

RESEARCH ARTICLE

Advance Care Planning: A Three-Phase Community Initiative, Educating Clinicians and Engaging Employers in New York's Capital District

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Abstract

Advance Care Planning (ACP) emphasizes the process of communication necessary to assist individuals in making informed decisions about their future medical care. In response to the Institute of Medicine's (IOM) call for enriching preparation of Advance Directives (AD) in their *Dying in America* consensus report of 2014, this author developed, designed and initiated a three-phase program to heighten awareness of ACP in New York's Capital Region.

Phase I, *Community Conversations*, is directed toward healthy individuals who are upstream from illness. Individuals in faith-based groups and civic organizations are provided tools and resources to prepare their own Healthcare Proxies, Living Wills and conduct important conversations with their loved ones about honoring their wishes and goals.

Phase II, *Advancing ACP Education in Medical Practices*, is a structured training program for clinical professionals who receive certification as ACP facilitators and conduct ACP activities with their patients including conversations about what matters most and preparation of ADs for their medical records.

Phase III, *Advance Care Planning Education Through Employers*, is a program which reaches people in their workplace. The purpose of this phase is twofold: to meet the needs of individuals who might not be otherwise exposed to ACP information, and to engage employers who sustain the important preparation of ADs through their human resources departments.

A blueprint for each phase was designed for replication in other communities. Over a five-year period, and phase implementation, the program has been recognized as a premier resource for Advance Care Planning outreach. The project demonstrates the initiative, scope and activities that have far-reaching implications for the preparedness and health of an aging community. This review represents key elements and discovery with respect to all three phases of the project.

1. Introduction

The Institute of Medicine's (IOM) consensus report, *Dying in America*, identifies a need for "public education and engagement about end-of-life care planning." Furthermore, education is needed to motivate and facilitate advance care planning and meaningful conversations with a person's family members and caregivers.¹ The *Respecting Choices* model provides compelling evidence that their advance care planning approach leads to more completed Advance Directives (AD) and fulfilled patient end-of-life preferences.² These two components formed the foundation of a burgeoning program launched through the Visiting Nurse Service of Northeastern New York³.

As observed in the medical records of patients being admitted to the palliative care program at a local hospital⁴, the paucity of ADs prepared by patients became very clear. As a result, the referred palliative care clinicians were spending significant amounts of time with patients and families to elicit patient goals and values pertinent to their wishes for end-of-life care and serious illness. Moreover, many of the patients lacked capacity to have these conversations⁵. Decision-making necessarily shifted to their loved ones, often family members who had not explored end-of-life wishes with the patient either. Struggles within families regarding substituted judgment⁶ and what was in the best interest of the patient for life-sustaining measures were stressful and disheartening at a time when their loved one's illness was causing emotional distress. It became evident that ADs, prepared ahead of serious illness, would benefit not only the patient by way of honoring his wishes, but also the family members and clinicians involved with the patient's care.

An opportunity presented itself when a bioethics master's candidate⁷ was willing to train as an advance care planning facilitator to establish a grassroots program in the community. She became a certified facilitator and instructor through *Respecting Choices*² and planned outreach activities in an effort to educate individuals who were upstream from illness. Her goal was to make a compelling case for healthy people to begin thinking about what mattered most to them in terms of life-sustaining treatment. Reaching healthy individuals who were not in the midst of emotional upheaval due to illness, she hypothesized, would allow them to carefully consider their personal wishes. She challenged them to express their thoughts based on personal goals and values, share the information through conversations with loved ones, and prepare advance directives as clear and convincing evidence of their wishes⁸. Hence, the vision and implementation of *Community Conversations* was born. The success of *Community Conversations* increased visibility of the initiative, and medical professionals became interested in learning the skills to hold these conversations. They realized they would gain important and insightful information about their patients through these conversations, which could potentially help direct their treatment trajectories as the patients aged. Furthermore, they would be able to retain a copy of a prepared AD for reference in future conversations about changing goals and plans of care; making the second and third conversations easier to revisit. As a result of clinician interest, trainings were established in medical groups and practices with a focus on skills, effective in initiating conversations with patients and developing a clear understanding of creating a legal document to support and honor a patient's wishes. A perk of this phase included issuance of a facilitator certification upon completion of the training.

