

Discordance in HIV-Positive Patient and Health Care Provider Perspectives on Death, Dying, and End-of-Life Care

American Journal of Hospice & Palliative Medicine®
 2015, Vol. 32(2) 161-167
 © The Author(s) 2013
 Reprints and permission:
sagepub.com/journalsPermissions.nav
 DOI: 10.1177/1049909113515068
ajh.sagepub.com


Katie E. Mosack, PhD^{1,2}, and Rachael L. Wandrey¹

Abstract

The purpose of this study was to investigate how HIV-positive patients and infectious disease health care providers think about death, dying, and end-of-life care (EOLC) planning. We conducted separate in-depth qualitative interviews with 47 patients and 11 providers. Interview data were transcribed and analyzed using a secondary comparative method. Patients and providers demonstrated profound differences in their perspectives on patient empowerment and attributions of control related to disease progression, imminence of death, and EOLC decision making. Notably, patients described fears related to life-extending interventions that generally went unaddressed within the clinical context. We argue for the routinization of EOLC discussions and suggest novel research approaches to improve patient empowerment and medical engagement.

Keywords

health care, health care providers, HIV/AIDS, end-of-life care planning, palliative care, patient-provider communication

Introduction

We live in the era of what has been referred to as the “paradox of AIDS medicine.”¹ That is to say, advances in the treatment of HIV over the past 2 decades have “transformed the practice of HIV/AIDS medicine in this country from one focused on acute critical care to one focused on managing medicines for a largely chronic condition.” Given that HIV is now treated as a chronic condition that can be effectively managed with highly active antiretroviral therapies,²⁻⁴ the trajectory that patients and medical providers came to expect in the earlier years of HIV/AIDS no longer typically exists. The first generation of physicians who treated patients with HIV is nearing retirement age and its progeny is approaching the field from a vastly different perspective. As Dr Howard Edelstein reports in Bardi’s communiqué,¹ “Patients come in, they are taking their medicines, and there is really nothing to discuss.”

Despite advances in the medical management of HIV, half of all people still die from an AIDS-defining illness,⁵ and in the United States, such deaths are likely attributable to late diagnosis or poor adherence to life-preserving HIV medicines. One key issue that has seemingly moved to the background in HIV care is palliative care. Palliative care provides patients with chronic illness and their families with support and focuses on the relief of symptoms and reduction in pain. Although it can be used at any illness stage, it is especially relevant at the end of life.

Researchers have conducted studies on palliative care communication among patients with cancer,⁶⁻⁸ but we could find no recent research on the discussion of death, dying, advance directives, or end-of-life palliative care among adults with HIV. We believe that the dearth of research in this arena is likely

due, in large part, to this paradox of AIDS medicine. We argue, however, that end-of-life care (EOLC) planning is relevant for all people, including patients with HIV. Indeed, EOLC planning discussions resulting in advance directives have been shown to improve EOLC and patient and family health care satisfaction and reduce stress, anxiety, and depression in surviving relatives in comparison to those patients who did not have such discussions.⁹

Furthermore, we contend that all health care providers should initiate EOLC discussions with all patients *before* such decision making becomes necessary. Unfortunately, patients with AIDS are actually *less* likely than those with other life-threatening illnesses to have discussed advance directives with their health care providers, although the reasons are not yet clear.^{10,11} During this second “generation” of HIV patients and particularly given a shift toward more patient-centered care in the United States, we wanted to investigate how HIV-positive patients and infectious disease health care providers think about death, dying, and EOLC planning and the ways in which patients and providers share or diverge in their perspectives on these topics.

