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Palliative care, hospice, and advance care planning: Views of people living with HIV and other chronic conditions

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Abstract

People living with HIV (PLWH) who survive to older adulthood risk developing multiple chronic medical conditions. Health policymakers recognize the role of early palliative care and advance care planning in improving health quality for at-risk populations, but misperceptions about palliative care, hospice, and advance care planning are common. Before testing a program of early palliative care for PLWH and other chronic conditions, we conducted focus groups to elicit perceptions of palliative care, hospice, and advance care planning in our target population. Overall, participants were unfamiliar with the term palliative care, confused concepts of palliative care and hospice, and/or associated hospice care with dying. Participants misunderstood advance care planning, but valued communication about health care preferences. Accepting palliative care was contingent on distinguishing it from hospice and historical memories of HIV and dying. Provision of high-quality, comprehensive care will require changing public perceptions and individuals' views in this high-risk population.

Keywords

advance care planning; HIV; multiple chronic conditions; palliative care

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As the growing prevalence of multiple chronic health conditions threatens the quality of life for aging populations, the effective provision of palliative care is gaining visibility as a major public health issue (Riffin et al., 2015; Stjernsward, 2007). Especially at risk are people living with HIV (PLWH) who, having survived life-threatening HIV infection, are now developing multiple chronic conditions associated with aging, medication side effects, and the HIV disease process (Balderson et al., 2013; Chu & Selwyn, 2011; Halman, Carusone, Stranks, Schaefer-McDaniel, & Stewart, 2014; Simms, Higginson, & Harding, 2011). HIV has evolved into a medically controllable, chronic condition. But in spite of high-quality medical treatment, PLWH often experience inadequate symptom control (Harding et al., 2010; Karus et al., 2005; Merlin et al., 2012). The aging of the PLWH population, their risks for other chronic conditions, and their needs for better symptom management suggest a critical need for palliative care services for PLWH with other chronic conditions (PLWH/OCC; Lofgren et al., 2015; Ruiz & Cefalu, 2011).

The association between palliative care and hospice care may be a barrier to acceptance of palliative care by PLWH/OCC. The World Health Organization (2016) has defined palliative care as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (¶ 1)

Hospice care, in distinction to palliative care, is specialized end-of-life care (including palliative care) provided for imminently dying individuals, (i.e., generally with a prognosis of 6 months or less to live; American Academy of Hospice and Palliative Medicine, 2015). Prior to development of effective treatment for HIV, hospice care addressed palliation of symptoms and provision of comfort for patients dying from AIDS. As medical advances shifted focus to improving survival for HIV-infected patients, hospice care, with its associated palliative care, lost its relevance for HIV. As in the majority of U.S. society, PLWH/OCC may equate palliative care with hospice care for dying patients. In the context of an aging society, however, there is growing appreciation that hospice care is intended for imminently dying patients while palliative care should be available for all people living with chronic diseases.

Palliative care and the presence of multiple chronic conditions often elicit discussions of additional planning for health care (i.e., advance care planning) as chronic diseases progress in severity and multiple conditions increase risk of mortality. Advance care planning takes many forms, from informal conversations to legal documents such as living wills and health care proxy designations. Advance care planning, including advance directives specifying more detailed instructions about care, supports patient preferences and ensures that treatment is consistent with these preferences if patients are unable to speak for themselves (Centers for Disease Control and Prevention, 2014). Advance care planning for PLWH was encouraged when mortality was high, even though 50% or fewer PLWH were reported to have engaged in such planning with their health care providers (Haas et al., 1993; Wenger et al., 2001). In the current era of improved medical outcomes due to better antiretroviral

therapy, the reported completion rate of advance care planning by PLWH continues in the range of 14-47% (Barocas, Erlandson, Belzer, Hess, & Sosman, 2015; de Caprariis, Carballo-Diequez, Thompson, & Lyon, 2013; Erlandson et al., 2012). These results compare to advance directive completion rates of 26.3% in the general U.S. population (Rao, Anderson, Lin, & Laux, 2014) and 63% in a U.S. population of adults 65 years of age or older (Alano et al., 2010). Factors associated with completion of advance directives included older age, higher income and education, race, and religion. Both studies reported higher completion rates by Caucasians and those with a greater awareness of advance directives (Alano et al., 2010; Rao et al., 2014).

