Introduction

The Institute of Medicine’s report, “Approaching Death: Improving Care at the End of Life,”1 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 “Last Acts” initiative sponsored by the Robert Wood Johnson Foundation have focused attention on improving the care of dying patients. These efforts include advance care planning and the use of written advance directives (ADs). Although previous studies have provided quantitative descriptions of patient preferences for life-sustaining treatment, including those documented in written ADs,2–9 to our knowledge open-ended written preferences have not been studied. Studies of these open-ended preferences could highlight issues with respect to quality end-of-life care. The purpose of this study was to explore the open-ended proxy, health, and personal care preferences of people with HIV as expressed in a written AD form.

Methods

Study Design

This study was part of an original study that compared the acceptability of a generic versus disease-specific AD form.10 The original study randomized participants to receive a generic AD form (the University of Toronto Centre for Bioethics Living Will), an HIV-specific AD form (the University of Toronto Centre for Bioethics Living Will), or both, and followed them over a 6-month period to examine the process of advance care planning.11 The ADs ultimately analyzed for this study were each participant’s preferred AD form.

Participants

Participants were a volunteer sample of persons with HIV who responded to study advertisements distributed through the AIDS Committee of Toronto and the Toronto Hospital Immunodeficiency Clinic. Participants were excluded if...
they (a) were less than 16 years old, (b) were not fluent in English, (c) were unable to read, (d) were incapable of completing an AD (as measured by a Standardized Mini-Mental Status test scores of \(<23\))\(^{12}\), (e) would experience undue emotional distress from completing an AD (as measured by self-report), (f) resided outside metropolitan Toronto, or (g) refused to participate in the research. A rejection log documenting reasons for exclusion and refusals was kept.

**Sampling Frame**

The sampling frame for this study was the 210 participants enrolled in the original study (106 through the Toronto Hospital Immunodeficiency Clinic and 104 through the AIDS Committee of Toronto). Of the other potential participants contacted, 41 were satisfied with a previously completed AD form and chose not to participate, 40 did not contact the study coordinator, 9 lived outside the study area, 6 refused to participate, 4 were too ill to participate in the 3 interviews, 1 scored below 22 on the SMMSE, 1 was not fluent in English, 1 was unable to read, and 5 booked interviews but did not attend them.

**Interventions**

Participants were involved in three interviews over six months, during which a trained research nurse encouraged and assisted participants to complete their preferred AD form. At interview 1, participants viewed an educational video about ADs and received the study AD document(s) to complete in draft form at home. At interview 2, two weeks later, participants rated the AD(s) and then reviewed how to complete the AD form. At the conclusion of this interview, all participants had both AD forms and were encouraged to complete the AD they preferred and to consult with potential proxies, physicians, and anyone else they wished. At interview 3, 6 months later, participants evaluated the entire process and provided a copy of their preferred, completed AD form. The AD forms contained the participants’ written proxy, health, and personal care preferences. This was the primary data source for this study.

Two ADs were used in this study: the Centre for Bioethics Living Will and the HIV Living Will. The purpose of the CFB living will, a generic living will, is to “document the wishes of competent persons regarding the use of lifesustaining treatments and regarding a proxy decision maker for situations for future incompetence.” The HIV living will, a disease-specific living will,\(^ {13}\) is a modification of the Centre for Bioethics living will that incorporates prognostic information from the published literature and was developed in consultation with physicians, nurses, social workers, clergy, lawyers, and representatives of consumer organizations who provide services to persons living with HIV.

Both ADs are 29- or 30-page booklets with chapters on questions and answers about ADs, the legal status of ADs, information about healthcare decisions, information about personal care decisions, a chapter containing the AD form itself, and an identification card. The primary difference between the two ADs is the chapter on information about healthcare decisions and the instruction directive part of the AD form. The Centre for Bioethics living will discusses the following health states: current health, mild, moderate, and severe stroke; mild, moderate, and severe dementia; permanent coma; and terminal illness. The
HIV living will focuses on health states relevant to people living with HIV: acute/potentially reversible illness; chronic/physical disability; and mild, moderate, and severe dementia. Moreover, the Centre for Bioethics living will presents dialysis as a treatment option; the HIV living will does not. Both AD forms have been evaluated with respect to face and content validity by an interdisciplinary panel of experts. The HIV living will was preferred over the generic Centre for Bioethics living will by people with HIV/AIDS. Both ADs are posted on the University of Toronto Joint Centre for Bioethics web site (www.utoronto.ca/jcb).

Outcome Measures

Proxy, health, and personal care preferences were elicited using the CFB living will and the HIV living will. As noted above, both AD forms contain sections regarding: (1) proxy decisionmaking, (2) healthcare decisions, and (3) personal care decisions.