¹ Department of Psychology, University of Wisconsin-Milwaukee, Milwaukee, WI, USA

² Department of Psychiatry and Behavioral Medicine, Center for AIDS Intervention Research, Medical College of Wisconsin, Milwaukee, WI, USA

Corresponding Author:

Katie E. Mosack, PhD, Department of Psychology, University of Wisconsin-Milwaukee, PO Box 413, Milwaukee, WI 53201, USA.
 Email: kemosack@uwm.edu

Methods

All methods were approved by the corresponding author's university institutional review board. Health care providers (including physicians, physician assistants, and nurse practitioners) who were identified as HIV specialists in a mid-sized Midwestern city and HIV-positive persons from the same area (and same clinics) were targeted for this study. Between March and August 2005, potential participants were invited to participate in a project designed to better understand provider perspectives on collaborative health care in HIV health care planning. Further detail about participant recruitment and enrollment has been described elsewhere.^{12,13}

Provider Sample

A total of 11 providers, who included 7 physicians, 3 nurse practitioners, and 1 registered nurse, reported being specialists in the treatment of HIV-positive persons for 2 to 20 years (mean = 10.6 years; standard deviation [SD] = 6.9 years). Their total patient load ranged from 40 to 1800 patients, although most reported having between 100 and 200 active HIV-positive patients on their caseload. They had between 3 and 20 appointments/day (mean = 9.3 appointments; SD = 4.3 appointments) and practiced at a major nonprofit medical center dedicated to the needs of HIV-positive people, hospital clinics, and private practice offices. The 5 men and 6 women ranged in age from 32 to 57 years (mean = 45 years; SD = 7.6 years). The vast majority were white ($n = 9$), and none reported being HIV positive.

Patient Sample

Patients ($n = 42$) ranged in age from 23 to 61 (SD = 41.8). Most participants identified as male (65.1%; 32.6% identified as female; and 2.3% identified as MTF transgender) and predominantly African American (90.7%). The sample included participants representing diverse educational backgrounds. Approximately equal proportions of the sample had not graduated from high school, had a high school diploma or its equivalent, or had obtained education beyond high school. One quarter of the sample reported having an AIDS diagnosis at the time of the interview.

Interviewing Procedures

The first author and 2 other members of the research team who had been trained in qualitative interviewing techniques conducted semistructured qualitative interviews. The interview protocol and informed consent procedures were approved by the institutional review board at the Medical College of Wisconsin in accordance with the American Psychological Association's ethical principles for research.¹⁴ Each interview generally lasted 1 to 1.5 hours. Patients were paid US\$30 and providers were paid US\$50 for their time. Participants were asked questions pertaining to their expectations regarding death and dying within the context of HIV and their understanding

of EOLC. In addition, they were asked about any conversations they had had related to EOLC and EOLC decision making. We attempted to elicit both positive and negative experiences through the use of detailed prompts. At the conclusion of each interview, basic demographic and, from physicians, practice-related information were gathered.

Data Analytic Method

For our study, we used a secondary comparative method to compare data from 2 previously published studies in which participants consisted of HIV-positive patients¹² and infectious disease health care providers¹³ who described their experiences with short- and long-term treatment planning and collaborative decision making (eg, family involvement in treatment planning). According to Harrison and Parker,¹⁵ this method is useful to compare phenomena from participants of different groups when the same research question is examined in the 2 groups. The process of coding and data analysis is described subsequently in greater detail; however, using this method, we compared patient and provider perspectives on death, dying, EOLC decision making, and the process by which discussions about these issues occurred (for patients) or typically occur (for providers). For those participants who did not have experiences with these discussions, we explored their preferences and expectations regarding such discussions.

All interviews were audiotaped, transcribed, and analyzed for themes using NVivo10 qualitative data management software (QSR International (Americas) Inc, Cambridge, Massachusetts).¹⁶ We initiated our analysis by reading all of the transcripts in their entirety. Next, we independently reviewed the first provider transcript by conducting open coding and analyzing the interview transcript line by line for relevant themes pertaining to our research question. This analytic strategy was then repeated for all provider transcripts. Then, we discussed our independent list of codes and developed a master list. In doing so, we considered how well these codes clustered together into emergent categories. A hierarchical coding structure emerged from these discussions, in which several of these categories were collapsed into higher level categories, while other categories were further subdivided. We repeated this procedure for all patient transcripts. Finally, we reexamined each code on the master list to ensure that each was explicitly represented within the transcripts. At this point, codes were dropped if they did not fit well within the emerging coding scheme or if sufficient evidence for these categories was not found across transcripts.

