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Multimorbidity with HIV: Views of community-based people living with HIV and other chronic conditions

Jacquelyn Slomka, PhD, RN [Assistant Professor], Maryjo Prince-Paul, PhD, APRN, ACHPN, FPCN [Assistant Professor], Allison Webel, PhD, RN [Assistant Professor], and Barbara J. Daly, PhD, RN, FAAN* [Gertrude Perkins Oliva Professor in Oncology Nursing] Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, Ohio, USA

Abstract

People living with HIV (PLWH) experience an increase in chronic conditions with aging, but little is known about experiences of living with multimorbidity with HIV. Because early palliative care services may improve well-being for individuals with multimorbidity, we planned to test an intervention to provide these services to community-dwelling PLWH with other chronic conditions. To tailor our intervention to the target population, we conducted 4 focus groups ($n = 22$) that elicited health-related needs, experiences, and views regarding palliative and other health services. We identified 4 themes related to patients' needs and experiences: views of HIV as background to other chronic conditions, challenges managing medications and provider interactions, concerns about coping with future health needs, and persistence of HIV stigma. In addressing multimorbidity with HIV, providers and patients may benefit from enhanced attention to communication when crossing specialty areas and from additional support to decrease stressors associated with HIV stigma.

Keywords

HIV; multimorbidity; multiple chronic conditions; older adults

Multimorbidity, often described as two or more co-existing chronic disease conditions diagnosed in an individual (Fortin, Stewart, Poitras, Almirall, & Maddocks, 2012), is a growing public health concern in an aging U.S. population. The interest in multiple chronic conditions or “multimorbidity” reflects a broad shift in focus over three-quarters of a century of health care, from infectious and acute disease to chronic disease, and currently to multiple chronic diseases. The prevalent specialty model of dealing with more than one chronic condition within an individual has been to focus on individual diseases. But as we learn

*Corresponding author: Jacquelyn Slomka: jacquelyn.slomka@case.edu.

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more about the phenomenon of multimorbidity, clinicians and investigators find that models addressing individual diseases as discrete entities may be insufficient (Parekh, Goodman, Gordon, & Koh, 2011). Multimorbidity is increasingly recognized as a multifactorial condition with a higher level of disease complexity than simply the co-existence of distinct diseases within an individual (Koroukian, Warner, Owusu, & Given, 2015; Parekh et al., 2011). Optimal management of patients with multimorbidity can be complicated by economic, social, emotional, and psychological issues, as well as by an individual's decreasing functional capacity and increasing need for multiple medications and specialty providers (Koch, Wakefield, & Wakefield, 2015). Furthermore, coordination of care is often lacking, and patients are at risk for poorer quality of life and higher health care costs (Parekh et al., 2011).

As an increasing number of people living with HIV (PLWH) are aging, they find themselves developing additional chronic conditions resulting from HIV, from the aging process, and/or from adverse effects of medications (Chu & Selwyn, 2011; Simms, Higginson, & Harding, 2011). While multimorbidity without HIV may involve psychosocial issues, multimorbidity with HIV also can be complicated by psychiatric and social factors such as depression, cognitive impairment, substance use, and housing insecurity (Halman, Carusone, Stranks, Schaefer-McDaniel, & Stewart, 2014). HIV infection and its level of control have been related to control of other chronic conditions. Inadequate viral suppression has been linked to inadequate management of the co-morbid conditions of hypertension and diabetes (Monroe, Chander, & Moore, 2011), while HIV-related neurocognitive disorders have been associated with both social and physical factors such as education level, poverty, violence, substance abuse, sleep disorders, cardiovascular disease, hepatitis, and chronic inflammation (Tedaldi, Minniti, & Fischer, 2015). Older PLWH are also susceptible to geriatric syndromes, i.e., clusters of impairments associated with aging such as early frailty, propensity to fall, and cognitive impairment (Calcagno et al., 2015; Chirch, Hasham, & Kuchel, 2014; Greene et al., 2015). Furthermore, for PLWH with other chronic conditions, quality of life has been shown to decrease as disease burden increases (Balderson et al., 2013; Rodriguez-Penney et al., 2013).

