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ORIGINAL ARTICLES

ACare: A communication training program for shared decision making along a life-limiting illness

JOSEPH S. WEINER, M.D., PH.D.[1] AND STEVEN A. COLE, M.D.[2]
[1]Long Island Jewish Medical Center, New Hyde Park, New York
[2]Stony Brook Health Sciences Center, School of Medicine, Stony Brook, New York

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ABSTRACT

Objective: This article describes an innovative 8-h training program that provides clinicians with the competencies necessary to conduct efficient, effective, and compassionate advance care planning discussions throughout the trajectory of life-limiting illnesses.

Method: The Advance Care Training Program (ACare) includes 6 h of group workshops and 2 h of one-on-one faculty–learner interaction. In this article, we describe the (1) objectives of ACare; (2) structure, training procedures, and educational rationale of ACare training; and (3) educational outcome studies in progress.

Results: ACare training in various forms has already been provided to over 100 medical professionals (medical students, medical residents, oncology and geriatric fellows, medical attendings, social workers, and nurses). Formative outcome data indicate considerable trainee satisfaction. Emerging summative outcome data indicate improved skills.

Significance of results: Widespread adoption of the program could increase the frequency and quality of advance care planning discussions between patients with life-limiting illnesses, their health care providers, and families.

KEYWORDS: Advance directives, Advance care planning, Physician–patient communication, Shared decision-making, Health personnel attitudes

INTRODUCTION

Improving the effectiveness, through shared decision making, of advance care planning for the seriously ill has been an elusive goal for medical care near the end of life (Omnibus Budget Reconciliation Act, 1990; SUPPORT Principal Investigators, 1995; Field et al., 1997; Covinsky et al., 2000; Martin et al., 2000). Even well-conceived, intensive projects like the SUPPORT study (1995) have not been able to change the troubling deficits in medical care for the patient with life-limiting illness. This article describes an innovative, highly focused professional training program designed to increase the frequency and quality of advance care planning discussions between health care providers, patients with life-limiting illnesses, and their families.

The authors have developed a conceptual model that provides the theoretical foundation for the new program (Weiner & Cole, 2004). In brief, we conceive that professional training efforts in advance care planning communication have not yet led to large changes in patient care, because they have not effectively overcome the clinician's individual and highly specific emotional, cognitive, and skill barriers to engaging in these discussions. The rationale and methods of a fully successful program must include educational strategies targeted at overcoming these individual clinician barriers (see Table 1).

Corresponding author: Joseph S. Weiner, Long Island Jewish Medical Center, Program in the Patient-Doctor Relationship, Departments of Medicine and Psychiatry, 400 Lakeville Road, Room 101, New Hyde Park, NY 11040. E-mail: weiner@lij.edu

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Table 1. *Three core professional determinants for effective end-of-life care*

Determinant	Consequences if absent
1. Specialized skills in shared decision making, distinct from general communication skills.	a. Poor self-confidence. b. Diminished motivation to initiate advance care planning. c. Ineffective advance care planning discussions.
2. Ability to deal with uncomfortable emotional responses to advance care planning situations.	a. Avoidance or other counterproductive behaviors. b. Ineffective advance care planning discussions.
3. Tools to assess and revise counterproductive beliefs about advance care planning situations.	a. Aversive emotions intensify, leading to further maladaptive responses. b. Ineffective advance care planning discussions.

Advance care planning involves far more than completion of advance directive forms. Experts agree that advance care planning refers to a process of *recurrent* clinician–patient–family interactions, which includes the following core elements: (1) the individualized delivery of medical information; (2) a shared decision-making paradigm that develops clear objectives for advance care planning discussion; (3) focus on multiple, evolving, and fluid medical treatment decisions, along the complete trajectory of a life-limiting illness; and (4) clarification and documentation of a patient's future treatment preferences in anticipation of his or her loss of capacity to express those preferences (Emanuel et al., 2000; Prendergast, 2001; Kolarik et al., 2002; Tulsky & Arnold, 2002).

Advance care planning incorporates spiritual and emotional issues as they help define medical treatment decisions, as they relieve suffering, and as they provide meaning and dignity (Breitbart, 2002; Chochinov et al., 2002; Kolarik et al., 2002). And advance care planning, as we conceive it, also involves the process of coordinating and implementing these medical decisions through the patient, physician, and family in advance of patient death.

