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# Clarifying Values and Preferences for Care Near the End of Life: The Role of a New Lay Workforce

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## Abstract

**Background**—Community health workers (CHWs) can engage elderly persons in advance care planning (ACP) conversations.

**Objective**—We report how trained CHWs used Go Wish cards ( $GW^R$  cards) to identify patients' highest priority preferences and evaluated whether engaging in ACP conversations was associated with subsequent health care utilization.

**Design**—A one-year long, pre-post longitudinal design was used to evaluate our educational intervention using mixed-methods.

**Patients**—392 patients (mean of 73.3 years, 82% women, 48% African American, 43% Caucasian) enrolled in the Aging Brain Care (ABC) program and participated in ACP discussions with CHWs.

**Intervention**—We expanded the role of the ABC's CHW, who work directly with individuals and caregivers during home visits to monitor bio-psycho-social needs, to include ACP conversations.

**Main Measures**—The CHWs received ACP training, practice with tools such as  $GW^R$  cards, and support from an electronic health record (EHR) clinical decision support tool. Quantitative measures of patients' ACP preferences and health care utilization were abstracted from the EHR.

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Qualitative data about patients' perceptions of CHWs in facilitating ACP discussions was obtained through semi-structured interviews.

**Results**—Eighty-six patients' data indicated that they had engaged in a preferences-for-care process using  $GW^R$  cards. The top-three card choices by patients was attending to spirituality and religious concerns, preparing for end of life, and maintaining personal wholeness.

**Conclusion**—CHWs were able to effectively engage in ACP conversations with patients and  $GW^R$  cards were a positive way to stimulate discussion of issues previously undiscussed.

## **Keywords**

End-of-life conversations; clarifying end-of-life goals; community health worker

#### 1. INTRODUCTION

Advance care planning (ACP) is important for all persons, particularly aging patients with chronic illnesses, to ensure the care they receive is aligned with their values, priorities, and preferences. Patients often desire to have these discussions and influence decisions about their care, <sup>1–5</sup> yet providers frequently fail to invite patients to explore care options. <sup>6–14</sup> Thus many persons' values go undocumented and preferences for care remain unknown. <sup>6,7,15</sup>

Although most people believe a physician should be involved in final decision-making about goals of care with patients, physicians believe all health care providers can play a role in initiating goals of care discussions. <sup>16</sup> As early as 1975, the World Health Organization identified lay community health workers (CHWs), as "key to [health care's] success… because [CHWs] are accepted and can deal with many of the local problems better than anyone." <sup>17</sup> CHWs are especially key to health care success when supported through frequent communications and electronic clinical decision support systems and when well integrated into multidisciplinary health care teams focused on developing holistic care plans. <sup>17</sup>

Given the shortage of licensed health providers with specialty training in geriatrics and palliative care, new models of health service delivery that address the needs of aging individuals and their caregivers are needed. CHWs who work in association with health care systems and share ethnicity, language, and socioeconomic status with their patients may be an effective strategy for engaging minority populations who often lack advance care plans and prefer more intensive treatments. <sup>18,19</sup> Responding to this need, the Indiana University Center for Aging Research implementation scientists developed, tested, and expanded a successful collaborative care coordination model, called the Aging Brain Care (ABC) program<sup>20–23</sup>, for older adults with multiple chronic conditions with dementia and/or depression. The expansion included a newly created frontline care provider position, the Care Coordinator Assistant. The Care Coordinator Assistants (CCAs) were CHWs recruited from the local community and were representative of the same racial, ethnic, religious, and socioeconomic mix as the patients served. The CCAs worked directly with individuals and caregivers through home visits and telephone consultations to monitor bio-psycho-social needs. The CCAs delivered evidence-based and individualized care protocols with close supervision from a registered nurse care coordinator and a social worker.<sup>24</sup>

The collaborative care team recognized that the CCAs were well positioned to facilitate advance care planning. CCAs were able to develop a trusting relationship with patients during visits in the patient's home and initiate and re-visit conversations about goals of care, life priorities, and topics related to bio-psycho-social-spiritual needs. The purpose of this paper is to report how our CHWs used  $Go\ Wish^R\ (GW^R)$  cards and what values and preferences emerged as patients' highest priorities (see Table 1). We also evaluated whether engaging in ACP conversations by using the  $GW^R$  cards was associated with changes in subsequent health care utilization. Further, semi-structured interviews were conducted to characterize patient experiences with their CCAs, particularly surrounding discussions focused on ACP and health care representation.

