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Improving advance care planning by accommodating family preferences.

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CONTEXT: Family members often lack the knowledge of patients' values and preferences needed to function well as surrogate decision-makers. OBJECTIVE: To determine whether differences in values and preferences for the advance care planning process may be reasons family members are inadequately informed to act as surrogates. DESIGN: Face-to-face and telephone surveys using structured questionnaires. PARTICIPANTS: Two hundred forty-two pairs of dialysis patients and their designated surrogates. MAIN OUTCOME MEASURES: Content and number of end-of-life care discussions; patient and surrogate attitudes toward having patients express preferences explicitly; factors most important to surrogates in decision making; and within-pair agreement about the values of suffering and certainty. RESULTS: Ninety percent of patients designated a family member as their surrogate. In most cases, having more conversations about end-of-life issues did not increase surrogate knowledge of patients' values or preferences. Surrogates wanted written and oral instructions more often than patients wanted to provide them (62% vs. 39%, $p < 0.001$). Knowing the patient's wish to stop treatment in the present condition was more important to most surrogates than the physician's recommendation to stop treatment (62% vs. 45%, $p < 0.001$). Compared to patients, surrogates were less likely to want to prolong the patient's life if it entailed suffering (12% vs. 23%, $p < 0.01$) and were more concerned about being certain before stopping life-sustaining treatments (85% vs. 77%, $p < 0.02$). CONCLUSIONS: Differences in preferences for the advance care planning process between patients and their surrogates and failure to discuss specific end-of-life values and preferences may explain why surrogates often lack information needed to serve as surrogate decision-makers.

Arch Intern Med. 1998 Feb 23;158(4):383-90.

Death and end-of-life planning in one midwestern community.

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BACKGROUND: The major health care organizations in a geographically defined area implemented an extensive, collaborative advance directive education program approximately 2 years prior to this study. OBJECTIVES: To determine for a geographically defined population the prevalence and type of end-of-life planning and the relationship between end-of-life plans and decisions in all local health care organizations, including hospitals, medical clinics, long-term care facilities, home health agencies, hospices, and the county health department. METHODS: For more than 11 months, end-

of-life planning and decisions were retrospectively studied for all adult decedents residing in areas within 5 ZIP codes. These decedents were mentally capable in the 10 years prior to death and died while under the care of the participating health care organizations. Data were collected from medical records and death certificates. Treating physicians and decedent proxies were also contacted for interviews. RESULTS: A total of 540 decedents were included in this study. The prevalence of written advance directives was 85%. Almost all these documents (95%) were in the decedent's medical record. The median time between advance directive documentation and death was 1.2 years. Almost all advance directive documents requested that treatment be forgone as death neared. Treatment was forgone in 98% of the deaths. Treatment preferences expressed in advance directives seemed to be consistently followed while making end-of-life decisions. CONCLUSIONS: This study provides a more complete picture of death, end-of-life planning, and decision making in a geographic area where an extensive advance directive education program exists. It indicates that advance planning can be prevalent and can effectively guide end-of-life decisions.

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Editorial

Communication, Trust, and Making Choices: Advance Care Planning Four Years On*

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INTRODUCTION

DISCUSSIONS OF ADVANCE DIRECTIVES and advance care planning are omnipresent in end-of-life literature. Most every organization provides some assistance with advance directives and is compliant with the 1990 Patient Self Determination Act (PSDA)[1] and accrediting standards. Despite all these activities we still do not have a consensus on what we mean when we talk about advance care planning, nor what we take to be meaningful outcomes. Advance care planning is, at its most basic, a process of thinking ahead to treatment choices, goals of care, and/or choosing another person (a proxy) to speak for oneself at a point in the future.

In this issue of *Innovations*,* we take as a starting point, the successful community-wide advance care planning program, Respecting Choices®, spotlighted in the inaugural issue of *Innovations* in January 1999, along with the articulate critique from five international experts[2] of this "American" approach to improving decisions near the end of life. We examine an array of current efforts to conduct meaningful advance care planning as a way to revisit how these questions are being framed today. The trajectory of the Respecting Choices effort foreshadows the evolution of the field from a legal, document-driven effort to one that privileges the process of engaging patients, families, and surrogates in conversations about hopes, wishes, values, and goals of care. Respecting Choices began as an advance directive, community-wide education project, which had a relational focus that made it stand out from other contemporaneous efforts. Today, it has broadened to include more focused planning for individuals with a life-limiting illness to help them live well with what time remains.

These conversations do not exist in a vacuum, however. Building a system that aims to expect, honor, and act on these preferences has been a second and equally distinctive feature of the Respecting Choices effort in La Crosse, Wisconsin.[3] The importance of thinking in terms of systems remains a distinctive and vital part of this approach. Since the inception of this program in the early 1990s, the La Crosse team has worked to identify the crucial elements of any effective advance care planning system as well as how to define the roles and responsibilities of various health professionals working as a team within such a system.

The gist of the international critique, as summarized by Mildred Solomon, Ed.D., in her 1999 editorial,[4] was that the American approach leaned too heavily on assumptions of autonomy, at the expense of the family and community values that surround a patient. This overemphasis on autonomy was perhaps natural, given that this movement emerged out of a series of court cases in which the absence of documentation about patient wishes and preferences led to battles between families wishing to withdraw treatments

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and the state refusing to do so.[5,6] Documentation of wishes remains important. However, the international critique of the utility of advance directives was aimed at the unexamined assumptions underlying these tools as they had been implemented in the United States. Shimon Glick, M.D., Linda Kristjanson, Ph.D., Juan Núñez Olarte, M.D., Ph.D., Zbigniew Zylicz, M.D., Ph.D., and Carla Ripamonti, M.D., articulated alternate understandings of the context for end-of-life decision making.[2] Namely:

- In many societies, the family or larger group is the unit of care, not the patient alone. Decision making then becomes a more communal process rather than solely assessing what the patient wants. The most basic assumptions of disease cause and effect may not, in fact, be shared by some cultural groups. These cultural differences can create a canyon of misunderstanding between health care providers and families, especially when patient autonomy is emphasized.
- Even when patients, families, and health care providers share basic assumptions about disease and health, the detailed medical plans we make when healthy may change dramatically when we become ill. A document that reifies these earlier preferences may be of little use in guiding clinicians at a later time.
- Checklists that name acceptable vs. unacceptable procedures rarely accommodate the complexity of the real choices physicians and families face when a loved one is gravely ill.

