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Authors

Bekelman, David B
Johnson-Koenke, Rachel
Ahluwalia, Sangeeta C
[et al.](#)

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Development and Feasibility of a Structured Goals of Care Communication Guide

David B. Bekelman, MD, MPH,^{1,2} Rachel Johnson-Koenke, LCSW,¹ Sangeeta C. Ahluwalia, PhD, MPH,^{3,4} Anne M. Walling, MD, PhD,^{3,5,6} Jamie Peterson, RN, MPH,¹ and Rebecca L. Sudore, MD^{7,8}

Abstract

Background: Discussing goals of care and advance care planning is beneficial, yet how to best integrate goals of care communication into clinical care remains unclear.

Objective: To develop and determine the feasibility of a structured goals of care communication guide for nurses and social workers.

Design/Setting/Subjects: Developmental study with providers in an academic and Veterans Affairs (VA) health system ($n=42$) and subsequent pilot testing with patients with chronic obstructive pulmonary disease or heart failure ($n=15$) and informal caregivers ($n=4$) in a VA health system. During pilot testing, the communication guide was administered, followed by semistructured, open-ended questions about the content and process of communication. Changes to the guide were made iteratively, and subsequent piloting occurred until no additional changes emerged.

Measurements: Provider and patient feedback to the communication guide.

Results: Iterative input resulted in the goals of care communication guide. The guide included questions to elicit patient understanding of and attitudes toward the future of illness, clarify values and goals, identify end-of-life preferences, and agree on a follow-up plan. Revisions to guide content and phrasing continued during development and pilot testing. In pilot testing, patients validated the importance of the topic; none said the goals of care discussion should not be conducted. Patients and informal caregivers liked the final guide length (~30 minutes), felt it flowed well, and was clear.

Conclusions: In this developmental and pilot study, a structured goals of care communication guide was iteratively designed, implemented by nurses and social workers, and was feasible based on administration time and acceptability by patients and providers.

Keywords: advance care planning; goals of care; provider patient communication

Introduction

STUDIES DEMONSTRATE the benefits of discussing goals of care and advance care planning, yet many patients with serious illness do not engage in such discussions with healthcare providers.¹⁻⁵ The Institute of Medicine reported that advance care planning is “critically important to ensure that patients’ goals and needs are met.”⁶ A recent review by

the American College of Physicians High Value Task Force defined goals of care communication to include advance care planning, goals of care, and end-of-life discussions.⁷ The review concluded that communication about goals of care in those with serious illness should be systematically integrated into clinical care structures and processes.

There are a number of patients, providers, and system barriers to integrate goals of care communication into

¹Veterans Affairs Eastern Colorado Health Care System, Denver, Colorado.

²Department of Medicine, University of Colorado School of Medicine, Anschutz Medical Campus, Aurora, Colorado.

³RAND Corporation, Santa Monica, California.

⁴Department of Health Policy and Management, UCLA Fielding School of Public Health, Los Angeles, California.

⁵Veterans Affairs Greater Los Angeles Healthcare System, Los Angeles, California.

⁶Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine at University of California at Los Angeles, Los Angeles, California.

⁷Division of Geriatrics, Department of Medicine, University of California, San Francisco, San Francisco, California.

⁸San Francisco Veterans Affairs Medical Center, San Francisco, California.

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TABLE 1. MAJOR SUBSTANTIVE CHANGES MADE TO THE GOALS OF CARE COMMUNICATION GUIDE DURING PILOT TESTING

