A New Model of Advance Care Planning

Observations From People With HIV

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Background: Although theoretical concepts from ethics and law have been applied, there is no conceptual model of advance care planning rooted in the perspective of individuals engaged in it.

Objective: To develop a conceptual model of advance care planning by examining the perspectives of individuals engaged in it.

Methods: In this qualitative research, we studied 140 individuals with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome who were engaged in advance care planning. Respondents’ experience with and opinions about advance care planning were noted in interviews that were audio-taped, transcribed, and analyzed.

Results: The primary goal of advance care planning was to prepare for death, which entailed facing death, achieving a sense of control, and strengthening relationships.

Conclusions: We have developed a conceptual model of advance care planning rooted in the perspectives of individuals engaged in it. The model has implications for theory, research, and practice regarding end-of-life care.

Arch Intern Med. 1999;159:86-92

Although death is one of the few universal truths in our society, end-of-life care practices may not adequately address the needs of the dying.1-3 Recent initiatives to improve end-of-life care (such as the American Medical Association’s Education for Physicians on End-of-Life Care Project, the Open Society Institute’s Project on Death in America, and the Robert Wood Johnson Foundation’s Last Acts Initiative) include efforts to improve advance care planning (ACP) and the use of written advance directives (ADs).6,7

Surveys show that although patients express positive attitudes toward ADs, they seldom complete AD forms.8-10 Research programs increase the rate of AD form completion, but usually only to modest levels,20-37 and they do not increase physician-patient communication.38 The Study to Understand Prognoses and Preferences for Outcome and Risks of Treatment (SUPPORT) study39,40 found that ACP interventions involving seriously ill hospitalized patients had no impact on incidence and timing of written do-not-resuscitate orders; patient-physician agreement on cardiopulmonary resuscitation preferences; days in an intensive care unit, comatose, or receiving mechanical ventilatory support before death; pain; and use of hospital resources. In a review of more than 100 research articles regarding ACP and AD, Miles et al41 concluded that “Advance treatment preferences have been shown to be difficult to form, communicate, and implement.”

How can these findings be explained? Although theoretical concepts from ethics and law have been applied, there is no conceptual model of ACP rooted in the perspectives of individuals engaged in it. Such a model could help with the interpretation of previous empirical research, help support initiatives to improve care for the dying, and help bioethicists and clinical ethics committees to develop hospital policies regarding end-of-life care, and help health care providers to assist their patients with ACP.

The purpose of this study was to develop a conceptual model of ACP by examining the perspectives of individuals engaged in it.

RESULTS

Participant characteristics are shown in the Table. From the perspective of participants, the primary goal of ACP is prepar-
PARTICIPANTS AND METHODS

STUDY DESIGN

In this study, interviews with patients yielded data that we analyzed and developed into a conceptual model. This process, called “grounded theory” by sociologists, is a general methodology for developing theory from data that are systematically gathered and analyzed, and is appropriately used for data that are conceptually dense and involve social processes.4,5 This study builds on our previous research in individuals receiving dialysis, which highlighted the inadequacies of traditional models of ADs and ACP.4

PARTICIPANTS

In this study, we followed up a cohort of participants enrolled in a previous study44 that examined the preference for either a human immunodeficiency virus (HIV)–specific or generic AD form for individuals with HIV or acquired immunodeficiency syndrome (AIDS). In the original study, participants were randomized to 1 of 3 groups: a group receiving the generic Centre for Bioethics Living Will alone, a group receiving the disease-specific HIV Living Will alone, or a group receiving both of these ADs. Participants were followed up over 2 visits. At the first visit, participants were screened for eligibility, received information about the study, provided consent to participate in the research, viewed a 17-minute educational video about ADs developed specifically for individuals with HIV, and received the generic Centre for Bioethics Living Will alone, the disease-specific HIV Living Will alone, or both ADs to review at home. At the second visit (2 weeks later), participants completed the AD they had received (those subjects randomized to receive both ADs completed the one they preferred), and rated the acceptability of the AD (those randomized to receive both ADs rated both).