Once again, success in training significant numbers of clinicians piqued the interest of other groups, namely large employers in the region. Their employees, as healthy working individuals, were less likely to learn about ADs on a doctor's visit, primarily because they didn't regularly go to the doctor. Employers saw an opportunity to help educate their staff on advance care planning topics, and established enrichment sessions, whereby the trained facilitator made presentations.

In all, three phases of outreach were developed, implemented and run concurrently from 2015 to the present - Phase 1: *Community Conversations* (for small groups in the community), Phase 2: *Advancing ACP Education in Medical Practices* (for clinicians), and Phase 3: *ACP Education through Employers* (for staff at work). Chart 1 displays phase models and venues/participants over the course of four years (2015 – 2018).

Chart 1.

Community Conversations	112 Venues
ACP in Medical Practices	485 Clinicians Trained/Certified
ACP Education with Employers	6 Employers 444 Employee Participants

2. *Community Conversations*

Community Conversations addresses the IOM's suggestions at the community and family/individual levels⁹: facilitating presentations, disseminating information, and encouraging conversations. The focus is on exploring and identifying an individual's values and goals leading to meaningful advance care planning and starting the conversation about what matters most.

PowerPoint presentations were created. Materials were printed as take-away reading. Groups were identified, and presentations were scheduled. Evaluations were developed and implemented to measure success of each session, as well as to capture data.

Groups included lay persons in: faith-based groups, civic organizations, senior housing venues.

Table 1.

# Presentations	# Participants	# Completed Evals.	% Response Rate
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Presentations: identified and defined commonly misunderstood terms, reviewed a sample Healthcare Proxy and Living Will, described role of a healthcare agent, described elements of starting a conversation with loved ones. Handout materials included: Advance Care Planning (ACP) information card, info card for Healthcare Agents, blank Healthcare Proxy¹⁰, tip-sheet of phrases for starting a conversation, checklist for disseminating completed Healthcare Proxy. Evaluations included: pre-program questions and post-program questions.

The group sessions were designed to fit into a one-hour time slot with an additional Q&A segment. Participants at each venue were asked to complete pre-program and post-program questions. This information was captured in an effort to evaluate program effectiveness. (Reporting period: Aug 2014 – Mar 2015)

15	208	162	78%
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Six questions were asked of participants, three of which are noted in the following charts:

