

Health Care Advance Directives: A Video Package Intervention for People Living with HIV

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Abstract

Objective: Health care planning is important for individuals who might become unable to make decisions for themselves. This study evaluated the effectiveness of a video package designed to influence people living with HIV to make an advance directive (AD).

Design: We used a randomized trial.

Methods: Personal interviews assessed baseline and 3-month follow-up experiences, knowledge, attitudes, intentions, and behavior concerning ADs of 344 people living with HIV.

Results: At baseline, participants felt moderately well informed, yet held several misconceptions about ADs. The highest rated benefit was “making things easier for loved ones.” Obstacles included “not knowing enough about ADs” and “difficulty discussing one’s future illness,” but not practical concerns. At follow-up, 20 (7%) of 290 participants had made an AD. They were, at baseline, less healthy and had felt better informed, but otherwise differed little from their counterparts. Participants in the intervention group felt better informed and were less influenced by drawbacks, but did not differ from controls in knowledge, intent, or number who made an AD. However, those who actually reviewed the video and/or printed materials felt better informed, were more knowledgeable, and were less influenced by drawbacks of ADs than the others. Furthermore, more of them had thought about, talked about, and intended to make an AD.

Conclusions: These results suggest that, considering the complexity and emotional difficulty of the topic, outreach is important, moving from contemplation to action takes time, and more extensive intervention may be required.

Key Words: Law, Psychosocial, Advance directive, Living will, Palliative care, Health care proxy

Introduction

Health care planning is one of the many challenges faced by persons living with HIV/AIDS. HIV/AIDS is an episodic and terminal illness, and is the 5th leading cause of death of all Americans aged 25-44 [1]. HIV/AIDS often entails progressive and prolonged deterioration of health, requiring extensive and long-term health care. Moreover, HIV/AIDS can lead to neurological and neuropsychiatric impairments, damaging one's ability to make and communicate health care decisions.

An advance directive (“AD”) is a legal document designed to communicate an individual’s decisions about medical treatment in advance of a time where he or she may be unable to do so. When a patient becomes unable to make or communicate medical decisions, health care providers who do not know the patient’s treatment preferences, or whom to consult, sometimes end up providing unwanted treatment or withholding desired treatment [2]. In such cases, misunderstandings, mistakes, conflict and even legal proceedings can ensue. Such events tend to exacerbate the emotional distress people experience when a loved one becomes critically ill. Advance directives are designed to increase the likelihood that a patient’s wishes will be followed, and to confer on a designated person the authority to make medical decisions on behalf of the patient.

As a result of these types of difficulties and the Nancy Cruzan legal case in 1991, Congress enacted the Patient Self-Determination Act (PSDA) requiring hospitals receiving Medicare or Medicaid to inform patients about advance directives. Prior to 1991, despite high interest and intent, the percentage of patients using ADs had been consistently well under 20%. Since enactment of the PSDA, execution of ADs has remained relatively unaltered. Studies since then show that although most individuals have heard of or intended to execute advance directives, but that still, under 20% of individuals make ADs, even among people who are very ill or very old [3,4].

In spite of the usefulness of ADs, and their particular relevance to individuals living with HIV or AIDS, many people living with HIV or AIDS may not be familiar with ADs and what they do or how to

use them. For example, one clinic based study of 84 patients with HIV found that only 5.9% had made their terminal care wishes in writing; 33.3% had made them known verbally [5].

One subpopulation of persons with HIV/AIDS for which ADs can be especially important is gay men. In the U.S., men who have sex with men constitute 47% of all adults diagnosed with AIDS [6]. Because most states do not legally recognize same-sex unions, it is critically important to legally document a gay patient's designation of a significant other to make health care decisions in order to induce the cooperation of health care providers who may otherwise be reluctant. HIV is also disproportionately prevalent among disenfranchised populations, such as injection drug users, individuals from ethnic minority backgrounds, and individuals experiencing economic hardship, homelessness, and / or mental health problems. For these people as well, who may not have a strong voice or an advocate within their health care system, ADs are especially important.

