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Development of a Community Advance Care Planning Guides Program and the RELATE Model of Communication

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Abstract

Objective: Quality communication is an important aspect of advance care planning (ACP). This study evaluates a certification program that trains lay people in communication skills to support community-based ACP conversations.

Methods: The program was developed with an emphasis on communication skills training. The testing of the program included ACP Guides and conversation partners, who were hospice volunteers, to assess the use of communication skills in ACP conversations. The evaluation used direct observations of conversations between trained ACP Guides and conversation partners as well as semi-structured interviews with those trained to become ACP Guides and those participating in the conversation.

Results: Twenty-two ACP Guides participated in the testing phase with a retention rate of 100% completing all 4 sessions. The RELATE model of communication emerged during program development and testing. Evaluation of 15 ACP Guides having ACP conversations found that trained ACP Guides could use the RELATE model of communication to support ACP conversations.

Conclusion: A community–academic partnership developed an ACP Community Guides Program that trained individuals to have community-based ACP conversations. Next steps include additional testing of the program and RELATE in small numbers, especially among minority populations, to evaluate acceptability and usability of this approach.

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Declaration of Conflicting Interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: The Colorado Multiple Institutional Review Board approved this study.

Practice Implications: Laypersons with concrete communication skills can facilitate effective peer-to-peer ACP conversations.

Keywords

community engagement; advance care planning; communication; health education; culture; volunteers

Introduction

Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.¹ The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness.² Ninety percent of US adults say that talking with their loved ones about end-of-life care is important, yet only 27% have actually talked with a loved one and even fewer (9%) have talked with their doctor.³ A recent systematic review summarized evidence for ACP benefits, such as improved end-of-life communication, documentation of care preferences, dying in preferred place, and health-care savings.⁴ However, barriers to ACP conversations include family, societal, and cultural barriers to talking about illness and death.^{5,6} This evidence supports the need for individuals to cultivate opportunities for initiating ACP conversations in their communities to increase the quality of conversations about future medical care planning.

To increase ACP conversations, some national recommendations suggest raising public awareness of ACP.^{7,8} One strategy to increase community engagement and promote ACP is through nonmedical laypersons such as volunteers, community health navigators, or peer educators.^{9,10} Trained laypersons can support ACP among general older adult populations and disease-specific populations,^{9,11} although a qualitative meta-synthesis found that no programs focused on layperson communication skills training.¹¹

Using key principles of community-based participatory research,^{12–14} relationship-centered approaches to communication,^{15–18} expertise in community-based ACP using laypersons,¹¹ and a long-standing community-academic partnership, the program objectives were to develop, test, and evaluate an ACP Community Guides Program that rigorously trains individuals to initiate ACP conversations within their own communities. Recognizing the need to improve both the quality and the quantity of ACP, this study aimed to develop, test, and evaluate an ACP Community Guides Program that trains individuals to engage in relationship-centered ACP conversations.

Methods

Advance Care Planning Community Guides Program

Leading up to the program, the partnership identified the need for early ACP conversations, the availability and opportunity of lay individuals to play a role in these conversations, and expertise in communication theory that could serve as an innovative foundation for the program. We developed the ACP Community Guides Program using 3 phases: program

development, testing, and evaluation. We leveraged expertise in communication theory and relationship-based models of communication, volunteer training, and strategies for connecting ACP conversations to the health-care system (eg, documentation).

Program Development Phase

The ACP Community Guides Program was created by a multidisciplinary team of community members (ie, a chaplain, nurse, volunteer coordinator) and academic members (ie, a geriatrician, a palliative care physician, and a social scientist). This generated expertise in ACP, communication, health literacy, decision-making (academic members), volunteer infrastructure, community needs, content expertise, recruitment, and retention (community members). Together, we iteratively developed the curriculum by combining relationship-based theories of communication, knowledge of ACP, expertise in volunteer infrastructure, strategies for linking ACP documents to the health-care system, a sensitivity to inclusion and difference, and an attitude of humility and curiosity around culture (see Figure 1). The ACP Community Guides Program includes a 16-hour training curriculum over 4 sessions in 5 weeks; 3 real-world conversations with peers that ACP Guides identified on their own between session 3 and 4; 3 quizzes and a final assessment. Table 1 provides an overview of the 4 sessions, core topics, and teaching exercises; the curriculum shown in Table 1 reflects the version that emerged by the end of the testing phase. As part of earning certification, ACP Guides demonstrated competency in ACP conversations, knowledge of ACP forms, and strategies for linking ACP to the health-care system. The curriculum was facilitated by an ACP Program Coordinator (previous hospice volunteer) during the testing phase. The roles of ACP Program Coordinator included: community outreach, ACP Guides training, and ongoing support. The Denver Hospice included the Program on their website and led the development of recruitment materials.