#### 2. METHODS

## 2.1 Subjects

392 patients of the 818 patients enrolled in the ABC program during the one-year study (July 1, 2014 to June 30, 2015) elected to participate in ACP discussions with CCAs.

# 2.2 Design

A pre-post longitudinal design was used to evaluate our quality improvement educational intervention.

The CCAs' ACP educational intervention consisted of 4 workshops, 2 simulation sessions, guidance from an electronic health record (EHR) clinical decision support tool, and monthly case conferences. Detailed descriptions of the curricular content of workshops, simulation sessions and the ACP EHR fields are reported elsewhere. <sup>24,25</sup>

During home visits, the priority goals for living were displayed for patients using the *GW*<sup>R</sup> 36-card deck (http://www.gowish.org). <sup>19</sup> Each card displays a phrase relating to a variety of EOL care preferences (see Table 1). Patients reviewed the cards in random order, separating them into three stacks (*not particularly important, somewhat important and very important to me*). They were then instructed to work with the *very important cards* to choose and rank-order their top 10 most important priorities. Their priorities and goals for care were captured in the ACP fields in the EHR and communicated to the clinical staff.

Data entered in the EHR were used to compare patients with whom CCAs had visits that included the use of  $GW^R$  cards to those not so served in the larger universe of patients who had documented ACP. Associations between prior and subsequent utilization of Emergency Department (ED) visits and hospitalizations before and after exposure to CCA ACP  $GW^R$  interactions were also explored. The study was approved by the Indiana University Human Subjects Institutional Review Board.

# 2.3 Quantitative Analytic Methods

We used Chi-Square tests and Wilcoxon rank sum tests to compare demographics, comorbidities, and prior utilization between patients with and without a goal-setting discussion during the study period. We used proportional hazards models to examine the association of goal setting discussions with time to inpatient admission or time to ED visit

while adjusting for demographics, comorbidities, and prior utilization over a one-year time period following ACP discussion with a CCA. Follow-up time for observations with no inpatient admissions or ED visits (censored observations) was calculated as the time from first ACP discussion to last documented utilization encounter. All observations with follow-up times greater than 1 year were censored at 1 year.

# 2.4 Qualitative Analytic Methods

To characterize patient experience with ACP discussions and use of the  $GW^R$  cards, we conducted 15 semi-structured interviews between August and October, 2015 with a convenience sample of patients who had been served by CCAs in the recent past. The purpose of these interviews was to explore patient experiences with emphasis on the discussions patients may have had with CCAs that were focused on ACP and designation of healthcare representatives (HCR). The interviews lasted between 15-40 minutes (mean interview time = 32 minutes). All interviews were conducted by one research assistant (KW) who used a semi-structured interview guide. A team of 4 reviewers (KW, DL, AC, TI), both independently and then together, used immersion and crystallization techniques to identify and assimilate like comments into thematic categories. <sup>26, 27,28</sup> These thematic categories were identified independently and then by consensus. Through this process, reviewers were able to appreciate the interviewees responses to questions including the interviewees' perceived importance of having this ACP conversation, life experiences each interviewee did or did not have involving ACP, and what the interviewees' feelings towards the CCA were. After reviewing and examining 15 interviews, the team of four analysts agreed that saturation of content had been reached. All but one interview took place in the patients' homes.

# 3. RESULTS

The average age of the 392 patients participating in ACP discussions was 73.3 years old and the majority were women (82.1%). The patient population was 48% African American and 43% Caucasian. The co-morbidities are included in Table 2. Table 2 shows the comparison between 306 patients who engaged in ACP (e.g. identified a health care representative) but without goal-setting conversations, 42 patients who engaged in goal-setting conversations but did not prioritize their goals for care, and 44 patients with whom CCAs completed prioritization of goals of care using GW cards. Patients formally diagnosed as having dementia were less apt to engage in or complete goal setting with CCAs. There was a higher percentage of Caucasian patients compared to African-American patients that started the goal-setting conversation and did not finish, but an equal percentage of patients in each group who completed goal setting. Those involved in establishing care priorities had more contacts with CCAs and a greater number of home visits.

