

Original Research

A Community Engagement Model to Drive Advance Directive Discussion and Completion

Kristin L. Hines, MD¹; Elyse Taylor, BA²; Emily Hollingsworth, MSW¹; Shana Rhodes, MPH¹; James S. Powers, MD^{1,3*}

¹Division of Geriatrics, Vanderbilt University Medical Center, Nashville, TN, USA

²Meharry Medical College, Nashville, TN, USA

³Geriatric Research Education and Clinical Center, VA Tennessee Valley Healthcare System, Nashville, TN, USA

*Corresponding author

James S. Powers, MD

Clinical Associate Director, Tennessee Valley Healthcare System, Clinical Center and The Division of Geriatrics, Vanderbilt University School of Medicine, Nashville, TN 37232, USA; Tel. 615-343-6726; Fax. 615-322-1754; E-mail: James.powers@vumc.org

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ABSTRACT

Background

Advance directives (ADs) describe individuals' preferences for life-sustaining treatments and/or surrogate decision-makers, to help avoid unwanted, burdensome treatments at the end-of-life. However, only 36.7% of adults have completed an AD. There is growing interest in adopting a public health approach to end-of-life care, including ADs. We describe the experience of Honoring Choices Tennessee (HCT) which developed a pilot program, Advance Directives at Work in Tennessee (AD@WorkTN), to enhance AD completion by the general public workforce.

Methods

The AD@WorkTN initiative targeted adults in the Tennessee workforce by engaging human resource (HR) leaders in educational presentations. Each workshop provided resources to employers to integrate ADs into the employee orientation and benefits enrollment process. Educational materials, web tools, podcasts, AD forms, and a demonstration of how to complete an AD were included. Participants were directed to the HCT website which contains the state advance directive documents and with detailed instructions, as well as the co-branded MyDirectives app (MYD), to securely upload completed ADs. In April 2021 a HCT sponsored PBS documentary on advance care planning was produced with statewide distribution.

Results

Over a 2-year period, 58 workshops were conducted for 260 human resources leaders representing 958 businesses. As a result, 23 businesses have included ADs as part of the employee benefit process. Additionally, a 2-year multifaceted public outreach campaign between 2019-21 has reached 2,950 employees and 958 businesses. Approximately 81,500 Tennessee viewers have seen the Public Broadcasting Service (PBS) documentary on advance care planning. There have been 2,954 visits to the HCT website and 411 visits to the co-branded MyDirectives site.

Conclusion

AD@WorkTN is a promising model to promote integration of ADs into the employee orientation and benefits enrollment processes. Enhanced discussion and completion of ADs among employed individuals and enhanced public discourse such as podcasts and television productions may encourage intergenerational conversations about end-of-life care and documentation in healthcare records.

Keywords

Palliative care; Advance directives; Community outreach.

INTRODUCTION

Medicine is innovative, but there is a threat that individuals may receive burdensome therapies at the end-of-life that can contribute to suffering. Advance care planning documents, includ-

ing advance directives, living wills, and health care powers of attorney, allow patients to describe their preferences for life-sustaining treatments and/or surrogate decision-makers, to help them avoid unwanted treatments in the setting of terminal illness or incapacity.¹

The initiative to complete advance directives has its origins in healthcare systems. In the wake of the Cruzan Supreme Court case, the Patient Self-Determination Act was signed into law in 1990 with a goal of increasing patient involvement in decisions regarding life-sustaining treatments by ensuring that advance directives are available to health care providers. This law required facilities and organizations to not only discuss advance directives with patients, but also to develop institutional policies concerning advance directives and decisions to withhold or withdraw life-sustaining treatment.²

Unfortunately, despite these healthcare mandates, few adults have completed documentation of their advance directives. One systematic review examining studies published from 2011-2016 found that only 36.7% of adults had completed an advance directive.¹ To combat these deficiencies, there is growing interest in adopting a public health approach to end-of-life care, including advance care planning, and to engage the community in completion of these documents.³

Historically, embracing hospice and palliative care has been slower in the Southeast than in other US regions. However, having an advance care plan alleviates anxiety among patients, and (surviving) family members report improved satisfaction with the quality of care received.⁴ Patients are also more likely to receive care according to their preferences, have fewer hospitalizations, and overall less costly care. Surveys and focus groups of patients have demonstrated that there is an overwhelming preference for opportunities to plan for the end of life. Public education on advance care planning has been conducted in various settings, including the workplace, and is important to promote intergenerational discussion and completion of advance directives.

