesota Council of Churches is sponsoring Graceful Journey, a program designed to help people think about decisions that need to be made at the

end of life. Graceful Journey offers tools to make those decisions¹⁸ and encourages congregations to provide care that helps families experience the end of life as a graceful journey.

TPT produced an eight-segment documentary series on end-of-life decisions (www.honoringchoices.org/documentaries/) that received a regional Emmy award in 2012. TPT has repeatedly broadcast the series on its main channel and the Minnesota Channel, a statewide service. TPT has aired public service announcements several thousand times and has advertised HCM in its monthly magazine. Among other communications, articles, editorials, and letters to the editor about have been printed in the regional newspaper, the StarTribune. The AARP Minnesota Bulletin has also featured HCM, and AARP has sponsored a call-in tele-town hall meeting about HCM.

Recording Advance Care Plans in the Medical Record

Five health systems have provided data on the inpatient EMR (Table 1). The proportion of inpatients with an HCD (defined as any document that describes the individual's wishes regarding end-of-life care) in their EMR ranges from 12.1% to 65.6% in these five systems. Seven systems have provided data for all patients. The proportion of all patients with an HCD in the EMR is 15.1% to 31.7% in these systems. The two smallest healthcare systems had the highest rates of inpatient HCDs.

DISCUSSION

With concerted and sustained leadership, HCM has been able to recruit all eight large healthcare systems in the Minneapolis–St. Paul metropolitan area to participate in a program that uses RC as a model. HCM has also been able to engage public communication channels—television, radio, and print media—in a discussion about ACP, but inclusion of advance directives in the EMR is not complete, and a significant opportunity for care improvement

Table 1. Unique Individuals Aged 65 and Older with a Healthcare Directive (HCD) in the Electronic Medical Record According to Healthcare System and Treatment Location

	Hospital Patients Only	Outpatients Only	All Patients
Healthcare System	With HCD/Total Target Population (% with HCD)		
A ^a	1,648/12,830 (12.8)		3,111/19,892 (15.6)
B ^b	2,638/21,809 (12.1)		4,448/27,483 (16.2)
Cc	4,836/7,371 (65.6)		8,352/26,307 (31.7)
D^d		812/12,701 (6.4)	
Ee	17,870/39,196 (45.6)		26,020/110,158 (23.6)
F ^f			33,553/222,438 (15.1)
G ^g H ^h			9,381/32,664 (28.7)
H ^h	3,707/8,113 (45.7)		13,874/54,044 (25.7)

 $[^]a Inpatients$ and outpatients aged ${\ge}65,$ May 1, 2010, to April 30, 2013.

^bOutpatients aged ≥55 and older, inpatients aged ≥18 as of April 2013.

^cOutpatients and inpatients aged ≥55 as of April 23, 2013.

^dOutpatients and inpatients aged ≥65 in 2012.

eInpatients aged ≥65, outpatients aged ≥65 with a clinic visit in last 2 years (through March 31, 2013).

^fOutpatients and inpatients aged ≥65, January 2012 to August 2013.

^gOutpatients aged ≥65 with at least 1 visit to a primary care provider in the 18 months before March 31, 2013.

^hInpatients and outpatients aged ≥65 with a visit in the 12 months before March 31, 2013.

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still exists. Only one health system reported that more than 50% of the inpatients in its target group (aged \geq 55) had an advance care plan in their record, and three of the healthcare plans reported that 15% or less of their inpatient medical records included HCDs. Outpatient medical records are less likely to have HCDs. The healthcare organizations that devoted the most resources to promoting ACPs report the highest proportion of medical records with ACPs. These preliminary results demonstrate that an infrastructure is in place to monitor ACP programs and that eight healthcare systems are willing to collaborate on this quality-improvement task.

Ongoing HCM efforts include work with Minnesota Community Measurement¹⁹ to implement the HCD in the EMR as a quality measure. The authors also expect to see adoption of ACP programs throughout Minnesota and nationally. HCM already has contractual agreements to support groups in Wisconsin, California, Washington, Florida, and Massachusetts.

The conclusions to be drawn from this report are limited because HCM was not organized as a research project. Most of the data are qualitative descriptions of activities, and HCM was not able to dictate the format of the data that the healthcare organizations provided. Each system determined its own target population and goals. Even so, the fact that HCM was able to obtain never-before-collected data as a baseline could be considered a success.

There are additional lessons to be learned from the experience. One of the authors of the current study (TEK) has published a perspective on the simple rules required to create value (in this case, ACPs) in health care. It appears that value can be achieved if just five rules are met: the stakeholders agree on a set of mutual, measurable goals for the health system; the extent to which the goals are being achieved is publically reported; resources are available to achieve the goals; stakeholder incentives, imperatives, and sanctions are aligned with the agreed-on health system goals; and leaders endorse and promote the agreed-on health system goals. HCM satisfied some, but not all, of the rules:

- 1 Goals: HCM was able to forge common goals for the eight large health systems in the Twin City metropolitan area.
- 2 Resources: The only resource required for an individual to complete an HCD is the form that is available on the HCM website. HCM experience suggests that organizations that wish to increase the number of their patients who have HCDs in their medical records will need to devote personnel and other resources to this goal.
- 3 Incentives, imperatives, and sanctions: One system provided incentives to hospitalists responsible for discharges from the hospital. The incentives improved HCD completion in the subpopulation but did not improve health system statistics as a whole. The program was discontinued. Further work needs to be done to satisfy this rule.
- 4 Public reporting: The rates at which advance care directives are recorded in the EMR of the various institutions are not publicly reported, but a significant boost may come when Minnesota Community Measurement includes HCDs as a measure of medical home quality. Care for individuals with diabetes mellitus, vascular

disease, and other conditions improved markedly after public reporting was introduced in Minnesota; it might be expected to do the same for HCDs.

5 Leadership by all stakeholders: Although leaders emerged throughout the community, leadership in the healthcare systems has been variable; performance appeared to be related to commitment to the program by officers at the highest levels.

In conclusion, preliminary data indicate that, given enough effort and time, it is possible to implement a uniform program that reduces redundancy and complexity of ACP in a large metropolitan area. This program may improve the care and experience of individuals whose lives are ending.

ACKNOWLEDGMENTS

Minnesota health plans, health systems, foundations, and common-interest organizations provided financial and inkind support to HCM.

Conflict of Interest: Kent S. Wilson is Medical Director of HCM. Sue Schettle is Executive Director of the Twin Cities Medical Society.

Author Contributions: Kent S. Wilson and Sue Schettle led the development of HCM and contributed to the text of the manuscript. Thomas E. Kottke was primarily responsible for the organization of the manuscript.

Sponsor's Role: None.

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