Once the coding scheme was determined, we independently reviewed all transcripts a second time and coded each in its entirety according to the newly developed coding scheme. To ensure coding reliability, we met to discuss our coding interpretations at each stage of coding. Coding discrepancies were discussed until consensus about the appropriate code was obtained. Decision trails were documented to assure that interpretations were supported by the data.^{17,18} Upon arriving at coding consensus, we reviewed the codes and refined, merged,

divided, or removed codes to derive the most parsimonious representation of the data. Together, we developed a framework related to the key themes and the ways in which the 2 participant groups demonstrated concordance or divergence of perspectives according to these themes. Subsequently, we present the findings and contextualize them within the framework of patient-centered care.

Findings

Our secondary comparative analyses revealed key differences between patients and health care providers with respect to philosophical thinking about death, dying, and EOLC in the context of HIV. Specifically, patients and providers imparted different accounts of what "EOLC" means, the degree to which they believed that living a long life with an HIV diagnosis is possible, and their perspectives on patient autonomy in the decision-making process about EOLC. We will first describe discordant perspectives about these specific topics. Then, we will conclude by describing epiphanies that both sets of participants reported having as a direct result of being asked direct questions about death, dying, and EOLC decision making.

Patient Uncertainty Versus Provider Clarity About EOLC

Our data suggested notable differences in the way HIV-positive patients and providers understand EOLC. Patients commonly discussed adjunctive components of EOLC rather than the process itself or their expectations of how EOLC would be enacted. For example, one 36-year-old female patient (note 1) responded

Nah [she hadn't talked about EOLC with his doctor]. But I told my brother. It's like a little will that I'm going to make, and I'll give it to my doctor. And then my doctor sign it, and I'll sign it. It'll be notarized. Ya know what I'm saying? Keep it—put in my doctor's safe.

This patient's definition of EOLC seems to be nothing more than a piece of paper void of any connection with the provision of EOLC itself. She gave no indication about the contents of the will nor makes much of a connection between "it" and her specific wishes should she become seriously ill. Likewise, when asked whether they had ever talked to their doctor about the medical care they would want to receive should they become ill, many responded by saying, "I have a living will," or that they "have it [their wishes] on paper." Some patients even seemed unsure about whether the living will or power of attorney was included in EOLC, "You talking about that will thing? About ah—what you call that? Ah...power of attorney thing?" Most notably, patients failed to conceptualize EOLC in terms of specific medical interventions.

Standing in contrast to the references to living wills and power of attorney, providers offered definitions of EOLC that are more medical in nature. For example, a female physician offered that "one [definition] of palliative care is keeping the

patient comfortable at their end-of-life, if that's the point we are at, and the other end-of-life care is...I think... what comes to mind is when you're too sick to make decisions, how your health care decisions for yourself, who is going to do that for you?" A male provider defined EOLC as encompassing "how [patients] want to die" or "how aggressive [patients] want to be with medical care as they get closer to the end of their life." Thus, providers' accounts referenced medical intervention at the end of life and patients referenced the paperwork that accompanies EOLC decision making rather than specific interventions that might be considered throughout the process.

Patient Fears and Fatalism Versus Provider Optimism With Respect to Living, Dying, and EOLC

Our questions about EOLC decision making seemed to elicit some ambivalence among both patients and providers. Some patients readily discussed concerns they had about death and dying. However, others had a hard time even considering the possibility of an eventual deterioration of health. That is to say, they simply could not see themselves "getting that sick," or they "never thought it would get that serious" to discuss EOLC issues. Some appeared to be overwhelmed by the question: "thinking about [being incapacitated or incoherent] that, is just like whoa...." (23-year-old man)

Other participants portrayed a fatalistic attitude in the face of their HIV diagnosis and prognosis. One 47-year-old male participant in particular expressed this attitude well:

[The EOLC discussion] was scary because I'm thinking long-run type thing, what would I do in the long run of this because if it was honestly left up to me, like I told them, let's just end this now because I didn't know how I was gonna deal with this thing.