Tables 3 and 4 display the result of analyses exploring the relationship of prior utilization (before CCA services) and subsequent utilization of health services (after CCA ACP discussions, Table 3) and proportional hazard modeling [Table 4 with Hazards Ratios (HR) and confidence intervals (CI)]. For the 1-year period prior to the first discussion date, patients who completed goal setting had fewer inpatient admissions than those who did not

complete goal setting. Adjusting for prior levels of utilization of ED and hospital-based services as well as co-morbidity, there was a significant difference (p=0.026) between level of goal-setting and time to first inpatient stay. Specifically, those who started goal setting had decreased risk of an inpatient stay compared to those with no goal setting (HR 0.27, 95% CI 0.09, 0.08) while there was no difference between those who completed goal setting compared to those with no goal setting (HR 1.49, CI 0.84, 2.66). There was no significant difference (p=0.280) between the level of goal setting when examining the time to first ED visit.

## 3.1 What were the patient views of CCA ACP discussions?

The mean age of the 15 patients interviewed was 71.8 years (SD=4.0), 73% were women, and 46.7% African-American, 46.7% Caucasian, and 6.7% other. All patients recalled meeting with a CCA and discussing ACP issues. All but one patient reported knowing about the completion of a HCR form, although nearly half of patients (46%) were not aware of its present location. A majority of patients had named either a spouse or another member of their family as the designated HCR (child 8/15 interviews, spouse 3/15, friend 1/15, other 1/15). Most patients had shared information from the HCR form with at least one other person in addition to the HCR him/herself, including children (4/15), doctors (4/15), others (3/15). In five interviews, the patient referenced their HCR as the only person aware of the HCR document.

After analyses of the 15 interviews by the reviewing team, three thematic categories emerged: the importance of ACP conversations and how their CCA facilitated these conversations, the usability of the GW cards, and their feelings towards their CCA. The following expands on each of those categories, highlighting the majority opinion.

#### 3.2 Importance of ACP conversations

The CCA conversations with patients about advanced care planning were described as helpful and important. These conversations stimulated systematic thinking about various issues pertaining to end-of-life care, death, and issues beyond death (e.g., body donation, funeral arrangements, and financial arrangements). It was often noted that patients who had a discussion with their CCA about advanced care planning were able to organize their thoughts, write down preferences and talk openly about their wishes without emotional involvement. While interviewees said that having these kinds of advance planning conversations with their families was uncomfortable because children or other members of the family simply did not want to talk about these matters with the person they would ultimately lose, the same patients found that conversations with CCAs about end-of-life preferences and care were certainly challenging but also comfortable. In the words of interviewed patients:

"Yes, she made it very comfortable. I didn't feel pressure from her. It allowed me to kind of speak in the details which made it easier to talk to my family. She didn't have the emotional involvement, so it was kind of an outsider who I was very comfortable with. I was grateful they thought to send somebody who could help me organize these thoughts. It gave me comfort that if something does happen, I have someone to call."

"Talking to your children about what you want and don't want is very uncomfortable. They don't understand my point of view.... I feel comfortable talking to her (CCA) about anything. I just enjoy her."

# 3.3 Usability of the GWR cards

When recalled, *Go Wish* Cards<sup>R</sup> were described as helpful and a positive way to stimulate discussion of issues previously undiscussed. In two instances, patients expressed a desire to go through the *Go Wish* cards<sup>R</sup> a second time to reaffirm values or see if their values had changed. In two other instances, patients who believed they had not previously gone through the *Go Wish* cards<sup>R</sup> expressed wishes to go through the cards with their CCA. A few patients said that their religion or 'faith' had generally been the main source of guidance for them on issues and questions that were discussed with the CCA. In addition, personal experiences of patients outside the CCA discussion had often served as background for decisions about care near the end of life. Caring for parents who died or participating in care for other family members with severe illnesses were cited by patients as relevant when thinking about themselves and their own end-of-life care. Further, these experiences were linked to a patient's own understanding of the importance of documenting their own preferences before the burden of decision making for them fell on the shoulders of other members of their family.

"I do know that she brought up how to donate my body and walked me through. It was so easy that I didn't think of it as anything special, just what I need to do. She made that pretty easy, writing the paperwork and making decisions. I think inside I had made the decision, but to put them on paper and to organize them, she helped me do that."