Section or question	Purpose of section or question	Original phrasing	Problem	Solution	Final phrasing
Introduction	Introduce the conversation	“Today we would like to spend some time talking about your future goals related to your medical care.”	Patients were unclear about the goal of the conversation.	Clarified the purpose of the conversation. Put in wording about next steps, including formalizing the plan with a written document.	“Today we want to do two things: First, we want to talk about your values and goals related to your health care if you were to become sicker or at the end of your life. Next, we want to come up with a [written?] plan to help to make those things happen.”
1	Elicit patient’s understanding of the future of their illness (i.e., prognosis, trajectory)	“What has your doctor told you about your illness? Based on what your doctor has told you, what is your understanding of where you are with your illness?”	Patients told the story of their illness and reported disease knowledge instead of talking about what to expect in the future.	Changed wording to ask about the future of illness.	“What have you been told to expect in the future with your [insert their words for their lung/heart] illness?”
2	Clarify values and goals	“What is most important to you?”	Patients responded with general things they cared about (e.g., pets)	Reworded the question and added probes.	“If you were to get sicker, what would be most important to you?”
3	Identify positive and negative perceptions and feelings about the future	“What are you most looking forward to?” “What are your biggest fears and worries?”	Patients found the “positives” question confusing and “biggest fears” unclear.	Removed the question about the positives; reworded question about negatives	“As you think about the future with your health, what are you most worried about?”
4	Identify end-of-life preferences to inform medical (portable) orders for life-sustaining treatment (MOST/POLST)	“All of us at some point will reach the end of our lives. For many people it can be helpful to think about what is important at that time. Certain things are important to some people and not as much to others. When you look ahead, what would be important to you?”	Patients responded with vague or not actionable wishes.	Reworded the question using alternative choices to illustrate specific end-of-life preferences.	“All of us at some point will reach the end of our lives, and different people want different things at that time. Some people are at one end of the scale where they want to focus on comfort and quality of life, and are willing to have their lives be shorter to be more comfortable.” Other people are on the other end of the scale where they want to live longer no matter what treatments or procedures or machines they would need. When you think about the scale, where are you? What would that include?
5	Motivate patients to complete written documents and speak with family and providers about values and goals	“How much do your family, loved ones, and doctors know about your priorities and wishes?”	Took too long to develop a follow-up plan; patients did not clearly understand the connection between values/goals and legal documents; legal documents did not always provide adequate structure to document values.	Reworded question to emphasize the importance of completing documents that articulate goals and preferences; added language to guide patients to commit to a plan for achieving goals and preferences.	“Now we are going to move onto the second part. I know you said [insert patient’s answers] is important to you. We would like to make a plan so we can help make sure your wishes are followed.”
6	Agree on a follow-up plan	“What should the next steps be?”	There was not enough structure to the follow-up plan.	Developed a take-home form for patients on which to write values and goals; put the contents of the form in a note in the electronic health record.	“We want to make sure we heard you correctly so I’m going to summarize our plan and we will put it on this form together. You can take the form with you and share it with the people you talked about.”

MOLST, medical orders for scope of treatment; POLST, physician orders for life-sustaining treatment.

clinical care.⁸⁻¹⁴ To address some of these barriers, specifically patient difficulty in identifying values and lack of physician time, we built on others' work^{7,15-19} to develop a structured goals of care communication guide for nurses and social workers. Such a guide could be used by a range of healthcare providers to help patients to identify their healthcare values, enhance illness understanding, and increase patient readiness to engage in other advance care planning steps with their physicians, such as having prognosis discussions and documenting their wishes in legal documents. Here we describe the

development and pilot testing of a structured goals of care communication guide.

Methods

Development

The communication guide was developed to facilitate goals of care communication among patients, families, and healthcare providers in the outpatient or home setting. The following objectives shaped the development of the communication guide: (1) be within the scope of

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Today we want to do two things: First, we want to talk about your values and goals related to your health care if you were to become sicker or at the end of your life. Next, we want to come up with a plan to help to make those things happen.

[If any resistance]: As health care providers we have seen people at the end of their life not getting what they wanted because they had not had conversations with their family and doctor(s) about what they wanted, and they didn't have it written down. We know these conversations are hard, and you might not know all the answers today but we at least want to start the conversation. Ideally, by the end of the time we work together, we will have talked about and written down what you would want if you were to get sicker.