The Advance Care Planning Training Program (ACare), grew out of a 12-year experience at Long Island Jewish Medical Center in intensive clinician–patient communication training for internal medicine residents, medical students, fellows in medical oncology and geriatric medicine, medical faculty, and nonphysician medical personnel (Gordon et al., 1996; Oh et al., 2001; Weiner et al., 2001). These training experiences have included broad patient-centered communication training as well as specific training focusing on advance care planning.

This article describes the objectives, training procedures, and educational rationale of ACare, which were elaborated with guidance from accepted educational theory and research (Cohen-Cole, 1980; Bird et al., 1983; Davis et al., 1999). In an effort to achieve adequate, measurable, and lasting benefits of training, ACare was modeled after other evidence-based communication programs that utilized 8 h of training time (Roter et al., 1995; Gerrity et al., 1999; Cole et al., 2000). These investigators believed that 8 h was the minimum necessary for participants to change ingrained clinical communication patterns.

ACare has been designed to be adaptable across medical disciplines and levels of experience. Encouraging pilot data have documented short and long term efficacy with oncology fellows (Weiner et al., 2002*a*, 2002*b*).

OBJECTIVES OF THE ACare TRAINING PROGRAM

Knowledge Objectives

At the conclusion of the training program, learners will be able to describe the following:

- The elements and appropriate clinical applications of advance directives, including a *Health Care Proxy*, a *Living Will*, and a *Do Not Resuscitate/Do Not Intubate (DNR/DNI) Order*;
- A structured approach to initiate and complete advance care planning discussions with patients and families.

Attitudinal objectives (including emotional, cognitive, and self-confidence outcomes)

At the conclusion of the training program, learners will report the following:

- Positive changes in their confidence and comfort in initiating and leading advance care planning discussions; and

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Table 2. *ACare structure*

Step	Format	Learner time	Facilitator time (for 6 learners)
1. Introductory seminar	Group workshop	1 h	1 h
2. Simulated patient exercise	Individual training session	1 h	6 h (1 h/learner)
3. Discussion of emotional barriers	Group workshop	1 h	1 h
4. Presentation of advance care planning approach	Group workshop	1 h	1 h
5. Demonstration of advance care planning approach	Group workshop	1 h	1 h
6. Group practice of advance care planning	Group workshop	1 h	1 h
7. Discussion of cognitive barriers	Group workshop	1 h	1 h
8. Simulated patient exercise	Individual training session	1 h	6 h (1 h/learner)
Total time	Six 1-h group sessions Two 1-h individual sessions	8 h	18 h (for 6 learners)

- A willingness to engage in the evolving process of advance care planning across the entire trajectory of illness from diagnosis through death.

Skills Objectives

At the conclusion of the training program, learners will be able to perform the following:

- Identify specific end-of-life situations that cause them to experience aversive emotional responses and counterproductive beliefs.
- Create alternate ways to experience these end-of-life situations by recognizing and reinterpreting these associated counterproductive beliefs.
- Facilitate shared decision-making with patient and family about medical treatment choices by engaging in the 10 communication behaviors described in the text below.

THE ACare PROGRAM: STRUCTURE, TRAINING PROCEDURES, AND EDUCATIONAL RATIONALE

ACare training consists of 6 h of group sessions and two 1-h individual sessions. The group sessions can be taught separately in 1-h blocks or combined into longer blocks (e.g., three 2-h sessions). These sessions are summarized in Table 2 and elaborated below.

1. Introductory seminar: Concepts in advance care planning.
   A. Teaching method: Group learning, teaching time 60 min.
   B. Description: At the beginning of the h, the participants take a 15-item multiple-choice exam on advance directive knowledge (J.S. Weiner & S. Sarij, unpubl.). They then receive a 15-min lecture on basic concepts of advance directives. After the lecture, the group reviews the multiple-choice exam.
   C. Educational rationale: Starting the workshop with a self-assessment examination demonstrates to learners their strengths and limitations in personal knowledge. This interactive session engages learners and helps ensure that all participants master basic concepts after the first h of the program.
2. Simulated patient exercise: Each trainee conducts a pretraining advance care planning discussion with a simulated patient.
   A. Teaching method: Individual learning, teaching time 60 min.
   B. Description: Learners conduct a videotaped advance care planning discussion with a trained actor or faculty member. Standardized vignettes are constructed so that the "simulated patient" (Maguire et al., 1986; Gordon et al., 1988) is in his/her 60s, with an incurable, but medically stable cancer, and the role play is scripted in an ambulatory setting (J.S. Weiner & R. Janicik, unpubl.).[1] This forces the trainee to have the advance care planning discussion earlier than is generally done, but at a time that experts suggest it should be initiated. The scenarios have been constructed to elicit moderate and realistic emotional intensity from the simulated patient. The video-

[1]Detailed scenarios are available from the first author upon request.

