

Go Wish: A Tool for End-of-Life Care Conversations

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ABSTRACT

The Go Wish card game is an advance care planning tool developed by Coda Alliance to help people have conversations about end-of-life care. Initially, this tool was designed as an easy, entertaining exercise for low-functioning assisted-living facility residents, their family members, and their CNA/nursing assistants (many of whom have limited English language skills.) Use of the tool can be proctored by staff or even a caregiver after minimal instruction. It turns out to be a widely applicable and inexpensive tool to help people discuss end-of-life care. The cards focus the conversations, provide important vocabulary to give voice to patients' needs and concerns, and offer a means for sharing those ideas. The Go Wish tool has developed into professionally designed and printed cards that are boxed as a game set. This paper describes the development of the Go Wish cards and reports on some of the diverse cases in which they have been useful.

BACKGROUND AND NEEDS

IN THE YEARS AFTER THE PASSAGE of the 1990 Patient Self-Determination Act (PSDA),¹ institutions have mostly focused on compliance by providing some assistance with advance directives. Although the legal and regulatory aspects of advance directives have evolved little, the field of advance care planning has evolved, driven in part by the failure of a document-focused model to yield substantive changes in the quality of care at the end of life.² Proponents of advance care planning are shifting focus from a legal, document-driven effort to one that seeks to engage patients, families, and surrogates in conversations about hopes, wishes, values, and goals of care.³⁻⁵

The Bill Moyers series *On Our Own Terms*⁶ gave impetus to some grass-roots efforts in communities to promote conversations about advance care planning. One such community organization is Coda* Alliance, the Silicon Valley (Santa Clara

County, California) coalition for end-of-life care. Founded as a not-for-profit organization in 2000, Coda's goal is to promote a culture shift in how our community thinks about end-of-life care, aiming to have the public talk about palliative care and hospice like they talk about financial planning or car insurance. Coda promotes conversations before the crisis arises, helping people discuss, "What's important to me?"

Coda Alliance started with promoting advance health care directives, modeled on the La Crosse community outreach project,⁷ training both professionals and interested volunteers in facilitating advance care planning conversations. Over a period of 4 years Coda Alliance conducted more than twenty 2-day community trainings. These trainings, which included lectures, videos, small group exercises roles plays and feedback, were expensive both in time invested and training materials, and were subsidized by a series of grants. In follow-up, many of the trainees had neither the

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*A coda is a final passage in a piece of music, summing up preceding themes and bringing the piece to a harmonious conclusion.

time nor felt the confidence to volunteer to speak to subsequent pairs or groups of individuals who wanted to learn more about advance directives.

Coda Alliance also trained physicians in the basics of end-of-life care using the EPEC curriculum.⁸ Many physicians reported frequent encounters with health care proxies who, faced with the tragic and sudden critical illness of their loved one, were paralyzed as to how to make decisions other than, "Don't let him/her die!"

In 2004, Coda Alliance embarked on a project to promote better understanding of end-of-life care and more advance care planning discussions between community members in assisted living facilities and their prospective health care proxies. Assisted living facilities were chosen as the setting because they are "upstream" from the hospital in the continuum of care and an appropriate place to begin these discussions. This is a population where cognition and language issues are often challenging. There was a need for a simple, easy to use tool that would promote discovery and discussion of the patient's most important values and goals. The tool had to be inexpensive and require only minimal training to use. In response to these needs, Coda Alliance developed the Go Wish cards.

TOOL DEVELOPMENT

Population-based research reveals a number of commonly cited statements about what is important when life is short, and provides a list of potential topics that can be used in a values history.⁹ However, asking the prospective patient to rank values on a Likert scale tends to show all of them as important. Even forced-choice priority ranking fails to promote discussion of what the patient is thinking about when he or she chooses a statement as being important.

Coda was also searching for a tool that would be easy to use with community members who have limited language skills. Many of the assisted living residents had impaired vision, hearing, and/or memory. Many of the facility aides and nursing assistants spoke English as a second language with limited fluency.