Here we describe a multifaceted, employer-based model of public outreach to enhance advance directive discussion and completion.

Context

Honoring Choices Tennessee (HCT) has been in existence since 2015 and is part of the national Honoring Choices movement that began in 2008. There are more than a dozen Honoring Choices organizations around the country, all with the common interest in helping Americans live their very best life. Honoring Choices is based on the training, principles, and overall methodology of Respecting Choices, the nationally and internationally recognized Advance Care Planning model developed by Gundersen Health System in La Crosse, Wisconsin. The Tennessee organization is sponsored by 12 organizations including the Tennessee Medical Association, the Tennessee Hospital Association, and the Tennessee Nurses Association. It has developed a public education website <http://advancedirectivestn.org>⁵ and sponsored Healthcare Decisions Day events at several large medical centers in Tennessee.

MyDirectives (MYD) at <https://mydirectives.com/>, is a site which is co-branded with HCT and contains advance directive forms permitting individuals to upload their advance directives for storage in the cloud.⁶ The Advance Directives at Work in Tennessee (AD@WorkTN) is an initiative led by HCT to encourage Ten-

nesseans within the workforce, particularly those ages 30 to 65, to create an advance directive. The AD@WorkTN program has the following objectives: 1) to implement a public engagement, communications, and educational outreach about advance directives to human resources and benefits professionals at businesses, healthcare systems and higher educational institutions across Tennessee; 2) to disseminate educational materials and web tools that enable employers to institutionalize advance directives as part of their employee orientation and workplace benefits enrollment process; and 3) to increase the numbers within the Tennessee workforce that complete advance directives (ADs). The overarching goal of the AD@WorkTN program is to create a large-scale cultural shift across Tennessee whereby employers integrate Advance Care Planning into their employee benefits programs. This program allows for a multi-generational focus on ADs, positively impacting the future of health care for geriatric and other patients across Tennessee.

METHODS

Between July 2019 and June 2021, the AD@WorkTN program, as part of HCT, a number of resources were created including a patient-friendly website with ADs in English and Spanish with accompanying videos explaining both ADs and how to complete an AD. Educational materials explaining the importance of completing advance directives were produced both to train speakers and for distribution to workplace audiences. These resources were utilized in presentations to human resource (HR) leaders as well as during health fairs and 'lunch and learns' held for employees. Additionally, workplace audiences observed demonstrations about how to easily create one's own advance directive. The program co-branded with MyDirectives to include an app with Tennessee state advance care planning documents and instructions for completion. The MYD app also permitted secure uploading and storage of completed ADs.

In April 2021, HCT partnered with Public Broadcasting Service (PBS) affiliate WNKO in Memphis, to produce a documentary program edition of BestTimes, an ongoing series of programs produced by the affiliate. The production was timed to coincide with National Healthcare Decisions Day, a national program initiated by Honoring Choices in order to promote advance care plan completion on the day following tax-day. This production featured current data and messaging around the importance and convenience of advance care planning in Tennessee. The program aired statewide through the six local PBS affiliates.

Our overall study was designed to meet standards for quality improvement reporting excellence (SQUIRE) criteria, and this report meets the quality improvement minimum quality criteria set (QI-MQCS) domains for reporting quality improvement work.^{7,8} The Vanderbilt Institutional Review Board (IRB) has determined and approved this study as a quality improvement initiative. This work is supported in part by the Geriatric Workforce Enhancement Program, HRSA Grant: 1-U1Q-HP 033085-01-00.

RESULTS

Over a 2-year period, HCT produced 58 workshops and health

fairs, reaching 260 human resource leaders, 958 businesses and 2,950 employees. During the same time, there were 2,954 visits to the HCT site and 411 visits to the co-branded MYD site with 10 advance directives uploaded. The PBS documentary was seen by some 81,500 viewers statewide over a 3-month period (Table 1). Data analytics of the HCT site indicated that a sharp rise in visits correlated with numbers of workshops held and employees reached, while the MYD site showed a slower steady upward trend in visits throughout the intervention period (Figure 1).