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taped discussion is privately reviewed with the trainee immediately afterward. During this review, the educator facilitates learner-driven self-assessment and learner-centered goal setting for the training (Knowles, 1973, 1990).

C. Educational rationale: This simulated patient exercise provides the learner and the teacher with a snapshot of the participant's strengths and weaknesses. The moderate emotional intensity of the scenario also allows the trainees to experience some of their emotional and cognitive barriers. While providing an opportunity for feedback and individual learning, the educator encourages the learner to set more detailed goals for the next 6 h of training.

3. Introducing the concept of emotional barriers: Eliciting and sharing physicians' emotional barriers to advance care planning discussions.

   A. Teaching method: Group learning, teaching time 60 min.

   B. Description: The group of 4–6 learners participate in the following exercise:

      "Think about the last time you spoke with a terminally ill patient about advance care planning. If you have only recently spoken to families because your patients were not able to communicate, then use one of those examples. What did the experience feel like? What do you think caused those feelings?"

      The trainees go around the room and exchange stories, facilitated by the faculty. The class develops a list of personal emotional challenges during end-of-life discussions, and the faculty supplements this list as appropriate (Weiner & Cole, 2004).

      Trainees without much clinical experience, such as medical students, may not have participated in advance care planning. In this case, we ask trainees what it might feel like for them to have such a discussion. We have observed that it is generally better to conduct training sessions for clinicians with similar levels of experience as this will facilitate the openness necessary to share emotionally laden challenges.

      After exchanging advance care planning vignettes and personal emotional responses, the class then discusses the specific precipitants that led to each clinician's response (Weiner & Cole, 2004). For example, a physician's anxiety about having advance care planning discussions with a terminally ill patient might stem from his or her conception that such a discussion would take away hope.

   C. Educational rationale: This exercise, along with the previous simulated patient role play, provides learners and the teacher with invaluable information about individual emotional barriers to engaging in advance care planning. The group format helps participants appreciate the universality of emotional distress and the variety of challenges clinicians face. The group also discusses how common and understandable it is for the clinician to avoid discussions that elicit such distress. Many clinicians find relief in this common emotional ground (Bailint, 1972).

4. Effective advance care planning: A 10-step model to facilitate shared decision making is presented in detail.

   A. Teaching method: Group learning, 60 min.

   B. Description: ACare training encourages the clinician to take an approach to advance care planning based on expert opinion (Lo et al., 1999; Larson & Tobin, 2000; Wenrich et al., 2001) and clinical experience.

      Table A1 lists 10 elements we believe are fundamental to advance care planning discussion, along with sample questions or statements. Note that "advance care planning" goes beyond advance directive determination. The clinician acts as a guide to help the patient participate in a shared medical decision-making process throughout the illness trajectory (Teno & Lynn, 1996; Charles et al., 1999; Elwyn et al., 2000; Kolarik et al., 2002). This is helpful not only to sort out complex treatment planning issues, but it also facilitates the patients' efforts to construct meaning around their illness experience. This may have, in itself, therapeutic effects (Breitbart, 2002; Chochinov et al., 2002).

   C. Most of these elements, list in the table in the Appendix, are self-explanatory. However, six deserve more attention:

      - Elicit and explore three forms of personal experience the patient may have had with death and dying issues:

        1. With loved ones who have died.

        2. With the patient's own prior medical illnesses, and

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Table 3. *Clinician barriers to advance care planning communications: Common counterproductive beliefs and*