The cross-cultural critiques of the value of advance directives that we published in our inaugural issue all pointed to the need for judgment, ongoing planning/conversation, and interpretation, in order to make appropriate treatment choices in real time, with real people. It is intriguing to note that the efforts we spotlight in this current issue of *Innovations* are all patient and family centered (that is, they move these relationships to center stage and simultaneously require more interpretation, ongoing planning/conversation, and judgment in order to make treatment choices that reflect patient and family values as well as clinical realities and the likelihood of particular treatments having the desired outcomes.

Because of the range and quality of recent work on advance care planning (ACP), we are devoting two issues of *Innovations* to this topic. The papers included in these two issues each report on ACP efforts taking place in a range of different settings (community, nursing home, outpatient clinic). Each sheds light on a particular aspect of ACP. The strengths and limitations of each effort, examined together in light of the work and commentary presented in the 1999 issue of *Innovations*, provide a real sense of the changing landscape of this topic. Taken together, this work demonstrates a greater focus on ACP models that privilege quality of communication, trust, and how family members and health care providers can function ethically in situations that are inherently ambiguous or even sometimes contradictory, rather than constructing checklists of to-do or not-to-do items. ACP is being considered more than just planning for or against particular treatments. It embraces a broader, needs-based view of care, necessitating coordination of resources and services within a community or region by an individual or a palliative care team, rather than the tendency to see the patient and family in isolation from their communities.

Moving from an individualistic focus to a more community-based focus is an ambitious undertaking because it puts the onus of planning on the health care providers as well as the patient and family. Considering what services might be needed when, ACP of this type is a more holistic, palliative approach to decision making, which includes time for considering alternative pathways, depending upon what stage of illness the patient is in and what the patient's goals of care are.

These efforts to make ACP more workable also shift medical care toward a much more family-centered[7]/relationship-centered model[8] of care. This move can allow for a figure-ground shift in the rationale for doing ACP. Instead of becoming an end, it becomes one vehicle or tool among many for enacting relationship-centered care, that is, care that includes patient and family input and mutually negotiated and evolving treatment choices.

This issue updates readers about the evolution of Respecting Choices and some of the statewide efforts it has spawned, and focuses on two approaches to conceptualizing and creating a trusting relationship among the patient, proxy, and health care provider, so as to best elicit and be faithful to the patient's values and wishes about their future care. Part 2 (Vol. 5, No. 3 of *Innovations in End-of-Life Care* at ⟨http://www2.edc.

org/lastacts/archives/archivesMay03/default/asp⟩) features a community-wide effort to improve ACP as part of a continuum of care, which also involves mapping and coordinating resources to meet a patient's particular needs, and a promising approach to ACP that includes palliative care pathways in a nursing home setting.

CONTINUING THE CONVERSATION ABOUT ADVANCE CARE PLANNING: PART 1

In the Featured Innovation, "Shifting the Focus of Advance Care Planning: Using an In-depth Interview to Build and Strengthen Relationships," Linda Briggs, R.N., M.S., M.A., reports on evolving work to come out of the La Crosse program: the patient-centered ACP interview, constructed for use with persons suffering from chronic life-threatening illness and their surrogates. Ms. Briggs reflects on how this in-depth interview moves the focus of the intervention squarely onto what Kolarik et al.[9] call the "social purposes" of ACP—i.e., educating patients and families about the possible or likely illness trajectory, opening up a conversation and communication among the members of a triad: health care provider, patient, and surrogate. Listening is a key part of the process. The conversation only goes where the patient and surrogate want it to go, allowing health care providers to offer various "truths," as advised by the late Canadian researcher Dr. Benjamin Freedman,[10] but it does not require patients to discuss topics that do not feel relevant or that they are plainly not ready to discuss. This interview also includes attention to documentation. Ms. Briggs' reflective report on the development of the patient-centered advance care planning interview provides theoretical underpinnings for this approach and raises the question: what is the purpose of ACP for persons with chronic life-threatening illness? Ms. Briggs maintains that offering opportunities for patients who are living with chronic, difficult conditions to speak openly with loved ones about current quality of life and future wishes was the most valuable element of this intervention, although clearly there is also much value to documenting these decisions and entering them into the system.

However, this approach surfaces the potential for real differences to exist between providers and patients regarding the prognosis and its meaning, and therefore, what actions are reasonable to take, given what is known. In order for this approach to stay patient-centered, it will require the health professional to enter into a dialogue with the patient and surrogate and not simply to trump the beliefs and goals of those receiving care.

The Promising Practice in this issue further delineates the ways that all ACP depend upon interpretation and judgment. Barbara Maltby, M.A., and Joseph Fins, M.D., FACP, have created a set of educational tools for communities to use,[11] based on Dr. Fins' argument for a patient–proxy relationship that has more in common with a covenant than a contract.[12] In "Informing the Patient–Proxy Covenant: An Educational Approach for Advance Care Planning," the authors describe the rationale for their interactive workbook. They summarize their earlier critiques of the proxy contractual model, one that they feel puts proxies in a straightjacket and cuts them off from the intimate, in-depth knowledge and variegated understanding of the patient that many proxies have. This covenantal model seeks to create a framework that can hold that deeper knowledge, and honor the trust in judgment that many wish to bestow on their proxies, unfettered by particular do's and don'ts to be applied against an unknowable future. The authors wish to acknowledge that entering into a patient–proxy relationship involves mutual responsibilities, and one of the goals of these materials to is to create a context for patients and proxies to explore the obligations and burdens assumed by the proxies in advance of the need to make decisions. To do so, they have created a series of vignettes designed to illustrate a variable prognosis and to serve as triggers for in-depth discussion of end-of-life situations and what patients might wish for in those times. The materials include commentary and helpful hints, so that participants are not left facing these discussions with no one right answer, in a void. The aim of this intervention is that in the face of uncertainty, participants should enter into meaningful dialogue about goals for care and potential treatment, not about exact procedures to undertake or avoid. Ultimately, this dialogue aims to deepen the proxy's understanding of the patient and for the patient to understand what may be asked of the proxy, as well as to confirm the proxy's confidence in his or her ability to take on the covenantal role of decision maker on behalf of the patient at an unknown point in the future. Again, this effort requires

trust, judgment, interpretation, and acceptance of a certain degree of "messiness" or a willingness to grapple with uncertainty—hallmarks of a relational approach.