A 35-year-old female patient discussed the physical symptoms she experienced and how she anticipated a shortened life. She shared:

You know because I find myself some mornings when I get up out of the bed...my legs give out. So, my ankles when I try to walk my ankles hurt. So, I'm like well my bones [are] deteriorating slowly. As though as—I'm feeling that already. My body hurt a lot. So...I looking forward to another maybe... if I'm lucky, ten more years.

Patients' fears about the dying process in some cases seemed to be informed by personal experiences with other family members and by discussions that were happening in the larger society. For example, one 35-year-old male patient referenced his great-grandmother's death:

Well he [the healthcare provider] thinks that I should go for all, everything that's available, but I don't want to – okay, my great-grandmother died and I watched her go through so much stuff with resuscitation and all that kind of stuff, and she was so weak and so frail that I don't want to go (that way).

Another 41-year-old female patient reflected on the care her mother received at end of life and does not wish to suffer like her mom did:

I said that if I have to have tubes, I don't want to suffer like that, you know. Just let me go ahead and die. I don't want to suffer like that, you know. I don't want them to do nothing to try and keep me alive, you know. Because I've seen it with my mom, you know. She wasn't able to remember that, but I'm just saying. I had seen it with my mom, and that wasn't, [whew] tubes and all that. She was dead all the time, you know. So, don't make me suffer like that [the way her mom did].

Still other patients were informed by the well-known example of Terry Shiavo, a Florida woman who was considered to be in a persistent vegetative state and therefore incapable of meaningful brain function recovery. Her parents and her husband were at odds with respect to keeping her alive and this debate was clearly salient for the participants during our discussion of EOLC decision making. From such vicarious EOLC experiences some patients described preconceived ideas that EOLC necessitates being hooked up to life support, and so forth and that they would not be allowed to make the decision to die.

In contrast to the fatalism some patients communicated about their futures with HIV, many providers discussed how important it was for them to communicate to their patients a message of hope. As an example of such a positive outlook, 1 male provider shared:

I mean one of the things that is so cool about HIV is that people [never] run out of drug options, you know.... Well there's about 3 or 4 new drugs in the next year and a half that are going to come out, including, you know, probably two new classes of drugs and so it's a field where there is constantly something to hold on to.

Indeed, some providers viewed EOLC discussions as being counterproductive. These participants focused their communication on the life-extending properties of HIV medications and how HIV is "not a death sentence." The same provider contended:

...it's such a pathetic thing to say, you know, 'You're gonna—you're gonna die of HIV,' Sure if you have aggressive lymphoma HIV, that's one thing. Dying of an infection—no one should die of an infection, you know, in my mind.

Patient Concerns About Personal Control Versus Providers' Respect for Patient Autonomy

Providers framed their descriptions of the EOLC discussions they have had in fairly autonomous ways by recounting that they typically provide patients with options and ask the patients what *they* want, including how aggressive they want to be with trying to extend their lives. Patients, however, commonly expressed concerns about providers wanting to use more medical care than what the patients themselves desired. A 48-year-old

male patient described how he wished patients could have more direct control over the decision of how and when to die:

You should have that choice of being able to make that decision that I just want to die! I mean you should be able say—well the doctor could say well, [patient's name], you know, you could push this button right here, and it's over with. All you do just push this button right and you can prolong it, it I'm in a state where I can't use the bathroom; I can feed; I can't eat; I can't hardly talk; hardly breathe. I want to push that button.

Many other patients also expressed a general concern for the quality of life on "tubes," reflecting a general anxiety about having their lives needlessly extended, resulting in a poor quality of life.