According to the theory of reasoned action, one's behavior is the consequence of intentions that are informed by one's knowledge and attitudes [7]. Thus, interventions that seek to influence behavior may do so indirectly by targeting improvement in knowledge and attitudes.

Knowledge about ADs is necessary, but not sufficient, for making an AD. Many people living with HIV or with other chronic or terminal illnesses fail to make ADs despite knowledge about them [5, 8]. In a randomized controlled trial, even when elderly outpatients were informed about advance directives and given forms and a reminder card to give their physicians, only 12% completed a living will within 1 year [9]. Thus, although increasing knowledge about ADs may help a person make one, other factors may interfere.

Attitudes about ADs can influence one's intentions to make an AD. For instance, a belief that ADs are relevant only for the elderly or chronically ill, may reduce intentions among people living with HIV/AIDS, most of whom are younger or middle-aged, and may not feel ill [10]. Both patients with HIV and physicians report difficulty discussing end-of-life treatments with each other [11, 12, 4]. Some patients put off discussions to protect their doctor from an uncomfortable topic or out of fear that their

doctor could not legally discuss these matters [11]. Doctors may be reluctant to bring up advance directives because they worry that patients will be discouraged about their prognosis, or will view them as not being aggressive enough in treatment.

Knowledge, attitudes and intentions may in turn be influenced by other factors that cannot be addressed directly by an intervention. For instance, in our preliminary study, persons who had a longer time to adjust to their positive HIV status were more receptive to ADs [13].

A number of interventions have proved successful, even though rates of executing ADs remain low in absolute terms. In one study, 18.5% of elderly who received an educational pamphlet completed a durable power of attorney, compared to 0.4% in the control group [14]. In person-to-person interventions, discussion with one's trusted others has been shown to be more influential in the completion of an AD than discussion with one's physicians, though group discussions focusing on ADs were also viewed as beneficial [15, 16]. In a randomized study comparing information about ADs presented in writing, verbally or by video, each type of intervention increased completion rates from 8% at baseline to 25%, 39%, and 40% respectively [17].

Among people living with HIV, in a study of 1,031 clients of community-based HIV care program, 28% had made an AD; those who were counseled about them were 3.5 times greater to execute one than those who had not [8]. Given that people living with HIV prefer an HIV-specific AD over a generic AD (Singer, 1997), it is likely that an intervention tailored for them will be more effective with that population.

Materials And Methods

The present study was a randomized controlled trial of a video package intervention designed to influence knowledge, attitudes, intentions and behavior regarding making a health care advance directive in people living with HIV. The video package was created specifically for people living with HIV, with extensive input at each stage of development from people living with HIV and their “trusted

others.” The video included information about ADs from a legal and a medical expert, along with the personal stories of four documentary subjects. The video was accompanied by an informational booklet, modeled on one published jointly by the American Medical Association, American Bar Association, and American Association of Retired Persons, with added photos and quotes from the video characters. A pocket in the back page of the booklet contained two sets of generic forms, a list of local resources, and stickers to be placed on a medical folder containing an AD. The comparison condition received a brief pamphlet about ADs.

Participants, Setting, and Procedure

Participants were recruited at five collaborating sites in the Greater Boston area. One is a health center offering primary care, with a predominately lesbian, gay, bisexual, and transgendered clientele. Two are agencies offering an array of social services. One is a firm that recruits research participants for privately sponsored studies, and one is a community center for persons of color. Participants were 229 men and 115 women (over 60% from communities of color) who were living with HIV and had never executed an advance directive (including a living will, health care proxy, or durable power of attorney). Sociodemographic characteristics of participants are presented in Table 1.

A study representative met with and screened potential participants at the study sites, and invited them to meet with a study interviewer. Those who were eligible and chose to enroll completed an informed consent process, which included a verbal and written statement of the study procedure, risk and benefits, and ability to discontinue participation at any time. Participants were given the opportunity to ask questions, and all who enrolled signed an informed consent form. They were then randomly assigned to either the intervention group (who received the video package of an AD video and information booklet) or the control group (who received an 8-page “Scriptographic” brochure about Ads^[18]). Randomization was stratified by site and by language (English or Spanish). Exceptions to

randomization were made in 38 instances where two participants lived in the same household or had a close relationship; to avoid cross-over, these participants were assigned to the same condition.