This issue of *Innovations* also includes Dr. Cameron Bopp's review of *Long Goodbye: The Deaths of Nancy Cruzan* by William H. Colby (Hay House, 2002). It is important to keep sight of the tragedy that can and did ensue in the absence of documentation of patient wishes and beliefs. Revisiting this family's struggle to remove a feeding tube from their 28-year-old daughter who was in a persistent vegetative state as a result of a car accident is sobering. The Supreme Court decision that emerged from this case provided clarification that patients and their health care proxies have the right to refuse or withdraw treatment at the end of life, and that there is no rational difference between "extraordinary" treatments, such as ventilator support, and "ordinary" treatments, such as medically supplied nutrition and hydration.

Last, this issue includes an update on the progress made on Respecting Choices in La Crosse, Wisconsin, and descriptions of two statewide efforts to adapt the Respecting Choices model. Since 1999, a great deal of work has occurred in La Crosse to develop the Respecting Choices model so it could be implemented in other communities and organizations. This required a more perceptive understanding of what aspects of the program contributed to success. It also required the development of print and teaching materials so the program could be disseminated to others. At this point, more than 25 groups in the United States and Australia are attempting to implement a Respecting Choices type of program in an organization, network, community, or across a whole state. Common barriers faced by these groups include a lack of resources (both time and money), difficulty in changing routines/medical cultures, and the lack of understanding of the value of effective ACP.

Two of the groups implementing a Respecting Choices type of ACP program are doing so on a statewide basis. These include the New Hampshire Partnership for End-of-Life Care and the Carolinas Center for Hospice and End-of-Life Care. The reports from these two state projects describe the steps that have been taken to improve the quality and prevalence of ACP. These are ambitious programs that are attempting to change the culture around planning by creating educational materials that motivate and assist discussion, training ACP facilitators, and changing state policy and practice. The La Crosse program itself continues to evolve and develop as more effective and broader approaches to ACP are identified.

It is still too early to measure the full impact of the statewide programs. Perhaps the biggest concern is that these programs have not had as much success working directly with hospitals, clinics, and other health facilities. This lack of buy-in from health organizations is the result of approaching the problem from a statewide perspective. It is still to be seen if success at respecting patient choices can be achieved without significant buy-in from these health organizations or if these statewide approaches will eventually lead to changes in the routine of these health facilities. What does seem to be evident is that a more process-oriented, relational approach to advance care planning can be taught and implemented in other settings. It also seems that this approach to ACP can be reflected in community educational materials and state policies. In short, the approach pioneered by Respecting Choices does seem amenable to adoption by communities outside of western Wisconsin.

CONTINUING THE CONVERSATION ABOUT ADVANCE CARE PLANNING: PART 2

In Part 2 (the May–June 2003 issue of *Innovations*), "A Framework for Collaborative Consumer-Centered Care" by Sally Okun, R.N., B.S.N., M.M.H.S., offers an example of a grassroots community effort to adapt the Respecting Choices materials in order to integrate the principles of ACP into the provision of health care across the community. Hospice and Palliative Care of Cape Cod (HPCCC) initiated a program called LifeCare Conversations®, which takes a community-organizing model and assimilates the tools and message of La Crosse into Sally Okun's homegrown concept of CAReTOGRAPHY, an assessment mapping tool that identifies the web of relationships and resources that may surround and support a person. The process of engaging in this mapping leads to uncovering both previously unrecognized needs as well as previously unknown resources. Ms. Okun's key message is

that if you engage in ACP planning with someone, and view the person as embedded within a community or region that includes a range of resources, this conversation brings to the fore the potential for coordination across entities and reimbursement streams of those community resources, the health care provider, patient, and family members. Hospice and Palliative Care of Cape Cod created a palliative care service to address the needs uncovered by these community awareness-raising activities.

As the name implies, LifeCare Conversations does not limit ACP discussions to end-of-life issues, but seeks to help health care consumers and their providers become more skilled in exploring options and understanding choices for any health care decision as a routine component of quality care across the life span. The broad community-based focus of this effort was started from within HPCCC (which holds the rights to the name LifeCare Conversations), but the vision Ms. Okun describes is of a community coalition to embrace and enact these ambitious goals. The element of community transformation is innovative, yet may also make this approach difficult to implement and sustain. This HPCCC effort has thus far been dependent upon the charismatic and tireless leadership of Ms. Okun and several key actors, and HPCCC has fully supported its operational expenses with some limited philanthropic grants; now, however, responsibility for the effort is being shifted to the organization's Community Advisory Board. Sustaining this kind of effort in tough economic times will be a challenge. However, the CAReTOGRAPHY tools and vision that underlie this approach offer some liberating lessons about transforming end-of-life care: Make the person in need the center of your puzzle, and then identify their needs along with existing relationships and health care resources that might be coordinated to serve those purposes, regardless of reimbursement streams, and begin to construct meaningful plans for coordinating care. As with many examples of innovation highlighted in these pages, mindfulness is one of the core features of this effort.

Muriel Gillick, M.D., in her article "Adapting Advance Medical Planning for the Nursing Home," moves us into the world of the nursing home, one she describes as a "wasteland" for ACP, in spite of the fact that as "home" to elderly frail residents, it is one of the health care settings patients are most likely to die in if they are not discharged to acute care settings. She describes a care pathway model that takes into account both patient and family goals of care, as well as evidence-based medicine and the likelihood that any given treatment would make a difference in patient quality of life. The care pathway model has advantages and limitations. Similar to the work of Fins and Maltby,[11] this model requires mindful judgment, in this case on the part of health care providers, because patients in this setting often cannot speak for themselves and families may be absent at critical times. Many of us would wish for practitioners who were authorized to use their best judgment, if we trusted that they understood our goals and values. However, risk taking, interpretation, and using best judgment thrive in systems characterized by trust, teamwork, and open communication, including feedback loops in which mistakes are characterized as opportunities for learning, rather than being penalized. Some nursing homes may live up to this high standard, but few institutions do across the board. One of the challenges of this model is how to create and sustain a system and culture that rewards mindful judgment and can tolerate anomalies.

