

ARTICLE

Stigma, isolation and depression among older adults living with HIV in rural areas

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Abstract

There is a growing population of ageing individuals living with the human immunodeficiency virus (HIV). Older adults living with HIV often contend with intersecting stigmas including HIV stigma, ageism and, for some, homonegativity and/or racism. Although the HIV stigma literature is quite robust, research on the relationship between HIV stigma, social support and mental wellbeing among older adults living with HIV is limited. This study begins to address this gap by examining how intersectional stigma affects social support and mental wellbeing among rural-dwelling older adults living with HIV. Qualitative interviews were conducted by phone with 29 older adults living with HIV, over the age of 50, living in rural areas of the United States of America. Interviews were transcribed verbatim and analysed using thematic content analysis in MAXQDA qualitative analysis software. Analysis revealed three primary themes. The first had to do with gossip and non-disclosure of HIV status, which intersected with ageism and homonegativity to exacerbate experiences that fell within the remaining themes of experiences of physical and psychological isolation and loneliness, and shame and silence surrounding depression. The prevalence of social isolation and the effects of limited social support among older adults living with HIV are prominent and indicate a need for tailored interventions within the HIV care continuum for older adults living with HIV.

Keywords: stigma; ageing; HIV; social support; mental health

Introduction

The confluence of increasing survival rates among individuals living with the human immunodeficiency virus (HIV) and new HIV infections has resulted in a consistent increase in persons, aged 50 and older, living with HIV. In 2014, an estimated 45 per cent of individuals living with HIV in the United States of America (USA) were aged 50 and older, attributable to the success of antiretroviral therapies (Centers for Disease Control and Prevention, 2017). Simultaneously, the incidence

rate of HIV among people over age 50 is growing; in 2015, people aged 50 and older accounted for 17 per cent of new HIV diagnoses in the USA (Centers for Disease Control and Prevention, 2017).

Concurrently, global rates of all rural-dwelling older adults are increasing (World Health Organization, 2015). Rural environments pose unique challenges and opportunities to health and wellbeing among older adults (Glasgow and Berry, 2013; Skinner and Winterton, 2018), which are reflected within the HIV epidemic. The presence of HIV in rural areas of the USA has become increasingly problematic, as non-urban regions are the only areas of the USA with increasing acquired immunodeficiency syndrome (AIDS) diagnoses (Centers for Disease Control and Prevention, 2015). Approximately 28 per cent of new HIV infections in non-metropolitan areas of the USA are among individuals aged 45 or older, higher than seen in urban areas (Centers for Disease Control and Prevention, 2016b). Rural patients tend to present later for care, which can contribute to increased risk for opportunistic infections and greater HIV transmission risk to others (Ohl *et al.*, 2010; Weis *et al.*, 2010) and higher mortality rates than their urban counterparts (Lahey *et al.*, 2007). Despite the increasing prevalence of HIV in rural areas, few providers have adequate training or experience in the care of people living with HIV (Grace *et al.*, 2010). HIV patients tend to report greater HIV-related discrimination within rural health-care settings and concern for their privacy when seeking local medical care (Pellowski, 2013).

With the increasing population of older adults living with HIV, greater attention has been paid to the barriers and facilitators of successful ageing with HIV, or the processes by which older adults actively cope with the changes associated with ageing, within the context of having a chronic disease (Baltes and Baltes, 1990; Vance *et al.*, 2011). One factor that may affect the lives and experiences of rural-dwelling older adults living with HIV is stigma. Stigma is most commonly conceptualised as the social identification and disapproval of a physical, behavioural or social trait (*e.g.* HIV), which often manifests in marginalisation or discrimination (Goffman, 1963). HIV stigma is a primary contributing factor to poor health outcomes and health disparities among persons living with HIV (Emlet, 2017; White House Office of National AIDS Policy, 2015). For example, HIV stigma is negatively associated with engagement in HIV care (Kinsler *et al.*, 2007) and viral suppression (Quinn *et al.*, 2017). Persons who perceive higher levels of HIV stigma have decreased access to medical care, poorer antiretroviral therapy adherence and lower rates of HIV care utilisation (Katz *et al.*, 2013; Rueda *et al.*, 2016).