Participants in the original study were a volunteer sample of individuals with HIV or AIDS who responded to the study advertisements or posters distributed in the community by the AIDS Committee of Toronto and placed in the waiting rooms of The Toronto Hospital Immunodeficiency Clinic, Toronto, Ontario. In addition, patients attending the Immunodeficiency Clinic were given information about the study and a telephone number to call if they were interested in participating. During the study period, the charts of all patients at the Immunodeficiency Clinic had study labels on which to note if a patient had been given the study information, chose not to participate, or had been excluded. Participants were excluded if they were younger than 16 years, were not fluent in English, could not read, were incapable of completing an AD (as measured by a Standardized Mini-Mental Status Evaluation test score <23), would experience undue emotional distress from completing an AD (as measured by self-report), resided outside metropolitan Toronto, or refused participation in the research. Further details are available in the report of the original study.45 To describe participants’ health status, they were asked at enrollment to rate their current health ranging from excellent to poor and to indicate hospital admissions, cardiopulmonary resuscitation, and intensive care unit events in the previous 2-year period. Since the researchers did not have permission to access patient records, we do not have information on viral load, or CD4 counts.

Of 203 participants enrolled in the previous study, 63 were not interviewed at 6 months because they chose not to be interviewed (n = 19), were too ill (n = 27), or had died (n = 17). Therefore, there were 140 interview participants in this study.

DATA COLLECTION

Six months after the end of the original study, we conducted a face-to-face interview with each participant. The interviewer asked open-ended questions, followed up participants’ responses, pursued themes as they arose, and sought clarification or elaboration as required. Specifically, participants were asked about their reasons for engaging in ACP, the content of their ACP discussions, their perspective on the importance of ACP, and their whole AIDS movement—community based and institutional—so much unwillingness to see it as a fatal illness and to talk about what that looks like. . . . I work over at [name of AIDS service organization] and the services that we provide are basically to healthy people. There’s that whole organization kind of taboo around sickness and death. According to participants, ACP helped them confront and accept the prospect of their death. One participant described the difficulty he had coping with his partner’s death and how that motivated him to confront his own death, I wasn’t ready for my partner to go. I recognized later that I had never really accepted that he was gonna die of AIDS until that night, and then I knew it was definite that he was gonna die. And so I needed, and his brothers needed too, we needed that space for us to get ready. And there was a lot of closeness, a lot of loving, a lot of caring. But it was then when we really got down to, we had not done our living wills at that point either. It was something we’d always discussed but never done. And so we got everything cleaned up.

Continued on next page
The ACP process gave participants a way to think about death and dying. One participant commented on the way in which ACP helped him to consider the manner of his death and the way in which that would affect his children. He concluded that confronting and planning for his death were important steps in helping him and his children cope. He said,

I've had a few friends that have gone through what seemed to be a really painful way to leave this planet. And I think the main focus for me was I have two children and I really wouldn't want them to go through it. You know, selfish as it may be. But I'd rather have them remember the good side and not that. For me, it was just an awful memory. It's like, I almost forgot about what the real person was like after visiting them for six months of their deterioration process. So, I figured out for me that, if there was some way around that? And then this Living Will thing came into play, where I thought maybe that could benefit, and possibly prevent some of this stuff.

Participants said that, although the issue of death was always present, if one did not confront it directly it became a vague, unmanageable concept. For example,

It helps me to realize what is down the road, what could happen. When you are forced to put the pen on the paper, it's somehow a little more realistic than just thinking in your head. "Well, yeah, I guess I'll get sick one day," or "Yeah, I guess that could happen." So, it brought things home a little closer for me. Maybe that was the most important thing. So, in a way, I think that I've been denying that anything is ever going to go wrong. I've been asymptomatic for nine years now. And you get tired of thinking, "Well, it could be this week. I hope I get another summer. I hope I see another Christmas before I get sick; or another good vacation or something." So you start thinking it's not real, it's not going to happen. But it is. I think it [ACP] kind of made me accept the reality of the situation.

Another participant commented on the value of self-reflection in this context,

It made me stop and think about these eventualities that I wouldn't necessarily have analyzed to that degree. . . . Now it's...
all spelled out and I don’t really have to worry so much about those things. You’re actually saying, ‘Well, this is going to happen to me.’ It’s a positive way to approach thinking about death.

Another participant appreciated that ACP forced him to face his own death and in doing so he learned more about himself. He said,

The thought of death has always been there and you think of dying, but you never necessarily think of how you’re going to die. I always imagine the wasting and the weakness and just basically just die in my sleep, kinda thing. But I never really specifically thought about those kinds of different scenarios and whether or not I would want a different kind of care in each case. So that’s what this made me do for the first time. Mentally it was a great exercise. I think I know more about myself.