Sometimes it can be hard for people to talk about their medical care if they were to be sicker. How do you feel about talking about it? [normalize feelings, provide example stories as applicable and address barriers]

If you feel uncomfortable talking about this, please let us know. I have some questions that will guide us in this discussion: *(text in italics are probes)*

1. What have you been told to expect in the future with your [insert their words for their lung/heart] illness?	
Probes	<ul style="list-style-type: none"> • <i>What do you think the future holds?</i> • <i>[If applicable]: I am not raising this issue because we are worried you are getting sicker right now, it can be helpful to think about the future.</i>
Listen for:	Patient responses
<i>So sick, don't have much time</i>	
<i>Doing great, don't have any problems</i>	
<i>Uncertainty</i>	
<i>Have been sick before and recovered, been sick before and haven't recovered</i>	

FIG. 1. Goals of Care Communication Guide.

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2. If you were to get sicker, what would be most important to you?	
Probes	<ul style="list-style-type: none"> • <i>What things do you do that are so important to your life that you can't imagine living without doing them? (i.e., driving, caring for yourself, living on own)</i>
Listen for:	Patient responses
<i>Be cured</i>	
<i>Live longer</i>	
<i>Improve health</i>	
<i>Maintain health</i>	
<i>Be comfortable</i>	
<i>Accomplish a particular life goal</i>	
<i>Not burden on family- ask if financial, emotional, physical, etc?</i>	
<i>Other (no pain, at peace with God, being with family, having treatment choices followed, finances in order, a feeling life was meaningful, resolve conflicts)</i>	

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3. As you think about the future with your health, what are you most worried about?	
Probes	<ul style="list-style-type: none"> • <i>What concerns you?</i>
Listen for:	Patient responses
<i>Being a burden- ask if financial, emotional, physical, etc? and a burden to whom?</i>	
<i>Being in pain or uncomfortable</i>	
<i>Prolongation of dying</i>	
<i>Not being in control or being not mentally aware</i>	
<i>Leaving behind loved ones</i>	

FIG. 1. (Continued)

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4. All of us at some point will reach the end of our lives and different people want different things at that time. Some people are at one end of the scale where they want to focus on comfort and quality of life, and are willing to have their lives be shorter to be more comfortable.

Other people are on the other end of the scale where they want to live longer no matter what treatments or procedures or machines they would need.

When you think about the scale, where are you?

What would that include [*see below options*]?

Probes	<ul style="list-style-type: none"> • <i>Could you describe a little more about why you pointed there?</i> • <i>If you become sicker, how much are you willing to go through for the possibility of gaining more time?</i>
Listen for (this is not a checklist)	Patient responses
<i>Death location (home, hospital, hospice in-patient, home with hospice, home with family, home with other supports)</i>	
<i>No pain or other symptom even if it meant not living as long(y/n)</i>	
<i>Tube in throat and machine to help me breathe(y/n)</i>	
<i>Feeding tube(y/n)</i>	
<i>CPR or cardioversion(y/n)</i>	
<i>I want everything done to keep me alive as long as possible</i>	
<i>Spiritual/religious preferences</i>	
<i>Family present</i>	

FIG. 1. (Continued)

practice for a general medical nurse or social worker, (2) be salient across different serious illnesses, (3) be structured to promote reproducibility and scalability, (4) yield clinically relevant results that can be integrated into the medical record, and (5) provide a clear path for next steps in goals of care communication. Building on prior work,^{7,15-19} a nurse (J.P.), social worker (R.J.-K.), and physician (D.B.B.) jointly developed the initial goals of care communication guide.

The initial guide included questions for nurses or social workers to initiate goals of care communication, provided

scripts to anticipate and respond to patient reactions, and included ways to customize questions and response options. This guide was presented for feedback to a group of 6 multidisciplinary palliative care researchers (physicians, psychologists, and nurses), and subsequently to a larger group of 30 multidisciplinary providers (chaplains, social workers, nurses, and physicians) from multiple specialties (primary care, geriatrics, oncology, and palliative care). The guide was additionally reviewed separately by several other nurses, a palliative care psychologist, and two advance care planning and communication researchers.