# 3.4 Feelings towards CCA

Patients were generally warm and effusive in their praise of CCAs, characterizing them as friendly and balanced in their interactions when discussing difficult issues.

She made it very comfortable. I didn't feel pressure from her. It allowed me to speak in detail, which made it easier to talk to my family... I was grateful they thought to send somebody who could help me organize these thoughts.

CCAs were very welcome in patients' homes and of great assistance with challenges patients' encountered.

Talking to your children about what you want and don't want is very uncomfortable. They don't understand my point of view.

...my daughters feel like my depression means I am crazy. It means you can't make decisions or if you made decisions you shouldn't have. This is where CCA comes in for me. I can talk to her and tell her things and not that she gives me answers... she listens, you know. I notice that she just listens!

CCAs had become important persons in patients' lives. Two patients were concerned that the interview might be used to end CCA visitations, or the CCA program overall, and needed reassurance that this use of the interview information was not contemplated.

I just can talk about things and I love her to pieces. If they would take her away from me, there wouldn't be a replacement.

# 3.5 Analysis of Goals for Living Priorities

It was possible to query the EHR data from CCA ACP visits to characterize patient priorities. Eighty-six patients' data indicated that they had engaged in a preferences-for-care, priority-setting process using  $GW^R$  cards. Forty-four patients' data from 46 visits included information about the selection of specific  $GW^R$  cards (range 1–17) and ranking ordering. Individual card selection was characterized by noting which one of seven domains the selection fell into, using Steinhauser's factors for EOL domains.  $^{1,14}$  Patient comments recorded verbatim in the EHR and additional GW  $^R$  cards not cited in Steinhauser's taxonomy were examined and categorized by consensus of the authors (KW, TI, DL, SI) to create the "modified Steinhauser Domains" (Table 1).

The following are the seven domains into which all  $GW^R$  cards have been sorted for this report (followed by the number of cards in each domain): dealing with symptoms and personal care (7), having a positive patient provider relationship (2), maintaining personal wholeness (8), preparing for the end of life (6), making personal and treatment preferences known (4), attending to spirituality and religious concerns (4), and achieving a sense of completion (4).

Data were explored to identify which cards patients chose for their highest-priority goals. These cards were grouped according to the aforementioned domains, and the number of times each domain was represented among the top-three priority goals was established. These citation scores were then divided by the number of cards that were in the domain to determine an 'affinity score' (number of times domain was chosen per number of cards in each domain) displayed in Figure 1, effectively adjusting the cumulative scores for the effect of having larger or smaller numbers of cards in the seven domains. The domain with the highest affinity calculated for the top-three card choices by patients was attending to spirituality and religious concerns with an affinity of 7.75, followed by preparing for end of *life* (affinity score of 4.83), and next by *maintaining personal wholeness* (affinity score of 4). The dominance of the attending to spirituality domain was confirmed by performing a Chisquare that compared the frequency of that domain versus all others (Chi-square=6.53, p = 0.011). This set of the three highest-affinity domains remained consistent when authors (TI, KW) categorized the affinity for as many as the top 4–10 selected cards. Looking at patients choosing attending to spiritual and religious concerns as one of their top three priorities, we found that African-American patients choose spirituality/religion items significantly more often than Caucasian patients (72.2% [13/18], 40.7% [11/27], respectively; p-value=0.049.

# 4. DISCUSSION

Trained CHWs were able to work with patients to identify their personal preferences for care and treatment. CCAs and their ACP service were well-received by our patients and their caregivers. Analysis of the  $GW^R$  card results indicated that the top three priority goals within this patient population were: 1) attending to spirituality and religious concerns; 2) preparing for end of life, and 3) maintaining personal wholeness.

These priorities were not ones we anticipated *a priori* would emerge from our data but were readily understood *a posteriori*. The interface of spirituality, religion, death, and dying is ubiquitous in all cultures.<sup>29,30</sup> For many persons, the influence of religion and spirituality remains strong, especially when confronting life's limits through frailty and finitude. The team's denotation of this domain ("*attending to spirituality and religious concerns*") reflects our attempt to use general, not faith-specific, meanings for the purposes of this research.