Given the great need for palliative care for community-based PLWH/OCC, we initiated a research project to provide a program of palliative care services to PLWH/OCC at the community level, in partnership with a local hospice organization skilled in the delivery of evidence-based palliative care. Prior to beginning a study to compare program outcomes with standard care for community-based PLWH/OCC, we wanted to know how individuals in our target population perceived palliative care, hospice care, and advance care planning. We also asked whether program administration, through a large hospice organization and discussion of advance care planning and advance directives for health care near the end of life, would be accepted by participants. In this paper, we address the research question, “How do PLWH/OCC perceive palliative care, hospice, and advance care planning?”

Methods

In March and April 2013, we conducted four focus groups to elicit information about acceptability and feasibility of a larger intervention project to test the provision of early palliative care services to high-risk PLWH/OCC at the community level. High-risk individuals were defined as PLWH who were at least 2 years post-HIV diagnosis and who had at least one other chronic condition (Table 1). Chronic conditions listed in Table 1 were self-reported at the beginning of each focus group. These numbers reflect an underreporting by participants who discussed several other conditions at screening or in the sessions but did not disclose them in their self-reports. The Institutional Review Board of University Hospitals Case Medical Center approved the study. Written consent was obtained from all participants.

A convenience sample was recruited from a large Midwestern university medical center's specialty HIV clinic through posted flyers, clinician referral, and use of a registry of PLWH who had given prior consent for research contact. Participants were compensated \$20 (USD) for time and travel. Three focus groups consisted of 5-7 participants, and one group had 3 attendees due to inclement weather. Theme saturation was achieved with four groups (total $n = 22$).

Investigators experienced in focus group methods and qualitative research facilitated each session using an interview guide of key questions. Sessions lasted approximately 90 minutes and were held in a private room on the university's main campus. All were audio-recorded and transcribed verbatim. Transcripts were checked for accuracy and coded by a single investigator using both conventional and directed content analysis (Hsieh & Shannon, 2005).

Coded segments were sorted into larger themes based on prevalence within and across the focus groups. Atlas.ti (Version 6.2, Qualitative Data Analysis & Research Software, 2002-2012) was used for data management. A second investigator skilled in qualitative analysis reviewed the coding scheme for alternative or competing themes (Barbour, 2001). All investigators participated in interpretation of results.

Results

Views about Palliative Care and Hospice

Characteristics of participants are listed in Table 2. Prior to presenting current descriptive definitions of palliative care and hospice, we asked participants about their perceptions of what the terms meant. In general, participants viewed hospice as “care of somebody that’s about to die.” Other meanings included “...to prepare somebody for death,” and “...trying to give them whatever quality of life without trying to do like all these extenuating circumstances to keep them alive.” While participants were familiar with the term hospice, most were unaware of the term palliative care. When asked for a definition of the latter, typical responses were “...you stumped me with that one” and “I’m sorry, I don’t have my dictionary with me—what’s the definition?” Other participants conflated the meaning of palliative care with hospice. As one individual said, “Well, basically palliative care is end-of-life or hospice type of care where basically they try to make the person comfortable.” Another participant noted, “You know, why do we not hear about it (palliative care) until someone gets to a point of hospice, okay, and then they start talking about palliative care, okay?” Others remarked that palliative care sounded “negative and scary...it sounds like you’re about to die.”

When the facilitator defined palliative care as comprehensive physical, psychosocial, and spiritual care, and symptom management throughout the course of chronic illness, participants presented a variety of opinions. One participant reacted ironically to the definition with, “Where’s my palliative care? I’m looking for it.” Another said, “...but this is the thing. During this whole time when you were giving us the definition of that (i.e., palliative care), I’ve received none of that. In the 15-plus years that I’ve been diagnosed with HIV...” Others noted decreasing visibility and/or relevance of palliative care (in the sense of hospice care) as HIV became treatable and survivable. As one individual said,

So when they gave you a diagnosis, they kind of implemented this palliative care right away because they were saying, “Five years from now you’re not gonna be here. So this is what we’re gonna do.” The funny part was that when people started living longer than that, the palliative care kind of faded away and they were like, “Well, you’re still here. We really don’t need to talk about...” Now, 27 years later...

