Reconceptualizing Advance Care Planning From the Patient’s Perspective

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Background: Traditional academic assumptions about advance care planning (ACP) include the following: (1) the purpose of ACP is preparing for incapacity; (2) ACP is based on the ethical principle of autonomy and the exercise of control; (3) the focus of ACP is completing written advance directive forms; and (4) ACP occurs within the context of the physician-patient relationship. These assumptions about ACP have never been empirically validated.

Objective: To examine the traditional academic assumptions by exploring ACP from the perspective of patients actively participating in the planning process.

Methods: Forty-eight patients (30 men and 18 women with a mean age of 48.3 years) who were undergoing hemodialysis were interviewed 6 months after receiving an advance directive form. Their experience of ACP was noted in interviews that were audiotaped, transcribed, and analyzed.

Results: The participants said that their purpose in ACP was to prepare for death and dying, and their underlying goals included the exercise of control and an attempt to relieve burdens placed on loved ones. Advance care planning was viewed as a social process, and completing a written advance directive form was often regarded as unnecessary. Participants often involved close loved ones, but physicians infrequently.

Conclusions: The traditional academic assumptions are not fully supported from the perspective of patients involved in ACP. The patients we interviewed stated that (1) the purpose of ACP is not only preparing for incapacity but also preparing for death; (2) ACP is not based solely on autonomy and the exercise of control but also on personal relationships and relieving burdens placed on others; (3) the focus of ACP is not only on completing written advance directive forms but also on the social process; and (4) ACP does not occur solely within the context of the physician-patient relationship but also within relationships with close loved ones.

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METHODS

In this qualitative study, interviews with patients yielded data that we analyzed and developed into a theoretical framework. This process, called grounded theory by sociologists, is “a general methodology for developing theory that is grounded in data systematically gathered and analyzed.”

For the study, we followed up a cohort of patients undergoing dialysis who were previously examined for the acceptability of generic vs dialysis-specific AD forms. In the previous study, which involved 3 interviews over a 2-week period, participants viewed a videotape about ADs, completed 3 different AD forms in random order, and rated the acceptability of the various AD forms. (See Singer et al23 for further details of the specific educational materials provided.) The previous study was conducted between September and December 1993, and participants were given a blank copy of their preferred AD form at their request in January 1994. Of 95 patients who completed the previous study, the 78 who requested a copy of an AD form to complete represent the sampling frame for the current study.

Between July and September 1994, 6 to 8 months after participants had requested and received a blank AD form, we conducted a face-to-face interview with each participant during a scheduled dialysis session. The interviewer asked open-ended questions, followed up participants’ responses, pursued themes as they arose, and sought clarification or elaboration as required. Our initial interview guide covered 3 themes: (1) Had the participant completed an AD form? (2) If not, why not? (3) If so, what was the process and was it acceptable? The interview guide was modified to follow up theoretical issues emerging from the data as the interviews and analysis progressed. Copies of the interview guide are available from us on request.

The interviews were audiotaped, transcribed, and evaluated by 2 analysts using a method called constant comparisons that breaks down the textual data into units of incidents or ideas. These units are then compared and contrasted with each other (both within each participant’s transcript and across the experience of different participants). Data analysis began after the first interview and continued after all the interviews were completed. During the course of the interviews, we had 3 interim analysis meetings at which the analysts presented their findings for comment by an interdisciplinary research group, which included a nephrologist, social scientist, physician-bioethicist, social worker, nurse, and philosopher.

Sample size was not formally calculated. Instead, participants were enrolled until no new concepts arose during the analysis of the successive interviews.

Written, informed consent was obtained from participants, and this study was approved by the Committee on Use of Human Subjects of the University of Toronto.

AD forms may not effectively stimulate physician-patient communication. Most recently, the disappointing results of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment23 showed that an intensive ACP intervention did not affect the care of seriously ill, hospitalized patients.