Testing Phase

The test phase occurred over a 6-month period in 2017. The ACP Program Coordinator developed a recruitment process and recruited participants through building community relationships with other community service organizations and the existing hospice volunteer program. The Coordinator recruited participants (referred to as ACP Guides) from 2 cohorts of up to 15 participants each. The multidisciplinary team met regularly to debrief the cohorts for the purpose of refining and formalizing the program.

Using relationship-centered theories of communication,^{15–18} we learned after the first cohort that participants wanted a model of communication they could connect with and find accessible. The team brainstormed potential mnemonics or names that accurately formalized the communication skills that the team and participants felt were most impactful: using communication to build relationships with others in order to have brave conversations. When we considered the word “relationship” after talking about the importance of starting with establishing rapport at the outset of these conversations, “RELATE” emerged. At that point, the team formalized the components of the RELATE model of communication, which was integrated into the curriculum.

The RELATE model of communication is a process of interaction—an ideal interaction—to encourage connection, understanding, and space to be heard and understood before decision-making (Figure 2). It is designed for peer-to-peer community-based interactions. It focuses on creating a communication process that promotes quality interactions to help people have quality conversations around difficult topics like ACP while increasing the likelihood of positive future interactions. The model includes 6 elements (Table 2), incorporating concrete skills that can be adapted to the content of the conversation. The RELATE provides ACP Guides with a new vocabulary and way of thinking about talking about ACP.

Evaluation Phase

The evaluation phase was designed as a qualitative study to understand the quality of communication between trained ACP Guides and a conversation partner that they had ACP conversations with. The conversation partners were also recruited by the ACP Program Coordinator. Conversation partners were recruited from existing Denver Hospice volunteers and were not otherwise involved in the ACP Community Guides Program. The conversation partners had a range of experience with hospice volunteering, including some individuals who were just beginning to volunteer in an end-of-life setting. The evaluation includes non-participant observations by the first author of conversations between trained ACP Guides and the conversation partners talking about ACP from November 2017 to January 2018, and semi-structured interviews. We chose not to observe the 3 real-world conversations that each ACP Guide had as part of the training (between session 3 and session 4) due to the potential added burden of consenting and observing these conversations.

Data Collection

Advance care planning conversations were observed, and field notes were taken to capture contextual information before, during, and after the interaction. Field notes included specific behaviors, activities, and emotions displayed and provided another layer of meaning to what was said. Advance care planning conversations were followed by individual interviews with the ACP Guide and conversation partners. An interview guide was used to provide structure and consistency but was flexible insofar as it did not limit what participants could discuss. Questions were designed to evaluate and understand ACP guides level of confidence and comfort with the curriculum in general and with RELATE in particular. The purpose of the conversation partner interview was to capture expectations for the conversation, overall feelings after talking with a lay guide about their own ACP, and evaluation of the quality of communication using RELATE. The ACP Guide and conversation partner provided permission before starting the observation and interview. There were no instances that either the ACP Guide or the conversation partner declined the presence of the first author or the interview. The observed ACP conversations lasted between 15 and 30 minutes.

Participants agreeing to be interviewed provided standard written informed consent. Interviews were conducted separately at The Denver Hospice. The first interview occurred with the conversation partner, and the second interview was with the ACP Guide. The resulting data set included 20 hours of direct observation and in-depth interviews with 15 ACP Guides and 15 conversation partners. Participation was completely voluntary without compensation and framed as an opportunity to talk about ACP.

Data Analysis

All interviews were audio-recorded and transcribed verbatim. Transcribed interviews and field notes were thematically coded and analyzed using critical discourse analysis in an inductive, data-driven approach.^{19–21} As much as possible, codes were developed for actions and meanings, rather than topics and themes, a move that allows processes that otherwise might remain invisible to appear.