We included in the "spiritual and religious concerns" domain those action items associated with religion and spirituality: prayer, peace, clergy, talk about death. In light of how narrowly we grouped items into this domain, it is remarkable how highly these domains were ranked. Indeed, other researchers have considered other GW Card topics as belonging within the religion and spirituality construct. For example, Milstein established "wholeness" as the goal of spiritual interventions in medical settings. Further, Pulchalski writes for many in the palliative care community when she links directly the patient's and family's spirituality with how they approach, prepare, and receive death. The fact that preparing for EOL and maintaining personal wholeness are the second and third highest domains makes the religion and spirituality domain even more striking as narrowly defined by this research.

The CCAs who engaged patients in ACP in this study built high levels of trust with the patients. These CCAs were members of the patients' community and were comfortable placing ACP in a spiritual and religious context. Would "stranger-conversations" have resulted in the same priority given to spiritual issues? Our belief is that hearing the full range of ACP concerns requires a degree of intimacy seldom achieved in physician offices. Our patients' comments indicate that familial relationships are frequently complicated by grief and denial when elders discuss their ACP wishes thereby depriving the elder of opportunities for "the conversation." It may be essential that health providers such as CCAs or trained persons within the elder's natural community (perhaps members of their religious congregation) be present to these welcomed but difficult conversations.

A second result of this study that we did not anticipate a priori was the complex association between the level of goal setting and the timing of hospitalization in the year after interactions with the CCAs. Even though we adjusted for co-morbidities, it is possible that patients who chose to complete  $GW^R$  prioritization with CCAs were sicker, more frail, or for other physical or psychological reasons were more aware of the need to communicate EOL preferences than those who declined or did not complete the process. It also seems possible that individuals, particularly those with strongly held spiritual/religious beliefs who completed goals of care documents did not resist hospitalization, instead leaving their fate to 'a higher power.' For example, African-Americans, who express strong spiritual/religious beliefs die in hospital more often than Caucasian patients. <sup>19</sup> It has been speculated that this is because African-American persons have completed less ACP, <sup>19</sup> but it is also possible this is a purposeful decision to accept whatever happens as part of 'God's will' rather than personally deciding when to terminate active medical care. This theory is consistent with the high prioritization of religious and spiritual beliefs by our African-American population who completed GW cards. Reciprocally, a significantly greater number of Caucasian patients than African-American patients fell into the "started goal-setting" category associated with

significantly later hospitalizations during the study period. Our findings may be seen as placing weight on the perspective that the depth of goal setting is more about patient autonomy and personally held beliefs and less about limiting utilization of medical resources. Additional qualitative research is needed to understand these complex results.

This study was descriptive and hypotheses generating in nature and should not end with statements about cause and effect. It was carried out in a particular locality with a special population of patients and with a specially trained cadre of new providers in an expanded role. Its limitations are also its strengths. To our knowledge, this study is a unique, multimethod description of what transpires when CHWs open conversations with their patients about preferences for care near the EOL. While our observations should not be overgeneralized to other settings, we hope that others will take heart to note that at least in one setting CHWs were able to expand the community of individuals who can effectively engage in much-appreciated conversations with patients about their values and preferred activities. At least in our setting, it will continue to be important to open any such dialogues to the spiritual and religious concerns of patients.