The definition of palliative care presented by the facilitators elicited other ideas from participants. One individual believed that “movements” (such as palliative care) could help, just as “when you talk to your plant, it’s supposed to grow better...” Another noted that concepts of palliative care could be applied in prevention, such as teaching techniques to prevent falls in the home, and in rehabilitation: “...If you go into hospice for some reason...where you get another wind and then come home and function.” However, in

querying participants about their opinions for palliative care services provided by hospice organizations, participants had primarily negative associations with the term hospice. "...for me it (hospice) would send chills down my back" and "they must think I'm dying," were two responses by participants. One individual explained "...I don't think it (hospice) has anything but negative connotations no matter where in the society. Hospice is hospice, man. That's where people are gonna die." But, later in the discussion, another person reflected,

My thought on that is kind of ironic, but if you think about the palliative care that's offered in hospice in the long run, the palliative care (if I'm pronouncing that right) will prevent you from having to be in a hospice.

Additionally, one participant offered this insight:

I think that part of the whole discussion about palliative care has basically arisen from HIV care, because they see that you have to be holistic in your treatment of a person in order to effectively help them. And I think that it's not going to be just about HIV care, that other illnesses and what have you in the other illness groups are gonna want the same thing too because they know that the model works in this community, so it's gonna work in the community at large. But you know we've always been the ones that's basically instituted a lot of the changes over the past 20 years in health care because of HIV, because we were the one that said, "Hey, let's do something about that," rather than just going along with the system.

Overall, participants associated hospice care with dying, conflated concepts of palliative care and hospice, or lacked familiarity with the term palliative care.

Views about Advance Care Planning

In addition to eliciting meanings of palliative care and hospice, we also sought participants' perceptions of the term advance care planning. Some participants associated the term with living long-term with HIV—"staying alive as long as you possibly can"—due to advances in medicine. Said another: "(The term means) that you have advanced yourself in the healing form and that this is of the caring now. To me it coincides with long-term survivor." Other meanings included, "Whatever your medical problem is, I'm willing to help you" and "Carrying it into the future like you have a future." Other participants defined the term according to current usage:

... it also has to do in terms of people who have chronic diseases, the idea that over the years perhaps your chronic disease may get worse and then what about planning for it towards the end of your life in terms of advance planning?

Participants also associated advance care planning with nursing home care and with living wills and durable powers of attorney for health care (DPAHC).

We further explored advance care planning with participants specifically in relation to living wills and/or DPAHCs. Some individuals said they had executed legal documents in response to the seriousness of their health status. "Because I mean as many times as I've been in the hospital, I made sure that I have one," said one person. Another saw multiple chronic conditions as "the door into talking about these (advance planning) things." Some participants expressed positive views about advance care planning and varied reasons for

doing so: “But I have both of those things (living will and DPAHC), but it wasn't the HIV that put me to that. It was the heart attack I had.” Another individual described an earlier lack of readiness for discussion about advance care planning that changed over time: “...I wasn't ready then...but I have come to a different point in my mind where it's an important part of my living, as well as my death, because my life is important to me.” Another person explained:

At one point when I was pretty bad several years ago, I do have a will and durable power of attorney, but what I did, I actually got a hardcover book and I wrote everything in there, like what my wishes were when I died, what I want, where my important papers are...and then I told my closest relatives where that book is...in case of anything.

Both families and physicians were viewed as having roles in advance care planning, apart from and/or in addition to the execution of legal documents. One participant explained, “Well I have 3 kids that they're my living will, especially my middle daughter.” And another noted, “My doctor knows exactly what I want.”