Dr. Gillick describes the nursing home as a setting in which it would seem most challenging and perhaps most important to enact ACP, given that more than half of nursing home residents suffer from dementia and may not be able to articulate their own wishes. These conditions make it all the more compelling for health care providers to create a system that can take patients' earlier preferences and a family's ongoing wishes into account, yet allows the health care providers the opportunity to draw on their knowledge and expertise.

Melodie Heland, R.N., M.S., describes the impact of implementing the Respecting Choices program in Australia in her Personal Reflection in this issue. Her experience confirms the salutary effects of engaging health care professionals in relationship-centered care, as she describes the ways in which this program can buffer feelings of futility and burnout. She contrasts this with earlier experiences of providing care that felt like it betrayed the trust of one's patients (e.g., reverting to "doing everything" in the absence of ACP) in ways that cause patients pain and suffering, and diminish caregivers' sense of professionalism.

CONCLUSION

ACP is now moving into the uncharted territory of trust—continuing to discuss hopes, dreams, and assumptions of future care—but often with less focus on particular interventions. Instead, ACP is now offering a more global promise to follow through with a consistent quality and kind of care—care that engages patients who are gravely ill earlier in their illness, and opens difficult conversations about an uncertain future among patients, their loved ones, and health care providers. Trust must be present in order for this approach to work. As David Barnard, Ph.D., notes, making a space for gravely ill persons to have these potentially meaningful conversations is in itself a valuable undertaking.[13] This slight shift in emphasis makes ACP a route to promoting patient-centered care.

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End-of-Life Care: Guidelines for Patient-Centered Communication

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When patients are diagnosed with cancer, primary care physicians often must deliver the bad news, discuss the prognosis, and make appropriate referrals. When delivering bad news, it is important to prioritize the key points that the patient should retain. Physicians should assess the patient's emotional state, readiness to engage in the discussion, and level of understanding about the condition. The discussion should be tailored according to these assessments. Often, multiple visits are needed. When discussing prognosis, physicians should be sensitive to variations in how much information patients want to know. The challenge for physicians is to communicate prognosis accurately without giving false hope. All physicians involved in the patient's care should coordinate their key prognosis points to avoid giving the patient mixed messages. As the disease progresses, physicians must reassess treatment effectiveness and discuss the values, goals, and preferences of the patient and family. It is important to initiate conversations about palliative care early in the disease course when the patient is still feeling well. There are innovative hospice programs that allow for simultaneous curative and palliative care. When physicians discuss the transition from curative to palliative care, they should avoid phrases that may convey to the patient a sense of failure or abandonment. Physicians also must be cognizant of how cultural factors may affect end-of-life discussions. Sensitivity to a patient's cultural and individual preferences will help the physician avoid stereotyping and making incorrect assumptions. (*Am Fam Physician.* 2008;77(2):167-174.

ILLUSTRATION BY MARK SCHULER

This article is one in a series created in collaboration with the American Cancer Society. Coordinator of the series is Ted Gansler, MD, MBA, Emory University, Atlanta, Ga.

▶ See related Close-ups on page 140.

Primary care physicians have the opportunity to maintain long-term, trusting relationships with patients and are well positioned to discuss difficult issues such as newly diagnosed cancer or terminal illness.[1] However, primary care physicians may not feel equipped to discuss end-of-life care. The lack of physician training in this area and patient or physician fear may lead to discomfort when communicating bad news.[2] Providing care throughout a patient's illness can be highly gratifying for physicians and may lead to better patient outcomes. Using a systematic approach can help primary care physicians discuss prognosis appropriately, offer realistic hope, provide therapeutic options, coordinate disease transitions, and relieve patient suffering.

Communicating Bad News

Illustrative case, part A: *A 57-year-old female schoolteacher recently received a screening colonoscopy. During the procedure, a 2-cm × 2-cm sigmoid mass was biopsied. The mass was diagnosed as a poorly differentiated adenocarcinoma. The patient is waiting at the clinic to see her primary care physician to discuss the results.*

Breaking bad news, particularly discussing prognosis, requires a combination of disease-specific biomedical knowledge and excellent communication skills.[3] When bad news is delivered incorrectly, it can lead to long-term consequences such as poor psychological adjustment for patients.[4,5] Therefore, recommendations have been developed to help physicians appropriately deliver bad news *(Table 1)*.[2,5-14]

SORT: KEY RECOMMENDATIONS FOR PRACTICE

Clinical recommendation	*Evidence rating*	*References*
When preparing to give bad news, it is important for physicians to assess the patient's level of understanding about the disease and expectations for the future.	C	2, 11, 12, 14
When preparing to give bad news, it is important for the physician to assess how much information the patient wants to know and to tailor the discussion appropriately.	C	3, 15
The primary care physician should remain involved with patient care during the early, middle, and late stages of cancer.	C	22
Physicians should initiate discussions about the availability of coordinated, symptom-directed services such as palliative care early in the disease process; as the disease progresses, physicians should transition from curative to palliative therapy.	C	23, 24
Physicians should avoid phrases and words that can be misconstrued by the patient and lead to negative interpretations such as abandonment and failure.	C	12, 14, 27
During end-of-life communication, physicians should assess and be sensitive to the patient's cultural and individual preferences.	C	28-34

A = consistent, good-quality patient-oriented evidence; B = inconsistent or limited-quality patient-oriented evidence; C = consensus, disease-oriented evidence, usual practice, expert opinion, or case series. For information about the SORT evidence rating system, see page 131 or http://www.aafp.org/afpsort.xml.