Results

Lay individuals who became guides ranged in age from 36 to 73 years of age and were from a variety of backgrounds: Latina/Latino, LGBTQ, Cameroon, married, widowed, religious and nonreligious, retired, and former health professionals. All but 2 were female. Observations and interviews occurred only with ACP Guides who participated in the program when the RELATE model had been developed and integrated into the curriculum. The majority of conversation partners came from hospice volunteer backgrounds and had not met the ACP guides prior to meeting with them. Based on our codes, we identified 4 themes related to communication quality between ACP Guides and conversation partners, including:

1. components of successful community-based ACP conversations,
2. challenges of peer-to-peer ACP conversations,
3. importance of communication in community-based ACP conversations, and
4. training led ACP Guides to become advocates.

Illustrative quotations from the 2 voices in this study, the ACP Guide and the conversation partner, are provided for each theme.

Theme 1: Components of Successful Community-Based ACP Conversations

Feeling heard, understood, comfortable, and motivated during and after talking with ACP Guides were key components participants discussed. Ensuring expectations are clear at the outset of the conversation were important to participants talking about ACP in the community. For instance, one ACP Guide said: “I wanted her to feel relaxed in that I wasn’t trying to pressure her, and I think I succeeded in doing that.” Additionally, meeting the conversation partner where they are in their own ACP was important as one conversation partner said,

One of the things that I haven’t gotten that far with, even though I wanted to, is talking with my family. That’s why I wanted to come today because I figured I could ask some questions and get some tips and the material is just what I need.

Similarly, another conversation partner expressed the importance of having the ACP Guide listen in a way that they felt heard:

I felt I was heard because she didn’t like force going through this stuff with me. Like when I saw the Five Wishes. I’m like, oh, she’s going to go through that with me (laughing) ... I’m not going to sit here, you know. But she obviously heard me

and she gave me the opportunity to ask questions about it and I came back to well, let me make sure that I have the documents. She made me feel comfortable.

For ACP Guides, many expressed they felt that the conversation went well when the conversation partner felt motivated or empowered to do something as a result of the conversation. One ACP Guide said, “I think she had ‘aha’ moments where it was like ‘oh, I’ve got some gaps here and I probably should get them done.’” Additionally, another ACP Guide said, “I felt real positive that, you know, there were things that she wanted and committed to doing that would be helpful for her.”

Theme 2: Challenges of Peer-to-Peer ACP Conversations

Participants expressed some challenges to conducting and having conversations around ACP. One ACP Guide expressed the challenge of establishing rapport: “The challenge was ... for me it was hard to know, have I built rapport enough to ask kind of an intimate question about what are your plans for if you were to get sick.” Establishing rapport was also expressed by another ACP guide,

It’s kind of like this is a stranger and you’re talking about stuff that she hasn’t even really talked with her partner about. So it was sort of like, ‘have I built enough rapport, does it feel like a warm, comfortable place for me to say something?’ She was giving me great non-verbal, you know, obviously she had thought about it before she got here. It wasn’t a surprise so I think if she had been a little more resistant I would have tried to build ... maybe disclosed a little of my own story or what I do in my work or ... some way to help her understand that kind of we’re in this together.

One conversation partner discussed the importance of starting with some rapport saying, “We just ... we started into the forms instead of saying well, you know, this is our goal or this is what we do and, you know, just having a little preface of that would be good.”

Similarly, another conversation partner shared:

I might have liked to do the rapport session a little longer but you never quite know because they are very task-oriented people of which I am one ... so I never quite ... so learning to make that shift from the rapport to the explorer stage I think is big.

Theme 3: Importance of Communication in Community-Based ACP Conversations

Developing concrete communication skills to facilitate ACP conversations in the community was important to participants. One conversation partner said:

I would say she listened at an excellent level because she picked up on the fact that I had to formally take my living will to the doctor, make sure it was put in my records. I think she picked up on that in a very big way ... to be able to make ... to inform people that that could happen that they might ask you if you have one but what good is it if they don’t actually have it?

Another conversation partner shared how she felt heard:

She is compassionate. She was personal and straightforward. She related to my situation and picked up on that and I think she had to change her questions a little bit because of it but she managed to do that and picked up on a couple of things of my experience that she felt was important.

Listening was central for another conversation partner who said:

I felt like she definitely listened to me. As I said, you know, she was thoughtful in listening to what I had to say, you know, from a listening perspective. I could tell definitely that she was listening. She wasn't just trying to present the information but she was actually feeling into what I was saying.

The way the conversation started was also important for the quality of the conversation:

I mean she started by asking if I was familiar with these documents which was a nice starting point. I think I may have made it easy for her in a sense that I just offered things up that oh, I have this document, I have this, I have this but, you know, I think she explored without being nosy.

