Shifting the Focus of Advance Care Planning: Using an In-depth Interview to Build and Strengthen Relationships

LINDA BRIGGS, R.N., M.S.N., M.A.

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Therefore, we have come to define "special patient populations" as those involving individuals (and their chosen surrogate) who, for a variety of reasons, need extra assistance and more skilled facilitation in making future health care decisions. They include: Individuals with end-stage chronic illness (those for whom we would not be surprised if they died in the next 1-2 years), such as congestive heart failure, renal disease, or acquired immune deficiency syndrome (AIDS); Individuals who, because of the timing of their illness or injury, have not been considered appropriate for ACP, such as those facing emergent and high-risk surgery, or those who experience a sudden event, such as a transischemic attack (TIA), and are at risk of repeated episodes; Individuals who have ACP needs beyond the more familiar decisions to withhold or withdraw life-sustaining treatment, such as those with early dementia or mental illness; Individuals who lack decision-making capacity (developmental disabilities) or authority (minors), and must rely on guardians or parents to make substitute decisions and plan for the inevitable.

We believe that all of these patients require a different approach to advance care planning, one that involves an experienced facilitator who has an understanding of a specific disease and its progression, can present benefits and burdens of life sustaining treatment, is able to assist an individual in understanding the options for future medical care, and who has honed the communication skills of listening, exploring, delivering bad news, and dealing with emotional responses.

PATIENT-CENTERED ADVANCE CARE PLANNING INTERVIEW

Stage 1: Representational assessment

The interviewer introduces the discussion as an opportunity for the patient and surrogate to understand and think about the life-sustaining choices that the patient would want in the future if unable to make decisions at that time. It includes an assessment of the patient's understanding of his/her current medical condition, prognosis, and potential complications, and explores the meaning of the illness to the patient, what makes his/her life worth living, and his/her expectations of the current plan of care. This information is useful as the interview progresses to assist the patient in reflecting on whether the burdens of a particular life-sustaining treatment match the goals for living well. The objective is to encourage the patient to verbalize his/her perspective (i.e., representation) as well as to assist the interviewer and surrogate to better understand these representations. In other words, the goal is to "see through the eyes of the patient" and allow that insight to guide and focus the discussion.

Dorothy, a 76-year-old end-stage renal patient, and her husband, Tom were interviewed while on dialysis during two separate 1-hour interviews. As I was explaining that one of the purposes of the interview was for the two of them to better understand what the future holds and what medical decisions may be needed, Tom interrupted me. "We've talked," he said. "I
know what Dorothy wants." Dorothy was quick to interrupt Tom. "I think I need to talk more, honey. We haven't talked enough," she said. She proceeded to describe how her life in the last several months had taken a turn for the worse. She had been on dialysis for 5 years, but in the last several months, her health condition had declined. She could no longer see, so needed Tom to feed her. She could no longer walk, so Tom had to help her with the simplest of tasks. "The only reason I see for living is that I know how much Tom loves me." When asked what she thought her potential complications might be, she was unable to verbalize specifics. "I guess I could get sicker, but I'm not sure how I could be any worse." Dorothy's representation was clear to her, but it was obvious this was new information for Tom.

**Stage 2: Exploring misconceptions**

The next stage of the interview explores misconceptions the patient may have regarding planning for future medical decision making. Previous hospitalizations and experiences with family or friends who have been seriously ill or died are explored to assess what the patient learned, and how these experiences might help or hinder the patient's ability to plan for the future. The quality of previous advance care planning discussions with family members is also explored, as often patients feel they have had enough discussion, but surrogates continue to lack understanding. Dorothy relayed experiences of other family members who had been "hooked up to machines," and she said: "I wouldn't want that." She stated that within the last year, she had completed a Power of Attorney for Health Care (POAHC) document naming Tom as her surrogate, but no specific preferences were identified in the document found in her medical chart. The staff in the renal dialysis unit that cared for Dorothy had a policy of reviewing and updating advance directives on at least an annual basis. It became clear, however, that once Dorothy had verbalized her declining quality of life and her past experiences with other family members, she wanted to know and discuss more. For example, she did not understand she had a choice to continue with dialysis, or to choose not to be resuscitated if her heart stopped while on dialysis. Tom had no idea that these might be decisions he would be asked to make if Dorothy became incapacitated.