The purpose of our present study was to examine the traditional academic assumptions by exploring ACP from the perspective of patients actively involved in the process.

RESULTS

PARTICIPANT CHARACTERISTICS

Of 78 eligible patients, 48 participated in the study. Of the 30 nonparticipants, 11 refused, 3 were too ill, 7 died, 8 had undergone kidney transplantation, and 1 had moved out of town. The mean age of participants was 48.3 years (age range, 20-80 years) and they had been receiving dialysis for a mean of 5.77 years (range, 1-26.5 years). Other characteristics of participants are shown in the Table.

The results of the interviews are reported in the sequence of the 4 traditional assumptions cited earlier for ACP.
Participants considered ACP a way of preparing not just for incapacity but also for death. As one participant said,

What was good about it? Well, first of all, it made me think about the future, what may be happening, and what different conditions that can happen, so that I can react to that ahead of time.

Another participant said,

Well, I certainly don't want to die, but at least I know I have that security there if I do. All I have to do is open up a book and read my will, you know. It's all written down there—what I want. It makes me feel secure.

**NOT ONLY AUTONOMY AND CONTROL, BUT ALSO RELATIONSHIPS**

Participants described their main goals of ACP as maintaining control and relieving the burden placed on loved ones. The role of an AD in helping participants to maintain control of decisions about their own treatment if they were no longer able to do so is noted as follows:

My understanding is that an individual should be able to, by writing in the living will, give directions about future medical treatment in the event that that individual becomes non compos mentis and names proxies or surrogates who will make decisions for the individual in the event that that individual is no longer able to make them.

For these participants, controlling treatment generally meant limiting treatment when they are incompetent so that the dying process would not be prolonged.

The important thing to me is that I've seen many patients die here, and, you know, it's depressing. . . . I've seen their condition and I don't want to be kept alive in this condition, you know, when I say kept alive it's like without [being] hooked up to dialysis . . . so for that reason I wanted to be protected from that . . . protected from being in that situation. You know, where I'm lying there and everybody's trying to hook me up to everything and I can't say no to it and I can't explain to them what I want. So if this is done, then they'll know this is what I want.

A second goal was to relieve the burden placed on loved ones who might be forced to watch a prolonged death. Participants said that ADs would provide information to help relieve the decision-making burden placed on loved ones who would be acting as substitute decision makers. In one example, it gives them the right to take you off the treatment and also the decision is not up to my brother or my mother or my, you know, any relative . . . if a family member has to do it then it has to affect them mentally and emotionally . . . It would affect me emotionally. Did I do the right thing? It would just be a lot of extra pressure and personal torment.

Several participants hoped to achieve both goals:

I think it takes a lot of pressure off the family to decide; at that moment it's very hard, and to put them through . . . they're going through enough, and if they know the wishes of the person who is sick, then they should follow through and just do what they want, because they're the ones that's going through it.

**NOT ONLY WRITTEN AD FORMS, BUT ALSO A SOCIAL PROCESS**

The Figure shows that the process of ACP, as described by the participants, began with a historical context that...
influenced their thinking about ACP. For example, some participants in their own life had previously confronted the issues of ill health and death during experience with dying family members or critical illness. Participants suggested that these experiences helped them prepare for death.

I’m not scared to die. It’s preparing me. I’m sort of preparing myself. I could go any time, any day, any second now. I’ve had a cardiac arrest. I’ve been on life support and I know what it’s like. It’s pretty scary.

Each participant had viewed a videotape about ADs and completed 3 different AD forms in random order. This action played an important role in the ACP process because it often forced confrontation of an issue many wanted to avoid. The confrontation was sometimes disturbing.

At first, when I was reading about some of the situations, some of the more severe ones, I thought, it gets your attention and you’re thinking, like, this could happen to me . . . it’s almost disturbing to think about that . . . . It’s frightening to think that, you know, I could be in this condition one day, not being able to move, not being able to talk, not being able to, you know, dress yourself, eat or anything; and this could happen to me.