Finding meaning in one’s death also held further rewards. Through ACP, participants achieved feelings of self-fulfillment, or in their words “peace” or “relief” to know that “everything was in place.” One participant stated,

I’m able to accept everything because I also know that I’ve done everything and prepared to the best of my ability and I feel very confident with that. Whereas before, without preparing, it would have blew my mind away, you know. While walking to the specialist I would have become emotionally upset or whatever. Whereas this time I only hesitated for a minute first, and then I said, “You know, it’s gonna happen. Let it happen, whatever. I’m prepared. I have eased the pain for the family and everything.”

ACHIEVING A SENSE OF CONTROL

The ACP helped participants achieve a sense of control. For example, a participant said,

I think it’s very important that I should do this because I want a say over what happens to me if I’m not able to make those decisions. Because I don’t want other people making decisions for me. I should make my own decisions.

Another participant said,

I wanted to say “This is what I want. This is what I don’t want.” Instead of someone else having to try and make the decision for me. Because it’s me going through it. I mean, yes, everybody else has to live with whatever I decided, but if they made a decision that I didn’t want, which maybe my life would linger on or something, and then they wish later on they never did it, so this way it’s my decision. I decided which way I want it. They’re to respect it and they won’t have any regrets as to whether they should or they shouldn’t have done what they did.

Achieving a sense of control involved establishing and articulating preferences. The main factor driving participants to achieve a sense of control was past experiences with ill health or death that showed participants the course of an AIDS-related death and the effects of intensive medical treatment. Advance care planning enabled participants to decide about acceptable quality of life and preferences for medical and personal care. One participant described the influence of her experience:

Both my husband and I have a really big concern about dementia. If I had severe dementia I really wouldn’t want anything life sustaining. Just, sort of, let me go. I know how much severe dementia can cause grief for people around you because I’ve had grief caused to me from people who have severe dementia. We’ve had friends who’ve had severe dementia and who would be calling and saying things that they have no idea what they’re saying, but really mean and hurtful things and it upset the people around the person who’s ill as well as the family. I’m thinking a lot about stuff like even restricting telephone access if I had severe dementia. I don’t want to hurt people. I sorta said in my HIV living will when I first filled it out that I would want my son to be around me as much as possible. If I had severe dementia or was lashing out with comments and stuff, I wouldn’t want him to see that. He’s only little, but I wouldn’t want him to see that.

For participants, this look into their own potential future generated fear. They feared the suffering they had watched others experience and the high technology medical treatments they had seen others endure. One participant said, “To me it’s very important. Cause, like, I wouldn’t want to be like my Dad is right now. I think that would be very demeaning.”

This fear caused participants to have a greater desire to control their treatment decisions and the dying process. Advance care planning, and especially the AD form, provided a language and framework that helped participants organize their thoughts and articulate preferences, which was the first step in achieving a sense of control. For example,

We didn’t talk too much about it until I got sick and then he mentioned that he had wrapped this [ACP] up. And if I wanted he would give me a copy of his [AD form] just to see how his

<table>
<thead>
<tr>
<th>Characteristics of Participants*</th>
<th>No. (%)</th>
</tr>
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<tr>
<td><strong>Mean (range)</strong></td>
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<tr>
<td>Age, y</td>
<td>39.2 (24-61)</td>
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<tr>
<td>Months since HIV diagnosis</td>
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<tr>
<td>Months since AIDS diagnosis</td>
<td>26.0 (3-108)</td>
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<tr>
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<tr>
<td>Female</td>
<td>10 (7.1)</td>
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<tr>
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<tr>
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<td>46 (32.9)</td>
</tr>
<tr>
<td>No</td>
<td>94 (67.1)</td>
</tr>
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</table>

* HIV indicates human immunodeficiency virus; AIDS, acquired immunodeficiency syndrome.
is, because basically I didn’t understand a lot of the terminology exactly. What things would be right for me and what wouldn’t. So he helped me out in that respect by just reading his and seeing the decisions that he made, and knowing him and knowing how he feels about his situation.

**STRENGTHENING RELATIONSHIPS**

Advance care planning helped participants to strengthen relationships. A major concern was the burden loved ones would bear during the participant’s dying. Here the concepts of control and relationships interact—a fundamental reason for wanting to achieve a sense of control was to relieve burdens on loved ones. There were 2 types of burdens about which participants were concerned: the emotional burden of the participant’s dying, and the burden of substitute decision making.

