CENTER FOR HEALTHCARE RESEARCH & TRANSFORMATION

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Advance Care Planning: Tying a Community Perspective to the National Conversation

Advance care planning (ACP) is a process where people talk with family members and doctors about their end-of-life care preferences and designate someone to carry out their wishes. ACP helps people plan for future medical treatment in the event of a serious illness. Controversies associated with ACP—perhaps most famously the accusations of “death panels” that demonized the Affordable Care Act[1]—have sometimes overshadowed substantial research on ACP’s benefits. Research shows that the preferences of patients who engage in ACP are more likely to be known and followed, and ACP reduces the burden of medical decision-making among family members.[2,3,4] Even with these benefits, few Americans, including older adults, have engaged in ACP.[5]

Leaders in geriatrics have argued for national- and community-level policy change to create an environment conducive to ACP.[6] In order to improve the environment for ACP, however, it is essential to understand the current obstacles. To that end, the Washtenaw Health Initiative (WHI), a volunteer collaborative in Washtenaw County, Michigan, examined community barriers and their relationship to nationally identified barriers. In early 2016, the WHI conducted a series of focus groups and interviews with over 80 Washtenaw County community members and physicians to understand the community’s experiences and

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[1] This claim was linked to Section 1233 of America's Affordable Health Choices Act of 2009 (HR 3200), a proposal debated in the House of Representatives, and did not appear in the final version of the Affordable Care Act. “10 FAQs: Medicare’s Role in End-of-Life Care,” The Henry J. Kaiser Family Foundation website, Nov. 5, 2015: http://kff.org/medicare/fact-sheet/10-faqs-medicares-role-in-end-of-life-care/ (accessed 6/19/2016).

[2] K. M. Detering and M. Silveira, “Advance care planning and advance directives,” UpToDate website, June 2016: http://www.uptodate.com/contents/advance-care-planning-and-advance-directives#H2095034 (accessed 6/19/2016).

[3] K. M. Detering, A. D. Hancock, M. C. Reade, and W. Silvester, “The impact of advance care planning on end of life care in elderly patients: randomised controlled trial,” *The British Medical Journal*, Mar. 24, 2010, 340:c1345.

[4] “The Case for Advance Care Planning,” The Pew Charitable Trust Website, Aug. 19, 2015: http://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2015/08/the-case-for-advanced-care-planning (accessed 6/22/2016).

[5] IOM (Institute of Medicine), “Dying in America: Improving quality and honoring individual preferences near the end of life” (Washington, DC: The National Academies Press, 2014); In the 2014 IOM Report, a committee of experts laid out the challenges and recommendations for the U.S. health system to promote high-quality end-of-life care for Americans.

[6] D. Tuller, "Medicare Coverage For Advance Care Planning: Just The First Step," Health Affairs (Project Hope), 2016, 35(3): 390.

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challenges with ACP. This brief summarizes key findings and policy recommendations related to challenges to ACP, based on the focus groups and interviews and a review of relevant literature.

About ACP

There are many alternative ways to engage in ACP. There are forms that can be used, such as a durable power of attorney for health care (DPOA-HC), which authorizes another person to carry out medical decisions on behalf of the patient, or a living will[7], which summarizes a person's preferences for future medical care, a do-not-resuscitate (DNR) order, or a combination of a DPOA-HC and living will, such as Five Wishes.[8] But fundamentally, ACP is a conversation between a patient and family and/or a care giver that is written down and available to the family and clinicians so the patient's wishes in the event of a serious illness can be followed. While an advance directive (AD) can include instructions or guidance for treatment decisions, the only legally binding part of an advance care plan is the designation of a surrogate to make medical decisions for the individual in the event that the individual cannot.[9]

While older adults and individuals with a serious illness are more likely to engage in ACP, these conversations can (and should) occur in virtually every stage of adulthood. In early adulthood, ACP conversations may involve broader discussions, such as how one's personal or spiritual values would influence treatment preferences and identifying potential patient advocates or surrogates; older adults may focus on concrete discussions about whether a person wants life support or other such treatments if he/she was in a coma.