**Stage 3: Creating conditions for change**

This stage of the intervention reviews the rationale for discussing future medical decisions the patient would want the chosen surrogate to understand and act upon. The goal is to prepare the surrogate to be able to fully represent the patient's wishes and to acknowledge the life-threatening nature of the person's illness or condition. The interview with Dorothy and Tom was one of my first, and I found myself feeling anxious about delivering the bad news of how sick Dorothy really was, and what potential complications she was likely to have. But I found that the initial two stages of the interview had allowed Dorothy to verbalize her fears and concerns, for example, her wish not to be hooked up to machines, and from this, it was clear that Dorothy understood her situation. Dorothy herself expressed how sick she was, so this was really no surprise to her. She was unaware, however, of the real potential complications she was likely to face, that is, cardiopulmonary resuscitation (CPR) or the need for hospitalization if she suffered a stroke or needed an amputation. I asked Dorothy for permission to give her and Tom more information regarding the potential complications she was likely to face and the related treatment decisions that would need to be made. She acknowledged: "I do want to know more." I reinforced to Tom that by discussing these situations while Dorothy was capable of expressing her beliefs, he would be more confident in any decisions he might be asked to make on her behalf.

**Stage 4: Introducing replacement information**
This stage of the interview uses disease-specific scenarios to introduce replacement information. The scenarios describe real clinical situations the patient may experience, and the related treatment choices that would need to be made by the surrogate. Benefits and burdens of specific life-sustaining treatment choices are explained as well as the importance of choosing a surrogate who can respect the patient's decisions. We created a disease-specific tool, the Statement of Treatment Preferences survey for three primary purposes. First, two scenarios are presented that realistically represent the patient's likely complications, not hypothetical ones. The decisions related to each of these scenarios are tied to the patient's perception of what living well means (e.g., does the patient want to continue to keep on fighting regardless of uncertainty or suffering, or have all life-sustaining treatment stopped?) The patient's responses represent values and beliefs rather than a list of treatment decisions and can provide the basis for a surrogate's decision if needed in the future. Second, we wanted to provide an opportunity for patients to understand the risks of CPR given the severity of their current situation, and not just whether or not they wanted it, so we offered an additional scenario to give them the opportunity to make a more informed CPR decision. Third, the survey includes a question regarding the degree of authority the patient wants the surrogate to have. The goal was to verbally communicate this to the surrogate in order to increase the surrogate's confidence in decisions that might have to be made at a future time. Dorothy now could envision a specific complication whereby real decisions would need to be made for her. She was allowed to express her values regarding situations of uncertainty (scenario #1) and suffering (scenario #2). As Dorothy reflected on these two scenarios, she was able to articulate that any life worse than what she was already living would be unacceptable. "Why would I choose to possibly be worse off than I am right now?" Tom heard her values, not just her decisions. He learned of the pain and agony of her recent decline. Both cried during this stage of the interview. I had a sense that it opened a new door of communication for them, and that the words Dorothy spoke had never been heard before. I almost felt as though I was imposing on their intimacy, yet felt privileged to be there. While Dorothy had been asked her preference for CPR on more than one occasion, it now became a different decision. Since there was a high likelihood that she would not live through the CPR attempt and a high possibility that if she did, there would likely be complications, her decision was emphatic. It was no longer a decision not to have something done for her, but a decision to choose how she wanted to control the end of her life. Dorothy, Tom, and I then discussed what would happen if her heart stopped while she was on dialysis or if she were at home. How would he react? What procedures did we need to put in place to honor Dorothy's wish? How could Dorothy remain comfortable if a complication arose? While I learned of Dorothy's preferences, I learned much more. I learned that the value of the tool was not in delivering information or in getting decisions to be documented. In fact, I worry that if this tool is used inappropriately, it could cause more harm than good. The tool was a powerful vehicle to have a meaningful and timely discussion between intimates and for building a shared decision-making relationship among the key people involved in Dorothy's care.

Stage 5: Summary

The last stage of the interview summarizes the value of the previous discussion for patient and surrogate, as well as the need for future discussions as situations and preferences change. It is also used to develop any follow-up plans, such as further discussions with the patient's physician and other family members, and changes to the advance directive document. Plans to have Dorothy's POAHC document amended were made and a no-CPR order was written in her medical chart. I later discussed these issues with her care manager and physician, with suggestions to implement an outof-facility DNR order as well. A summary of the discussion was written in Dorothy's medical chart. I thanked Dorothy and Tom for their frank discussion and the courage they demonstrated in facing some difficult decisions together. I asked them to give me feedback on what they felt about the interview. "I've needed to talk about this, but didn't know how to begin talking with my husband," Dorothy said. Tom replied, "I don't want to lose her, but will follow her wishes."
After Tom left the room, Dorothy summoned me to her bedside and asked if I would do her one more favor. "Would you please tell Tom that I am really ready to stop dialysis altogether? I just don't know how to tell him since I'm afraid to leave him alone." Once given the opportunity to reflect on her current medical situation and quality of life, Dorothy saw another opportunity to discuss a wish that was unspeakable to her. I represented a chance to convey a message to the person she loved most, but whose reaction she feared.

LESIONS LEARNED FROM A PILOT STUDY OF THE PC-ACP INTERVIEW

Lesson 1: This is hard work
Lesson 2: Intimacy among strangers is not difficult to achieve
Lesson 3: Patients are often afraid to talk to their loved one
Lesson 4: Listening is the intervention