In spite of a general agreement with the value of advance care planning and the potential usefulness of documents, some participants expressed cynicism about legal documents relating to end-of-life care. Formal documents could not ensure that one's end-of-life wishes would be honored, either because no one person was able to take charge or because too many individual viewpoints complicated the situation. One person said, “...I don't have any family okay? I don't have really anybody that's gonna be there and say, ‘Hey, you've got to follow this document’.” One individual explained,

I have very little faith in these so-called documents that we prepare and what have you because in the end don't nobody pay attention to it and people end up doing the most efficient thing for the situation to get it off their plate.

Another individual agreed with this viewpoint,

... because I've had 2 partners to pass and I've seen the after-effects of the living will thing kicking in and family overriding it. I've been in the middle of all that, and so I can agree that you kind of have to put this trust in an imaginary system that's gonna follow through with what you want, your request or want, and it is more psychological that they ask you every time you go to the hospital, “Do you have this in place?,” to give you some kind of comfort and give them some kind of comfort, but in reality, if you don't have anyone following through ...

While a few participants expressed skepticism about living wills, others believed they were not ready for advance care planning, or simply did not wish to focus on the topic. According to a participant, “...I know there's certain things, I know as I get of age, more mature, that need to be done, and I won't say I'm overlooking it now, but it's not my main focus.” Another individual commented, “I don't make that priority. You know I live for today.”

In summary, participants lacked understanding of the term advance care planning. While they recognized the importance and relevance of advance directive documents, some

participants were skeptical about whether the documents would actually work. Others declined to prioritize planning for future health needs in the event of failing health.

Discussion

We elicited views on palliative care, hospice, and advance care planning from PLWH/OCC. Participants tended to be unfamiliar with the term palliative care, but those who knew it often equated it with hospice care for dying patients. Confusion of palliative care with hospice care appears widespread in U.S. society and may impede progress in providing palliative care services at an earlier stage of chronic illness, services that could improve quality of life for all people living with chronic and life-limiting illnesses, not only PLWH/OCC. The association of palliative care with hospice may be stronger in PLWH who have lived the history of HIV and survived a time when palliative care within a hospice was the sole intervention for a new and devastating terminal disease.

Discussions about advance directives and advance care planning suggested participants had thought about these issues, whether or not they agreed with the processes. A common value was communicating one's wishes to others. Talking with adult children, discussing with a primary physician, and writing in a book for one's relatives were expressed by different participants as ways of making one's preferences known. Statements of cynicism and/or mistrust of advance directives could reflect actual experiences or feelings of mistrust stemming from the marginalized status of populations affected by HIV (e.g., men who have sex with men) or a general mistrust by ethnic minorities toward a White-dominated health care system. One study (Jones, Messmer, Charron, & Parns, 2002) suggested that HIV-infected women were skeptical of advance directives because they feared health care providers might not want to provide care to them based on their HIV status. However, fears surrounding treatment of individuals solely due to their HIV status seem to have lost relevance in the post-antiretroviral era. Although we did not focus on specific reasons for completing advance directives, responses of our participants reflected issues discussed in recent literature. For example, one study suggested that neglect of advance care planning based on a focus on living rather than dying or on a lack of prioritization might reflect a fear of facing death or may relate to an individual's stage of illness (de Caprariis et al., 2013). Of interest, one participant initiated advance directives as a result of a heart attack rather than as a result of HIV infection. Such action may demonstrate the evolution of HIV as a chronic, controlled condition, less feared than a heart attack or other acute life-threatening diagnoses.

Our findings address a gap in knowledge about perceptions of palliative care by PLWH/OCC. While studies of utilization of advance directives have been conducted with PLWH, as well as other specific and general populations, little is known about how populations of individuals with multiple chronic conditions might perceive palliative care and advance care planning early in the disease trajectory of chronic illness. Our participants had one or more chronic conditions in addition to HIV infection. All were living independently and had a reasonably good functional status. Their acceptance of palliative care was contingent on distinguishing it from hospice and historical memories associated with AIDS and dying. The association of hospice with giving up hope has been reported in the cancer literature (Ford, Nietert, Zapka, Zoller, & Silvestri, 2008) and appears to be a common association in the

United States, by both patients and providers. The need for effective communication between health care providers and patients with life-limiting illnesses has been recognized (Green, Gardiner, Gott, & Ingleton, 2011; Martin, 2015; Morita et al., 2004). Our participants acknowledged having such conversations with their providers, whether or not written documents were completed.