A total of 344 people were interviewed at baseline, of whom 290 completed a follow-up interview approximately three months after baseline (84% retention rate).

Measures

Sociodemographic and Health Status Indicators: Sociodemographic information included age, sex, ethnicity, relationship status and partner's gender, children, education, employment and annual household income. Participants also provided the following health background: date of probable infection, date of diagnosis, self-assessed current health and expected health 6 months in the future (1=excellent, 2=very good, 3=good, 4=fair, 5=poor), T-cell count, viral load, and history of opportunistic infections. Quality of life was measured using the Multidimensional Quality of Life Questionnaire for Persons with HIV/AIDS ("MQOL-HIV"), developed by the New England Research Institutes [19]. Participants respond to 40 statements indicating how often (on a 7-point Likert-type scale, from "never" to "always") they had been true for them in the past two weeks. The MQOL-HIV measures ten domains: mental health, physical health, physical functioning, social functioning, social support, cognitive functioning, financial status, partner intimacy, sexual functioning, and medical care.

Beliefs and Experiences Regarding HIV and Advance Directives: The baseline interview elicited both qualitative and quantitative information about the extent of participants' experience of knowing others living with HIV or AIDS, or who had died from AIDS, knowing others who had made and/or used an AD, information received about ADs.

Knowledge. Knowledge about ADs was computed as the number of correct answers to six true-false questions. The statements were derived from a booklet published jointly by the American Medical Association, American Bar Association, and American Association of Retired Persons. We also asked

participants to indicate how well informed they felt they were, on a 5-point Likert-type scale, about six topics concerning ADs (what it is; the benefits; procedures; what would happen without an AD; the medical decisions they might face; and how an AD would be used) (Cronbach's $\alpha=0.88$).

Attitudes. To measure attitudes at baseline, participants rated nine perceived general benefits of advance directives (e.g., being in control; making things easier for others) and ten perceived general problems of advance directives (e.g., not having anyone to be your agent; getting the forms). The lists of items were derived from responses to open-ended questions in an earlier phase of this research. Responses used a 5-point Likert-type scale and were averaged (Cronbach's $\alpha=0.85$ for benefits, 0.80 for problems). To measure attitudes at follow-up, participants rated on a 5-point Likert-type scale how important certain factors in favor of or against making an AD had been in influencing their own decision. We used the same list of items with two additions (influence of others), but omitted "having to get the forms" because the intervention package contained blank forms. (Cronbach's $\alpha = 0.85$ for both scales).

Intent. Intent included three distinct items: having thought about making an AD (yes or no; at follow-up, it was assumed those who had made an AD had also thought about it), having talked with someone about ADs (yes or no), and the likelihood of making an AD in the next 6 months (measured by percent, in increments of 10%; at follow-up, if the person had made an AD, likelihood was deemed 100%).

Behavior. Behavior consisted of making an AD (yes or no) during the time of the study.

Use of materials. At follow-up, participants were asked for specifics about their use of the intervention or control materials: whether they read or viewed any part of the materials, or all of them, how many times, whether they shared them with anyone and with whom, and their rating of the usefulness of the materials, on a 5-point Likert-type scale.

Analyses

First, we provided descriptive statistics on the characteristics of all 344 participants.

Second, we examined participants' experiences and views concerning ADs during the study period, and compared those who executed an AD (n=20) to those who did not execute an AD (n=270), using Fisher's exact tests for categorical outcome measures and t-tests for continuous outcome measures using the Satterthwaite correction. We also reviewed participants' qualitative feedback concerning the materials distributed to participants in both conditions.

Third, to assess the impact of the intervention, following a strict intention-to-treat model, we compared outcomes (knowledge, attitudes, intention, and behavior) at follow-up for participants assigned to the intervention (n=143) and control (n=147) conditions. For categorical outcomes we used Fisher's exact test, and for continuous outcomes we used analysis of covariance, controlling for baseline levels of the comparable outcome, and baseline variables that differed by condition.