Table 1. Recommendations for Patient-Centered Communication When Discussing Bad News

Recommendation	*Comments*
Prioritize: Prioritize what you want to accomplish during the discussion	Ask yourself: What are two to four key points that the patient should retain? What decisions should be made during this encounter? What is reasonable to expect from the patient during this encounter?
Practice and prepare: Practice giving bad news; arrange for an environment conducive to delivering the news	Rehearse the discussion; arrange for a private location without interruptions; set cell phones and pagers to vibrate or turn them off; ask the patient if he or she wants to invite family members
Assess patient understanding: Start with opening questions, rather than medical statements, to determine the patient's level of understanding about the situation	Ask the patient: "What do you already know about your condition?" "What does it mean to you?" "What do you think will happen?"
Determine patient preferences: Ask what and how much information the patient wants to know	Assess how the patient wants the information presented; ask the patient, "Some of my patients prefer hearing only the big picture, whereas others want a lot of details. Which do you prefer?"
Present information: Deliver information to the patient using language that is easy to understand (do not use medical jargon); provide a small amount of information at a time; check periodically for patient comprehension	Provide a few pieces of information, and then ask the patient to repeat it back to you
Provide emotional support: Allow the patient to express his or her emotions; respond with empathy	Assess the patient's emotional state directly and often (ask the patient: "How are you doing?" "Is this hard for you?" "You look frustrated/disappointed/angry—is that true?" "Let me know when we should continue"); use nonverbal cues such as eye contact; listen to what the patient says and validate his or her reactions with empathic statements such as "I understand that this is very difficult news."
Discuss options for the future: Devise a plan for subsequent visits and care	Help the patient understand the expected disease course and how the disease may or may not respond to treatment; schedule follow-up visits (ask the patient: "Can we meet next week to discuss treatment options and any questions you may have?")
Offer additional support: Provide information about support services	Bring handouts and pamphlets to the visit; refer the patient to support groups, psychologists, social workers, or chaplains
Consider individual preferences: Assess patient preferences, and tailor the discussion appropriately	Consider the patient's sex, age, health literacy, health status, previous health care experiences, social status, culture, and race/ethnicity; avoid assumptions about what the patient is likely to want; ask the patient directly about values and preferences

Information from references 2 and 5 through 14.

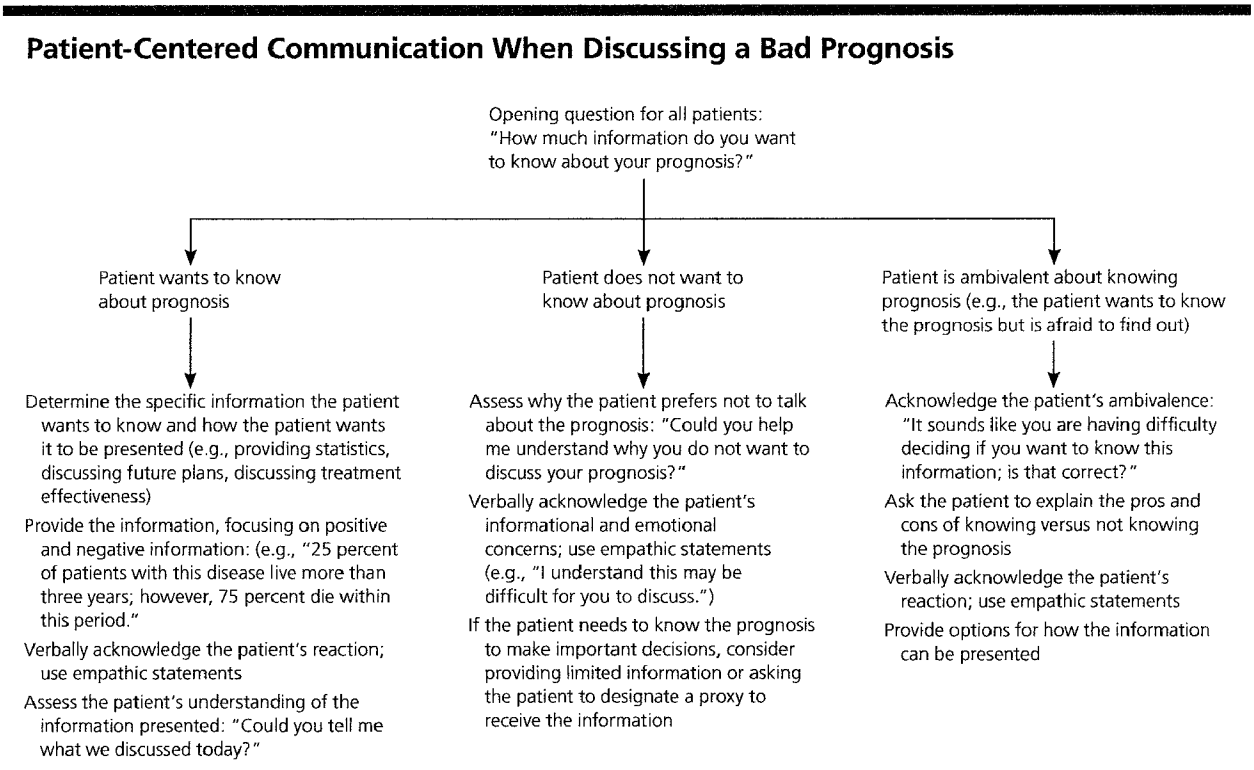

Figure 1. Algorithm for patient-centered communication when discussing a bad prognosis.

Information from references 3, 15, and 16.

Physicians should customize discussions, especially in situations that are stressful for the patient. Specifically, physicians should assess the patient's understanding ("Tell me what you know about this disease."); emotional state ("This is a lot to take. How are you doing?"); and readiness to engage in the discussion ("Let me know when you're ready to continue."). At each visit, physicians should assess whether patients have physical or psychological symptoms that need to be addressed ("How are you doing/coping?" "Is anything interfering with your quality of life?").[2,6-13]

Discussing Prognosis

Illustrative case, part B: *After surgery, the patient was diagnosed with stage III, two–node-positive colon cancer. Her oncologist discussed the prognosis with her and recommended adjuvant chemotherapy. The patient is still confused about what to do. Distraught, she calls her primary care physician and asks, "What should I do? Will I die soon?"*

It is best to discuss prognosis after accurate cancer staging. In preparation, all physicians involved in the patient's care should coordinate their key prognosis messages to avoid confusing the patient. Physicians should be prepared to discuss the natural history of the disease, treatment and its adverse effects and outcomes, and the patient's probable quality of life. Additionally, physicians should discuss expected five- to 10-year survival rates, with and without treatment, and should address patient fears (e.g., fear of undergoing treatment, suffering, abandonment, or death). Empathic listening can ease and comfort patients.

Physicians should assess the patient's desire and readiness to receive the prognosis.[3,15,16] The desired amount of information varies among patients. Approximately 80 percent of patients want detailed information about their prognosis, whereas 20 percent prefer not to know complete prognostic information.[17,18] Thus, physicians should assess how much information to provide using patient-centered communication *(Figure 1[3,15,16])*.