It is noteworthy that those patients who believed they are or would be on the same page with their providers about EOLC understood this as the case because they had a positive relationship with their providers, believed their providers had no other choice but to listen to them, or believed their providers had their best interests in mind and thus, would not disagree with providers' opinions in the first place. A positive patient-provider relationship stood out as the most salient reason for why a patient believed their provider was or would be in agreement and subsequently act in accordance with the patient's EOLC wishes. The patients who cited this reason described how their providers "really [know]" him or her as opposed to staying on a "professional plane." Others described positive relationships where their physician listened, engaged the patient in nonmedical conversation, or conveyed genuine concern for the patient's well-being. A physician who "takes feelings into consideration" was also mentioned by a 38-year-old woman as portraying such a relationship attribute that led the patient to have confidence that they were in agreement about the patient's EOLC wishes. Thus, some patients described what might be considered a benevolent deference to providers' recommendations, trusting their providers implicitly. In response to a question about whether or not the patient thought that he would be on the same page with their provider about EOLC, one 37-year-old male patient responded, "Well, I would—if he recommended something I would probably, I probably wouldn't second guess it." A 48-year-old female patient, however, reported "It [EOLC discussion] wasn't a discussion. He just told me what's going to happen."

Indeed, when patients discussed EOLC provisions, we were struck by how much they focused on what they *did not* want than what they did:

I just didn't want to go through a whole lot of that... respirators and – you know, and all of that type of thing. And I -Plus I didn't... want to depend on, you know – depend on anybody else to be doing certain cares and stuff for me. (48-year-old man)

Likewise, patients who raised concerns about family involvement primarily did so because of what they were worried might happen against their will:

You have like an emergency contact, you know, as far as family members, you know, if something serious happens to you. I changed my mind and I said yeah, but I want to change that now because if something serious happens to me and my family be will be already know they don't like it or they already know this. I don't want their input in like any decision makings on if I stay hooked up to tubes or, you know, stuff like that. I want just to be able to make my own decisions with all that. (38-year-old woman)

When considering the actual provision of EOLC, providers tended to focus on the decision tree that would dictate the type of care that they might consider implementing in any given situation. Most notably, their focus, both in the recounting of conversations they had with participants and with how they described their philosophy regarding EOLC was squarely on quality-of-life issues. That is to say, providers demonstrated a thoughtful and nonaggressive approach to EOLC delivery. This stands in sharp contrast to the concerns a few patients had and their general anxiety that their quality of life at the end of their lives would suffer within the medical context. Much of what they discussed involved educating patients on treatment options, family planning (ie, determining who would become guardians for children), hospice care, and, as we have noted, palliative care. This particular provider, who admitted to not having had this discussion very often, described the process of how he discusses EOLC:

And so in that context here again, let's review our treatment goals and what is realistic for us to accomplish... I need to make sure they understand kind of where things are at and what may or may not happen in the future and what expectations they have and therefore we can discuss what treatment options are at this point. I think an important point of this is-is to make sure people that you're not talking about abandoning them. That you're not-that we're not talking about giving up and I'm usually very careful when I talk about it to-to be clear about that and I'll usually explicatively state that-that I'm not talking about giving up and not taking care of them. I'm talking about perhaps changing the goals of our treatment within the context of what we can realistically do. (male provider)

Another recounts a specific EOLC encounter:

So now we need to talk about keeping you comfortable, keeping you pain free or, ah, in as little pain as possible. 'You know, just comfortable until you know, you die.' It's never an easy thing to do to talk to patients about that (female provider).

When we consider the general differences between patients' and providers' accounts of EOLC, however, a dominant theme that emerged was the contrast between patients' concerns about having their rights taken from them and providers' ostensible commitment to respecting patients' autonomy within EOLC decision making. As mentioned previously, in recounting the ways providers had or would have EOLC discussions providers emphasized the importance of giving the patient options and thus, respecting their right to choose how to die. Additionally, providers described their role in EOLC as providing as much

comfort to the patient as possible. A male provider demonstrated how he talks with his patients about comfort and EOLC: "My goals for your care would be to keep you with us as long as possible and to keep you as comfortable and interactive as possible." Other providers mentioned how they "work to [their] best ability to relieve pain" at the end of life. Despite misunderstandings that might occur between patients and providers, a nurse suggested what might be the most salient issue surrounding them: "I think we always end up discussing, and what people are comforted by is, that we will work to our best ability to relieve pain. People want to hear that."