# References

- 1. Steinhauser KE, Christakis NA, Clipp EC, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. J Pain Symptom Manage. 2001; 22(3):727–737. [PubMed: 11532586]
- California Healthcare Foundation. Final Chapter: Californians' Attitudes and Experiences with Death and Dying. 2012. http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/F/PDF %20FinalChapterDeathDying.pdf, 2016
- 3. Tobler D, Greutmann M, Colman JM, Greutmann-Yantiri M, Librach SL, Kovacs AH. Knowledge of and preference for advance care planning by adults with congenital heart disease. Am J Cardiol. 2012; 109(12):1797–1800. [PubMed: 22459306]
- Pardon K, Deschepper R, Vander Stichele R, et al. Preferred and actual involvement of advanced lung cancer patients and their families in end-of-life decision making: a multicenter study in 13 hospitals in Flanders, Belgium. J Pain Symptom Manage. 2012; 43(3):515–526. [PubMed: 22048004]
- Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. Bmj. 2010; 340:c1345. [PubMed: 20332506]
- 6. Earle CC, Neville BA, Landrum MB, Ayanian JZ, Block SD, Weeks JC. Trends in the aggressiveness of cancer care near the end of life. J Clin Oncol. 2004; 22(2):315–321. [PubMed: 14722041]
- Wright AA, Zhang B, Keating NL, Weeks JC, Prigerson HG. Associations between palliative chemotherapy and adult cancer patients' end of life care and place of death: prospective cohort study. BMJ: British Medical Journal. 2014:348.
- 8. Anonymous. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators. [Erratum appears in JAMA 1996 Apr 24;275(16):1232]. Jama. 1995; 274(20):1591–1598. [PubMed: 7474243]
- 9. Heyland DK, Barwich D, Pichora D, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. JAMA Intern Med. 2013; 173(9):778–787. [PubMed: 23545563]
- 10. Keating NL, Landrum MB, Rogers SO, et al. Physician factors associated with discussions about end-of-life care. Cancer. 2010; 116(4):998–1006. [PubMed: 20066693]

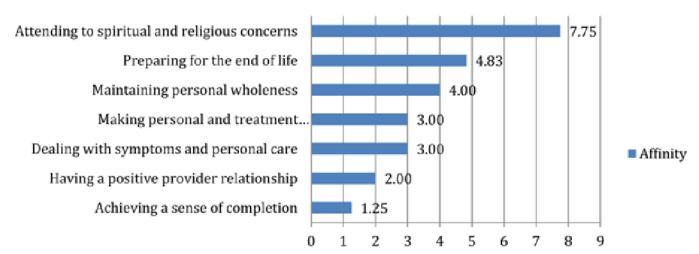
 Nelson JE, Gay EB, Berman AR, Powell CA, Salazar-Schicchi J, Wisnivesky JP. Patients rate physician communication about lung cancer. Cancer. 2011; 117(22):5212–5220. [PubMed: 21495028]

- Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: how do physicians communicate about advance directives? Ann Intern Med. 1998; 129(6):441–449. [PubMed: 9735081]
- Agledahl KM, Gulbrandsen P, Forde R, Wifstad A. Courteous but not curious: how doctors' politeness masks their existential neglect. A qualitative study of video-recorded patient consultations. J Med Ethics. 2011; 37(11):650–654. [PubMed: 21610269]
- 14. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA: the journal of the American Medical Association. 2000; 284(19):2476–2482. [PubMed: 11074777]
- 15. Johnston SC, Pfeifer MP, McNutt R. The discussion about advance directives. Patient and physician opinions regarding when and how it should be conducted. End of Life Study Group. Arch Intern Med. 1995; 155(10):1025–1030. [PubMed: 7748044]
- You JJ, Downar J, Fowler RA, et al. Barriers to goals of care discussions with seriously ill hospitalized patients and their families: a multicenter survey of clinicians. JAMA Intern Med. 2015; 175(4):549–556. [PubMed: 25642797]
- 17. Kangovi S, Grande D, Trinh-Shevrin C. From rhetoric to reality—community health workers in post-reform U.S. health care. The New England journal of medicine. 2015; 372(24):2277–2279. [PubMed: 26061832]
- 18. Saith S, Brock D, Daaleman T. An Exploratory Study of Peer Support and Advance Care Planning in African American Elders with Serious Illness. J Am Geriatr Soc. 2014; 62:S279–S279.
- Institute of Medicine. Committee on Approaching Death: Addressing Key End-of-Life Issues.
   Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.
   2015
- Cottingham AH, Alder C, Austrom MG, Johnson CS, Boustani MA, Litzelman DK. New workforce development in dementia care: screening for "caring": preliminary data. Journal of the American Geriatrics Society. 2014; 62(7):1364–1368. [PubMed: 24916743]
- 21. Unutzer J, Katon W, Callahan CM, et al. Collaborative care management of late-life depression in the primary care setting: a randomized controlled trial. Jama. 2002; 288(22):2836–2845. [PubMed: 12472325]
- 22. Boustani MA, Sachs GA, Alder CA, et al. Implementing innovative models of dementia care: The Healthy Aging Brain Center. Aging & mental health. 2011; 15(1):13–22. [PubMed: 21271387]
- 23. Callahan CM, Kroenke K, Counsell SR, et al. Treatment of depression improves physical functioning in older adults. Journal of the American Geriatrics Society. 2005; 53(3):367–373. [PubMed: 15743276]
- 24. Litzelman DK, Cottingham AH, Griffin W, et al. Impact of community health workers on elderly patients' advance care planning and health care utilization: moving the dial. Med Care. 2016:1–11. doi:org/10.1017/S1478951516000353. [PubMed: 26783856]
- 25. Litzelman DK, Cottingham AH, Griffin W. Enhancing the prospects for palliative care at the end of life: A statewide educational demonstration project to improve advance care planning. Palliat Support Care. 2016:1478–1515.
- 26. Crabtree, BF., Miller, WL. Doing Qualitative Research: Methods for Primary Care. Thousand Oaks, CA: Sage Publications; 1999.
- 27. Bernard, HR. Research Methods in Anthropology: Qualitative and Quantitative Approaches. Thousand Oaks, CA: 1994. 0803952449
- 28. Glaser, BG., Strauss, AL. The discovery of grounded theory: Strategies for qualitative research. New Brunswick, USA: Transaction publishers; 2009.
- 29. Perkins HS, Geppert C, Gonzales A, Cortez JD, Hazuda HP. Cross-cultural similarities and differences in attitudes about advance care planning. Journal of general internal medicine. 2002; 17(1):48–57. [PubMed: 11903775]
- 30. Spector RE. Cultural diversity in health and illness. J Transcult Nurs. 2002; 13(3):197–199. [PubMed: 12113150]