Patient Barriers to ACP

Many Americans think it is important to talk about their end-of-life wishes, but few engage in these conversations. Our societal norm reflects a general reluctance to think or talk about dying.[10,11] In a recent national poll, most Americans (89 percent) were in favor of doctors discussing end-of-life issues with their patients; however, fewer than one in five (17 percent) have had such a conversation with a provider.[12] In 2008, an estimated 18 to 36 percent of Americans had completed an AD.[13]

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[7] Living wills are not legally recognized in Michigan. For more information, visit: http://www.legislature.mi.gov/documents/Publications/PeaceofMind.pdf.

[8] For more information about Five Wishes, visit https://www.agingwithdignity.org/five-wishes/about-five-wishes.

[9] Most states consider an out-of-state advance directive valid if it was valid in the state it was created. For more information, visit: http://www.americanbar.org/content/dam/aba/uncategorized/GAO/2013sep16_hhs_testimony.authcheckdam.pdf.

[10] D. C. Mooney and J. G. O'Gorman, "Construct Validity of the Revised Collett-Lester Fear of Death and Dying Scale," *OMEGA-Journal of Death and Dying*, Sept. 2001, 43(2), 157–173.

[11] J. Jong, "Why contemplating death changes how you think," The BBC Website, Feb. 9, 2016: http://www.bbc.com/future/story/20160208-why-contemplating-death-changes-how-you-think (accessed 6/19/2016).

[12] "Kaiser Health Tracking Poll: September 2015," The Henry J. Kaiser Family Foundation website, Sept. 30, 2015: http://kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-september-2015/ (accessed 6/19/2016).

[13] "Advance Directives and Advance Care Planning: Report to Congress," U. S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, August 2008: https://aspe.hhs.gov/sites/default/files/pdf/75811/ADCongRpt.pdf (accessed 6/19/2016).

Research has identified several factors that contribute to the low incidence of ACP. For all populations, an individual's knowledge of ACP and overall health literacy have a major impact.[14] Poor communication between patients and their family is also a significant barrier to ACP. For example, people may assume their family already knows their care preferences or want to avoid the emotional distress of discussing dying with them.[15,16] Cultural, racial, and historical influences also are influential: some racial minorities are more hesitant to discuss end-of-life plans or more likely to choose curative over palliative measures.[17] For African Americans, resistance to ACP can be rooted in a distrust of the health care system due to previous negative experience with medical care.[18,19]

Provider Barriers to ACP

Even providers who initiate ACP conversations with their patients experience challenges. Some barriers include discomfort discussing end-of-life issues, confusion about which staff should engage in ACP, lack of time, fear of causing the patient to lose hope, and lack of family involvement in a patient's care.[20,21] Almost half (46 percent) of physicians in a recent poll frequently felt unsure of what to say to patients and less than a third (29 percent) had any formal ACP training.[22] Research on patients with advanced illness suggests that more of these patients would engage in ACP if providers were trained in discussing ACP, palliative care, and hospice with their patients.[23,24]

Similarly, many health systems lack the processes or the technology to properly engage in ACP. Few doctors (29 percent) from the same national poll reported that their health system had a formal process for assessing a patient's preferences. About a fourth (24 percent) could note whether a patient had an advance care plan in their electronic health record (EHR), and among those that did, only half (54 percent) could access the contents of the AD.[25]

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[14] Dying in America—2014 IOM Report.

[15] Dying in America—2014 IOM Report.

[16] H. Malcomson and S. Bisbee, "Perspectives of healthy elders on advance care planning," *Journal of the American Academy of Nurse Practitioners*, 2009, 21(1): 18–23.

[17] K. Johnson, M. Kuchibhatla, D. Tanis, J. Tulsky, "Racial Differences in Hospice Revocation to Pursue Aggressive Care," *Archives of Internal Medicine*, 2014,168(2):218–224.

[18] C. Waters, "Understanding and Supporting African Americans' Perspectives of End-of-Life Care Planning and Decision Making," *Qualitative Health Research,* 2001, 11(3): 385–398.

[19] H. Washington, "Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present" (New York: Anchor, 2007).

[20] N. Keating et al., "Physician factors associated with discussions about end-of-life care," *Cancer*, Feb. 15, 2010, 116(4): 998–1006.