To assess the impact of exposure to the video package or the pamphlet, we compared outcomes across four groups based on self-reported exposure: no completed exposure to any materials (n=135); read the entire pamphlet given to controls (n=62); read the entire booklet or viewed the entire video (n=44); read the entire booklet and viewed the entire video (n=38). However, we excluded 11 participants reported having read the materials, but whose recollection of condition was at odds with our record and, therefore, we could not determine which materials their answer referred to. To aid in the interpretation of these findings, we also performed comparisons of baseline characteristics of participants in each of the four groups. We used analysis of variance, with a Bonferroni correction for pairwise comparisons, for continuous outcomes. For discrete outcomes, we used Fisher's exact test to test for overall differences in proportions among the four groups. There is no standard follow-up procedure, as for continuous outcomes, to check for differences in proportions between pairs of groups.

However, we report whether pairs of groups are statistically significant using Fisher's exact test with a Bonferroni adjustment for multiple comparisons. This procedure is not perfectly consistent with the overall test of table significance, since different margins are used for the entire table and the pairwise comparisons.

Results

Description of Participants

Socioemographics and Health Background. The sociodemographic characteristics and health background of participants at baseline are presented in Table 1. The average age was 41 (sd=7). On average, participants expected their health to be better in 6 months (mean difference = 0.34, $p < .0001$). Although 28% had noticed or been told their mental ability had been affected by HIV or AIDS, 90% felt they were currently able to make all health care decisions on their own. Assessments of the likelihood that they would at some point become unable to make their own decisions were evenly distributed from 0% to 100%.

Experience. At baseline, although 91% (312) of participants knew someone who had died of AIDS, only 20% (69) knew anyone who had an AD. In half (49%; $n=34$) of those instances it had been used, and of those, 79% (27) of the participants felt it had worked well. Nineteen percent (66) of the participants reported having previously received materials about advance directives, but barely half of them rated the materials as either “helpful” (27%; $n=18$) or “very helpful” (21%; $n=14$).

Knowledge. On average, participants felt moderately well informed about advance directives (mean=2.67, sd=1.13 on a scale from 1 to 5). Scores were similar across items which included what an AD is (mean=2.81, SD=1.39), its benefits (mean=2.87, SD=1.43), how it would be used (mean=2.91, SD=1.45), how to make one (mean=2.33, SD=1.36), and what would happen without one (mean=2.35, SD=1.43). Most respondents correctly answered three statements about ADs: that an agent does not

have to be a relative (81%), that a person does not need a lawyer to make an AD (61%), and that a person with an AD who recovers can resume control of their health (87%). However, about half (48%) incorrectly believed that a doctor must be involved in setting up an AD, and incorrectly believed that doctors would ask a same-sex partner to make health care decisions (50%) when a person without an AD can't make decisions, and a third believed that a person does not need an AD if their loved ones know their wishes (33%).

Attitudes. Perceived general benefits of ADs were high, with the a mean rating of 4.43 (sd=0.66) on the 1 to 5 scale. Perceived general problems of ADs were moderate, on a similar scale (mean = 2.86, sd=0.93) (See Table 2).

Intent. Nearly half the participants (49%; n=168) had thought about making an AD. Forty percent (136) had discussed with someone (a partner, parent, sibling, or friend) what would happen if they got too sick. However, only 27% (91) had discussed an AD with someone, most commonly with a health care provider (n=35), or social service provider (n=34). Participants estimated their likelihood of making an AD in the coming 6 months at an average of 45% (sd=34%).

Experiences Between Baseline and Follow-Up

Two hundred ninety (84%) of the participants completed a follow-up interview. Those who did not complete the follow-up interview (three of whom died) were less likely to be employed, had lower income, were less likely to own/rent their home and had lower t-cell counts; they did not otherwise differ in sociodemographic or health characteristics. Of those who did complete the follow-up interview, 15% (n=43) reported having had an opportunistic infection during the study period of approximately 3 months. While self-assessed health status declined by .15 on a 5-point scale (p=.008), quality of life improved in several domains: medical care (p=.02), financial status (p=.01), and sexual

functioning ($p < .001$). Forty percent ($n=115$) reported knowing someone who died of AIDS during the study period.