After assessing the patient's readiness to receive prognostic information, the physician should focus on communicating the prognosis without giving false hope.[19] One approach focuses on expectations (hoping

for the best, planning for the worst), which allows physicians to discuss the worst-case scenario with the patient without taking away the possibility of the best-case scenario. After acknowledging the patient's expression of hope, the physician can ask whether the patient thinks that hope is realistic or probable.

Another approach focuses on providing the patient with a full spectrum of treatment options. A recent study showed that some patients elected to participate in phase I clinical trials of chemotherapy, even though the likelihood of benefit was low. When asked why they chose to participate in these trials, patients reported feeling like they had to do something.[20] Providing options can validate the patient's need to be actively involved in his or her care.

As terminal illness progresses, physicians should transition from curative to palliative therapy.

Similarly, another approach focuses on sequential treatment options. In this approach, the physician supports the patient in undergoing a treatment, but also discusses what the next step would be if the initial treatment is unsuccessful. This approach sets practical parameters and allows discussion of alternatives if the goals of care are not attained.

The goals of care change as the disease progresses. At each stage, the physician should help the patient create realistic, achievable goals and hopes. Initially, patients might hope that the cancer responds to chemotherapy or surgery. When disease control is no longer possible, patients might hope to live pain free, achieve closure on personal issues, or die surrounded by friends and family. Focusing on stage-specific goals and hopes can prevent over- and undertreatment while relieving the patient's psychological distress.[21]

The Physician's Role at Different Stages of Disease

Illustrative case, part C: *The patient's functional status has deteriorated rapidly. During chemotherapy, she developed esophagitis and recurrent neutropenic fever. Now, abdominal studies demonstrate early obstruction. Her primary care physician asks himself, "At this stage, what is my role in her care?"*

The primary care physician's role changes at each stage of a patient's illness (*Table 2*[2,6,12,16,22]). Ideally, primary care physicians form the backbone of an integrated team by providing an unbiased medical perspective, providing continuity during a stressful disease course, supporting patients and their families through emotional ups and downs, negotiating or mediating decisions, monitoring for complications, and providing perspective on the illness.[6] This role is tempered by practical considerations such as the physician's practice and relationships with colleagues, available resources, and individual patient needs.

Negotiating this role to the satisfaction of everyone involved in the patient's care requires open communication. Simple questions can be asked to clarify each participants expectations: (1) to the patient: "Do you understand what is going to happen next? How are you and your family coping with this news?"; (2) to the subspecialist: "What are the expected benefits and harms from this new treatment? How much benefit accrues to the patient?"; and (3) To the health care team: "What additional resources can we mobilize for the patient?"

Primary care physicians may need to be proactive to stay involved in the patient's care.[2] When referring a patient to an oncologist, primary care physicians can communicate their desire to continue caring for the patient. The physician also can ask subspecialists who are caring for the patient to provide periodic updates, and the physician can offer input or advice if the subspecialists have questions. The physician can schedule follow-up visits with the patient, even while the patient is undergoing chemotherapy or radiation.

However, primary care physicians may be uncomfortable with cancer care and may wish to transition the care of the patient to an oncologist or palliative care subspecialist. In this instance, it is important for the physician to communicate to the patient that the physician is still available, but that the subspecialists will be the main caregivers.

Table 2. The Primary Care Physician's Role in Patient Care During Different Stages of Cancer

Role	*Early stage*	*Middle stage*	*Late stage*
Breaking bad news	Discuss diagnosis, disease course, therapeutic options, patient/family values and goals, and treatment preferences	Discuss treatment effectiveness	Assess patient/family understanding of prognosis and disease course
Communicating prognosis	Discuss expected prognosis	Help the patient understand changes in prognosis and refocus expectations; revisit values and preferences	Objectively discuss the advantages and disadvantages of experimental treatment, if offered by a subspecialist; discuss palliative care options such as hospice
Discussing disease transitions	Focus primarily on medical treatment while assessing palliative needs; the goal is extending life while improving quality of life	Focus on medical treatment and palliative needs	Focus explicitly on palliative care to relieve symptoms (e.g., pain, shortness of breath, fatigue, nausea); the goal is improving quality of life, including treatment of metastatic disease that is causing symptoms (e.g., bowel obstruction, bony metastasis)
Coordinating care	After referring the patient to a subspecialist, request that the patient schedule follow-up visits with you; ask the subspecialist to update you on the patient's care	Monitor the patient for symptoms and adverse effects (physical and psychological); discuss hospice as a therapeutic option; encourage the patient to begin advance care planning (e.g., advance directives, durable power of attorney for health care, living will) in case of deteriorating health	Discuss likely benefits and harms of major therapeutic options; discuss palliative care options
Providing support	Allow the patient to express emotion; answer questions and address concerns; provide emotional support and empathy; refer patient and family to support groups or counseling	Answer questions and address concerns; provide emotional support and empathy	Answer questions and address concerns; provide emotional support and empathy; reassure the patient that he or she will not be abandoned

Information from references 2, 6, 12, 16, and 22.

During the disease course, the patient's palliative and medical needs intensify. Innovative models can help physicians bridge the gap between traditional curative care and palliative care.[23-25] Physicians assess palliative needs (for relief of suffering) throughout treatment. As the disease progresses, the focus shifts from curative therapy to palliative therapy. During this transition, the primary care physician should offer realistic hope and provide guidance in choosing appropriate treatment and palliative strategies.

Using simultaneous-care models, physicians can provide palliative and curative care at the same time. Newer open-access hospices provide full hospice care while allowing patients to receive disease-directed therapy. In many open-access hospices, patients may receive chemotherapy, radiation, blood transfusions, dialysis, or total parenteral nutrition.

Patients also may receive intense skilled palliative care at home (home-based hospice), often with family members as paid caregivers. A home-based hospice program is a modified version of the traditional home care model and, based on the argument that palliative care is a skilled need, is paid for by most insurance companies. Research shows that, compared with traditional home care, home-based hospice programs can improve patient satisfaction, reduce emergency department and physician office visits, and shorten nursing home and hospital stays while reducing costs by 45 percent.[26]

When discussing the option of hospice or other palliative care, physicians must be careful not to convey to the patient a sense of abandonment. Early in medical training, physicians may learn to use phrases that reflect a singular focus on curative therapy.