Epiphanies

Although the primary purpose of this article was to investigate how HIV-positive patients and infectious disease health care providers think about death, dying, and EOLC planning, we were struck by the fact that the very questions we asked seemed to elicit important epiphanies for both patients and providers. For patients, these epiphanies arose after being asked whether they had ever talked to their doctor about EOLC and whether or not they believe they were on the same page about the patient's EOLC wishes. For a number of patients, being asked to think about these topics did not result in notable distress (as we had been prepared for) but rather prompted measured thinking about it. For example, in response to such a question, a 40-year-old woman replied, "Nope. I haven't thought about that. I should be doing some thinking about that." A 45-year-old man also remarked, "So ya know, this is something which is good that that it came to mind because I hadn't even thought it." Some came to realize that they had "blocked out" the sickness part of having HIV because they feel healthy in the present. Furthermore, we noted that patients who reported experiencing significant symptoms and patients who had had EOLC discussions with their providers were likely to more freely discuss their own mortality.

Likewise, it was clear that the providers in our study were not particularly used to being asked questions about EOLC care, their philosophy about it, and the importance of discussing it with patients. For instance, when asked to provide examples of EOLC discussions that went well, or went poorly, many of the health care providers admitted that they rarely had these discussions and that maybe they should. One female provider said "I think we need to be more proactive in our clinic practice of just bringing up with patients the issue of a living will or some type of understanding of... having that available ... cause we don't do that, but I actually think that should be a clinic thing that we do." Another female provider discussed plans to increase the likelihood of having EOLC discussions by routinizing them, "I think that talking about it now makes me realize perhaps I need to make an annual reminder... I need to do a better job of... integrating that into my routine care."

Discussion

We asked HIV-positive patients and HIV health care providers to consider what EOLC means to them. Our secondary comparative

analysis revealed key differences between patients and providers with respect to their definitions of EOLC, fatalism in relation to death and dying with HIV, and preconceptions about relative patient autonomy within the context of EOLC decision making. On balance, patients' vague descriptions and references to paperwork alone (eg, living wills, health care power of attorney) suggest a lack of clarity about specific EOLC options. Those who had more concrete information were also more likely to describe dreadful or fatalistic scenarios, often involving the unwarranted use of "tubes" to prolong life. In contrast, providers' descriptions, although perhaps no more specific than patients, were quite squarely focused on keeping patients "comfortable" and respecting their wishes at the end of life.

Whether the information we elicited during these interviews mirrors the nature of the information shared within the context of HIV medical appointments is unclear. However, we suspect that patients may not have an adequate grasp of what this sort of care might look like. Furthermore, we are concerned about the disconnect between patients' fears about abdicating their rights at the end of life and providers commitment to upholding them. We believe that such discrepancies in their reports are likely a direct consequence of not having routine and frank conversations about death, dying, and EOLC. In a similar vein, patients' preconceived notions about medical care at the end of life (including fears about being kept alive on "tubes") may impede effective patient-provider communication, particularly if these assumptions go unacknowledged.

Study Limitations

This study is the first of its kind to involve the analysis of data from both HIV-positive patients and HIV (infectious disease) health care providers. Still, it is not without its limitations. We would have benefited from using principles from grounded theory in our recruitment and analytic plan for this study. For example, had we interviewed some patients, coded these data, then interviewed providers, we would have been able to prompt 1 group about themes that seemed relevant to the other group and vice versa. Likewise, our analyses were constrained in part due to the secondary data analytic nature of the current study. For example, we asked patients about their own experiences with having had EOLC discussions, but almost none of the patients in our sample described having had near-death experiences or even experiences of severely compromised health that would have required any EOLC plans to be enacted. Indeed, some had had the discussion or series of discussions and some had not. On the other hand, providers had had experiences with, in some cases, thousands of patients and when we asked about their experiences with EOLC discussions and decision making, they had their entire career experiences to draw on and were able to reflect on trends over time and across patients. They had, of course, also had the experience of ushering patients through end-of-life issues. Therefore, we must acknowledge the very different perspectives from which they described their comfort with and experiences related to initiating or participating in discussions related to death and dying.