Cognitive barrier: A clinician who cannot improve a medical condition has nothing to offer.
Reframing task: Encourage the clinician to consider the gratifying care we can provide when cure is not possible, such as the successes in helping a patient die well.
Cognitive barrier: Patients generally do not want to discuss issues related to death and dying.
Reframing task: Shift this global generalization to consideration of what the *particular* patient needs. Gather data that clarifies what the patient needs, "What are your thoughts about your illness? What is the hardest part for you?" Understand you are providing the patient and family an important opportunity to have input into their care.
Cognitive barrier: The clinician will take away hope if he/she raises advance directive issues.
Reframing task: This narrowly defines hope as "hope to not die." Redefine other kinds of hope we can offer patients, although they may lose their hope not to die. This allows hopeful opportunities to occur through good advance care planning discussion.
Cognitive barrier: End-of-life decisions should have clear answers.
Reframing task: In the absence of clear answers, understand that we can help patients and families make the best decisions for themselves, by eliciting their values and facilitating shared decision making. Also reconsider that a lack of clear answers should have no bearing on a physician's self-worth.
Cognitive barrier: If the clinician gets close to patients who die, he or she cannot be effective in his work.
Reframing task: Clinicians may experience enormous gratification by getting close to a dying patient. They may reevaluate their own priorities and values by getting close to a dying patient. Such possibilities may increase a clinician's effectiveness rather than reduce it. The provider can reevaluate his/her concerns about managing grief and approaches to self-care. The provider can increase his awareness about his own human limitations in what feelings or patient situations he can tolerate or work with effectively. This will generate mature self-assessment leading to adaptive choices rather than failure that may generate avoidance or other inappropriate enactments.
Cognitive barrier: The clinician must always have something to say.
Reframing task: The clinician should consider what he/she can offer by quietly listening. The clinician should attend to what is being transmitted during the silences he/she feels the need to fill.
Cognitive barrier: A clinician who cannot cure a patient fails.
Reframing task: The clinician should consider the differences between curing disease and healing suffering. The clinician should examine his/her openness to assume other roles besides curing disease.
Cognitive barrier: A clinician needs to "handle" his/her own concerns about death and dying in order to have open discussions with patients about mortality issues.
Reframing task: The clinician might think more about what the patient can teach him/her about dying and coping with adversity, rather than what wisdom the clinician should provide to the patient. The clinician might talk to patients from a standpoint of curiosity of their dying experiences, rather than what he/she thinks that experience should look like. If the clinician avoids this, the patient will be deprived of a meaningful opportunity to teach the physician something that will be remembered after the patient dies.

3. With the patient's own current medical illness.

Ineffective advance care planning discussions are overly technical and abstract. It is easier to make good decisions when they can be framed within prior personal experiences. For example, if a clinician can help a patient recall the last days, weeks, or months of a loved one's life, the patient can consider what aspects of that medical care they might or might not want for themselves.

- Help the patient actively link past experiences to the decisions he or she should ponder. Once such experiences are drawn out, it becomes a bit clearer for the patient to sort through decisions. The physician should help the patient by asking questions like, "You saw how your mother did on a breathing machine. What were the pros and cons of that experience for you? If you would ever be in a similar situation what would you want and not want for yourself?"
- Carefully listen for cues the patient gives that invite the clinician into a discussion about end-of-life issues. Clinicians are often reluctant to raise end-of-life issues, because they feel patients won't want to discuss it. This is usually an incorrect assumption. Data indicate patients commonly wait for physicians to

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raise the issue (Johnston et al., 1995). In practice, patients drop cues for physicians to discuss emotionally based topics, but these cues are frequently missed (Branch & Malik, 1993; Suchman et al., 1997). The ACare training helps clinicians pick up these cues by illustrating them during role play or a modeling videotaped interview that the class views.

- Help the patient and loved ones link the medical decisions they are making with losses they are suffering. Sometimes patients or family members refuse to accept imminent death. They might request ineffective treatments in the hope of a miracle. Sometimes they angrily demand constant attention from the medical staff or anxiously overinterpret small movements of a dying patient as a sign of recovery. These behaviors commonly cloak the grief of patients and family, which is rarely addressed in the acute care setting. Rather, the staff adapts by labeling people as "in denial," "irrational," or "difficult." This establishes adversarial relationships that often escalate the demands of patient and family. Often the health care team unknowingly participates in "irrational denial," by not acknowledging how painful it is for the patient and family to say goodbye. If this were more directly addressed, the maladaptive behaviors of patients, families, and staff might diminish.
- Provide accurate prognostic information and treatment recommendations, as requested by the patient or as needed by the patient to make adaptive decisions. In an attempt to protect patient hope and perhaps avoid emotionally upsetting bad news, clinicians may not share frank clinical information with patients. Providing this necessary information must be guided by the provider's assessment of the patient's desires and needs, not by the provider's personal distress (Buckman, 1992; Novack, 2000). By withholding crucial clinical opinion, the patient or family cannot exercise truely informed consent. Although it varies from patient to patient, studies have shown most patients would like to hear the truth (Buckman, 1996). Superimposing cultural preferences, however, must be taken into account (Crawley et al., 2002).
- Find opportunities for growth at the end of life. Clinicians sometimes narrowly frame patients into "treatable" and "terminal," causing the misunderstanding that discussion about a noncurable condition may cause the patient or family to lose hope. Rather, the opposite has been amply described (Byock, 1997; Block, 2001). Patients and family members can hope for many other things besides a cure, including the hope for symptom reduction, to stay connected to and become closer with loved ones, to leave a legacy, and to emotionally grow (Nuland, 1994). With such a perspective, there is always the possibility for hope and growth near the end of life.