With these factors in mind, Coda developed a prototype card game that had a single value or goal written on each of 39 cards, plus one wild card to keep the options open-ended. At educational sessions for the residents, family members,

and staff, in addition to using lectures, discussions, and handouts, the Go Wish cards were used in a structured exercise. The cards were introduced as some examples of what people might say would be important to them if they were seriously ill or nearing the end of their life. Participants were asked to sort the cards into three piles: one pile of what they felt would be very important to them, a second pile for what was "important," and a third pile of those items that were "not important to me." There was initially no requirement about the number of cards in any of the piles. The second step in the exercise was to choose the top 10 in the "very important" pile. After they had successfully struggled with that step, they were asked to rank the top 10 choices, and then record their choices on a grid sheet.

In initial trials, Coda found that the task of recording their choices on the form was confusing and burdensome to many residents. Another drawback of the recording task was that it became the focus of the exercise, detracting from opportunities for discussions. Some of the cognitively impaired patients were so stressed out by the task of finding each of the top 10 items on the list that they refused to play card games at the assisted living facility for weeks afterward. Subsequently, the recording grid was used only if a facilitator or family member was present to assist, or if the person doing the sort requested to keep a record of all their choices. The residents and their family members seemed to get much more out of the exercise by talking about why the most important things were important and why the unimportant things had been chosen for the discard pile.

For the participants who had difficulty reading the cards, the exercise could be completed much more successfully and with less stress to the resident if there was a family member or volunteer who could read each card to the participant and ask their opinion about the simple statement they had just heard. Even participants with poor short-term memory seemed eager to hear the options and express their opinions, and their facilitator was able to keep track of the sorting.

In initial trials of the Go Wish cards, some options were consistently chosen as being of little importance, and others were deemed to be process steps rather than goals, so these items were discarded or revised. The prototype cards, printed on business card stock, were difficult for

arthritic hands to manipulate. When several people played the game together at a table, cards frequently fell on the floor or got mixed up from one pack to another.

The final design of the cards incorporated lessons learned during the assisted living facility trials, as well as from other tryouts of the cards with community groups and in training conferences with health care professionals. With the advice of a communication consultant, the wording on the cards was revised to be consistent in tone, predominantly stated in a positive voice, and simplified in reading level. The text was put onto large, easy-to-read layout. A graphic designer created an attractive colorful back for the cards. To make it easy to sort the cards back into their original packs, sets were made available in four different colors. The packaging box was designed to further the image of this tool as a “card game” (Figs. 1 and 2). The list of goals and values on the cards, the game instructions, and information for ordering the cards are available on the Coda Alliance website: www.codaalliance.org.

CASE EXAMPLES

The following are examples of cases in which the card game has been useful, sometimes as expected, sometimes in unexpected ways. Rather than the often blank response to the question,

“What is most important to you?”¹⁰ the cards provide important vocabulary to give voice to patients’ needs and concerns, and give opportunity to explain and personalize those ideas. In the acute care setting, the Go Wish cards exercise can impact care planning, expose quality-of-life issues, and identify activities that are amenable to intervention.

The ICU intubated patient

The palliative care physician was asked by the intensive care unit (ICU) attending physician whether she might begin some discussions of end-of-life issues with a 46-year-old man in the unit who had been on a ventilator for 6 weeks after multiple traumas in an automobile accident. He had a T6 spinal cord injury, multiple fractures, bilateral chest tubes, bullous emphysema, and recurrent pneumonias. The ICU attending doubted that the patient could ever survive off the ventilator, and doubted that he would leave the hospital alive. Nonetheless the patient was usually alert enough to communicate by nods or mouthing words, although he could not write.

The palliative care physician met with the patient and his wife, explaining that in the last couple of months there had been a lot of attention paid to his lungs, bones, kidneys, digestion, infections, and skin, but that she was hoping to help them take inventory on “the rest of what makes him who he is.” She showed them the pack of Go



FIG. 1. Go Wish game box.



FIG. 2. Go Wish game box contents.

Wish cards and asked the wife to show him each card and help him do the three-category sort.

The palliative care physician came back the next day and found that in the “not important” pile were all the cards that had any mention of death. But there were plenty of cards in the “very important” pile, and the couple was asked to sort through the “very important” cards again for him to pick out the top 10. Later that day they worked on ranking the top 10.

Both the patient and his wife commented that the exercise had brought forth conversations that they had needed to have, but not gotten around to before that. His “wild-card” was to help his teenage son to cope; the patient noted that his son had been left out of a lot of the prior discussions about what had been going on.