[21] A. D. Vleminck et al., "Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review," *Scandinavian Journal of Primary Health Care*, Dec. 2013, 31(4): 215–226.

[22] T. Fulmer, "Talking with Patients about End-of-Life Care: New Poll Reveals How Physicians Really Feel," The John A. Hartford Foundation website, April 14, 2016: http://www.jhartfound.org/blog/talking-with-patients-about-end-of-life-care-new-poll-reveals-how-physicians-really-feel/ (accessed 6/19/2016).

[23] S. Snyder, K. Allen, S. Hazelett, and S. Radwany, "Primary Care Physician Knowledge, Utilization, and Attitude Regarding Advance Care Planning, Hospice, and Palliative Care: Much Work Remains," *Journal of Pain and Symptom Management*, Jan. 2011, 41(1): 307.

[24] S. Alexander, S. Keitz, R. Sloane, "A Controlled Trial of a Short Course to Improve Residents' Communication With Patients at the End of Life, "*Academic Medicine*, Nov. 2006, 81(11): 1008–1012.

[25] Fulmer, "Talking with Patients about End-of-Life Care.

WHI Community Focus Group and Interview Findings

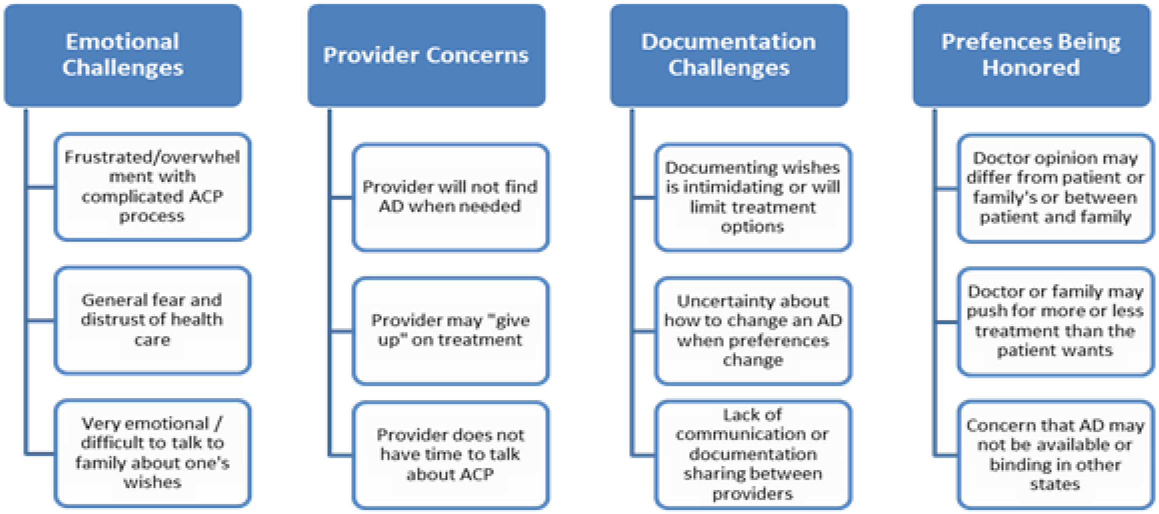
In the WHI community focus groups, participants expressed several barriers that complement or support national research findings:

1. Uncertainty about how and when to begin ACP conversations,
2. Uncertainty about providers' willingness or ability to honor preferences,
3. Concerns about the complexity of documenting treatment preferences, and
4. Concerns about preferences not being honored.

Participants associated ACP with dying, not with making choices about medical care. They felt challenged by ACP because they could not predict all the potential circumstances they might face. Some participants assumed their family knew their wishes and did not see a need for an AD. Participants also expressed concerns that documenting preferences would limit their treatment options or encourage their physician to "give up" on curative treatment. African-American participants cited general mistrust of the healthcare system as a major barrier to ACP. Participants also had concerns about how they would update their AD if their preferences changed; many believed that they needed an attorney to complete or update an AD. Others, particularly in the veterans' focus group, feared that even with an AD, health practitioners would not honor their preferences, while rural community residents worried that their ADs might not be accessible when needed. Figure 1.