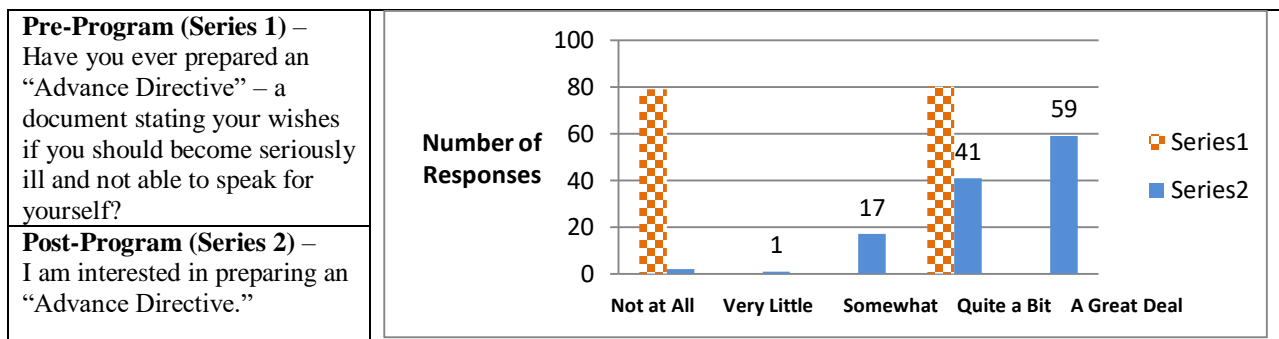
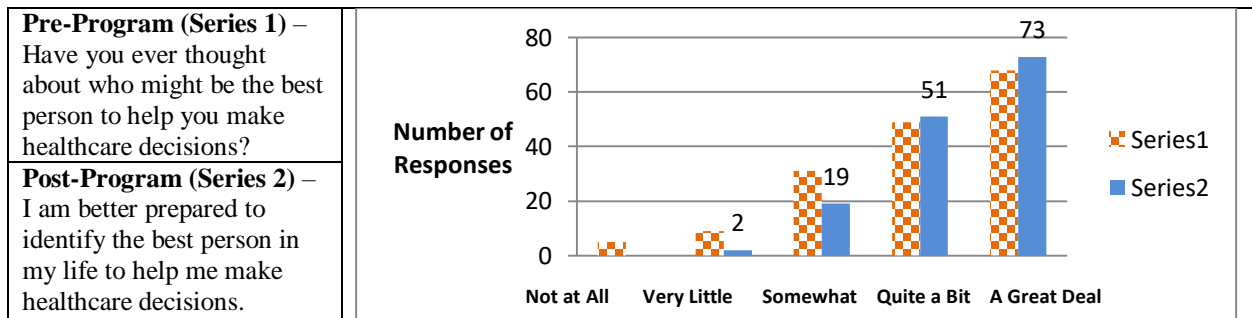
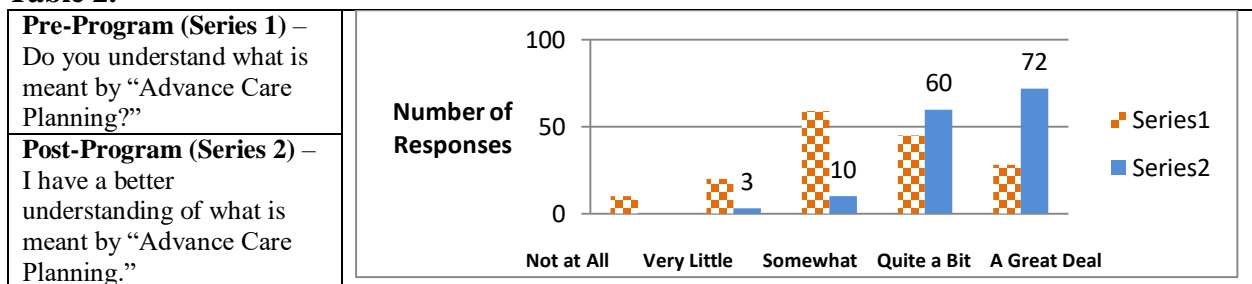
- 1) Pre-program: Do you understand what a “Healthcare Proxy” is?
- 2) Pre-program: Have you ever spoken with your family or loved ones about your

concerns/wishes if you are unable to make healthcare decisions for yourself?

- 3) Pre-program: Has your physician(s) ever discussed Advance Care Planning with you?

Charts show a sampling of pre- and post-program evaluations.

Table 2.



The post-program results show a marked shift to better understanding. Community outreach through *Community Conversations*, group by group, person by person, is having an informational impact on participants.

Participants are stimulated to begin conversations about Advance Care Planning topics including Healthcare Proxy, Living Will, CPR, Advance Directives, and more. They have learned how to identify their

values and goals for future healthcare. They have acquired tools for starting the conversations with family and physician. They understand the importance of planning. These conversations were poised to expand exponentially and influence the way people think about and plan for their future healthcare wishes. Presentations exceeded five times the anticipated number for the period, and an additional 16 presentations were scheduled in May and June 2015; due in large part as a result of attendees telling their friends about this empowering, values-driven approach to decision-making.