Participants too disturbed by the topic were unable to proceed with ACP, whereas others stopped because of more practical reasons, such as needing assistance or more information. Others, although positively disposed to ACP, did not continue because they did not perceive it to be a priority.

Fourteen participants (29%) completed a written AD form, which, as shown in the Figure, was not believed necessary to satisfy the goals of ACP. An additional 7 participants (15%) did not complete their AD form, but still considered their ACP to be complete because their loved ones were well prepared for substitute decision making if necessary.

Q: And you haven’t felt the need to write it down and do the form?
A: Right . . . . With my husband, he’s the one who has total control over me and I trust he would follow . . . . He’s been quite good about it, and, again as I said, we fully discussed it because he then felt the same way for himself, that if anything happens to him, he wants the same things, so we . . . . if this happens, if that happens. We went over the whole thing together. So I know what he wants. He knows what I want.

**NOT ONLY PHYSICIANS, BUT ALSO LOVED ONES**

Thirty-three participants (69%) involved loved ones in ACP discussions. Reasons for not involving others included the following: loved ones would be unwilling to discuss the subject or would become upset (n=5); unable to arrange discussion, never got around to it, or it was a low priority (n=5); too uncomfortable with the subject to raise it with loved ones (n=2); did not want others telling me what to do (n=1); had already completed an AD form without involving others (n=1); and past ACP discussions with loved ones were satisfactory (n=1). The choice of who to involve was determined by emotional closeness or intimacy. Most participants involved spouses, children, or parents. Those without their own families involved siblings or selected close friends.

The disposition of loved ones, as revealed by their reaction during the discussion, had a profound influence on the course of events. For example, one young woman believed she needed to involve her fiancé, but his recent life experiences made it hard for him to join in.

I wanted to show him [fiancé] all 3 of them [ADs] . . . . so that he could see what I could choose from, but it’s very hard to talk about death with him, because he’s just lost his dad, and it was kind of a hard subject, so I didn’t pursue it. I just kind of dropped it . . . . I would start talking about a living will, and try to get into what it was and explain it to him the best I could without the paper, and he would just change the subject, or I don’t have time right now, and it was, like, avoiding it. So I didn’t really want to push it. Okay, I’ll give you time to mourn your dad, and then we’ll talk about it.

The negative disposition of the fiancé made the participant unable to proceed with her ACP. Other participants encountered similar barriers. Of those who received a negative response in discussion with others, none were able to proceed with their ACP.

Despite the often essential role of loved ones in ACP, health care providers played a less prominent role. Only 4 participants reported discussing their ACP or their AD with a health provider: 2 with their physician and 2 with their dialysis nurse. These discussions seemed to be an insignificant part of the process. For example,

Q: Did you talk to any of the nurses here or the doctors?
A: Yeah, there was one nurse here and we talked. I forget who it was though.
Q: Do you recall the conversation?
A: No, I guess it wasn’t very long.

Participants often did not engage in discussions with providers because of beliefs that the topic was personal, deserving the attention of trusted loved ones, not outsiders. For example,

Q: Did you show it or talk to your dialysis nurses or doctor?
A: No . . . . Well, what business is that of them? They can’t help me. It’s my business. And if it is so far that it has to be handled, my son will tell the nurses or the doctor what’s going on.

Participants also felt that health care providers were too busy, and seemed to change too frequently. For instance,

Q: What about your nurses here, have you talked to them about your living will, or that you’ve done one?
A: No, not at all . . . . They’re always passing . . . . Why bother? . . . . It’s too much of a turnover, they’re here for maybe a couple of months and then they transfer into another type of field or another job and then they’re always moving all the time. So it’s not worth it.

The traditional assumptions about ACP—preparing for incapacity, exercising autonomy and control, and completing an AD form in the context of the physician-patient relationship—are not fully supported from the perspective of patients involved in the process. These distinctions may explain some of the difficulties, documented in previous studies, in implementing ACP and ADs.