Challenges to health care management of patients with multimorbidity have been qualitatively described from the patient's perspective in terms of factors that lessen treatment burden (Ridgeway et al., 2014), functional abilities to enable self-management (Liddy, Blazkho, & Mill, 2014), and patients' values in prioritizing competing outcomes of multimorbidity (Fried, McGraw, Agostini, & Tinetti, 2008). Factors affecting treatment burden in multimorbidity include the ability to self-manage one's health, social support, future planning, positive thinking, spirituality, and the ability to deal with negative emotions (Ridgeway et al., 2014).

However, little is known about how PLWH with other chronic conditions experience medical conditions and whether HIV infection significantly affects perceptions of living with and managing multimorbidity. A variety of models have been implemented to address the health care needs of patients with multiple chronic conditions as well as the costs of caring for these populations (Bleich et al., 2015). Early palliative care, with its emphasis on symptom management and comprehensive care, has been identified as a strategy for improving quality

of life and care coordination for PLWH with other chronic conditions (Lofgren et al., 2015; Perry et al., 2013).

In a larger clinical trial, we tested a palliative care model intervention to determine whether such services provided at the community level and as an adjunct to standard care might improve the well-being of PLWH with other chronic conditions. Prior to beginning our larger study intervention, we investigated the perceptions of PLWH with other chronic conditions regarding health care-related needs and their views regarding palliative and other health care services. In doing so, we were also able to elicit the lived experiences of multimorbidity with HIV. Focus group findings were used to tailor the intervention to the target population. Themes addressing the question of participant attitudes toward hospice, palliative care, and advance care planning were the topic of an earlier publication (Slomka, Prince-Paul, Webel, & Daly, 2016). We report here on the remaining primary themes related to the research questions, *Do PLWH with other chronic conditions have specific needs and, if so, what are they?* and *How do people experience living with multimorbidity and HIV?*

Methods

As reported previously (Slomka et al., 2016), four focus groups were conducted in March and April 2013 with a total of 22 English-speaking PLWH who were diagnosed with at least one other chronic condition. Participants were recruited from a large specialty HIV clinic in a Midwestern medical center using posted flyers, clinician referral, a registry of PLWH who gave prior consent to be contacted, and word of mouth. Each focus group lasted approximately 90 minutes, and was facilitated by trained investigators using an interview guide. All sessions were audio-recorded, transcribed and analyzed using conventional and directed content analysis (Hsieh & Shannon, 2005). Data were managed using ATLAS-ti (Version 6.2, Qualitative Data Analysis & Research Software, 2002–2012; ATLAS.ti, Berlin, Germany) and coded by a single investigator.

The most frequently recurring codes were grouped into sub-theme categories; related categories were merged into larger themes. A second co-investigator reviewed the coded data for competing and/or alternative themes (Barbour, 2011). Differences in interpretation were minimal and negotiated by all co-investigators. The study was approved by the Institutional Review Board of University Hospitals Cleveland Medical Center. All participants provided written consent.

Results

Participant characteristics have been reported elsewhere (Slomka et al., 2016); characteristics by focus group are listed in Table 1.

Overall, participants were primarily male (73%), African American (81.8%), older (mean age = 51), and fairly well-educated (mean years of school = 13.4). All except one assessed their health conditions as either excellent or good. Other chronic conditions self-reported by participants at enrollment were hypertension, heart disease, heart failure, kidney disease, hepatitis C, liver disease, mental health conditions, and diabetes. Over the course of focus group discussions, participants also mentioned asthma, sarcoidosis, dermatological

problems, and arthritis as affecting their health. Themes that related to the needs and experiences of individuals with multimorbidity with HIV were (a) HIV as background to other chronic conditions, (b) managing medications and provider interactions, (c) coping with future health care needs, and (d) stigmatized social environment of multimorbidity with HIV.