The results of his card-sort were used to identify issues that were amenable to physician or other health care provider intervention and other issues that were important to quality of life more generally. Within the top five were “to be free from pain,” “not being short of breath,” and “to be free from anxiety.” The patient’s priority for improved symptom control was communicated back to the ICU attending. The social worker was asked to arrange a family meeting that would in-

clude the son. Because preparing for death was clearly not the patient’s chosen agenda, that topic was dropped, and in fact he was later successfully weaned from the ventilator and sent to a rehabilitation inpatient program.

Sorting the family’s issues

Mrs. K had lung cancer with t-spine metastases, cord compression treated with radiation therapy, and profound hyponatremia resulting from syndrome of inappropriate antidiuretic hormone secretion (SIADH). She was delirious, with suspected meningeal carcinomatosis. The series of attending hospitalists had convened multiple family meetings, trying to address the family’s innumerable questions on details of her medical care, complications, explanations of her symptoms, medications, test results, etc. The three adult sons and husband all had different approaches to information and different emphases on issues.

Using four packs of cards, the palliative care physician asked the husband and each son to pick out from his deck the cards that he thought would be the patient’s top ten if she were doing the sorting herself. The physician then went through each

of the four groups of ten cards with the family as a group, laying out the cards and stacking the ones that got more than one "vote." This exercise allowed the group both to acknowledge the range of their interpretations of her concerns and to direct the focus toward those goals and values that a majority of the family members agreed on as being most important to the patient.

Preserving hope

Mrs. M was a 69-year-old first-generation Hispanic married woman with treatment-resistant acute myelogenous leukemia. Her experience with her illness so far was that each time she had been ill and hospitalized she had recovered and returned home. A devoutly religious Catholic, she stated, "God will heal me." The admitting physician had indicated "full code" on her admission orders.

At the request of the attending physician, the palliative care team suggested convening a family meeting with the couple and their sons, but the sons declined the meeting. The sons explained that the dynamics of the family were such that their father's role was a gender-based traditional cultural role. Their father was reluctant to bring up end-of-life issues for fear of their mother losing hope. The sons felt that their mother had been keeping a strong front as a means of protecting her family. She had a reputation with both friends and family of being a strong, capable woman. At work and in her community, others frequently turned to her for support and advice.

The palliative care social worker introduced the Go Wish cards to the patient and spouse with the suggestion that they choose some that were most important to Mrs. M, and to think about whether other important things were missing from the deck. The pack of cards was left in room for the family to use when the patient was feeling like talking. The sons later commented that they were grateful and appreciative that the cards were available to review and discuss as the patient's condition declined. The simple but direct statements on the cards made it possible for them to talk with their mother about her hopes and wishes. She still felt strongly about wanting to have family around and wanting to help others, so they arranged for many extended-family members and friends to visit. Mrs. M gave each visitor blessings and asked them to look after her husband and sons. As the family saw her condi-

tion worsening, they felt there was no "unfinished business" and requested that no resuscitation attempts be made at the time of her death.

A different side of mom

The patient was a 60-year-old female physician suffering from breast cancer with metastases to the lungs who had two children, a son, age 29, and a daughter, age 27. The hospice chaplain had convened a family meeting to discuss the patient's wishes since both of the children had been away from home and had now moved back to care for their mother. The chaplain suggested they use the Go Wish cards as a segue into the discussion.

When the patient identified the things that were most important to her, her children were amazed. Because she was a doctor and also a scientist, the children said that they thought she would be more clinical about her selections and would pick the cards having to do with the nurse and/or doctor, being mentally aware or not being in pain. They were surprised that she chose cards having to do with emotions like human touch, helping others, keeping a sense of humor, having family near and not being a burden. They said this gave them a look at the emotional side to their mother, and they then felt more comfortable being able to express their own emotions about her dying. They had been afraid to hold her hand or tell her funny stories until the meeting with the cards. It opened up a whole new discussion for them about death and dying and life in general, and at the end of the discussion they all hugged.

Comparing in pairs

One of the physicians who had piloted use of the Go Wish cards discovered at a Thanksgiving family reunion that he had been named as alternate agent for his stepmother-in-law in her durable power-of-attorney for health care document, with her own daughter being named as the primary agent. He gave a pack of cards each to the mother and daughter. He asked the mother to pick out what would be her top 10 concerns if she were near the end of life, and asked the daughter to pick from her pack the ten concerns she thought her mother might be choosing as the most important. When both of them were fin-

ished picking the top 10, they compared cards. The daughter had picked 8 of 10 of her mother's top 10. As he watched the mother and daughter in an animated discussion about the mismatching 2 cards, he felt confident that the daughter was going to be a knowledgeable surrogate for her mother.