For the ACP Guides, RELATE provided a framework for communicating. One ACP Guide shared:

This skill was from the training class. I appreciated that [RELATE] was actually given as a way that you're asking permission. You're saying is it OK if we go through these things instead of being pushy, like here's what I want you to do. I felt like using that as a technique really helped her not feel pressured. She was probably feeling it but she didn't say that to me and by just asking her instead of telling her, I feel like that got her on board too ... just everything that we've learned as far as how to have that conversation is helpful.

Another ACP Guide elaborated on the communication training saying:

I think the "r" (rapport), the "e" (explore) and the "l" (listen) really do belong first though because ... the "a" (adapt), and the "t" (tailor) and the "e" (empower) are based on information that you get. I didn't feel like it was hard to pry out of them once you've built rapport and been able to explore then get to listen.

Theme 4: Training Led ACP Guides to Become Advocates

Feeling confident about communication skills and knowledgeable about ACP was important to ACP Guides before they met with individual conversation partners. One ACP Guide shared, "So I had more confidence talking about it because of what we've done in our training class; I think more so than just being handed the Five Wishes and telling us, go out and do it." Another ACP Guide described the importance of empowering the conversation partner saying:

I feel good about it. I feel like she will actually do the things that she said she will do, you know, whereas sometimes when you're interacting with people, you never really know if they're in agreement or they're on board. I felt like she was engaged. I felt comfortable using the RELATE model like it was good sort of making sure

I've covered all the bases and it was nice having had the comfort level with the Five Wishes and Your Right to Make Health Care Decisions" (Two advance directives).

The ACP Guides' training, in turn, allowed the conversation partners they spoke with to feel empowered. One conversation partner expressed:

I feel pretty motivated. I'm not sure how much of that is me or how much of that is her. But I'm pretty motivated to take a look at it and review it and I have a legal background too.

Additionally, the ACP Guide conversations with conversation partners prompted further conversations and actions, such as, "I'm going to talk to my parents to do this. So it's information that I learned from her that I could pass along."

Conversation partners had clear steps after talking with the ACP Guides as expressed by another conversation partner who said:

I'm thinking in my mind like where are the papers and do the right people have them and if I don't know where they are, who is going to know where they are? So, like, have we given them to the right people or ... or are they in the right place so that people know where to find them and stuff like that. We need to work on that.

Discussion

This study describes the development of the ACP Community Guides program, the emergence of the RELATE model of communication for community-based ACP conversations, components of successful community-based ACP interactions, and use of peer-to-peer conversations for motivating action. Establishing rapport, listening to the other person, and empowering individuals were 3 skills that ACP Guides described as important for their conversations. Although RELATE is designed as an ideal interaction, individuals are trained to use different components at different times depending on the context and circumstances, establishing rapport was fundamental to a quality interaction, and listening to understand and learn (as opposed to listening to respond) was fundamental.

Analysis of the ACP Guides' conversations demonstrated that individuals needed to feel connected, heard, understood, and motivated by the ACP Guide to engage with ACP. It was clear that the conversation partner could not move toward action without trusting the ACP Guide. Some individuals couldn't hear about next steps related to ACP if they felt that the ACP Guide didn't understand where they were coming from, and their own unique circumstances that might influence how they think and act with respect to ACP. For some individuals, talking about advance directives was irrelevant if they didn't have a degree of rapport with the ACP Guide.

Drawing from communication theory, our goal has been to give individuals a new vocabulary to talk about ACP in a way that seeks learning and understanding. An individual who is skilled in informing, showing respect, and supporting patient involvement in communication and decision-making can transcend issues of race, sex, and ageism to establish a connection with the patient who contributes to greater patient satisfaction, trust,

and commitment to care planning.^{22,23} These are long-term outcomes for the ACP Community Guides Program and warrant further research.

The limitations of this investigation around the program are that it includes a small set of individuals during the testing, involved conversation partners who were existing hospice volunteers, and is located in 1 geographic location in the United States. Additionally, while the program emphasized equipping ACP Guides with strategies to help conversation partners connect the ACP process with their usual source of health care, we were not able to assess whether this occurred. Additionally, for pragmatic reasons, we were not able to evaluate the real-world ACP conversations that ACP Guides initiated as part of the training program. Future study should evaluate the quality of ACP conversations by ACP Guides after the program.