31. Koenig HG. Religion, spirituality, and medicine: research findings and implications for clinical practice. South Med J. 2004; 97(12):1194–1200. [PubMed: 15646757]

- 32. Milstein JM. Introducing spirituality in medical care: transition from hopelessness to wholeness. Jama. 2008; 299(20):2440–2441. [PubMed: 18505954]
- 33. Puchalski CM. Spirituality and end-of-life care: a time for listening and caring. J Palliat Med. 2002; 5(2):289–294. [PubMed: 12006231]

# **Domain Affinity for Top 3 Choices**



Affinity= Number of times domain was chosen per number of cards in each domain

Figure 1. Screen Shots of the Electronic Health Record Advanced Care Planning Clinical Decision Support Fields

Domain Affinity for Patients' Top 3 Priority Goals

**Table 1**GoWish Cards Mapped to Modified Steinhauser Domains

Modified Steinhauser <sup>1, 14</sup> Domains	Go Wish Card (Card #)		
Achieving a sense of completion	To feel that my life is complete (19)		
	To say goodbye to important people in my life (20)		
	To remember personal accomplishments (21)		
	To take care of unfinished business with family and friends (22)		
Attending to spiritual and religious concerns	To be at peace with God (2)		
	To pray (3)		
	To meet with clergy or a chaplain (6)		
	To be able to talk about what death means (7)		
Dealing with symptoms and personal care	To be able to talk about what scares me (5)		
	To be kept clean (31)		
	To have human touch (32)		
	To be mentally aware (16)		
	To be free from pain (28)		
	To be free from anxiety (29)		
	Not being short of breath (30)		
Having a positive patient provider relationship	To trust my doctor (14)		
	To have a nurse I feel comfortable with (15)		
Maintaining personal wholeness	To be able to help others (1)		
	To have family with me (8)		
	To have a doctor who knows me as a whole person (10)		
	To have close friends near (11)		
	Not dying alone (12)		
	To have someone who will listen to me (13)		
	To maintain my dignity (26)		
	To keep my sense of humor (27)		
Making personal and treatment preferences known	Not being connected to machines (4)		
	To have an advocate who knows my values and priorities (24)		
	To be treated the way I want (25)		
	To die at home (35)		
Preparing for the end of life	To have my funeral arrangements made (17)		
	Not being a burden to my family (18)		
	To prevent arguments by making sure my family knows what I want (23)		
	To have my financial affairs in order (33)		
	To have my family prepared for my death (34)		
	To know how my body will change (36)		
Not classified	Wild Card (9)		

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Table 2

Comparison of Patients with Advance Care Planning Discussion with and without Goal-Setting

