Palliative Care, Hospice, and Advance Care Planning: Views of People Living with HIV and Other Chronic Conditions

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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.

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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

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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, as distinguished from 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-Dieguez, 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 Whites 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