Of course, patient and provider perspectives will inevitably vary. If we fail to consider their different perspectives, we may fail to acknowledge key misunderstandings that could harm the very patient-provider relationship that keeps patients engaged in patient care and providers from becoming overly desensitized about the importance of responding to patients' anxiety about EOLC planning. Likewise, we must assume that a self-selection bias existed and that those who choose not to participate were different from those who did. Whether they differed with regard to patient-focused or family-centered orientations, philosophy of care, or other characteristics that are germane to patient-provider communication or the involvement of informal supporters in the health care context is not clear. Finally, the purpose of this study was to describe the diversity of themes and the degree to which they coalesced or differed. We do not intend for these data to be considered representative of the larger population from which these individuals come.

Implications for Practice

Major global health organizations have described "best practices" for palliative care. These include a focus on addressing symptoms, bolstering social support, and helping the patient prepare for death and to address existential concerns,¹⁹ but the patients' voice has been less well documented. A key exception is from Pierson and colleagues recent study in which 35 patients with advanced AIDS were asked to describe both a "good" and a "bad" death.²⁰ Although our participants were notably healthier than the participants in Pierson et al's study, they also identified symptom control, quality-of-life issues, and patient autonomy (ie, patient control of treatment) as being germane to the discussion of optimal EOLC. It appears as though patients who can only portend the end-of-life share very similar concerns (eg, having the fear of "being kept alive by machines"^{20(p590)}) with those who are much closer to dying. This suggests to us that anxieties about death and dying likely develop before the experience becomes salient. Therefore, we argue that health care providers have not just an opportunity but also a responsibility to initiate discussions about EOLC earlier in the treatment planning process and to revisit the topic on a regular basis to ensure that patient fears and misconceptions are comprehensively addressed.

Future Research Directions and Conclusions

The secondary comparative analyses we conducted proved fruitful in illuminating key differences patients and providers have with respect to their perspectives on death and dying. These findings should serve as a mirror to other key "stakeholders" in HIV care (ie, health care providers, other professional supporters [eg, case workers, psychotherapists, pharmacists, lawyers], patients, and informal supporters and advocates [eg, partners, other family members, friends, and other HIV-positive peers]). However, as it was not our intention to consider the dynamic of specific patient-provider dyads in the exploration of EOLC decision making, we gathered data from independent

samples of HIV-positive patients and HIV health care providers. Therefore, we have data on these 2 independent populations and have no data on specific dyad experiences from both perspectives.

In a review of direct observation of EOLC communication among patients with various chronic conditions and their health care providers, Fine and colleagues concluded that providers focus on medical or technical issues instead of emotional or quality-of-life issues and that they tend to dominate EOLC discussions.²¹ We recommend that researchers investigate which approaches work best to bolster the patient-provider relationship, improve EOLC expectancies, and increase patient and informal supporter engagement and empowerment in health care. One approach would be to interview patient-provider dyads about these important but often neglected health care issues. We suspect that such interviews, themselves, would serve as a prompt for more open, in-depth, and productive communication during subsequent health care appointments.

Note

1. To balance the usefulness of providing sociodemographic descriptors with the need to protect participant confidentiality, we provide gender and age information for patients; we describe providers by their genders only.

Authors' Note

This research was conducted in part while Dr Mosack was a postdoctoral fellow at the Center for AIDS Intervention Research (CAIR) at the Medical College of Wisconsin.

Acknowledgments

We would like to acknowledge Geri Cotrell-Wynn, Cheri Treffinger, Cheryl (Caz) Sitzler, Jean Gust, and Leah Przedwiecki for their assistance with data collection and transcription. We would also like to thank Maral Safavi for her assistance with article preparation. Finally, we thank the participants for their willingness to participate and make this research possible.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship and/or publication of this article: This research was funded in part by center grant P30-MH52776 from the National Institute of Mental Health, NRSA postdoctoral training grant T32-MH19985, and a CAIR Developmental Core grant.