D. Educational rationale: A concrete, structured model for advance care planning discussion provides a framework for learners to develop skills. We believe having this structure also helps increase clinician comfort and confidence with this difficult task. This reduces their emotional distress.

5. Demonstration of advance care planning: A modeling videotape is shown of an actual advance care planning discussion with a terminally ill patient.
   A. Teaching method: Group Learning, 60 min.
   B. Description: A videotaped advance care planning discussion with actual patients and families is used as a demonstration tool for the 10 elements of good advance care planning. The video is stopped many times to elicit trainees' thoughts and emotions. Counterproductive beliefs (see below) are challenged and reframing tasks are assigned.
   C. Rationale: Modeling videotapes are used as a springboard to elicit group discussion. As discussed by Bandura (1977, 1992), modeling provides a template to improve clinician self-confidence.
6. Skills-based practice: Group "rolling role plays" based on personally challenging scenarios constructed by trainees.
   A. Teaching method: Group learning, 60 min.
   B. Description: Instead of trainees doing individual role play, we repeatedly utilize "rolling role play." This is where the whole group assumes the role of the clinician: Group members sequentially ask one question or make one statement to the simulated patient (a faculty member). As role

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plays proceed, the facilitator will get a sense of specific situational-based skills each trainee needs to work on. For example, a nurse may have difficulty saying the word *dying*, when trying to ask, "Have you ever thought of dying?" This can be practiced within the context of a role play, and then given as an assignment to practice with the next appropriate patient in the clinical setting. When the nurse returns to the next class, the facilitator can follow up to see whether he or she was able to perform this skill. It is important to encourage participants to have advance care planning discussions with actual patients between classes, so they can bring in real vignettes to discuss and practice.

C. Rationale: This group role play effectively diffuses emotional discomfort among several people. As participants watch each other struggle during the role play, they feel validated in their shared distress, which facilitates open dialogue. And because the entire group participates in each role play, everyone remains involved in time-effective learning. Although these exercises and associated discussions about trainees' personal reactions are carefully controlled not to deflect into psychotherapy, they nevertheless can enable clinicians to overcome substantial personal anxieties related to discussions near the end of life (Bandura, 1977, 1992; Weiner & Cole, 2004).

7. Reduction of cognitive barriers: Counterproductive beliefs of trainees regarding advance care planning are elicited and challenged. Links between counterproductive beliefs and emotional barriers are made.

   A. Teaching method: Group learning, 60 min.

   B. Description: The group format of the course allows trainees to examine and share their misconceptions about end-of-life care. We do not attempt to address unconscious conflict in the training. Rather we facilitate a group process to help trainees reevaluate their cognitive assumptions (Weiner & Cole, 2004). This approach is based on the cognitive-behavioral work of Beck et al. (1979) and Beck (1995). Table 3 illustrates common counterproductive beliefs clinicians have about end-of-life care and ways to reframe these misconceptions.

   C. Rationale: Misconceptions can cloud clinical decision making. *By clarifying and reframing counterproductive beliefs, we improve clinical effectiveness and reduce emotional distress*. Clarification and reframing becomes part of the group process.

8. Each trainee conducts a final advance directive discussion with a simulated patient that serves to demonstrate and solidify improved skills.

   A. Teaching method: Individual learning, teaching time 60 min.

   B. Description: Each trainee has a second advance care planning discussion with a simulated patient that is videotaped and reviewed immediately after. During private review of the videotape with the clinician, faculty facilitates a learner-driven self-assessment and learner-driven goal setting for the future.