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5. Now we are going to move onto the second part. I know you said [insert patient’s answers] is important to you. We would like to make a plan so we can help make sure your wishes are followed. [ask Plan Questions below]	
Plan Questions:	
How much does your family know about your priorities and wishes?	<ul style="list-style-type: none"> • <i>If family knows a lot, affirm benefits of good family communication and ensure MDPOA set up</i> • <i>If family doesn’t know a lot, troubleshoot barriers and perhaps role model discussion with family members. Educate about MDPOA below.</i> • <i>Identify and document family dynamic issues</i>
How much does your doctor or nurse practitioner know about your priorities and wishes?	<ul style="list-style-type: none"> • <i>If doctor knows a lot, affirm benefits of good communication and ensure MDPOA set up</i> • <i>If doctor doesn’t know a lot, ask how much they would like their doctor to know and troubleshoot barriers and perhaps role model discussion with doctor. Educate about the importance of having doctor aware of wishes and in the medical chart.</i>
What documents do have in place about your priorities and wishes?	<ul style="list-style-type: none"> • <i>If have documents below in place, ask if they are in their medical chart?</i> • <i>If unsure, educate about each of the documents below.</i>
Possible Steps	Patient responses
Portable Orders for Life-Sustaining Treatment (e.g., POLST, MOST) form [only for applicable patients in states that have such a form]. Discuss appropriateness with physician or nurse practitioner.	
MDPOA- Complete for all patients	
<ul style="list-style-type: none"> • <i>If participant is hesitant, explain the need for a MDPOA. Identify barriers to completing the MDPOA.</i> • <i>If participant refuses, acknowledge their choice and offer education about MDPOA and leave a copy with them for future consideration.</i> 	
Meeting with Physician or Nurse Practitioner-Ask if they would like to talk to their primary care or other providers about these issues. Also ask if they would like the RN or SW to be present for this discussion.	
Palliative care referral	

FIG. 1. (Continued)

Pilot testing

We piloted the goals of care communication guide with a convenience sample of patients with New York Heart Association (NYHA) III or IV heart failure or Global Initiative for Obstructive Lung Disease (GOLD) III or IV chronic obstructive pulmonary disease (COPD) from the VA Eastern Colorado Health Care System who would be able to provide feedback on the guide. This population was chosen in preparation for a clinical trial that is evaluating the effect of palliative care in heart failure and COPD.²⁰ There were no exclusion criteria. Patient demographic/clinical information

was not collected because analyses based on this information were not planned. Informal caregivers were present per participant request. This study was reviewed by the Colorado Multiple IRB and deemed exempt.

A social worker and nurse took turns using the guide to lead one-on-one patient or patient and surrogate goals of care discussions. Study staff took notes during the discussions, and these notes along with social worker and nurse observations and reactions (elicited after each goals of care discussion) were compiled in a semistructured debrief form (Supplementary Fig. S1; Supplementary Data are available online at www.liebertpub.com/jpm). After the discussion, patients were asked

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6. We want to make sure we heard you correctly so I'm going to summarize our plan and we will put it on this form together. You can take the form with you and share it with the people you talked about.	
<i>What is most important to me</i>	
<i>Who I need to talk to about what is important to me</i>	
<i>What forms do I need to complete</i>	

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7. What are your thoughts about how this conversation went?	
Probes	<ul style="list-style-type: none"> • <i>How did this conversation make you feel?</i> • <i>What were some of your thoughts about what we talked about today?</i> • <i>Did our conversation bring up things for you to think about or that were hard to talk about?</i>
<i>Patient responses</i>	
We covered some important topics today and you might start thinking about things later. If you do and would like to talk more, please feel free to contact us.	

FIG. 1. (Continued)

semistructured, open-ended questions (Supplementary Fig. S2) to obtain reactions to the communication guide as well as to elicit feedback regarding improvements.

Process for making revisions

Revisions to the communication guide were made after input from patients and healthcare providers at each step of guide development and refinement based on consensus within the core analytic team (J.P., R.J.K., and D.B.B.). During pilot testing, data from the patient interviews and the nurse/social worker debriefing form were placed into a matrix and compared and contrasted throughout the study to identify commonalities that should lead to changes in the goals of care

communication guide.²¹ The core analytic team discussed communication guide changes every three to five patients. Pilot testing was continued until no new information was obtained from patients or nurse/social worker debriefing. After pilot testing was completed and feedback incorporated, the revised communication guide was reviewed by a VA-based clinical team comprising a geriatrician, pulmonologist, internist, and cardiologist to obtain additional perspectives.