DISCUSSION

Our results suggest that human resource directors and employers are willing to educate employees about advance directives and offer this service as part of the benefits program. Outreach to large numbers of individuals through health fairs and workshops is feasible. Our results indicate that employees visit the HCT site during the time frame of the educational intervention but the correlation between website activity and advance care planning completion is not a direct relationship. Translation to a completed advance care plan may be more gradual over a prolonged time frame.

Public engagement to create advance directives is a process with multiple interactive effects. Early completion of advance care plans continues to be a challenge. A systematic review of 795,909 US adults revealed that most ADs are completed by

persons with advanced disease states and are more likely to be completed by persons older than age sixty-five and/or in a nursing home.¹ Advance care planning documents are often general, lacking specificity for individual health status, and only represent a person's wishes at one time, requiring updates as health and surrogate decision-makers change.⁹⁻¹¹

Despite the challenges of advance care planning, this continues to serve an important purpose for guiding healthcare decisions. In one study, 42.5% of elderly decedents had required decision-making about treatments in the final stages of life, and 70.3% of those lacked decision-making capacity.¹² Of those who lacked decision-making capacity, the presence of a living will was associated with a strong agreement between stated preferences and the care received.¹²

LIMITATIONS

Time course of this study was short, and it may be too early to know the influence of the PBS documentary on driving traffic to the HCT site, and the influence of employee education on inter-generational discussion with older family members regarding advance care planning. Additionally, other social influences and individual factors affect visits to the HCT and MYD sites such as internet access or other connectivity issues.