If physicians see their role as only to cure disease, they may subconsciously convey their sense of failure to the patient if curative treatments are unsuccessful, and that cessation of curative options means the end of the physician's care. The shift from curative to palliative care is merely a change in the type of care that the physician is providing. *Table 3* offers alternatives to commonly misconstrued physician phrases used in end-of-life discussions.[12,14,27]

Cultural Diversity and Individual Preferences

When a patient and physician enter into end-of-life discussions, each brings individual cultural backgrounds and values, which influence the discussions. Although understanding cultural norms is important, physicians must be careful to avoid stereotyping patients based on their culture.[28]

Individual culture is influenced by the culture of the family, religion and spirituality, education, occupation, social class, friends, and personal preferences. Asking open-ended questions can elicit the patient's preferences for physician frankness, decision making, and direct versus indirect communication *(Table 4[28-34])*. Conflicts may arise when patients and families want care that physicians think is medically futile. Physicians may prevent misunderstanding and promote trust by respectfully listening to patients' beliefs and values and by negotiating mutually acceptable goals.

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Table 3. Commonly Misconstrued Physician Phrases Used in End-of-Life Discussions with Patients

Physician phrase	*Possible patient interpretation*	*Alternative phrase*
"There's nothing we can do for you"	Abandonment: "My physician doesn't want to see me anymore"	"We can offer many options to control your symptoms and make you feel better"
"It's time to think about withdrawal of care"	Cessation of care: "My physician doesn't want to care for me anymore"	"Do you think that it is time to consider a different type of treatment that focuses on your symptoms? I'll be here with you no matter what you decide"
"Do you want us to do everything that we can to keep you alive (e.g., artificial life support)?"	Cessation of appropriate care: "If I don't have them do everything, I won't get the best medical care"	"If you become extremely ill, would you want to be put on artificial life support, or would you prefer a natural death?"
"You've failed the treatment (e.g., chemotherapy, radiation)"	Personal failure: "I've disappointed my physician"	"The cancer has not responded to the treatment as we had hoped. How are you doing?"
"I think you should consider hospice"	Despair and hopelessness: "I'm going to die soon"	"I want to provide intense, coordinated care with a team of professionals who will treat your symptoms and help you stay comfortable"

Information from references 12, 14, and 27.

Table 4. Considerations for Cultural and Individual Patient Preferences in End-of-Life Discussions

Considerations	*Questions for patients*	*Potential consequences*
Physician frankness (indirect or direct communication)	"How much do you want to know about your medical condition at this time?" If the patient prefers not to know everything: "Do you want to talk about this again at another time?"	Physician may be regarded as rude, cruel, and uncaring if the physician is frank about the patient's condition when the patient is not ready to hear it or prefers to learn the information indirectly from a family member The patient may experience feelings of hopelessness, depression, or anxiety if not psychologically ready to hear a bad prognosis or if he or she prefers to remain hopeful about the condition
Involvement of family members or preference for autonomy	"Would you prefer that I discuss your medical condition with you directly, or would you prefer that I discuss it with a family member?" If the patient prefers that you discuss it with a family member: "Would you like to be present during the discussions about your medical condition?"	Disagreements between the family or patient and the physician may occur when the physician does not assess whether the patient or family prefers family members to be involved The patient may feel isolated if the family is not involved in discussions
Decision making	"How do you want to make decisions regarding your health care?" "Do you want to make a decision yourself after I have given you all of the options?" (nondirective counseling) "Do you want me to suggest what I think is the best option?" (directive counseling) "Do you want to discuss the pros and cons of treatment and then make a decision together?" (shared decision making)	Unwelcome decisions may be made for the patient, and there can be a lack of collaboration between physician and patient (and family) if the physician uses directive counseling when the patient prefers nondirective counseling The patient can lose confidence in the physician if the physician uses nondirective counseling when the patient prefers directive counseling
Advance care planning	"What are your goals for your life, right now?" "How do you feel about prolonging your life with artificial life support, even if there was no chance that you'd be able to live independent of the machines?" "If you became unable to make your own health care decisions, who would you want to make them for you?"	Overuse of potentially futile, aggressive care at the end of life and underuse of hospice services may occur if the patient does not endorse or understand available advance care planning options
Social, educational, and family factors	"Tell me about your family" "Have you or your family had significant experience with someone with a serious illness?" "If so, how did that experience affect you?"	The physician may offend or stereotype the patient because of incorrect assumptions if the physician does not ask about the patient's background Misunderstandings between physician and patient may occur if the physician does not assess social, educational, and family preferences
Religious and spiritual factors	"Is there anything I should know about your religious or spiritual views before we discuss your medical condition?"	The physician may be regarded as disrespectful if the patient's religious and spiritual preferences are not addressed The patient may reject medical advice if the physician does not understand how the patient views the physician's role and advice in the context of religion or spirituality

Information from references 28 through 34.

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Case Discussion

I was consulted to see a patient in the SICU with a complicated hospital course. She had an open abdomen secondary with peritonitis and multiple abdominal abscesses requiring wash out procedures every 48 hours. She had developed renal failure and was dialysis dependent. She had developed respiratory failure and was ventilator dependent and had failed to wean multiple times. She was s/p tracheostomy placement.

(Patient) was initially reluctant to come to the hospital and had said many times that she just wanted to go home. She would say, "I don't want to die but I don't want to be here anymore." Palliative care was consulted on hospital day # . To clarify goals with the patient as she started to make statements to the staff about stopping treatment.

Palliative care became involved and discussed the hospital course with the patient and her daughter, health care surrogate, who wants everything done. We explained that if her mom is to survive the hospitalization that she would need to be treated in an LTAC and at this point would likely be ventilator dependent. She said, "My mom wants to live". She said that she is frustrated and confused when she makes those statements and she doesn't want to die.

The following week the patient refused dialysis. Her husband had been dialysis dependent and had died after choosing to discontinue treatment. She requested that no more dialysis be done and the SICU attending said, "I believe that with time she can recover from these injuries and we should continue providing care."

We were consulted to clarify goals of care.