Follow-up ratings of the importance of factors in favor of and against making an AD paralleled baseline ratings of the general benefits and problems of ADs. The least important factors in favor or against making an AD were factors that had not been on the baseline lists, namely, recommendations by health care or social service providers and support or opposition by loved ones.

Making an Advance Directive

Twenty participants (7%) out of 290 reported having completed an AD during the study period. All 20 of these participants named a proxy, 60% ($n=12$) named an alternate, and 55% ($n=11$) gave instructions for their future health care. The most often reported reasons for making an AD were “so that there wouldn’t be confusion about my health care decision,” so they would “not become a burden on their family”, and so “my wishes will be carried out.” The most often reported reasons for not having made an AD were because they were “still healthy at this point,” did not have anyone close enough to name as a proxy, had an “informal arrangement” with someone, were “not informed” enough about AD and it was “too depressing, don’t want to think about death.”

There were very few baseline differences between participants who did and did not make an AD. The two groups did not differ in any sociodemographic characteristics, nor did they differ at baseline on most health measures, quality of life, or assessment of the likelihood of becoming unable to make decisions. They did, however, differ in their T-cell counts (482 vs 333; $p=.02$) and viral loads (3.96 vs 4.17 on the log scale; $p=.05$).

The two groups did not differ at baseline in having thought about, talked about, or in their expectation of making an AD. The most notable difference was that participants who subsequently made an AD had felt at baseline that they were better informed (3.49 vs 2.65; $p=.0004$). Differences

were significant for four of the six items. They did not, however, have better overall scores on the knowledge questions, although they were less likely at baseline to believe that one's agent must be a relative (1.8 vs. 2.2; $p=.002$). They did not differ in their overall assessment of the benefits or problems of ADs, although on a single item they considered "facing reality" to be a greater benefit (4.8 vs 4.3, $p=.004$). At follow-up, however, participants who had made an AD assigned a higher rating to the problems that doctors might not follow it (adjusted mean=3.8 vs. 2.9; $p=.03$) and others might not respect it (adjusted mean=3.7 vs. 2.8, $p=.02$).

Using the Materials

Participants' reports concerning their use of the pamphlet and video package (how much of it they read/viewed, how often, with others, and their rating of its usefulness) are summarized in Table 3. Participants who saw the video felt it was "informative" and easy to relate to because it included "real people, going through the same thing as me." The video also "helped me to look at my life and how long we have left" and reemphasized what choices are available. Participants felt that the intervention booklet "gave me all the information I needed" and was clear and easy to understand. Those in the control condition felt that the booklet was "informative, especially for those who didn't know too much about ADs before," and that it was "short and direct". However, the control booklet was considered by many to be "too simple" and not detailed enough; "it made me aware but it didn't give me enough information." When shared, written materials were shared most commonly with a partner or friend. When a video was shared, it was usually viewed together.

Of the 11 participants in the intervention condition who made an AD, five used the forms provided, four filled out the wallet card (though only one had it with him or her), and only one gave anyone file stickers.

Effectiveness of the Intervention

Intent-to-Treat

We analyzed the outcomes at follow-up by treatment group (see Table 4). In analyses of continuous outcomes, we controlled for baseline levels of the comparable variable, and in one instance where it was significant, we controlled for employment, because more of the participants assigned to the control group were employed (28% vs. 18%; $p=.03$). We found significant group differences in only two outcomes: Those in the intervention condition felt better informed, and rated factors against making an AD as less important. Twelve participants in the intervention condition and eight in the control condition had made an AD; this was not a significant difference by condition (one-tailed $p=0.22$).

Exposure to the Video Package or Pamphlet

Next, in the smaller sample of 279 participants who completed the follow-up interview, we compared outcomes at follow-up by level of exposure to the materials, rather than by assigned condition (see Table 5). In analyses of continuous outcomes, we controlled for baseline levels of the comparable variable. Those who saw/read the whole video package not only felt more well-informed about all six aspects of ADs, but also answered more of the knowledge questions correctly. Although the groups did not differ in their ratings of factors in favor of an AD, those with no exposure to the materials gave higher ratings to factors against making an AD (in particular, not knowing enough about ADs, not having an agent, difficulty changing it or getting forms, the amount of effort involved, and concerns about loss of privacy/confidentiality). In terms of intent, more of the participants who saw and read the entire video package thought about making an AD and had discussed it with someone, and they had a higher expectation of executing an AD. Group differences in actually executing an AD during the follow-up period fell just short of statistical significance ($p=.056$).