The proxy decisionmaking section asked participants to identify someone they knew and trusted, who was “capable of making health care and other personal care decisions and willing to be [a] proxy.” Space was provided for respondents to name up to 4 proxy decisionmakers, to indicate whether the proxies should act individually or as a group, if disagreements should be resolved by following the directive of a certain proxy or by majority vote, and if they wanted particular proxies to have specific domains of decisionmaking. At the end of the proxy section, the document asked respondents how much leeway they wished to give proxies in interpreting preferences.

The healthcare decisions section provided a table in which participants could indicate their preference (treat, do not treat, treatment trial, or undecided) regarding a number of treatment options in a variety of health states. The main difference between the generic and HIV-specific ADs was found here. The particular health states and treatment options varied depending on whether the participant completed the generic or HIV-specific AD. The respondents then were asked, in an open-ended format, to document details that they consider important for proxies to know: “In the space below, you may express in your own words your wishes about health care decisions. Use this space to express any personal beliefs or values that you think may make it easier for proxy decision makers or health care providers to understand and follow your wishes.”

The personal care decisions section provided participants with an open-ended format to express their wishes regarding other types of care: “In the space below, you may express in your own words your wishes about other personal care decisions, such as shelter, nutrition, hygiene, clothing, and safety.” Participants were referred to a previous section of the AD document for definitions of these terms.

Data Analysis

The data consisted of participants’ open-ended written comments, which were essentially responses to categories provided in the AD form. Both major categories (proxy, health, and personal care) and subcategories (e.g., shelter, nutrition, hygiene, clothing, and safety) were contained in the AD form. The comments were analyzed using a modified Ethnographic Content Analysis. The ana-
Proxy (PA) reviewed the comments and identified recurrent themes, which were then coded and sorted using the Ethnograph v.3.0 software.17

Research Ethics
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.

Results
The AD forms of 124 participants were analyzed. Of the 210 participants enrolled in the original study, 21 died, 22 were too ill to continue, 3 withdrew, 3 were unable to schedule a time for interview 3, and 21 were lost to follow-up. Thus 140 participants attended interview 3; however, 20 did not provide a copy of an AD and 4 who did not attend interview 3 provided a copy of their AD.

Of the 124 participants who supplied AD forms for this study, 94 completed the Centre for Bioethics HIV living will, 25 completed the generic Centre for Bioethics living will, and 5 completed their own AD document. Of those who completed the HIV living will, 88 provided supplementary qualitative data. Of those who completed the generic living will, 23 provided supplementary qualitative data. If respondents completed both the HIV and generic AD form, their preferred form was used in the analysis.

Participant Characteristics
The majority of respondents were white males. The average age of the respondents was 39.2 years (SD 8.2; range 24–61). The average time since diagnosis of HIV was 6.5 years (SD 3.4; range 0.58–13.9). Forty-three (35%) participants said they had AIDS. Other participant characteristics are shown in Table 1.

Proxy Decisions
After designating their proxy(ies), respondents were asked, “How much leeway do you want to give your proxies in interpreting your wishes?” Almost all participants responded to this question; some granted proxies full leeway in interpreting their wishes,

As every situation is unique, I give [my brother] all the leeway he feels is required to make decisions that he feels are the right ones under the prevailing circumstances.

others wanted proxies to follow their instructions exactly, granting no interpretive freedom,

I would like all of my wishes to be followed “to the letter”: no editing, no interpreting, no second guessing.

Participants who did not grant interpretive freedom to proxies were influenced by their concern for the proxies,
Follow my directions to the T, because I do not want anyone to feel guilty that they made the wrong decision.

Six participants (4.8%) identified people who were to have no decision-making power. These participants explicitly prohibited specific family members from having any say in treatment decisions,

Under no conditions whatsoever is my mother to have any control over or say in decisions about my care.

### Healthcare Decisions

Participants were also asked to express, in an open-ended manner, important details with respect to their healthcare preferences. Significantly, they wrote about their preference for “a high quality of life” over extension of life span. Most used vague terms,

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Proxy, Health, and Personal Care Preferences

I want quality not quantity of days, i.e., any illness or injury that would make me unable to enjoy and appreciate what is around me, I would not want to be kept alive.

In general, participants did not want their life prolonged if they were ill. They used phrases such as “I do not wish to linger” and “Measures of artificial life support in the face of impending death . . . are especially abhorrent to me.” Some explained that their preferences stemmed from a personal philosophy that “death is only part of life” and “death is merely stepping into another and probably better kind of life.”

Other respondents were more explicit in what a high quality of life meant to them.

If I have any illness or injury that makes me unable to personally care physically or mentally for myself—or I am unable to recognize or communicate with friends or family—I would not be kept alive just to be living.