HIV as Background to Other Chronic Conditions

The experience of having other chronic conditions with HIV was not necessarily viewed as different from having chronic conditions without HIV. One participant stated that HIV with other chronic conditions was

... just like a person who didn't have HIV...it's not a death sentence anymore so I don't think that just because you have HIV and have a chronic disease it should really...you don't have to do anything more special than somebody who didn't have it. (Focus Group [FG] III)

On the other hand, chronic care needs were also seen as varying according to the specific type of chronic condition other than HIV. One participant explained that PLWH with other chronic conditions do have specific needs that may stem from complications due to treatment of non-HIV-related conditions:

...because you're dealing with two different diagnoses apparently. For me you know we've gotten the HIV/AIDS thing under control. It's the (other disease) that I have now that we're dealing with, and that includes treatments of (certain medications)...So yeah, there are special needs and I think they vary depending on what the other disease is or what the other illness is. (FG I)

One individual described HIV as “hibernating — like bears hibernate in the wintertime...it's like nonexistent inside of us, 'cause it's non-detectable” (FG III). For most participants, HIV was considered under control and often overshadowed by other chronic conditions, which also had to be managed:

I'm undetectable. I've been undetectable for almost 8 or 9 years due directly because I follow what my doctor tells me to do, but that does not mean that I don't have other medical issues. I had a heart attack. I'm not diabetic or anything like that. Once I lost the weight, my cholesterol is in order. So, there's a lot of pluses that goes along with following what your doctor tells you. (FG IV)

Another person noted,

I was never affected or scared, I want to say, that HIV would be my cause of death, you know. There are so many other things. I've got high blood pressure or liver functions and all this kind of stuff... (FG II)

Furthermore, because HIV tends to be managed successfully nowadays, PLWH with other chronic conditions may not automatically assume that any new symptoms they experience are related to HIV. As one individual noted, “I went to the hospital because I felt kind of bad and I knew it wasn't necessarily my AIDS diagnosis, but something else was going on...” (FG I).

While people living with HIV and other chronic conditions perceived specific health care needs, they viewed HIV as in the background. That is, HIV was a persistent but controlled condition, often overshadowed but occasionally complicated by the presence of other chronic conditions and their treatment.

Challenges in Managing Medications and Provider Interactions

Although individuals perceived their HIV as under control, they noted challenges in dealing with multiple chronic conditions specifically related to HIV medications and the need to interact with multiple health care providers. Many of these challenges involved coordinating medications and managing potential adverse effects or untoward drug interactions when trying to coordinate HIV management with treatments for other chronic conditions. Several participants noted that other chronic conditions they were experiencing (e.g., hypertension, high cholesterol) were the result of adverse effects from treatment with potent medications for HIV. Adverse effects of medications and medication interactions were common concerns of participants:

...the difficulty is in the fact that if you have more than one condition, you're probably being medicated for it, and drug interaction is another concern there that you have because, yeah, it may work for that condition, that medication, but it may interact with the drugs that you're taking for another condition. So, therefore, it may limit your ability to take certain drugs because of strong drug interactions, 'cause I've had that in the past where my heart medicine, my psych[iatric] medicine was interfering—or my HIV medicine was interfering with that, or the HIV medicine lowered the effectiveness of the other medication. (FG I)

In addition to vigilance in monitoring medication effects and interactions, individuals with HIV and multiple chronic conditions were active in working with physicians to manage their care. Participants expressed wariness of referrals to health care providers who were unfamiliar with their situations or who did not maintain effective communication with primary physicians. One person declared, “The patient has to be his own advocate and very proactive in whatever. You can't sit back and let the doctors say ‘well this is what's going on'...” (FG I). Another person noted that even though patients have a “say” in their health care, “a lot of times we don't say it. We don't speak up (to physicians). We don't say the things that's going on and I don't know why that is, but it is...” (FG II).

Participants tended to value proactivity in self-managing illness and dealing with health care providers. Medication interactions, adverse effects, and communication between multiple specialty physicians were viewed as problematic, even for those with long-term experiences with the health care system.

Coping with Future Health Care Needs

When asked about their health care needs, participants listed a number of specific physical issues (symptom relief for itching, shortness of breath, depression) and social needs (transportation to a grocery store or doctor's appointment, management of social isolation). Some participants expressed opinions about HIV in the broader societal context and worried

about the ability of the current health care system to meet their needs in the future. Some concerns about future care were related to a belief that the public had lost interest in HIV:

I just feel like the HIV/AIDS syndrome has run its course now...It's there, but it's not there. It's not as bad as it used to be because people aren't dropping like flies like they used to be. To me that doesn't mean that it's been cured or that we've even come to a conclusion of it. It just means that we don't care as much about it anymore. It's not as dramatic as it was before, but it is dramatic in the lives of the people that have it... (FG I) Participants recognized the potential for needing more complex care as they aged, and a concern voiced by one participant was whether the Medicaid/Medicare safety net would continue. Another patient noted that "we (the patients) were the main focus" in the early years of the HIV epidemic, but now "they're making it more difficult to qualify for some of the benefits" (FG III).