COMMENT
PREPARATION FOR DEATH

The participants in this study considered ACP a way to prepare for death and dying, not just a preparation for possibly being incapacitated in the future. This finding connects ACP with the central theme noted in the literature about psychosocial issues in death and dying: people in contemporary North American society are struggling to find ways to cope with death.26 Because death has been privatized and desacralized in modern society, the consequences may have stripped away conventions and rituals that help in organizing and constructing the social meaning of death, and in preparing and coping with it.27 Our participants said that ACP, by providing a language and a process for open communication, helped them ready themselves to face death and dying.

RELATIONSHIPS

The ethical principle of autonomy, which is traditionally assumed to be the philosophical basis of ACP, does not account for the prevalence and importance of relationships. Although control was often cited as an important goal for ACP, many participants also sought to mitigate the burdens placed on others of either being forced to provide care or watching an unnecessarily prolonged process of dying. Some participants explicitly said that their main goal in ACP was to relieve loved ones of the burden of substitute decision making.

The goal of relationships, not just autonomy, is cited by contemporary writings in liberal philosophy as compatible with the “social nature of our shared community.”28 Moreover, communitarian and feminist philosophical perspectives have recognized that personal relationships can affect ethical decision making. The results of this study suggest that the philosophical basis of ACP be reconsidered and possibly broadened to account for the value of personal relationships.

SOCIAL PROCESS

With the traditional assumption that completing written AD forms is the goal, ACP has been focused and evaluated according to the completion, format, and content of written AD forms.20-38 Since the research has not increased rates of AD form completion to acceptable levels and has not stimulated communication among physicians, patients, and loved ones, the apparent difficulties in implementing ADs and ACP may arise from the focus on written AD forms. Although embedded and regarded as within the social process of ACP,11,37 written AD forms may not be the central or defining feature of the process. Our research suggests that written ADs are not necessarily the desired output for ACP. Many patients may be more satisfied by a discussion about their wishes with their loved ones.

LOVED ONES

The exclusive context of the physician-patient relationship has been assumed and emphasized with arguments that written ADs instruct physicians about a patient’s treatment choices,52 and that the forms should be completed in collaboration, or at least in consultation with physicians9 who will “shepherd”10 or “manage” the completion process as part of a “good physician-patient relationship.”91 This approach was not the view of the patients who frequently involved loved ones but seldom health care providers for 2 main reasons: patients felt health care providers were too busy and ACP was a private matter. It is possible that straightforward, open, and warm communication initiated by a trusted personal physician might overcome patients’ perceived barriers to physician-patient dialogue. Our findings also suggest that the focus of ACP should be broadened to include the important role of loved ones, and that ACP educational programs should be aimed at the family as well as the patient. It might be helpful for physicians to discuss with patients how difficult it is for family members to “pull the plug,” which families might view as “killing mother” rather than “letting nature take its course,” and how ACP might protect loved ones from having to make this kind of decision.

LIMITATIONS AND STRENGTHS

As in any survey, the generalizability of our study is limited by the choice of participants and by their possibly incomplete memory. Moreover, patients’ perceptions may have been affected by the specific educational materials they were given as part of the ACP. Nevertheless, the major strength is that we studied patients’ actual experiences with ACP and ADs, rather than their opinions about the hypothetical possibility of doing so.

CONCLUSIONS

The perspective of patients actually involved in ACP does not fully support the traditional academic assumptions about ACP. The patients we interviewed stated that (1) its purpose is not only preparing for incapacity but also preparing for death; (2) it is not based solely on exercising autonomy and control but also on personal relationships and relieving burdens placed on others; (3) the focus of ACP is not only on completing written AD forms but also on the social process; and (4) ACP does not occur only within the context of the physician-patient relationship but also within relationships with close loved ones.

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