Yet, HIV stigma rarely operates independently of other stigmas, and the effects of HIV stigma may be magnified when coupled with homonegativity, ageism or mental health stigma. Examining intersectional stigma, or the intersection of multiple, co-occurring devalued identities or labels (*e.g.* HIV status, age, sexual orientation, mental health challenges; Earnshaw *et al.*, 2013) may shed light on the experiences of older, rural-dwelling adults living with HIV. Rooted in intersectionality theory, intersectional stigma can help explain how persons simultaneously experience multiple stigmas and how such stigmas affect social, mental and physical wellbeing (Logie *et al.*, 2011). Intersectional stigma, and its manifestations and consequences, can contribute to poor quality of life in older people living with HIV (Catalan *et al.*, 2017). Older adults living with HIV are often subject to the

intersecting stigmas of ageism and HIV stigma, and some may also have to contend with racism and/or homonegativity, the combination of which may multiply the negative effects on their mental health and access to social support (Emlet *et al.*, 2013). As a result of ageism, older adults are stigmatised and perceived as incompetent, unemployable, unattractive and asexual, and is common among older adults living with HIV (Emlet, 2006). Like other forms of discrimination, ageism can inhibit social support, contribute to social rejection and make it difficult to establish sexual or romantic relationships (Webel *et al.*, 2014). For example, older gay and bisexual adults have lower condom use than their younger counterparts, partially attributable to social stigma and conservative norms around sexuality when they were younger (Ritter and Ueno, 2018). Rural communities create environments in which HIV stigma may be intensified due to decreased or antiquated knowledge about HIV and little interaction with individuals living with HIV (Hall *et al.*, 2005; Zukoski and Thorburn, 2009; Rosenfeld *et al.*, 2016). Indeed, rural-dwelling persons living with HIV often experience high levels of HIV-related stigma (Sweeney and Vanable, 2016).

The HIV stigma literature is quite robust, and there is a growing literature base on rural ageing (Skinner and Winterton, 2018), yet research on intersectional stigma among older adults living with HIV and our understanding of ageing with HIV in rural communities remains limited. Much of the research on ageing with HIV has occurred within an urban context and, thus, may not adequately capture the stigmas experienced by rural-dwelling persons living with HIV. This study begins to address this gap by examining how intersectional stigma affects older adults living with HIV within a rural context. We conducted qualitative interviews with 29 older adults living with HIV in rural communities to understand better the manifestations of stigma in their lives and the effects of stigma on their health and wellbeing.

Methods

Participants and enrolment procedures

Inclusion criteria included being HIV-positive, aged 50 or older, and living in a rural county in one of four US states: Alabama, Tennessee, Vermont or Wisconsin. These states were selected to represent different geographic areas of the USA. We used the US Office of Management and Budget's definition of rural counties, which designates rural counties as those that do not contain a Metropolitan Statistical Area – defined as a city with a population of 50,000 or more – and do not have social or economic integration with an adjacent county that does contain a Metropolitan Statistical Area (US Department of Health and Human Services, 2017). We recruited participants through partnerships with AIDS Service Organizations (ASOs) in the four designated states using purposive sampling methods. Case workers and other ASO staff distributed flyers with information about the study to potentially eligible participants and hung flyers in waiting areas and clinic rooms. Those who were interested in participating called the study screening line, were screened for eligibility and were scheduled for a telephone interview with a member of the research team if they met the eligibility

criteria. Potential participants were mailed or emailed a copy of the consent form or could view a copy of the consent form on the study's website. Prior to the start of the interview, interviewers reviewed the consent form with participants, described the study, provided an overview of interview topics, described potential risks to participants and received verbal consent from all participants. Participants were reminded they could end the interview at any time or skip any questions they did not want to answer. Upon interview completion, participants who were interested were given contact information for their local ASO and referred to their case manager if they needed additional information on local treatment, support or services. Participants were also mailed a cheque for US \$100 as compensation for their time. The study protocol was approved by the Medical College of Wisconsin Institutional Review Board.