Conclusion

While several ACP-related programs exist for increasing the quantity of conversations and completion of advance directives, the ACP Community Guides Program is unique because it seeks to provide concrete communication skills—a new vocabulary—to train ACP Guides to initiate and facilitate peer-to-peer conversations in the community around ACP. The next steps for the ACP Community Guides Program include outreach to more rural and minority populations, like LGBTQ communities. Furthermore, future program success will need to evaluate in real-world scenarios and in small numbers about guides about acceptability and usefulness and usability of this approach outcomes and identify additional opportunities for overall scalability and sustainability.

Practice Implications

Trained volunteers may be able to increase the quality and quantity of ACP discussions and documentation of their wishes thereby decreasing the burden placed on health-care providers and increasing the link between the community and the health-care system.

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Figure 1.
Phases of curriculum development.

Figure 2.
RELATE model of communication.

Table 1.

Advance Care Planning Community Guides Program Curriculum.

Session	Topics	Teaching Exercises
One	<ul style="list-style-type: none"> • Introduction to ACP • Confidentiality and Code of Conduct for Program • Active and Reflective Listening • RELATE Model of Communication Overview 	<ul style="list-style-type: none"> • Debunking Assumptions Video • Communication Inventory and Reflection of individual communication styles and biases • Session 2 Preparation Work • Quiz
Two	<ul style="list-style-type: none"> • Introduction to ACP Documents • Advance Directives Legalities • Responsibilities of a Medical Durable Power of Attorney <p>If available—Q&A with a clinician about ACP</p>	<ul style="list-style-type: none"> • Meaningful Conversations Video • Session 3 Preparation Work • Quiz
Three	<ul style="list-style-type: none"> • Advanced Communication Skills using RELATE • Diversity, Inclusivity and Cultural Sensitivity 	<ul style="list-style-type: none"> • Death and Dying TED Talk • RELATE Demonstration Video and Role-play • Cultural Sensitivity Video • Session 4 Preparation Work including plan for 3 real-work conversations • Quiz
Four	<ul style="list-style-type: none"> • Connecting Back to the Health-care System • Identification of Personal Communities • Summary and Wrap-Up 	<ul style="list-style-type: none"> • ACP Conversations Debrief • Connecting to the Healthcare System Video • Final Exam • Receipt of Program Certificates

Abbreviation: ACP, advance care planning.

Table 2.

RELATE Elements, Description, and Skills.

Element	Description	Skill(s)
Rapport	<ul style="list-style-type: none"> • Be curious about the other person and inquire about well-being—resist labels, assumptions and interpretations. • Share something about self to establish common ground and build trust. 	<ul style="list-style-type: none"> • Greet appropriately. • Identify hope/wish for interaction. • Adapt verbal/nonverbal behavior to match circumstances.
Explore	<ul style="list-style-type: none"> • Explore the other person's circumstances to understand their story: what are they for (purposes), what are they against (concerns) and what are the facts of their life (circumstances). • Explore what the other knows, has seen/read/heard. 	<ul style="list-style-type: none"> • Open ended and closed ended inquiry. • Assess understanding and knowledge around condition, situation and circumstances.
Listen	<ul style="list-style-type: none"> • Listen to understand their goals rather than listen to respond. • Confirm that you are hearing them in the way that is intended. 	<ul style="list-style-type: none"> • Reflective and active listening. • Use summaries and signposts to help maintain structure and relationship; balance talk time.
Adapt	<ul style="list-style-type: none"> • Adapt to the style in which the other individual is using—pay attention to tone, pitch, rate, and nonverbals. • Ask clarifying questions to determine what type of information the other person might be seeking and what might be tangible next steps. Ask permission to share information. 	<ul style="list-style-type: none"> • Adapt communication style, approach and amount of information to meet the other person where they are. • Reflective and active listening, respect and adapt nonverbally.
Tailor	<ul style="list-style-type: none"> • Share information tailored to the other person's needs and capacities to identify appropriate action based on what you have heard and learned about their unique circumstances • Encourage other person's participation and planning around next steps. 	<ul style="list-style-type: none"> • Ask questions to confirm understanding and share information in easy-to-understand portions. • Use teach-back method to establish information recall.
Empower	<ul style="list-style-type: none"> • Resummarize main ideas and commitments from the interaction as a bridge for future interactions. • Empower other person by partnering around next steps. 	<ul style="list-style-type: none"> • Check for final questions or concerns and organize supportive resources. • Establish time and place for next interaction, and provide summary of interaction for them to share with significant others.