Our study has implications for health policy. If a goal is to improve quality of life for PLWH/OCC as well as other aging adults with multiple chronic conditions, it is essential that society have a clearer understanding of the definition and role of palliative care. Part of the problem stems from lack of standard definitions for terms used in palliative care and care near the end of life (Hui et al., 2012; Hui et al., 2014). Varied interpretations of end-of-life in terms of days, weeks, months, or years of remaining life, as one example, can impede the determination of goals of care at both individual and policy levels. Professional and patient perceptions may change as language becomes standardized and the public becomes familiar with comprehensive care goals delineated in the Patient Protection and Accountable Care Act and in other efforts to improve care for people with multiple chronic conditions. The importance of incorporating palliative care earlier in the trajectory of life-limiting chronic diseases, such as cancer and chronic respiratory illness, is becoming recognized in the formal recommendations of professional organizations (Lanken et al., 2008; Smith et al., 2012).

Research is beginning to validate positive outcomes of palliative care in cancer patients, but research on palliative care for non-cancer conditions in the face of a need for such care is lacking (Moens, Higginson, & Harding, 2014). Palliative care has been shown to enhance quality of life, optimize treatment, and lengthen survival in one type of cancer (Greer et al., 2012; Temel et al., 2010). Although such outcomes have not yet been shown with PLWH/OCC, comprehensive care with physical and psychological symptom management is beginning to be addressed in innovative models of palliative care delivery for this population (Perry et al., 2013). More research is needed to find additional ways to deliver effective palliative care for PLWH/OCC.

Our study had some limitations. Our participants were recruited from a single urban geographic area and most perceived themselves as healthy. PLWH/OCC recruited from other geographic settings and/or less healthy patients might have expressed different views about palliative care and advance care planning. In addition, our participants were fairly medically sophisticated and well educated about HIV. Another population may have provided different knowledge, opinions, and values regarding palliative care for PLWH/OCC.

Conclusion

As with other aspects of care near the end of life, effective delivery of palliative care is a growing public health concern as multiple chronic conditions add to the burdens of disease and the potential for suffering (Rao, Anderson, & Smith, 2002). Provision of high-quality, comprehensive care for PLWH/OCC will require changing public perceptions as well as the views of this population, which is situated in the unique historical context of HIV.

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Key Considerations

- A growing prevalence of multiple chronic health conditions threatens the quality of life for aging populations, including people living long-term with HIV and other chronic conditions.
- Early palliative care has the potential to improve quality of life for people living with HIV and other chronic conditions but, as with many Americans, people living with HIV may not accept palliative care due to its associations with hospice care and dying.
- In the context of an aging society, there is growing appreciation that hospice care is intended for imminently dying patients while palliative care should be available for all people living with chronic diseases.
- Nurses and other health care professionals can help educate patients and the public about the benefits of early palliative care to improve quality of life for all older individuals with multiple chronic conditions, but especially for those living with HIV and other chronic conditions.

Table 1

Other Chronic Conditions Self-Reported by Participants

Condition(s) reported	# of participants reporting	%
No response	8	36.4
Hypertension	5	22.7
Heart disease/ heart failure	2	9.1
Kidney disease	1	4.5
Hepatitis C	1	4.5
Liver disease	1	4.5
Mental health/mental health and tremors	2	9.1
Hypertension and diabetes	1	4.5
Heart disease and mental health	1	4.5
TOTAL	22	100

Table 2*Characteristics of Participants (n = 22)*

Gender
Male = 16 (73%)
Female = 6 (27%)
Age in years
Range = 23-63
Median = 54.5
Mean = 51.14
Ethnicity
Black = 18 (81.8%)
White = 3 (13.6%)
Other = 1 (4.5%)
Years of schooling
Range = 8-18
Median = 13.00
Mean = 13.41
Self-reported health status
Excellent = 10 (45.5%)
Good = 11 (50%)
Fair = 1 (4.5%)