3. Advancing ACP Education in Medical Practices

Clinicians comprised the audiences of the training sessions in medical practices. Therefore, the approach and materials involved in these presentations reflected the strategy the clinicians would need to employ with their patients. The footprint of the clinician trainings was markedly different from the general audiences of lay persons in several ways. First, the dynamic was that of a train-the-trainer model whereby the instructor was preparing facilitators to then go forth and disseminate the information on an individual level.

PowerPoint presentations were developed, and videos were added which demonstrated actual conversations taking place. In conjunction with information on ACP and AD components, participants demonstrated their skills in eliciting responses by roll-playing and utilizing scripted scenarios. General interview skills were honed in this way, and repeated a minimum of three times throughout the day-long trainings. Repetition of the language and verbal practicing of the dialog showed increased confidence and ease in starting conversations. These practice sessions also

provided a “safe” learning environment for clinicians who were admittedly awkward initially. By the third practice session of roll-playing, the exercises became more relaxed and comfortable. Clinicians agreed unanimously that getting started was the hardest part, and through practice, their skill in leading the conversation was strengthened. Indeed, once they completed the facilitation training, they would be leading these conversations in their own medical practices and clinics. Concluding with a skills competency demonstration, the sessions were adjourned and participants received official certifications as facilitators, authorized by *Respecting Choices*.

Additional formats of *Advancing ACP Education in Medical Practices* were developed to meet a growing interest by medical professionals who did not find full-day training possible for their staff. As opportunities afforded themselves, the trainer developed customized programs to meet the situation and need of the clinicians. Some of the modified formats follow below:

- Facilitator trainings with medical professionals included collaboration with individual physicians. The trainer met with their patients on a regularly scheduled day every other week. The 20-minute sessions were held in a private setting to discuss ACP. In most cases, the medical office staff also became engaged in the subject matter.
- Casting a wider net, the trainer was invited to give presentations to medical professionals at regional and quarterly meetings. She also collaborated with hospital systems and home health agencies to train greater numbers of medical providers.
- A community coalition involving several large employers of medical professionals invited the trainer to

participate in strategic and tactical planning for a community-wide initiative. By joining the coalition, she was able to describe the trainings and collaborate with the group to scale the outreach to larger audiences. At the direction of the coalition leadership, she prepared grant applications to secure funding for training and marketing.

- Opportunities for developing liaison relationships included connecting college student volunteers in health sciences majors with local medical clinics. The trainer certified the students as facilitators so they would be able to conduct ACP conversations in clinics. There were numerous benefits to these relationships. Students gained experience in patient interaction; practitioners gained time in allowing the students to start the conversations; patients received

information in this layered approach of provider services; and there was no financial cost to student or provider.

Professionals trained in ACP become validated stakeholders in the commitment to change the way their patients think about advance care planning. These clinicians have the ability to influence the number of meaningful conversations about goals, values and preferences that lead to the preparation of advance directives. The medical practices who participated represented varied disciplines in a range of settings, from primary care providers to cardiologists and pulmonologists, and in private practices as well as community clinics. Medical doctors, physician assistants, medical students, RNs, LPNs, nurse practitioners, social workers, chaplains, physical therapists, occupational therapists, and community healthcare workers were among the attendees.

485 Clinicians Trained/Certified	September 2016 – August 2018
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As a direct and positive result of the facilitator trainings, clinicians also demonstrate confidence in skills. They have been able to envision new opportunities for implementation in their practices. Moreover, they are primed to conduct more conversations with their patients on ACP topics. The trainings help clinicians find their comfort levels when approaching the subject, along with realizing patients' discomfort, relieving their own anxieties about the topics.

Training medical professionals in ACP techniques is creating a richer forum for expanding the conversation in our community. Discussion and engagement of ACP topics is demonstrating to patients that these conversations are important and valued by their physicians. Far-reaching opportunities exist for incorporation of ACP topics within a variety of medical practices

and health care agencies. In six months, over 200 medical professionals were trained by one trainer...it is estimated that on average each of those 200 have had ACP conversations with five patients in subsequent months. That translates to 1000 more conversations on ACP topics than had happened previously.