There were a number of baseline differences among the four groups. More of those who read/viewed the materials were white and not African American, had greater than high school education, were employed, had income over \$10,000 per year, did not have any children, and were referred by the primary care health center, which had the largest proportion of gay clientele. Participants in the treatment group who viewed the video and read the booklet were more recently diagnosed with HIV (5.2 years vs. 7.2, 6.7, 7.6, $p=.029$). More of them had previously received materials about ADs (36.8% vs. 22.7, 22.6, 12.6, $p=.008$) and thought about making an AD (73.7% vs. 53.5, 62.9, 39.1, $p=.003$), and they considered themselves more likely to make an AD (56.8% vs. 49.3, 51.3, 37.9, $p=.004$). Conversely, those who did not use the materials were less likely to have received materials previously, or to have thought about making an AD, and considered themselves less likely to make one.

Summary of Results

A majority of participants had poor knowledge, beliefs, and attitudes about advance directives at baseline. Few participants knew anyone who had an AD, or had ever spoken with anyone about an AD, and a third believed an AD is not needed if one's loved ones know their wishes. Participants felt poorly informed about how to make an AD, and felt that not knowing enough about ADs was an obstacle, although practical concerns (such as the effort involved, and getting the forms) were not. Another obstacle was others' difficulty talking about one's future illness; correspondingly, one of the greatest benefits was making things easier for loved ones. Participants also felt poorly informed about what would happen without an AD, and indeed nearly half believed that even without an AD, doctors would ask a same-sex partner to make decisions. These findings underscore the importance of finding effective ways to increase awareness and knowledge about ADs among persons living with HIV.

By follow-up, 20 (7%) of 290 participants had made an AD. At baseline, they were less healthy as measured by T-cells and viral load, and they felt better informed, but otherwise differed little from those who did not make an AD. There may be other differences between those who did and did not

make an AD that we did not have sufficient power to detect in this sample due to small number of persons who did make an AD. Participants in the intervention group felt better informed at follow up about ADs and were less influenced by drawbacks, but there was no significant difference in knowledge, intent, or the number who made an AD. However, comparing participants according to whether they actually watched the whole video and/or read the materials, those who did so felt better informed and performed better on knowledge questions, and were less influenced by drawbacks of ADs. Furthermore, more of those who watched the whole video and/or read the materials had thought about, talked about, and intended to make an AD.

Discussion

Study participants living with HIV have taught us that the experience of making an AD, and indeed the very thought of doing so, is charged with conflicting emotions. Getting people to entertain the notion, talk about it, and take even a first step is a complex problem. However, the difficulty of the challenge must be weighed in light of the tremendous costs of failing to meet the challenge. According to the transtheoretical model, behavior change occurs in several *stages* over time: pre-contemplation, contemplation, planning, action [20]. Each stage is a step *toward* action. Thus, it is not surprising that simply giving the package to individuals who did not already exhibit an interest in the topic did not, in itself, prove to be a very effective intervention when measured in terms of the behavioral outcome. Similarly, a study of an intervention for cardiopulmonary patients found improvement in knowledge about ADs but no change in behavior [21].

This study did effectuate change in thinking about and planning an AD among participants who did review the materials, including the control pamphlet, even though for most it did not result in action within the 3-month timeframe. If we view the making of an AD as the final step in a process of change,

then it is quite plausible that some of the participants who took steps to plan an AD proceeded to execute one after the follow-up interview.