References

1. Bardi J. *The Coming Dearth of Doctors Who Specialize in HIV/AIDS*. San Francisco, CA: University of California; 2011. <http://www.ucsf.edu/news/2011/12/11065/coming-dearth-doctors-who-specialize-hiv-aids>. Accessed August 22, 2013.
2. AIDSinfo. *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*. Bethesda, MD: Department of Health and Human Services (DHHS); 2012. http://aidsinfo.nih.gov/contentfiles/lvguidelines/glchunk/glchunk_9.pdf. Accessed August 22, 2013.
3. García F, De lazzari E, Plana M, et al. Long-term CD4+ T-cell response to highly active antiretroviral therapy according to baseline CD4+ T-cell count. *J Acquir Immune Defic Syndr*. 2004;36(2):702-713.
4. Palella FJ, Delaney KM, Moorman AC, et al. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *N Engl J Med*. 1998;338(13):853-860.
5. The Antiretroviral Therapy Cohort Collaboration. Causes of death in HIV-1-Infected patients treated with antiretroviral therapy, 1996–2006: Collaborative analysis of 13 HIV cohort studies. *Clin Infect Dis*. 2010;50(10):1387-1396.
6. De Graaff FM, Francke AL, Van den Muijsenbergh ME, van der Geest S. Talking in triads: Communication with Turkish and Moroccan immigrants in the palliative phase of cancer. *J Clin Nurs*. 2012;21(21-22):3143-3152.
7. Roscoe LA, Tullis JA, Reich RR, McCaffrey JC. Beyond good intentions and patient perceptions: competing definitions of effective communication in head and neck cancer care at the end of life. *Health Commun*. 2013;28(2):183-192.
8. Mun Poon P. The information needs, perceptions of communication and decision-making process of cancer patients receiving palliative chemotherapy. *J Pain Manage*. 2012;5(1):93-105.
9. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010;340:c1345.
10. Mouton C, Teno JM, Mor V, Piette J. Communication of preferences for care among human immunodeficiency virus-infected patients. Barriers to informed decisions? *Arch Fam Med*. 1997;6(4):342-347.
11. Wenger NS, Kanouse DE, Collins RL, et al. End-of-life discussions and preferences among persons with HIV. *JAMA*. 2001;285(22):2880-2887.
12. Author. Anonymized paper; 2009.
13. Author. Anonymized paper; 2011.
14. American Psychological Association. Ethical principles of psychologists and code of conduct. *Am Psychol*. 2002;57(12):1060-1073.
15. Harrison T, Parker RA. Issues in cross-cultural comparative research. *Res Theory Nurs Pract*. 2010;24(4):233-240.
16. QSR International. NVIVO10 [Computer program]. Cambridge, MA: QSR International (Americas) Inc; 2012. http://www.qsrinternational.com/products_nvivo.aspx. Accessed September 12, 2012.
17. Sandelowski M. The problem of rigor in qualitative research. *ANS Adv Nurs Sci*. 1986;8(3):27-37.
18. Hall JM, Stevens PE. Rigor in feminist research. *ANS Adv Nurs Sci*. 1991;13(3):16-29.
19. Barazzetti G, Borreani C, Miccinesi G, Toscani F. What “best practice” could be in palliative care: An analysis of statements on practice and ethics expressed by the main health organizations. *BMC Palliative Care*. 2010;9:1.
20. Pierson CM, Curtis JR, Patrick DL. A good death: a qualitative study of patients with advanced AIDS. *AIDS Care*. 2002;14(5):587-598.
21. Fine E, Reid MC, Shengelia R, Adelman RD. Directly observed patient-physician discussions in palliative and end-of-life care: a systematic review of the literature. *J Palliat Med*. 2010;13(5):595-603.