Interview content

Interviews lasted approximately 60 minutes. We followed a semi-structured interview guide that covered topics including family and social life, stigma and discrimination, HIV medical care, and mental health. To assess social support we asked: 'Who would you describe as your main sources of practical support/emotional support/social support', along with a series of probes. To understand participants' mental health, we asked about current life stressors and coping mechanisms, how they would describe their general state of health, and what medical conditions they currently had or were being treated for. We also asked participants to describe their general mood and whether they had ever been diagnosed with or treated for a mental illness. Finally, to understand experiences of stigma and discrimination, we asked participants whether they had ever been treated unfairly or felt discriminated against. The semi-structured format allowed for flexibility within the interview and participant-guided discussions. Accordingly, many of the conversations around stigma emerged organically and were often discussed in conjunction with other topics. Interview prompts or conversation summaries are included with the interview excerpts presented below. All interviews were audio recorded, transcribed verbatim, reviewed for quality and accuracy, and uploaded into MAXQDA qualitative software for analysis.

Data analysis

Transcripts were initially coded using descriptive and *in vivo* codes to categorise the data (Saldana, 2016). We used a three-stage analytic coding strategy including open, axial and selective coding along with memoing to record initial observations and reflections (Corbin and Strauss, 2015). We began the coding process by having four members of the research team read through two selected interviews to generate an initial list of codes. We compiled the individual code lists, compared and discussed codes, and generated a new coding scheme. Team members applied the new coding tree to another two randomly selected interviews. We again discussed coding discrepancies, clarified code definitions, and repeated this process until we reached final consensus and finalised a coding tree. Codes included: stress, isolation, support (with sub-themes of support groups, emotional support, social

support), HIV medical care (including sub-themes of barriers to care, concerns about confidentiality, health-care discrimination, comfort with physician), physical environment (including sub-themes of home environment, geographic isolation), stigma and coping mechanisms. Two members of the research team then applied the coding tree to all 29 interviews. We used thematic content analysis to identify inductively themes that captured individuals' experiences of stigma and ageing with HIV within a rural context. We explored how intersectional stigma affected quality of life, social support and mental wellness. Constant comparative method (Boeije, 2002) was used to explore variations within concepts, categories and themes. Analyses revealed three primary themes: the desire to control information in small towns; loneliness and isolation as a result of HIV status, age and geographic isolation; and the effects of age, geographic isolation and stigma on mental health. Results are organised around these themes. Pseudonyms are used throughout.

Results

Participant demographics

We interviewed 29 older adults living with HIV. Participants' ages ranged from 50 to 73 years old, with a mean age of 57.5. Participants were primarily White and heterosexual and had been living with HIV for between five and 34 years (mean = 22 years) (Table 1).

Although not intended to be representative, in general, this sample is representative of older adults living with HIV in the USA (Centers for Disease Control and Prevention, 2016a) and the rural population of persons living with HIV in the USA (US Department of Health and Human Services, 2013), although in this study, we have a larger percentage of White participants, which is a reflection of the racial makeup of Wisconsin (80% White) and Vermont (94% White; Henry J. Kaiser Family Foundation, 2018). Twelve participants (41%) had lived in a rural environment or in their same community their entire lives. Most others were born or raised in rural areas, left to live in large cities for several decades (*e.g.* Los Angeles, New York City, Chicago), and returned after they retired or were no longer able to work.

Qualitative themes

'You don't talk about that in this area': controlling the spread of private information in small towns

Participants lived in small, close-knit communities where 'everyone knows everyone's business' and social norms dictated that community members impose social and conversational barriers to preserve a modicum of privacy. When asked about his social support system, John explained the need to tread carefully when establishing and maintaining friendships in rural communities:

Let me explain something, and this is hard for an urban person to understand. And that's not a criticism. You know, in a very close community where you know everybody, generally, in fact almost always, they build walls around themselves. We learn each other's friends and we don't go beyond that, you know, it's kind of a live and let live thing. It helps us in many ways and it's a hindrance in other ways, but it helps us to

Table 1. Participant characteristics

	N (%)
Male	23 (79)
Heterosexual/straight	16 (55)
State of residence:	
Alabama	6 (21)
Tennessee	1 (3)
Vermont	8 (28)
Wisconsin	14 (48)
Race:	
White	21 (72)
Black	5 (17)
Native American	2 (7)
Mixed race	1 (3)
Hispanic Latino	2 (7)
Mean age	57.5
Mean years living with HIV	22

Notes: N = 29. HIV: human immunodeficiency virus.

figure out how we can be an individual and still in very close proximity. I mean, I don't know, it's hard to explain. There are not many people and so you choose your friends wisely and you choose what you are going to share carefully and you make an attempt not to invade too much, and that's a common courtesy. (John, 62-year-old White heterosexual male, Vermont)

In John's view, the norms surrounding privacy in rural communities are unique to these settings to the degree that it would be difficult for an 'urban person' to understand. The respect for this 'live and let live' way of life results from a common understanding that the smallness of rural communities means that private information, once disclosed, can reach all community members in a matter of time. This sentiment was echoed by others:

Interviewer How many people know about your HIV status?