The SICU attending and surgery resident met with the patient but they couldn't get her to change her mind. I communicated with her and she was awake and alert communicating with lip reading. Her expressions supported her statements and she said, "I want to stop this now. I don't want to wait for my daughter and son to get here." During an extensive interview she said, "I talked with my PCP and he said I would be off the ventilator by this week. I want to be disconnected from the ventilator and taken down to the lobby and he will drive me home. Call him!" I called the doctor as she requested and he said he hadn't spoken with her or the family for over a year. I called the daughter and explained that her mom likely was experiencing ICU delirium and I would treat this condition but if the delirium resolves and she maintains this wish to discontinue life prolonging interventions then we would respect her wishes. I encouraged her to come to the hospital and contact her siblings as well and she complied.

The next day the family had visited and the patient was communicating clearly and told them that she didn't want to continue further treatment and she new she would die. They supported her decision and requested only that we leave the tubing connected to the tracheostomy. We ran humidified oxygen through the heater unit on the ventilator and turned off the support. She became asystolic within an hour and died peacefully with her family at the bedside.

CE EVALUATION FORM

Respecting Choices POLST Paradigm Program Advance Care Planning Facilitator Course

July 28, 2015 N = 25

A. Circle the number that represents how you rate the conference:

CONTENT: 5.0	IMPRACTICAL	1	2	3	4	5	USEFUL
KNOWLEDGE: 4.8	CONVENTIONAL KNOWLEDGE	1	2	3	4	5	NEW KNOWLEDGE
AUDIO/VISUAL AIDS: 4.9	INADEQUATE	1	2	3	4	5	HIGHLY USEFUL
PRINTED MATERIALS: 4.9	INADEQUATE	1	2	3	4	5	HIGHLY USEFUL
LEARNING ENVIRONMENT: 4.8	NOT CONDUCIVE	1	2	3	4	5	CONDUCIVE
HOSPITALITY: 4.9	POOR	1	2	3	4	5	EXCELLENT
GENERAL OVERALL RATING: 5.0	POOR	1	2	3	4	5	EXCELLENT

B. We are interested in assessing the impact of this educational activity. Please consider the objectives and then rate with (1) being Not Confident and (5) being Very Confident, how confidently you can...

Objectives:		Not Confident		Neither		Very Confident
Identify skills to initiate POST-type conversations with persons with life-limiting illness, designated healthcare agents, and their loved ones	Prior to Participation: 3.0	1	2	3	4	5
	After Participation: 4.6	1	2	3	4	5
Identify skills to assist in making informed end-of-life treatment decisions to include CPR, limitations on treatment, time limited trials, and comfort care	Prior to Participation: 3.0	1	2	3	4	5
	After Participation: 4.5	1	2	3	4	5
Identify techniques to create a POST document that accurately reflects an individual's treatment decisions	Prior to Participation: 2.7	1	2	3	4	5
	After Participation: 4.5	1	2	3	4	5

C. What, if anything, hindered your learning?

1. How I have filled these forms out in the past.
2. cold.
8. Slightly cold room-but not that bad.
17. Hadn't taken time to education myself

D. What is your profession? 10 Nurse 11 Social Worker 1 Clergy 4 Other

E. Do you plan to change your practice based on what you learned today? 25 Yes 0 No

What will you do differently in your practice as a result of this conference?

1. Explain the form more in the work place; investigate how I can be of help in my facility.
2. Provide more opportunity for discussion with the patient and family and also provide training to other staff.
3. Keep a list of advance directive conversations with patients.
4. Improved open ended questions and flow of conversation facilitating patients experience/wishes.
5. Take more time for discussion and understanding.
7. I will take more time to have thorough discussion with people.
8. Use of "scripts" to help better facilitate EOL discussions/POST introduction and completion.
9. Be able to explain the POST form better, answer questions for families better.
10. Encourage further discussion.
11. Feel more confident in discussing options available to patient/family.
12. Listen to residents and families more.
14. Utilize the script and gain more knowledge form pt. statements.
15. Use POST form appropriately-ask surprise questions.
16. Take more time to talk to residents and families to assess their needs.
17. Go back to SNR and implement new processes and systems and read through QA committee.
18. More aware of language and process.
21. Spend more time with the patients and family to make sure all areas have been covered and discussed appropriately.
23. Work harder at facilitating family involvement.
24. I will use the CPR handout a lot.
25. Have better information available and incorporate the interview skills.

Did information you learned today reinforce your confidence in your current practice? 22 Yes 0 No

F. Did you perceive this presentation to include a bias towards any commercial health care product or service, produced by for-profit companies? 0 Yes 26 No

G. What topics would you like to see discussed at future conferences?

3. What consequences are there for people who do not follow a person's instructions.
5. MPOA/living will and HCS guidelines.
7. Health Care surrogacy.
10. More reference materials or directing towards educational materials for patients/families.
11. Barriers of communication when goals cannot be met and what additional words or phrases help to open lines of communication.
13. Advanced directives and the direction they are going with new electronic records.
14. Palliative care practices.
18. Introduction of POST to community organizations.
25. More info on specific end of life health care needs.

H. What do you consider to be the single biggest problem that you face in your practice?

2. Getting other providers on board to provide the type of discussion and follow through.
7. Limited amount of time available.
8. preconceived ideas/mis-information.
9. Being able to spend efficient time with the patient and families.
10. No prior discussions w/patients/families.
11. Fear of comfort measures equals giving up on loved ones.
13. no one wanting have end of life conversations with patients/families.
14. Time.
15. Misunderstanding of appropriate use of POST form.
17. Lack of knowledge of families and residents on their disease, options, and disease process.
18. Getting all family members on board w/pts. decision.
20. One time visits in the home.
21. Time limits, form higher authorizations for POST form completion.
23. Initiating advanced planning conversations.
25. Not enough medical knowledge to create better discussion with clients.
26. Changing the XXX.

I. Additional Comments:

2. Excellent training.
6. A good source of information was provided.
8. The computer modules did not work well and created much anxiety!
11. Great course, very informative.

Please rate ONLY the speakers who presented at your training on the following:

Only rate speakers present at your training:	. . . was organized and clear in their presentation			. . . presented useful information			I Would Like to Hear This Speaker Again	
Juanita Bishop, BSW, LSW	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~
Jacqueline N. Cole, MD	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~
Alvin H. Moss, MD	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~
Marie Newcomb-Lewis, MSW, LPC	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~
Vickie Powell, RN, CHPCA	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~
Hanna Thurman, MSW, LGSW, MPA	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~	~~Somewhat~~	Yes	~~No~~