These findings also suggest that the intervention can be even more effective in moving people along through the stages if we can build in ways to get the recipient to read and view the contents of the package. This might be accomplished by directing the intervention toward individuals who are apparently already sufficiently motivated to use them – for example, those who purchase or request the materials. Timing can be critical; since shorter time since diagnosis was a factor, the topic may best be broached sooner than seven years after diagnosis. For people who are not already motivated, a more extensive intervention may be warranted. Individuals may be more likely to benefit if the video is viewed in a group setting, in the context of a discussion. Another approach might be for health care or social service providers to recommend or distribute the package directly to the individuals they serve, perhaps in conjunction with motivational interviewing. Having a client read the materials or watch the video as part of an office visit could not only enhance motivation, but also contribute to compliance with the PSDA. The fact that participants who had previously received materials were more likely to read or view the materials in this study also suggests that multiple contacts over time – for example, even once a year – may be necessary if the process of change is to continue to progress.

Finally, while making an AD is the valuable culmination of a process, each step on the path can have inherent value. Participants in a qualitative study of individuals living with HIV who were involved in health care planning identified a number of benefits and milestones [22]. It can help one confront and prepare for death and dying, for instance, by considering its meaning. Discussions with one's family and friends can strengthen intimate bonds that for some may have been frayed.

Appendix of Study Sites

AIDS Action Committee

Cambridge Cares About AIDS

Community of Color

Community Research Initiative

Fenway Community Health

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Table 1. Background Characteristics (N=344)

Variable	% (n)	
Age		
23 - 30	7% (25)	
31 - 40	48% (164)	
41 - 50	38% (130)	
51 - 62	7% (25)	
Sex		
Male	67% (229)	
Female	33% (115)	
Ethnicity *		
White	43% (146)	
African-American	42% (144)	
Latino	18% (63)	
Relationship		
Not married/not committed	56% (192)	
In committed relationship	33% (113)	
Same gender	31% (35)	
Other gender	69% (78)	
Married	11% (36)	
Children		
None	46% (157)	
One or more	54% (187)	
Education		
Less than high school degree	28% (96)	
High school degree	33% (112)	
More than high school	39% (134)	
Employed		
Full-time or part-time	23% (78)	
On disability	56% (192)	
Other	21% (73)	
Annual Household Income		
Below \$10,000	59% (198)	
\$10,000 or more	41% (136)	
Any opportunistic infection	49% (168)	
Any effects on mental ability	28% (95)	
Able to make decisions about health care	90% (307)	
Variable	Mean (SD)	Median
Years since infection (0.2 - 23.5)	9.8 (5.4)	9.6
Years since diagnosis (0.2 - 20.2)	7.0 (4.5)	6.5
T-cells (0 - 1600)	440 (305)	380
Viral load (0 - 6,000,000)	60,708 (385,081)	399
Self-assessed health (1=excellent ... 5=)	3.0 (1.1)	N/A

poor)		
Expected health in 6 months (1=excellent ... 5= poor)	2.6 (1.0)	N/A
Times saw health care provider in past 4 weeks (0 – 30)	1.9 (2.4)	1.0

* Total exceeds 100% because respondents could select more than one category.

Table 2. Perceived Benefits and Drawbacks of Advance Directives at Baseline (n=344)

Variable	Mean* (SD)
<u>BENEFITS:</u>	
Making things easier for people close to me	4.65 (0.79)
Knowing whom I can count on to make decisions for me if necessary	4.54 (0.88)
Taking responsibility	4.54 (0.90)
Learning about future treatment choices	4.47 (0.93)
Planning ahead so there's less to worry about	4.41 (0.95)
Knowing in advance how I'll be treated	4.37 (1.03)
Facing reality	4.37 (1.04)
Talking with my doctor about the future	4.35 (1.00)
Being in control of the future	4.18 (1.18)
<u>DRAWBACKS:</u>	
Not knowing enough about health care advance directives	3.47 (1.39)
It's hard for others to think and talk about how sick I might get	3.40 (1.45)
Not having anyone to be my agent	3.11 (1.72)
Other people might not respect it	3.02 (1.57)
Doctors might not follow it	2.87 (1.54)
It might be hard to change or cancel it	2.65 (1.52)
It's hard for me to think and talk about what lies ahead	2.60 (1.54)
Concerns about privacy or confidentiality	2.58 (1.66)
It takes a lot of effort	2.53 (1.42)
Having to get the forms	2.37 (1.47)