The participants felt that merely witnessing the participant’s dying process would be emotionally burdensome for loved ones. Participants wanted to limit life-sustaining treatments to relieve their loved ones of the burden of a protracted death watch. One participant said,

“I would never want to be on a life support machine longer than 30 days. The rest I leave up to God, eh. Because you put a lot of family and friends through stress hanging around waiting; don’t know when you’re going to die and that. So I couldn’t. That extra stress, putting people through stress and you don’t even know what’s going on. And meanwhile people worry.”

Another participant said,

“This makes dying easier. It would kill my mother to come to visit me everyday on a ventilator. I mean it would just. What would be the point?”

Moreover, participants felt that the responsibility for substitute decision making would also be very burdensome. Participants wanted to make decisions ahead of time to relieve loved ones of the burden of decision making. I knew what I wanted and it made it easier for me to explain to my family what I do and don’t want. So that way they won’t have...so long as they go by my Living Will they go by my wishes and then they don’t have to worry, ‘Well should we have done it or shouldn’t we have?’

Another participant stated,

To me it’s very important. ‘Cause I just want to make my death and dying easy for my family. I don’t want them to, you know, have to worry about decisions. That’s my main concern—it’s for my family.

Another participant noted that loved ones might be emotionally overwhelmed when he becomes very sick and close to death. He hoped that his words contained in the AD form could counsel loved ones when he would not be able to.

I was glad I’d done [the AD form] at this point in my health. Because the families, they’re just as affected, crippled, incapacitated by the shock of what happens to you as you are sometimes. They’re so empathetic that they sometimes lose their perspective. So [the AD form] is a kind of like a clear rational voice speaking to them.

Advance care planning and the AD form helped participants to share their thoughts about death with loved ones, which enabled the loved ones to participate in their dying experience.

The first one that I did in pencil, that’s the one that she (sister) read and we discussed all my decision and my care giving. Well she was a little bit [chuckles] because she doesn’t, well she just hates the thought that I’m going to die and it’s gonna be hard on her. Right? And so she just found it very emotionally hard to have to read through this, knowing what the outcome is going to be. But she also understood why we’re doing it, so that she wouldn’t have to make any decisions or feel guilty about any decision that are made. She was quite understanding about that even thought it was emotionally upsetting to her.

Shared past experiences were often a means whereby participants could engage loved ones in dialogue over difficult issues concerning death. Through analyzing shared experiences and relating them to the matter of their own death, participants opened channels of communication with loved ones.

I discussed it with [proxy-friend]. But he’s been on board, about death and dying, since before [husband] died. So it was very easy to talk to him about what I wanted because he was there when [husband] was dying and there was things I definitely don’t want to happen to me.

For participants who were homosexual men, the status of a same-sex partner was a central concern. Participants were concerned about their partner’s legal authority to be proxy and the status of their partner as perceived by others. Participants feared that same-sex partners would be shunned and excluded by others if the participant became too sick to stand up for his partner. One participant described how ACP helped him provide for his partner’s needs,

It’s also a safeguard for them [partner and friend] as well because they’re much closer to me than my family is. My family is not from the city and I don’t see them that often and I think, particularly my parents who do not know that I’m HIV positive at this point, may want to do things differently and I don’t want there to be any sort of conflict between them and the rest of the people involved in my care. And it also, I think, gives my lover and my proxies a sort of peace of mind too. They’ve got something to back up their actions.

According to our participants, the primary goal of ACP is preparing for death, which entailed facing death, achieving a sense of control, and strengthening relationships. First, participants could confront death, consider its meaning, begin to accept their own death, consider the goals they still wanted to achieve and the situations they wanted to avoid, and gain a feeling of self-fulfillment. Second, participants could appoint their preferred proxy, express their treatment preferences, and achieve a sense of control. Third, participants could communicate with loved ones about their death, and feel they were helping relieve loved ones of the burden of witnessing a protracted death, and of substitute decision making. Therefore, the primary goals of ACP are psychosocial, and they can be achieved while the patient is still competent. This is a new way of looking at ACP and challenges the no-
tion that the primary goal of ACP is to direct the patient's treatment when incompetent.