"Aha" comes later

One son who attended an assisted living facility workshop told the facility director, months after the training, "I went to that class under duress thinking 'why do I have to come?' " He went for his mother's sake and immediately afterwards he wouldn't have said he had any "aha" experiences. Over the subsequent months his mother had become much more ill. He told the facility director, "I didn't 'get it' till months later. As we were sitting talking to Mom's doctor in his office, I remembered those cards and talking about those things with Mom. I was much better equipped . . . It never dawned on me why this was so important. I knew more what I have to do for Mom and have a whole different attitude [about the training] because of what happened in the doctor's office. That was really worthwhile, although I wouldn't have said it at the time."

The unbefriended: introducing hospice

A 75-year-old man was admitted to custodial care in a skilled nursing facility with a history of malnutrition and failure of self-care, weight loss, and anemia. Fifteen months prior he had stage 2C transmural colonic adenocarcinoma with regional lymph node involvement, and now had multiple hepatic metastases. He had a 4-year history of urinary retention, reportedly attributed to prostatic hypertrophy, but now also had a markedly elevated prostate specific antigen (PSA). He had a history of medical noncompliance with multiple failed outpatient appointments, failure to take medications on an outpatient basis, involvement of adult protective services, and a diagnosis of mild dementia following a cerebrovascular accident (CVA) 18 months ago. Despite his history, psychiatric evaluation had deemed him to have intact decision-making capacity—at least sufficient to sign himself in for the skilled nursing facility admission—and determined that he did not need court-appointed conservatorship. "Wants full code" said the prior physician's report, "Code status

discussed with patient: full life-sustaining interventions for now. He says 'life is precious.' "

In answer to the "tell me what you understand about your illness" question,¹¹ the patient was able to acknowledge that his life expectancy was in months rather than years. So the nursing facility attending physician introduced the card-sorting exercise, saying, "These are things that other people whose time might be short have said are important to them. I was wondering if any of them are really important to you, or if there are other things not on these cards that are very important to you." The patient had difficulty reading the cards for himself, but listened to each one being read aloud and indicated whether he thought it was important, so-so, or not important. For one who had distinguished himself as a loner, it came as a bit of a surprise that it was very important to him to have medical care givers who know him as a person and whom he could trust. He wanted to have an advocate who would know his wishes and who would help him sort out some financial issues.

Review of the preferences he had expressed in the Go Wish exercise revealed opportunities where hospice could help meet several of his expressed needs: He could develop a relationship with a hospice nurse that he could trust, the hospice social worker could help him with getting his financial affairs in order and also help with his funeral planning, and hospice staff would pay attention to his physical comfort. Hospice was introduced as a program that could help him meet these goals, he agreed to the referral, and his goals were incorporated into the hospice plan of care.

CONCLUSION

As used in our clinical experience to date, the Go Wish cards have been beneficial for promoting conversations between patients, their loved ones, and their medical care providers. Go Wish cards can be proctored by both professional and quasi-professional staff or even by a caregiver after minimal instruction. It is a useful, very inexpensive, and intuitive tool for furthering goals and value-oriented conversations about illness and preferences for care, for facilitating patient-proxy-provider understanding, and for identifying hopes. The conversations seem to come easily when the task is framed as, "These are some things that people have said would be important

if their remaining time was short. Which of these might be important to you?" The cards provide a wide selection of examples of concerns with which the patient can agree, disagree, or amend and interpret.

Coda's intention in developing the tool was to promote conversations in advance care planning well in advance of serious illness. However, the Go Wish cards can be useful even in situations that require care planning for the needs of those with current life-threatening severe illness and families in crisis.

Further research is underway to test the effectiveness of the Go Wish cards on patient, provider, and caregiver communication, and to evaluate satisfaction with this tool for promoting values clarification in inpatient and outpatient settings. A Chinese-language version is in development. Because of its low cost and ease of use, providers may want to be aware of this tool and employ it in ways similar to the above examples. Clinical trials will need to clarify how the tool should be most effectively deployed to prepare surrogates for their roles in goals-based medical decision-making.

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