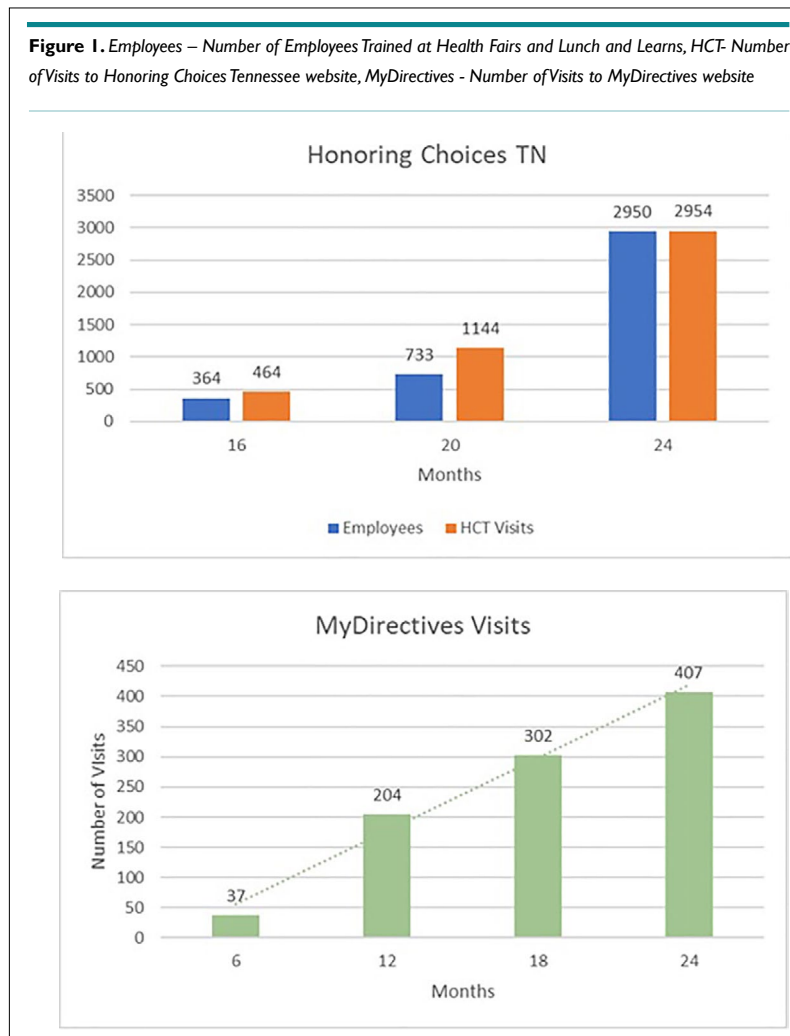


Table 1. HCT- Honoring Choices® Tennessee Website, MYD-MyDirectives Website

Interventions	Date	Cumulative Nnumber		
Workshops	Oct 20	11 events	154 businesses	364 employees
	Feb 21	38 events	674 businesses	733 employees
	June 21	58 events	958 businesses	2,950 employees
PBS Documentary	Apr/May 21	9 broadcasts	18,500 views	
Outcomes	Date	Cumulative Number		
Visits to HCT Site	Oct 20	464		
	Feb 21	1,144		
	June 21	2,954		
Visits to MYD Site	Dec 19	37		
	June 20	204		
	Dec 20	302		
	June 21	407		

CONCLUSION

AD@WorkTN is a promising model to promote integration of ADs into the employee orientation and benefits enrollment processes. Enhanced discussion and completion of ADs among employed individuals and enhanced public discourse may encourage intergenerational conversations about end-of-life care and enhance documentation in healthcare records.

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AUTHOR CONTRIBUTIONS

KLH, ET, JSP: Concept, design, analysis, interpretation; EH, SR: Preparation of manuscript.

INSTITUTIONAL REVIEW BOARD APPROVAL

The TVHS Institutional Review Board (IRB) has determined and approved this study as a quality improvement initiative.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

REFERENCES

1. Yadav KN, Gabler NB, Cooney E, Kent S, Kim J, Herbst N, et al. Approximately one in three US adults completes any type of advance directive for end-of-life care. *Health Affairs*. 2017; 36(7): 1244-1251. doi: 10.1377/hlthaff.2017.0175
2. Greco PJ, Schulman KA, Lavizzo-Mourey R, Hansen-Flaschen J. The Patient self-determination act and the future of advance directives. *Annals Int Med*. 1991; 115(8): 639-643. doi: 10.7326/0003-4819-115-8-639

3. Abel J, Kellehear A. Palliative care reimagined: A needed shift. *BMJ Supportive & Palliative Care*. 2016; 6: 21-26. doi: 10.1136/bmj-spacare-2015-001009
4. Curtis JR, Patrick DL, Caldwell E, Greenlee H, Collier AC. The quality of patient-doctor communication about end-of-life care: A study of patients with advanced aids and their primary care clinicians. *AIDS*. 13(9): 1123-1131.
5. Honoring Choices® Tennessee. Web site. <http://advancedirectivestn.org>. Accessed June 30, 2021.
6. MyDirectives. Web site. <https://mydirectives.com/>. Accessed June 30, 2021.
7. Ogrinc G, Mooney SE, Estrada C, Foster T, Goldmann D, Hall LW, et al. The SQUIRE (Standards for Quality Improvement Reporting Excellence) guidelines for quality improvement reporting: explanation and elaboration. *Qual Saf Health Care*. 2008; 17 Suppl 1: i13-32. doi: 10.1136/qshc.2008.029058
8. Hempel S, Shekelle PG, Liu JL, Danz MS, Foy R, Lim Y-W, et al. Development of the quality improvement minimum quality criteria set (QI-MQCS): A tool for critical appraisal of quality improvement intervention publications. *BMJ Qual Saf*. 2015; 24: 796-804. doi: 10.1136/bmjqs-2014-003151
9. Halpern SD. Shaping end-of-life care: Behavioral economics and advance directives. *Semin Respir Crit Care Med*. 2012; 33 (4): 393-400. doi: 10.1055/s-0032-1322403
10. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: The disability paradox and health care decision making. *Health Psychol*. 2005; 24(4S): S57-S62. doi: 10.1037/0278-6133.24.4.S57
11. Halpern J, Arnold RM. Affective forecasting: an unrecognized challenge in making serious health decisions. *J Gen Intern Med*. 2008; 23(10): 1708-1712. doi: 10.1007/s11606-008-0719-5
12. Silveira MJ, Kim SYH, Langa KM. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010; 362: 1211-1218. doi: 10.1056/NEJMsa0907901