* 1=Not at all a benefit/drawback to 5=Very much a benefit/drawback

Table 3. Use of and Response to Materials (n=290)

Variable	Control pamphlet (n=147)	Intervention booklet (n=143)	Intervention video (n=143)
Read/viewed at least some	59% (87)	58% (83)	61% (87)
Rated as “very helpful” (“5” on scale of 1 to 5)	45%* (39)	64%* (53)	53%* (46)
Read/viewed whole	42% (62)	35% (50)	49% (70)
Read/viewed parts more than once	17% (25)	20% (29)	20% (28)
Shared with someone	14% (21)	19% (27)	21% (30)

* of those who read/viewed at least some

Table 4. Outcomes at Follow-Up by Condition (Intent to Treat) (n=290)

	Control (n=147)	Intervention (n=143)		
	Adj Mean	Adj Mean	t	p***
<u>Knowledge:</u>				
No. correct answers* (0-6)	3.89	3.84	.36	.72
Felt well informed* (1-5)	3.46	3.72	-2.29	.023
<u>Attitudes:</u>				
Importance of factors in favor of AD* (1-5)	4.57	4.57	-.003	.98
Importance of factors against AD (w/o "get forms") ** (1-5)	3.20	2.90	2.68	.008
<u>Intent:</u>				
Likelihood of making an AD (0%-100%)*	52.1	56.3	-1.08	.28
	% (n)	% (n)		p****
Thought about making an AD	68.5% (100)	75.6% (102)		.23
Discussed making an AD	25.2% (37)	27.3% (39)		.69
<u>Behavior:</u>				
Made an AD	5.4% (8)	8.4% (12)		.22*****

* Adjusted for baseline level

** Adjusted for baseline level and employment

*** T-test

**** Fisher's exact test

***** 1-sided

Table 5. Outcomes at Follow-Up by Exposure to Materials about Advance Directives (n=279)

	No exposure (n=135)	Read control pamphlet (n=62)	Read booklet <u>or</u> watched video (n=44)	Read booklet <u>and</u> watched video (n=38)		
Outcome	Adj Mean*	Adj Mean*	Adj Mean*	Adj Mean*	F	p**
<u>Knowledge:</u>						
No. correct answers (0- 6)	3.56 ^a	4.15 ^{bc}	3.85 ^{ab}	4.39 ^c	6.74	.0002
Felt informed (1-5)	3.46 ^a	3.43 ^{ab}	3.68 ^b	4.16 ^b	6.28	.0004
<u>Attitudes:</u>						
Importance of factors in favor of AD (1-5)	4.55 ^a	4.58 ^a	4.53 ^a	4.66 ^a	42	.74
Importance of factors against AD (1-5)	3.25 ^a	2.96 ^{ab}	2.86 ^{ab}	2.53 ^b	6.33	.0004
<u>Intent:</u>						
Likelihood of making an AD (0%-100%)	46.4 ^a	53.2 ^{ab}	60.7 ^{bc}	72.3 ^c	7.03	.0001
	% (n)	% (n)	% (n)	% (n)		p***
Thought about making an AD	57.8% (74) ^a	80.7% (50) ^b	79.1% (34) ^{ab}	94.6% (35) ^{bc}		<.0001
Discussed making an AD	20.0% (27) ^a	29.0% (18) ^a	29.6% (13) ^a	42.1 (16) ^a		.044
<u>Behavior:</u>						
Made an AD	5.9% (8) ^a	4.8% (3) ^a	9.1% (4) ^a	10.5% (4) ^a		.56

^{a, b, c, d} Cells with no common letters in the superscript are significantly different, using the Bonferroni adjustment for continuous outcomes (cutoff p-value of .0083). For discrete outcomes, cells with differing subscripts are significantly different using Fisher's exact test in a two-by-two table (using a cutoff of p=.0083 to account for 6 two-by-two tables); these results are not, by their nature, entirely consistent with the overall Fisher's test of a four-by-two table.

* Adjusted for baseline level of outcome

** Overall F-test

*** Fisher's exact test

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