(I):

Anita: Just me. Because it all comes back on me ... It's more like we are a close-knit community around here and once the word gets out, it travels more in a small community. It's just like the wind blowing by. People just talk. (Anita, 53-year-old Native American female, Wisconsin)

This threat of gossip within small communities is heightened for those protecting information that would make them vulnerable to stigmatisation, including HIV and

sexual orientation. Charles responded similarly when asked about who knew about his HIV status.

Charles: I don't discuss my status with people unless there is somebody that I really feel like would really be ok with it. It's not that I'm ashamed of it but, I am in an area where everybody knows everybody's name, like the theme song for *Cheers* you know. And all it takes is one person to go around and start talking about it. And eventually somebody is going to find out that has an issue with it. And so I've been rather private about that.

I: Sure, so how many people would you say in your small town or just around the area you live know about your HIV?

Charles: Just my partner.

I: Ok, and do you worry that people will find out?

Charles: I think about it a lot! I think about it because I'm just concerned about the stigma that goes along with it. I realise that now most people don't have an issue, you know, but I also realise that there are people, especially in a small community, especially right now with the gay marriage issue being at forefront, it's brought out a lot more anti-gay reaction among a very small, minute group of people and I don't want to come home one day and have graffiti all over my house like it's happen to other people. So I just kind of think that for me, it's best not to divulge that kind of stuff. (Charles, 57-year-old White gay male, Tennessee)

Caution regarding disclosure is a common stigma management tactic when judgement or discrimination is anticipated upon disclosure. However, the smallness of participants' communities meant that they exercised this caution with everyone, even when, like Charles, they believed that 'most people' would not have an issue with their HIV status. Effectively, anyone knowing about his status threatened everyone knowing it, including what Charles perceived to be a small minority that he wants to protect himself from. Hence, maintaining control over information about their HIV status was profoundly important to nearly all participants. The results of losing that control included confronting homonegativity and ignorance about HIV, and losing important personal relationships because of their HIV status. While these consequences of involuntary disclosure are not unique to towns with 'one red light', the smallness of participants' social worlds meant that once the word was out, they were utterly isolated:

Sam: It's real quiet here. There is one red light and um, you don't talk about this in this area.

I: And when you say 'this' are you talking about HIV?

Sam: Yeah.

I: And why do you say that?

Sam: Well, I had plenty of friends. I was a superintendent. Once people found out, don't anybody want to do anything with me anymore ... it got out through the drug store. When I had to order my HIV meds, it leaked out

... you just don't have no friends no more. You just kind of have to live to yourself. (Sam, 59-year-old White heterosexual male, Alabama)

In an attempt to maintain control over who knows about their HIV status and minimise involuntary disclosure, some participants described receiving care in distant towns to avoid seeing local physicians, or travelling long distances to avoid picking up HIV medications at local pharmacies. Nearly all participants described situations similar to Sam's, where one's HIV status was subject to rumours:

You know everybody that works in the local pharmacy and/or at the doctor's offices that may have the ability to serve me. I mean, the receptionist and the nurses are all people that I know. I have had some experiences that weren't very comfortable, like having been told by a mechanic that I have HIV. Well, actually he told me that I have AIDS. It was kind of weird thing. He wasn't working on my car and I was wondering how come. It was there for a day or two and how come he hadn't started on it. And he said 'oh yeah I wanted to ask you, so can I go in the car because you have AIDS and I didn't know' that kind of thing. And the mechanic heard from the radiologist who works for the Department of Care you know what I mean? And their remarks is more like gossip. I mean, that's what we do, and that's what people do here and so they got to get a juicy thing going on and like that. But to defend the mechanic a little bit, he just didn't know. He was ignorant and that was a good teaching moment actually, but he just didn't know. He wasn't like being, what do you call it, he wasn't stigmatising, he was just uneducated. (Paul, 62-year-old White heterosexual male, Vermont)

Stigma is often rooted in ignorance about the stigmatising attribute. Paul's interaction with the mechanic constituted a 'teaching moment' not just in disabusing the mechanic of his erroneous ideas about HIV transmission, but also by showing the mechanic that a person with HIV is not abnormal or dangerous. Contact with, and normalisation of, individuals living with HIV may counter HIV stigma, but requires that people living with HIV disclose their status. This is problematic for many people, as disclosure can make persons living with HIV vulnerable to the same stigma they are trying to combat.