   C. Rationale: The trainee sees objective evidence of improvement, which increases motivation to put these skills into practice. The trainee also sees objective evidence of skills that he or she can continue to improve.

VALIDATION STUDIES IN PROGRESS AND FUTURE DIRECTIONS

Pilot data indicating formative and summative measures of efficacy[2] have been reported for ACare training of medical oncology fellows (Weiner et al., 2002*a*, 2002*b*). Self-reported comfort and confidence increased in advance care planning communication skills. Additionally, objective measures of skills improved as assessed by a modified RIAS analysis (Roter et al., 2000) of videotaped advance care planning discussions with simulated patients (Weiner et al., 2002*a*, 2002*b*). Medicine interns trained with ACare also reported increased self-efficacy in several tasks related to advance care planning discussion (Weiner et al., 2001). Details of these studies will be formally reported elsewhere. In addition to these uncontrolled outcome studies, a randomized controlled study of ACare is currently in progress, assessing the knowledge, attitudes, and skills of medicine interns in advance care planning discussion.

DISCUSSION

This article describes an innovative training program for clinicians in shared decision making across the trajectory of life-limiting illness. The effective-

[2]Formative measures are typified by trainee satisfaction and self-assessment. Summative measures are typified by objective assessment of knowledge, skill, attitude, routine behavior, and patient outcome (Bird et al., 1983).

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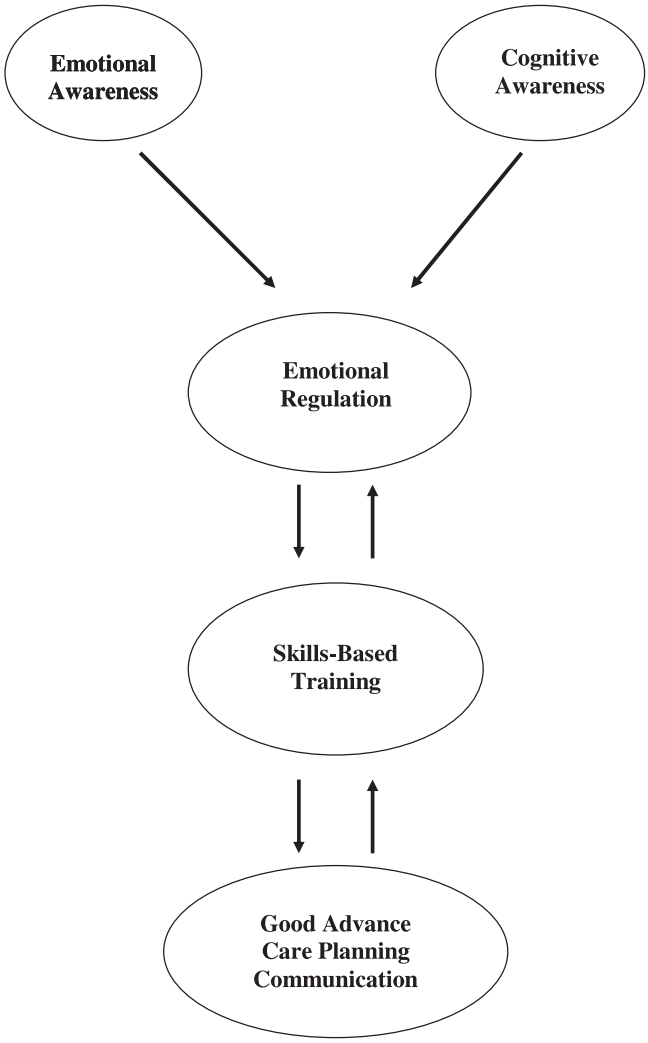


Fig. 1. ACare: A conceptual paradigm.

ness of the program is supported by current formative and emerging summative outcome data. The conceptual paradigm underlying ACare has been described in a separate publication (Weiner & Cole, 2004). ACare emphasizes the need for trainees to learn to recognize and manage their personal distress during advance care planning, reinterpret their individual cognitive barriers, and practice specialized communication skills in shared decision making. Along with focused exercises designed to overcome participants' emotional and cognitive barriers, ACare develops skills through highly structured role plays. Figure 1 displays the educational paradigm.

It is clear that the time demands of this training are considerable and may even be prohibitive for some settings—8 h for the trainee and 14–18 h for the trainer, based on a group of four to six participants. We believe that this time investment, including the individual faculty–trainee interaction is important for effective outcomes. However, once the initial validity of the program has been established, further educational studies can be undertaken to determine which elements of the program may be trimmed.