4. ACP Education through Employers

Another market segment of the community where it was felt ACP could make an impact was on individuals in the workforce. When employers offer ACP informational sessions, they demonstrate an understanding of the work/life balance...and a new approach to employee health and wellbeing. Skill building in these sessions served to provide practical approaches to personal concerns.

Employers and the tactics applied to engaging their staff varied by discipline and activity. A health insurance company requested facilitator certification training for some of their clinicians, so the model utilized in the *Advancing ACP Education in Medical Practices* was suitable. But there were others who were non-clinicians, who had an interest in the approach used for lay persons. Thus, the *Community Conversations* model was employed.

The New York State Department of Health learned of the *ACP Education through Employers*, and their goal was to provide interactive workshops for their staff. In this way, the focus was on practical ways to start the conversation, and was facilitated through participation exercises and role-play. By offering these sessions in two subsequent years during the National Healthcare Decisions Day initiatives, the state met their own goals of providing information as a public service.

A local hospital asked for another approach to inform their staff. The Clinical Ethics

Table 3.

Intranet Quiz	Responding True	Responding False	Correct Answer
A power of attorney in NYS allows the named individual to make Healthcare decisions for an incapacitated adult.	52%	48%	False
If a patient does not have decision making capacity and has not named a health care agent, their domestic partner is not allowed to make healthcare decisions unless they were legally married.	56%	44%	False
The next of kin can appoint a health care agent if the patient has lost decision making capacity.	56%	43%	False
A living will is an active medical order that must be followed similar to a MOLST form.	70%	30%	False
The hospital ethics committee should be consulted if a doctor disagrees with a health care agent's request to remove life sustaining treatment for an incapacitated adult.	89%	11%	True
MOLST does not need to be signed by a provider.	17%	83%	False
MOLST expires after six months.	29%	71%	False

Three local colleges hosted lectures on ACP for students and adult learners. Two requested interactive formats, and another

Committee at Ellis Hospital in Schenectady, NY found strong staff participation by offering an online intranet quiz. The purpose of the quiz was to ascertain if staff had an understanding of some commonly observed Advance Directive situations. The Ethics Committee felt that they could better address deficits in understanding by first assessing the level of knowledge. The quiz consisted of seven true/false statements relative to ACP challenges the Clinical Ethics Committee frequently encounters¹¹. Results of the quiz helped to identify opportunities for providing enrichment and education. Participants numbered 120 and included both clinicians and lay persons in the hospital. It became clear that there were gaps in knowledge, and next steps included interactive workshops scheduled throughout the year to provide accurate information. The hospital also offered follow-up through workshops as their tribute to National Healthcare Decisions Day. They reported that greater participation was realized through these workshops than through pamphlets alone, as done in previous years.

integrated the information into a Bioethics Pro-Seminar Workshop for Leadership in Medicine students^{12, 13}. Those undergraduate

students had recently been accepted into medical school programs. This author

developed learning objectives and outcomes, and was the lecturer for the programs.

Table 4.

Learning Objectives	Identify key interview skills for ACP discussions
	Describe strategies to create a clear and complete Advance Directive
	Identify strategies for conversations with family
	Demonstrate beginning competency in ACP discussions
Learning Outcomes	As a result of this program, I will...
	Complete my own AD in the next 6 months
	Have the conversation with a family member
	Have the conversation with my physician

5. Conclusions

The three distinct phases of ACP outreach and education provided a variety of forums to extend information to a community which was interested in how to go about approaching their concerns.

Recognizing opportunities is a key to growth and expansion within a community. The project demonstrates that ACP information

can be disseminated through standard models but also through special events including National Healthcare Decisions Day, Medical Grand Rounds, employer in-services and team meetings. Expanding outreach of information beyond the constraints of standard mailings and posted notices (by meeting with people and offering practical examples and training opportunities) engages and encourages everyone to take action in the preparation of ADs.

Resources

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