FIGURE:1

Most Common Themes: Challenges and Concerns about ACP Mentioned by Washtenaw County Resident Participants, 2016



Physician Focus Group and Interview Findings

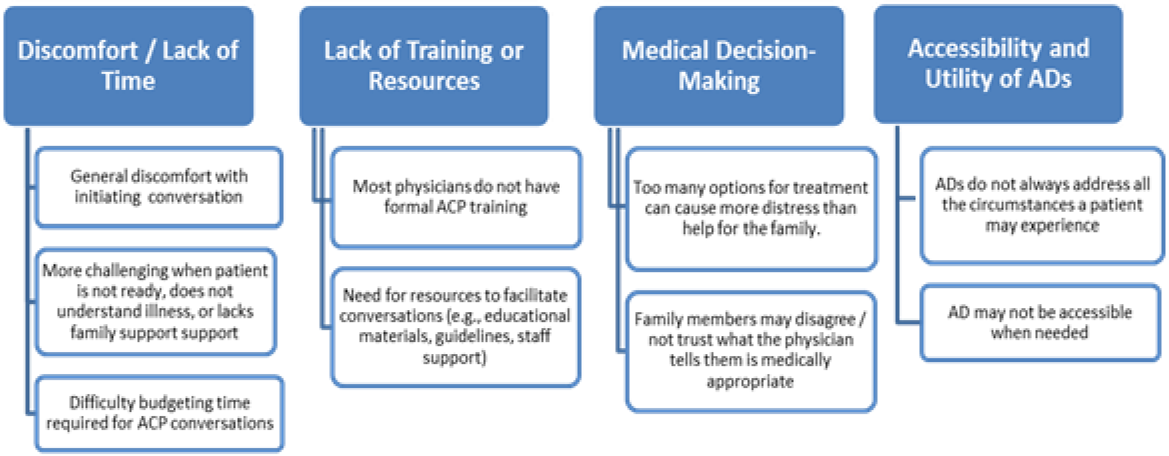
In the physician focus groups and interviews, the main challenges to ACP were seen as:

1. Discomfort and lack of time,
2. Lack of training or resources,
3. Difficulty navigating family preferences or prognoses and treatment options recommended by multiple providers, and
4. Accessibility and utility of ADs.

Physicians who felt uncomfortable with ACP reported that they did not have the necessary training to begin the conversation. They found it difficult to settle on a course of action when faced with differences of opinion among the patient and family members, or among multiple practitioners. Physicians were also concerned about documentation of patient preferences. Some found that even though ADs are a vehicle for recording ACP conversations, they are not useful clinically because the AD often does not address specific conditions or circumstances a patient may experience. Ideally, physicians felt that ACP was an iterative process with the patient and family in the outpatient setting about values, goals and wishes, rather than trying to determine preferences for a myriad of detailed scenarios. However, even when given the opportunity in the outpatient setting, many physicians felt it was difficult to find the right words to say to initiate ACP conversations, especially when the patient was not ready, did not understand their illness, or did not have a family support system. Figure 2.

FIGURE:2

Most Common Themes: Challenges and Concerns about ACP Mentioned by Washtenaw County Physician Participants, 2016



Policy Recommendations

Despite some hesitancy, both community members and physicians wanted to learn more about ACP and recommended ways to increase and improve these conversations. These recommendations fell into three major categories[26]:

- **Normalizing the conversation:**
    - ACP should become a standard health care process for all patients. Such a process should include a community-based approach to incorporate ACP across health systems and over the course of a person's life through standardized processes for patient education, professional training, and policies and practices to collect and utilize advance care plans.[27]
    - Neutral trusted leaders (such as civic leaders and faith-based organizations) should raise awareness, educate, and promote ACP by hosting community forums in safe spaces to build the case for why ACP conversations are important.[28]
- **Investing in ACP training and reimbursement**:
    - Health systems should train clinicians about how and when to begin ACP conversations (e.g., what words to use) through informational materials or video tutorials. Medical schools should invest in training all physicians how to have ACP conversations with patients, not just those specializing in geriatrics or hospice and palliative care.
    - Medicare should continue to refine its recent administrative decision to reimburse for ACP. Medicare can encourage a more team-based approach to ACP by ensuring mid-level providers are included in the conversation and facilitation process, allowing clinicians to focus on more clinical services or conversations with patients who are more resistant to ACP.[29,30] Medicare should also consider reimbursing for conversations that cannot be face-to-face with a family or surrogate (such as a phone call), particularly when the patient cannot participate.[31]

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[26] These recommendations include those mentioned during the focus groups and interviews as well as broader policy recommendations.