Specific descriptions of quality of life included,

- Do not resuscitate if I can no longer control my bladder.
- I do not want any measures taken to save me which will leave me with no mobility, however limited.
- A high quality of life is most important to me, physically and mentally! I will not tolerate pain or physical deformities.

Sixty-two respondents (50.0%) wrote about pain in their AD. They cited fear of pain and discomfort as a reason to discontinue treatment.

- I would like lots of pain medication even if it could bring on my death.
- My horror is a fear of prolonged pain while being extremely ill.
- I wish to be kept free of pain!

Six respondents (4.8%) expressed a desire for assisted suicide or euthanasia,

- Active euthanasia if made legal is desirable if I no longer have reasonable hope of regaining/sustaining a quality of life as expressed above.

Personal Care Decisions

Participants were also asked to express personal care preferences. Almost all participants who discussed shelter wished to remain at home “for as long as possible.” However, they acknowledged that their decision to remain at home would put a burden on their caregivers, whether that be emotional, physical or financial,

- Having watched friends die, I am aware of the burden that can befall the primary caregivers. For this reason I have expressed to my proxies that should the burden of home care become too great then I would prefer to be moved to an AIDS hospice . . .
I do not wish my treatment and prolonged life to be an unreasonable burden on anyone.

Many respondents provided examples of situations in which it would be acceptable to be transferred to another location, such as a hospice or hospital, in order to relieve the burden placed on their caregivers.

I would like to remain in my own home as long as it is possible without being an undue burden to others. When it is necessary, I want to be cared for by my mother in her home. This should be with the aid of visiting nurses. When this arrangement is no longer feasible or too much strain on my mother, I would like to be moved to a hospice or hospital.

Some wished to be cared for in one specific local AIDS hospice because they viewed this particular hospice in a positive light.

Participants considered hospital care a last resort. “I would like to avoid hospitals at all costs,” said one respondent. Another stated “I would prefer to stay out of hospital/nursing facilities, but am not totally opposed to this option.”

Respondents also expressed preferences with regard to diet, grooming, and clothing. Many respondents gave very explicit details of their dietary likes and dislikes and stated that they wished dietary vitamin supplements or holistic diets. Others stated that they wanted “great desserts” or “chocolate pudding.” A number wanted nutritionists or herbalists to be involved in their care.

Many participants were concerned about grooming and clothing—they wished to be “presentable.” They detailed a desire to be washed, shaved, have their nails and hair trimmed, and that they should not smell,

I’m not a vain person but just because I’m dying, it doesn’t mean that my appearance should not be kept up.

Another respondent placed great importance on his appearance and surroundings,

It is important that I am clean and neat at all times. That my residence is clean and neat. If it is not possible for me to be maintained in a state of cleanliness this should affect decisions about quality of life.

Respondents also generally wished to remain in their own clothing rather than wearing hospital garments.

A few other idiosyncratic personal care issues emerged. One respondent wanted “a bed near a sunny window”; another preferred “to have a television and a telephone at [his] bedside”; some wished regular visits from clergy; one stated, “Symbols of religion are not to be placed on or near me.” Issues of privacy arose in a small number of responses. Some respondents were concerned that others not be informed of their HIV status. Some participants were concerned that visitors not be denied access to visit; however, those who prohibited decisionmaking by a family member also prohibited the family member from visiting. A few respondents described actions that they wished taken after their death. Many of those concerned funeral arrangements, the notification of friends, the continued care of pets, or property arrangements.
Discussion

Both the innovation and limitation of this study is that we analyzed the open-ended written preferences of people as expressed in their advance directive forms. This type of data offers the potential for new insights into end-of-life care. However, the data are also limited by the structure of the AD form by which they were elicited. Participants viewed a videotape about the process of advance care planning and completed an AD form, which contains specific prompts related to issues in proxy, health, and personal care decisions. These prompts themselves already structure categories for participants’ responses; for instance, with respect to personal care decisions, we prompted participants on categories such as shelter, nutrition, hygiene, clothing, and safety. Nevertheless, what participants say about those categories is unprompted and unstructured. Analysis of open-ended responses on AD forms offers more room for participants to provide their own perspectives than does previous research using closed-ended quantitative data. Participants had some interesting and important things to say with respect to end-of-life care.

Proxy Decisions

Perhaps the most interesting finding with respect to proxy decisionmaking—a finding that emerged even though we did not directly ask about it—was that a few respondents wanted to prohibit specific people from serving as proxies. The proxy directive component of an advance directive is usually thought of as a vehicle to choose a person (or persons) to make decisions on the patient’s behalf. It is not commonly considered as a way to exclude people from substitute decisionmaking, a phenomenon that can be referred to as “antiproxies.” However, from the patient’s perspective, this is a useful aspect of the proxy directive. This finding may be a manifestation of the stigmatization and alienation that AIDS patients often endure, especially from family members. Most AD forms do not ask respondents whom, if anyone, they want excluded from proxy decisionmaking. This question would be a useful addition to AD forms and advance care planning.