In spite of concerns about adequacy of future health care and social support, participants expressed a positive outlook on life. They stated a commitment to taking care of their health through self-education and managing their conditions by following medical advice and remaining connected to the health care system.

Because addressing spiritual needs is an aspect of palliative care programs, we asked whether spirituality had a role in one's health. Individuals expressed a variety of opinions. Some participants acknowledged the incorporation of spiritual meaning into their lives, with one individual stating that he owed his survival to belief in a higher power, with an embracing of spirituality, "positive things started happening" (FG IV). Others believed health and spirituality were "two separate entities" (FG II) or wanted others to recognize differences between spirituality and religious beliefs.

Stigmatized Social Environment of Multimorbidity with HIV

Seemingly as important to the well-being of participants as health care issues was a perception of persistent stigma associated with HIV, leading to a reluctance to share information and/or disclose one's HIV. While one participant claimed to be very open about having HIV, others were cautious about sharing this information, sometimes even with family members. As one individual remarked,

...they're trying to make HIV like cancer or anything else. I mean we all kind of wanted that kind of acceptance, but it's still not as common as cancer or lupus or anything. You know it still has its stigma to it. So, we really didn't fix it. We kind of started to fix it and then we kind of just let it go... (FG I)

One result of the continuing stigma attached to HIV for these participants was the difficulty sharing the stresses and distresses of having HIV and other chronic conditions with others. One long-term survivor of HIV explained how he once was open about disclosure of his HIV status, but has since learned that "...everybody can't handle certain things..." and, depending on the person and situation, he would "put out little feelers and just see how they (others) respond about that and then take it from there..." (FG III). Other participants noted prejudice in the health care system and society stemming from both HIV and race. One

individual said, “I’ve been African American all of my life and I can feel certain (negative) vibrations from certain entities (because of race)” (FG II). Another participant explained,

The first stigma was within society itself, and the second stigma came within the culture of the Black community, unfortunately, and the third stigma was your family, you know, but again all it boiled down to awareness and lack of knowledge and/or education... (FG II)

A contradiction in societal response to HIV was noted by another individual:

We have HIV characters in our soap operas now, in our TV shows, in our cop shows, cops are coming up with victims who are HIV-positive, and it’s great, it’s great. We’re all over the media, but it hasn’t resolved or I don’t want to say helped, but it hasn’t really done anything, except put it out there. (FG I)

In spite of long-term survival and the development of other potentially serious medical conditions, the stigma associated with HIV remained problematic for participants.

Discussion

We explored the needs and experiences of individuals who were living with multimorbidity with HIV. We found that participants viewed HIV as background to their overall chronic illness state. Because most participants viewed their HIV as controlled, the fact of having HIV was often overshadowed by conditions that were relatively more serious or difficult to manage medically. This finding underscored the need for health care providers who treat patients with multimorbidity to elicit what is important to the patient’s understanding of his/her illness needs rather than focus on the “index condition” (Valderas, Starfield, Sibbald, Salisbury, & Roland, 2009).

Participants recognized HIV as adding to the complexity of other chronic conditions. Of greater importance for participants, however, were the difficulties involved in managing multiple medications and the interactions with different specialists involved in the care of other chronic conditions while still maintaining equilibrium in their HIV management. The significance of having HIV came into play (a) when participants encountered specialists not attuned to HIV management issues, or who failed to communicate or work collaboratively with HIV primary care providers; and (b) when use of multiple medications caused adverse effects, led to or exacerbated other chronic conditions, or complicated the treatment of HIV and/or other chronic conditions. Adverse effects of polypharmacy are well-recognized in aging patients with multimorbidity. One review, for example, noted that polypharmacy in older adults could lead to toxic drug interactions and/or ineffectiveness in achieving therapeutic effects, as well as falls, increased resource utilization, and higher mortality (Gleason, Luque, & Shah, 2013). For PLWH with other chronic conditions, the prevalence of adverse interactions of antiretroviral therapy and non-HIV medications has not been extensively documented, but it has been linked to potentially serious drug interactions and interruptions in antiretroviral therapy (Holtzman et al., 2013; Krentz & Gill, 2016).