Future research directions will address four key areas: (1) the development of valid measures for the content of an advance care planning discussion; (2) the development of reproducible, testable (i.e., manualized) approaches to advance care planning; (3) the determination of how improvements in a clinician's advance care planning capabilities translates into actual changes in clinical behavior; and (4) the determination of whether a clinician optimally trained in advance care planning skills improves the outcomes of terminally ill patients and their families.

There has been widespread recognition of the need to help professional providers address their emotional discomfort with terminally ill patients, yet without clear guideposts. We hope that adoption of this training by others, with concomitant validity studies, will increase the ability of a clinician to more comfortably and effectively discuss the crucial treatment decisions that terminally ill patients and their loved ones need to make. As important, we anticipate that these discussions will be more emotionally meaningful and dignified for the patient, family, and clinician.

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APPENDIX

Table A1 lists the 10 elements of a good advance care planning discussion.

Table A1. *The clinician as guide: Ten elements of a good advance care planning discussion*

Element	Facilitating statements/questions
1. Clarify current experience and treat suffering	How is this illness affecting your life? What is it like for you to have _____? (e.g., cancer) What are the hardest things about this cancer for you? (medically, psychologically, spiritually, financially) What kinds of suffering are you going through? What are the things that give you greatest meaning/pleasure/dignity in your life? How has this illness affected that? How can we help you now?
2. Elicit prior experience with life limiting illness and medical decision making	
a. Deaths of loved ones	(Utilize the patient's family medical history to look for relevant experiences.) I see from your medical history that your father died from colon cancer. . . . What was his experience with cancer like? . . . What were the best and worst parts of his medical care? . . . If you would ever be in a similar situation, what would you want us to do for you? What would you want us not to do?
b. Patient's medical history	Tell me about medical illnesses or surgical experiences you've had. Were any of those illnesses so serious that you thought you might die? . . . What was your experience like with that illness? . . . How did you feel about how your medical care was handled? (continue as for 3a). . . .
c. Patient's current illness	What do you understand about your current medical illness? Where do you see things going? What are your hopes? What are your expectations? Do you ever think about dying?
3. Listen for an invitation to discuss death/dying issues	You mentioned that you understand this is a serious illness. Tell me more. . . You say that you just take things a day at a time. What happens when you think past that? You said that after you got the diagnosis, you became very scared. What scared you most? Where do you see things going with your illness in the future?
4. Link medical decisions with:	
a. Life experiences	Your mother was on a respirator for several weeks and she didn't have a health care proxy. You can see why it would be important for us to have such a discussion. Your friend fought her illness hard to the end, and endured many painful side effects of chemotherapy. We're approaching a similar decision now. You want to live long enough to see your granddaughter graduate college. Do you want us to treat you aggressively at all cost?
b. Loss	It must be so hard to say goodbye to all the people you love. . . . Most people have a hard time letting go. You have lost so much during your illness. . . . How does this affect how you think about the kinds of medical you would like?

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Table A1. *Continued*

Element	Facilitating statements/questions
5. Health care proxy transitions	Who have you confided in about your medical situation? How well does that person understand your values regarding your treatment wishes? Could that person represent your views about medical decisions well? What would you want your loved one to know that would relieve their burden if they had to make such a decision for you?
6. Clarify and summarize	So you wouldn't want to live like a vegetable? Tell me more about what that means. You say you wouldn't want to be hooked up to a machine. Is that under any circumstances? Let me make sure I understand everything you've told me so far. . . .
7. Share your clinical opinions	Under these circumstances, chemotherapy would have little chance of extending your life. You would also have less time to spend at home with your loved ones. Yes, I expect that you will die from this illness. We would be very surprised if your spouse would regain consciousness or be able to breathe again without the machine's help.
8. Involvement of loved ones	How would you like your loved ones involved in our discussions? I'd like to ask the people closest to you to come to our next appointment. Is that something you would want?
9. Discuss opportunities for growth	What opportunities exist for you or your loved ones to grow, despite all that is going on? How would you like to spend your remaining time? What things do you need to say to people you haven't yet?
10. Negotiate goals of care	Although we believe strongly that placing your husband on a breathing machine won't improve the worsening in his acute leukemia, we'll agree to try it for several days to see if his pneumonia improves. Will you agree to meet again at that time to reevaluate the treatment plan?

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