A secondary finding with respect to proxy decisionmaking related to the issue of leeway. Some participants granted permission to proxies to freely interpret their written preferences; others restricted their proxies’ freedom to interpret their written preferences, insisting that proxies follow their instructions precisely. This confirms the finding of Sehgal et al. in patients receiving dialysis. Our study yields further insight into why this is so. Participants who granted their proxies freedom to interpret their preferences were focused on the applicability of their present wishes to future circumstances and their trust in the proxy. Those participants who restricted their proxies’ freedom to interpret their preferences were focused on relieving the guilt of the proxy.

Healthcare Decisions

Perhaps the most interesting finding with respect to healthcare decisions was the issue of pain. Respondents repeatedly turned to the concept of ‘quality of life’ to justify and explain their treatment preferences. Although most people did not articulate what they meant by quality of life, half the respondents
referred to the undesirability of pain. Pain has a direct impact on the physical, psychological, social, and spiritual well-being of all individuals. The respondents' concerns about pain are justifiable. For example, in the SUPPORT study, 50% of conscious patients who died in hospital had moderate or severe pain at least half the time.

How should these concerns about pain be addressed? One option would be to include pain control as a choice in the context of ADs and advance care planning. However, this approach suggests that the treatment of pain is an option. In its recent decisions on assisted suicide, the U.S. Supreme Court suggested that palliative care, including pain control, may be a constitutional right. In our view, palliative care and effective control of pain and other symptoms is an essential component of quality end-of-life care and a fundamental ethical obligation of healthcare providers. Palliative care, including pain control, should not be presented as an option, but rather patients should be counseled in a reassuring way about the end-of-life care they will receive. Healthcare providers must realize that pain during the dying process is a prevalent concern for people completing ADs. This fear should be addressed by reassuring dying patients that their pain will be relieved and by redoubling efforts with respect to palliative care to ensure that it is. By recognizing its importance and dealing openly with the topic of pain, providers will be giving immediate psychosocial benefits to their dying patients. Such psychosocial outcomes may be among the most important effects of advance care planning.

Personal Care Decisions

The findings with respect to personal care decisions offer a little more insight into the issue of home care and dying at home. Consistent with other research, most of our participants wanted to receive treatment at home. For instance, in a study by McCormick et al., 73% of hospitalized AIDS patients preferred home care, and a recent study of palliative care patients found that 47.2% expressed a preference for dying at home. The greatest factor influencing whether these patients actually died at home was the ability of caregivers to provide home support. Our participants were concerned about the burdens on caregivers and were willing to accept an alternative location of care if the burden on caregivers was too great. The issue of relationships with loved ones is an essential and perhaps underappreciated aspect of advance care planning.

A secondary finding related to the issue of hygiene and clothing. Because we specifically asked about these categories, it would be circular to argue that we have discovered that they are important to people. However, many respondents wanted to look presentable and be well groomed and comfortably dressed, even if they were unable to perform these tasks on their own. Our search of the literature did not reveal any studies that examine the issue of grooming and dress with respect to dying patients. Healthcare providers should be aware of the importance for patients of grooming, dress, and appearance, even during the dying process.

Study Limitations

This study has 4 main limitations. First, as discussed above, the AD forms prompted participants with respect to certain issues. Second, the study popu-
lation was largely made up of white males living with HIV; the findings may not be generalizable to other groups. Third, the documents analyzed were, in some cases, incomplete. Participants were asked to provide a copy of their AD form whether or not they felt they had finished completing it, and all documents that were provided were analyzed. Fourth, AD forms have been criticized as being difficult to interpret and implement. However, these criticisms are mitigated when ADs are understood within the context of advance care planning. Advance care planning is a process of communication involving people and their loved ones that helps individuals prepare for illness and death. AD forms may be a component of advance care planning, even a useful tool in the process, but completion of forms is not necessarily the primary focus.

Conclusions
To our knowledge this is the first study that examined the open-ended preferences of people reported in advance directive forms with respect to proxy, health, and personal care decisions. Two genuine findings that have not been emphasized in the literature on ADs relate to the issue of “antiproxies” and the prevalence and importance of concerns about pain. These findings highlight important issues with respect to quality end-of-life care.

Notes
11. Martin DK, Thiel EC, Singer PA. A new model of advance care planning: observations from people with HIV. Archives of Internal Medicine, in press.
Peter J. Aikman, Elaine C. Thiel, Douglas K. Martin, and Peter A. Singer

31. See notes 11 and 25.