These findings have implications for theory, research, and practice. With regard to theory, the findings make 3 contributions. First, although the traditional ethical foundation of ACP emphasizes the importance of control and autonomy, our study shows that individuals engaged in ACP also highlight the importance of strengthening relationships with loved ones. Although not inconsistent with liberalism (the philosophical theory in which the principle of autonomy is based), these relationship interests are better explained using other theories, for example feminist perspectives. Second, the findings of our study provide a previously missing link between ACP and palliative care, in which “control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount.” By emphasizing the psychosocial benefits of ACP, our study provides an explicit link between ACP and the psychosocial goals of palliative care. Third, in the past, an individual’s experience of death had a shared public meaning, with family and friends participating in the experience openly and collectively in familiar, habitual ways. Today many of the traditional social and religious conventions related to death have been stripped away and replaced by conventions of scientific medicine, and our society has developed a “pornography” of death—talking about death is unseemly, indecent, and taboo. Our findings show ACP provides a way for individuals to confront death in the context of their loved ones.

Our study also helps explain the findings of past research. People express positive attitudes toward ADs but seldom complete one because they can achieve their psychosocial goals without completing a written AD form. Similarly, although research programs increase the rate of completed AD forms only to modest levels, these studies underestimate the effectiveness of ACP because they do not measure the psychosocial goals that are important to patients. Advance care planning programs do not increase physician-patient communication because a goal of ACP is to strengthen relationships with loved ones (not health care providers). The SUPPORT study did not show any effect of ACP on the outcomes measured because it conceptualized ACP as occurring primarily in the context of the health care provider-patient relationship (our findings show ACP occurs in the context of the relationship between patients and their loved ones) and emphasized clinical and administrative outcomes (our findings suggest that psychosocial outcomes are important). The one study that measured psychosocial outcomes found no effect of ACP on these outcomes, perhaps because the trial was conducted with a focus on the completion of AD forms within the physician-patient relationship (rather than on communication within the patient–loved one relationship), and the outcome measures were not specifically tailored to ACP. Future ACP research could be designed using the conceptual model outlined herein.

The findings of our study also have implications for practice, in particular, for the role of AD forms and health care providers in ACP. Completing an AD form is not an end in itself. Rather, AD forms are tools that can provide a framework to facilitate discussion and meet the goals of ACP. Health care providers (and other professionals) have an important but supportive role to play in ACP. They may raise the issue; direct patients to appropriate resources; tailor information about health states and treatments to their patients’ individual health situations; address any information needs that arise; review the results of the process, including completed AD forms, to ensure the patient has understood the relevant information; and, finally, once patients become ill, become involved in end-of-life care. However, the real “action” in ACP occurs between individuals and their loved ones.

The main limitation of this study is its generalizability. We studied a group of largely white, educated men living with HIV who volunteered for a study of ADs and survived at least 6 months to be interviewed. Haas et al showed that patients with AIDS were less likely to have discussed resuscitation with their physician if they were nonwhite, had never been hospitalized, or were cared for in a health maintenance organization. Curtis and Patrick found that discrimination by the medical system against individuals with AIDS, women, nonwhite individuals, homosexual men and lesbians, drug users, and poor and poorly educated individuals constitutes a barrier to patient-physician communication about end-of-life care. However, it is noteworthy that the findings in this study confirm and expand on our findings in an earlier study of hemodialysis patients. Generalizability is not an all-or-none phenomenon. Although some of our findings may be limited to the population of patients we studied herein, the similarity to our earlier findings in hemodialysis suggest that many of the concepts may be generalizable, with the appropriate cautions and caveats, to other patient groups. Of course, further research would confirm the degree to which our model is generalizable to other patient populations.

In conclusion, we have developed a conceptual model of ACP from the perspective of individuals who were engaged in it. According to the participants, the primary goal of ACP is preparing for death, which entails facing death, achieving a sense of control, and strengthening relationships. This model has important implications for theory, research, and practice. The prevailing pessimism regarding ADs and ACP is perhaps more related to our misunderstanding of patients’ goals with respect to ACP than to the failure of ADs and ACP to achieve those goals.

Accepted for publication April 29, 1998.

This project was funded by a grant from Physicians Service Incorporated Foundation of Ontario and by the Institute for Clinical Evaluative Sciences, Toronto, Ontario. Dr Singer is Sun Life Chair in Bioethics at the University of Toronto. He was supported by the National Health Research and Development program through a National Health Research Scholar award, and is currently supported by a Scientist Award from the Medical Research Council of Canada.

The views expressed herein are those of the authors and do not necessarily reflect those of the supporting groups.