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	No Goal-setting (n=306)	Goal-setting, started (n=42)	Goal-setting, completed (n=44)	P-value
Age/Gender				
Mean Age (SD)	73.7 (7.3)	73.4 (7.1)	72.8 (5.8)	0.76
% Female	80.7	76.2	84.1	0.65
Race				0.009
% African-American	53.4	29.0	45.0	
% Caucasian	41.2	68.4	42.5	
% Other	5.4	2.6	12.5	
Co-morbidities				
% Depression	81.0	88.1	86.4	0.47
% Diabetes	64.0	54.8	70.4	0.32
% Coronary Artery Disease	48.0	33.3	36.4	0.10
% Chronic Obstructive	40.8	42.9	31.8	0.48
Pulmonary Disease				
% Congestive Heart Failure	34.3	23.8	31.8	0.40
% Stroke	33.0	23.8	31.8	0.50
% Cancer	32.4	26.2	25.0	0.53
% Dementia	21.9	14.3	4.6	0.009
% Arthritis	9.8	7.1	9.1	0.95
Mean # Total Contacts (SD)	13.2 (7.4)	11.4 (7.0)	18.2 (9.5)	< 0.001
Mean # Home Visits (SD)	3.8 (3.1)	4.2 (2.0)	5.1 (2.3)	< 0.001

Table 3

Health Care Utilization in the Prior Year and the Year Post Advance Care Planning Discussion

	No Goal-setting (n=306)	Goal-setting, started (n=42)	Goal-setting, completed (n=44)	P-value
% Hospitalized Prior Year	29.1	26.2	11.4	0.03
% Making ED *Visit Prior Year	33.0	40.5	45.4	0.20
% Hospitalized — Subsequent Year	26.1	7.1	36.4	0.003
% ED Visit — Subsequent Year	36.9	23.8	38.6	0.23

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<sup>\*</sup> ED=Emergency Department

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Table 4

Proportional Hazard Modeling Results for Time to Inpatient Stay or Any Emergency Department Visits within 1 year of Advance Care Planning Discussion Date

	Any Inpatient Stay		Any ED* Visit	
	HR <sup>†</sup> (95% CI) <sup>‡</sup>	P-Value	HR <sup>†</sup> (95% CI) <sup>‡</sup>	P-Value
Age	0.96 (0.93, 0.99)	0.04	0.99 (0.97, 1.02)	0.85
Female	0.90 (0.53, 1.52)	0.67	1.05 (0.66, 1.67)	0.83
Any Prior Inpatient	1.57 (0.99, 2.48)	0.05	1.37 (0.94, 2.01)	0.11
Stay				
Any Prior ED *Visit	0.99 (0.65, 1.54)	0.99	1.83 (1.28, 2.62)	0.001
Log (Outpatient Visits)	1.27 (0.91, 1.77)	0.17	0.98 (0.75, 1.27)	0.85
<b>Goal Setting Level</b>				
Goals Started	0.27 (0.09, 0.87)	0.03	0.59 (0.31, 1.15)	0.12
Goals Completion	1.49 (0.84, 2.66)	0.17	0.87 (0.51, 1.49)	0.62
No Goals Discussion (reference)	1.00		1.00	
Co-morbidities				
Depression	1.19 (0.62, 2.28)	0.59	1.17 (0.70, 1.93)	0.55
Diabetes	1.32 (0.81, 2.15)	0.27	1.09 (0.75, 1.58)	0.66
Coronary Artery	1.54 (0.98, 2.44)	0.06	1.29 (0.89, 1.87)	0.55
Disease				
Chronic Obstructive	1.02 (0.67, 1.55)	0.92	1.01 (0.70, 1.44)	0.97
Pulmonary Disease				
Congestive Heart	1.37 (0.88, 2.15)	0.17	1.20 (0.82, 1.76)	0.36
Failure				
Stroke	1.50 (0.97, 2.32)	0.07	0.87 (0.59, 1.27)	0.47
Cancer	1.28 (0.83, 1.95)	0.26	0.77 (0.53, 1.13)	0.18
Dementia	1.06 (0.61, 1.83)	0.84	1.28 (0.83, 1.98)	0.26

<sup>\*</sup> ED=Emergency Department

 $<sup>^{\</sup>dagger}$ HR=Hazards Ratio

 $<sup>^{\</sup>cancel{t}}$ 95% CI=95% confidence interval