[27] One such example is the Respecting Choices model, which was developed by the Gundersen Health System in LaCrosse, Wisconsin. For more information on Respecting Choices, visit www.gundersenhealth.org/respecting-choices.

[28] This recommendation aligns with the 2014 IOM Report recommendation to work with civic leaders, including faith-based organizations, to reach out, raise awareness, and promote ACP in communities.

[29] T. Harter, "What Kind Of Advance Care Planning Should CMS Pay For?" *Health Affairs Blog*, March 19, 2015: http://healthaffairs.org/blog/2015/03/19/what-kind-of-advance-care-planning-should-cms-pay-for/ (accessed 6/19/2016).

[30] M. Ross, "Advance Care Planning: Who, What, When, Where, and How," *PYA Healthcare Blog,* Jan. 5, 2016: http://healthcareblog.pyapc.com/2016/01/articles/reimbursement/advance-care-planning-who-what-when-where-and-how/ (accessed 6/19/2016).

[31] A. Smith, "Questions about Medicare payment for advance care planning," *GeriPal Blog*, Sept, 4, 2015: http://www.geripal.org/2015/09/s-about-medicare-payment-for-advance.html.

- **Establishing metrics and operationalizing ACP:**
    - Best practices in ACP must be collected and disseminated. For example, Medicare should clarify what should constitute a reimbursable ACP conversation (e.g., simply handing out a pamphlet does not seem appropriate) to encourage best practices and to ensure that ACP is meaningful for the patient, family members, and the physician.[32]
    - Federal efforts to encourage the interoperability of EHRs, or the ability to exchange EHRs and share information, should make ADs readily available and should work with online registries such as MyDirectives, a private service, or Michigan Peace of Mind, a state AD registry.

Conclusion

Findings from the literature and Washtenaw County focus groups highlight the complexity of ACP and the barriers to broaching these conversations, but also ways to improve and increase them. While participants acknowledged the challenges—and their own personal fears—regarding end-of-life care, they realize the importance of making their preferences known. By understanding these community-level challenges and recommendations, local leaders can increase the number and improve the quality of conversations about health care choices.

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[32] Through the reimbursement system, CMS can disseminate information on what should be included in the conversation to be reimbursable as well as to gather more information about who is billing. Providing additional guidance does not necessarily have to be prescriptive but could establish some best practices on what meaningful ACP should look like for purposes of reimbursement. For more information, visit: http://www.hfma.org/content.aspx?id=47288.

About Washtenaw County, the Focus Groups, and Interviews

More than 350,000 people live in Washtenaw County. The community's median age is 33 and median income is about $61,000; the population is 74 percent white, 12 percent African American, 8 percent Asian, and 6 percent of another race or multiple races.[33]

WHI conducted five focus groups with community residents, two focus groups with inpatient providers, and eleven interviews with outpatient providers. The populations were:

1. African Americans (two focus groups),
2. Veterans,
3. Participants in Huron Valley Program of All-Inclusive Care for the Elderly (PACE),
4. Residents of a rural community in Washtenaw County,
5. Inpatient providers at University of Michigan Health System,
6. Inpatient providers at Saint Joseph Mercy Health System, and
7. Outpatient providers.

Community participants were men and women aged 40 and older who reside in Washtenaw County. Participants did not need to have completed an AD to participate. Physician participants specialized in internal medicine, family medicine, geriatrics, oncology, palliative care, pulmonology, neurology, transplant hepatology, and hospital medicine. Participants in the outpatient physician interviews specialized in family medicine, geriatrics, hospice and palliative care, and internal medicine.

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[33] U.S. Census Bureau, 2010–2014 American Community Survey 5-Year Estimates, Washtenaw County, Michigan: http://factfinder.census.gov/faces/nav/jsf/pages/index.xhtml.