Results

Development

Iterative input resulted in the goals of care communication guide. The guide included questions to (1) elicit patient

understanding of and attitudes toward the future of illness, (2) clarify values and goals, (3) identify positive and negative perceptions and feelings about the future, (4) identify end-of-life preferences, (5) motivate patients to complete written documents and speak with family and providers about values and goals, and (6) agree on a follow-up plan.

Multidisciplinary providers recommended changes to increase brevity, improve the clarity of certain questions, and include questions pertaining to documentation of healthcare goals. For example, the initial question was changed from “What is your understanding now of where you are with your illness?” to “What has your doctor told you about your illness?” At this stage of development, the communication guide included multiple prompts, anticipated reactions from patients alongside suggested responses, and ways to customize each question.

Pilot testing

During pilot testing, 15 patients and 5 of their informal caregivers participated (17 patients were approached, 2 refused and 1 agreed but ultimately did not participate). Every patient said this was an important topic; none said the goals of care communication should not be conducted. For example, one patient said, “It is necessary. It takes the guesswork out of what other people should be doing for you. I am thinking about my daughter; she doesn’t have to anguish over what I do want and don’t want. It clears everything up.”

The communication guide prompts, anticipated reactions, and ways to customize each question were removed and placed into a user manual because they distracted from the main communication guide questions, were uncommonly used, and cluttered the guide. Removing this text also allowed for greater spontaneity and flexibility.

Major substantive revisions (all of which were made during piloting among the first 10 patients) are listed in Table 1. The communication guide wording was changed for each question. Patients and informal caregivers found the length acceptable (~30 minutes), felt it flowed well, and was clear. The final communication guide is presented in Figure 1. No changes were made during piloting in the final five patients or with review by the VA-based clinical team.

Discussion

We developed and revised a structured goals of care communication guide based on providers’ feedback and pilot testing among patients with heart failure and COPD. The communication guide was designed for social workers and nurses to initiate and facilitate further discussions and actions among patients, family members, and healthcare providers. In this small study, the goals of care communication guide was feasible based on administration time and acceptability by patients and providers.

Weiner et al.²² advocated for the need to formally develop communication interventions through a series of steps, based on a similar process used in the development of psychotherapeutic interventions such as interpersonal psychotherapy.²³ Our study represents such an effort. Key strengths of our approach include the grounding in prior literature and the iterative development and refinement of the communication guide using patients and a diverse sample of

providers. Challenges included how to balance the need for communication guide structure with flexibility for the providers based on patient questions or responses, how to balance the need for brevity with comprehensiveness, and how much detail to place in the communication guide versus a user manual.

Although this intervention builds on substantial work in goals of care communication and advance care planning, this is a developmental and feasibility study and should be interpreted in that context. Based on our results, and given the significant time constraints of physicians, it is possible that nurses and social workers can use this guide during stand-alone visits to prepare patients and family members for further conversations and treatment decisions. Depending on the experience and expertise of the practitioner, different levels of training and supervision would likely be helpful in using the guide. The intervention was pilot tested in a mostly white and male VA population with serious lung and heart diseases. Further testing is needed in other illnesses, patient populations, and over time to explore how it works in coordination with other members of the medical team; how training and supervision can be tailored based on provider and patient needs and context; and how to adapt it for longitudinal use. Future studies could also explore whether the communication guide is useful in the context of speaking with a surrogate decision maker or for others besides nurses and social workers who are involved in caring for those with serious illness.

In summary, a structured goals of care communication guide developed for nurses and social workers was iteratively developed with multidisciplinary providers and patients and was acceptable to patients during pilot testing. Further testing of this intervention is planned in a VA-funded clinical trial.²⁰

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Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:
David B. Bekelman, MD, MPH
VA Eastern Colorado Health Care System
1055 Clermont Street, Research (A3-151)
Denver, CO 80220

E-mail: david.bekelman@ucdenver.edu