Our findings regarding specific needs of PLWH with other chronic conditions were similar to challenges reported by HIV-uninfected patients with one or more chronic conditions.

HIV-uninfected individuals with multimorbidity also experienced medication burdens and other barriers to care both at the provider and health system level (Eton et al., 2012; Ridgeway et al., 2014). In addition to the physiological and clinical effects of multimorbidity with HIV, our participants expressed needs related to the sociocultural and psychological contexts of HIV infection. Their concerns about future health care were not unexpected in the current era of uncertainty regarding provision of health care for uninsured or under-insured and/or older Americans. Similar to Ridgeway et al. (2014), self-management of health and reliance on spiritual support were noted by our participants. Such positive coping strategies have been identified previously in long-term survivors of HIV (Brown, Hanson, Schmotzer, & Webel, 2014; Slomka, Lim, Gripshover, & Daly, 2013) as well as in HIV-uninfected elderly (Bayliss, Edwards, Steiner, & Main, 2008) and may be essential to improving quality and quantity of life for patients with multimorbidity.

Stigma associated with HIV remained a pervasive concern. While their own health focus had shifted to chronic conditions other than HIV, participants perceived that the wider society had not followed suit, even though the natural history of HIV, its treatment, and their own lifestyles had undergone significant changes during the past decades. The persistence of HIV stigma and its adverse health consequences support a consideration of multimorbidity with HIV as exceptional in its difference from multimorbidity without HIV. HIV exceptionalism, i.e., the idea that HIV is different in a variety of aspects from other diseases and requires different socio-medical responses (Smith & Whiteside, 2010), could justify additional resources needed to improve the lives of PLWH with other chronic conditions.

The developers of the U.S Department of Health and Human Services' (2010) strategic framework to identify medical and psychosocial issues associated with multiple chronic conditions acknowledged that the framework did not include lived experiences of multimorbidity by patients and providers (Parekh et al., 2011). Our research adds to the literature by identifying perceived health needs and experiences of PLWH and other chronic conditions. Our study was limited by its definition of multimorbidity as two or more co-existing chronic conditions based on self-report. We did not collect data on physical function or geriatric syndromes that would inform the more complex definitions that are emerging in the literature (Koroukian et al., 2015).

Conclusion

As the U.S. health system moves toward greater understanding of multimorbidity, continuing exploration of the dimensions of multimorbidity with HIV will include testing clinical interventions to manage treatment complexities to improve both quantity and quality of life. Health care providers and patients may benefit from enhanced attention to communication and follow-up when crossing specialty treatment areas. In addition, public health and political efforts should be encouraged to change perceptions of HIV stigma and to provide the social supports needed to decrease social stressors associated with HIV multimorbidity.

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Key Considerations

- Because many PLWH with other chronic conditions viewed their other co-morbidities as having greater consequence than their HIV, health care providers who treat PLWH with multimorbidity should consider heightened attention to eliciting the patient's understanding of his/her health needs rather than prioritizing HIV as a "default" index condition.
- Although numerous challenges in managing multimorbidity are common for both HIV-infected and uninfected patients, the risk of adverse health consequences due to the persistence of perceived HIV stigma remains for PLWH with multimorbidity.
- Enhanced communication across specialty areas and focus on the challenges of balancing HIV medications with those used for other co-morbid conditions remain essential to the care of PLWH with other chronic conditions.

Table 1

Characteristics of Participants ($N = 22$) by Focus Group

Focus Group	# Participants	Male Gender	Age Range (years)	Ethnicity (Black/African American)	Years Schooling (range)
I	6	5	50–59	5 ^a	11–16
II	3	3	53–58	3	12–14
III	7	2	35–63	6 ^b	8–16
IV	6	6	23–60	4 ^c	10–16

Note. Other ethnic categories represented: a. Other = 1; b. White/Caucasian = 1; c. White/Caucasian = 2