I: Have you ever felt discriminated against?

George: Yeah, certainly for being gay. The whole thing came out during the whole gay marriage, civil union debate because I was heavily involved in that too, and it was horrible. You had to listen to all these things. And me being gay, almost got me to like a nervous breakdown point as a traumatic experience. And the HIV piece of it. Being gay is bad enough. If they knew I have HIV? One of the arguments was 'they're spreading disease'. And then if I said, 'oh yeah, and by the way, in addition, I am positive', that to me was like one extra stigma I'd have to deal with. So that slowly abated, but that really was a gaping wound for a while. (George, 62-year-old White gay male, Vermont)

For George, disclosure of his HIV status could have added to the burden of his own stigmatisation while inadvertently providing support for an offensive stereotype fuelling oppression of gay people. Participants described many ‘catch-22’ situations like George’s predicament, in which the pathways to ameliorate the negative effects of HIV stigma entailed outing themselves and educating those perpetuating stigma, thereby simultaneously making themselves vulnerable to stigma. Stereotypes of HIV that conflate HIV with homosexuality meant that nearly all participants experienced the intersection of HIV stigma and homonegativity, despite the fact that only 45 per cent of study participants identified as gay or bisexual. For example, Sam was heterosexual and described peoples’ responses to finding out that he was living with HIV through unwanted disclosure by the pharmacy:

I: Did people say anything to you about it?

Sam: Yes ma’am. Uh, they would call me queer, faggot and stuff. You know, anybody could have this. I just got caught in the wrong place one time. (Sam, 59-year-old White heterosexual male, Alabama)

The association between HIV and homosexuality was strong and contributed to further stigma for all individuals, regardless of their sexuality. Participants who did identify as gay or bisexual also discussed the intersection of HIV stigma and homonegativity and their challenges contending with both stigmatised identities.

‘It would be nice to have a support system’: experiences of loneliness and isolation

Participants described challenges to meeting people in a small town, friends and relatives retiring to other states or passing away, and challenges making social connections due to their HIV status or sexual orientation. Loneliness and isolation, in conjunction with limited social support, were among the most commonly reported challenges associated with stigma, ageing and living in a rural environment.

Barriers to romantic and sexual relationships

The intricate and uncertain implications of ‘who knows what’ meant that maintaining important relationships was particularly fraught and often painful for participants. Most participants had disclosed their status to at least one person outside the medical community, but nearly all worried about involuntary disclosure and feared the consequences they might face if particular individuals or the broader community was aware of their HIV status or sexual orientation. For a few individuals, fear of what might result from disclosing their status prevented them from sharing that information with anyone, including spouses and close family members. One Alabama resident, for example, had not told anyone about his HIV status, including his wife:

I: What would you say has been the most difficult thing for you about having HIV?

Gregory:

When I first found out I had it, it seems like I was mad at the world. But once I found out I had it, I just couldn't do anything about it. Just had to learn to live with it.

I: Yeah, has it been difficult for you to keep that a secret from your wife?

Gregory: Yes it's difficult. I want to tell her and I don't want to lose her really.

I: Yea are there any other people in your life or any of your friends who know you that you are HIV-positive?

Gregory: Uhh, no. (Gregory, 65-year-old Black heterosexual male, Alabama)

The threat of losing or being unable to maintain or establish romantic and sexual relationships loomed large in participants' anxieties about what would result if they disclosed their HIV status and was a common response to interviewers' questions about the most difficult thing about living with HIV. While Gregory was unique in his non-disclosure to his spouse, several participants described challenges to meeting new partners.

I: What has been the most difficult thing for you about being diagnosed with HIV?

Deborah: I'd have to say boyfriend material. It's really hard. I say boyfriend material more along the lines of disclosing.

I: Can you tell me a little more about that?

Deborah: It just makes you turn around and everyone that you would consider dating, the first thing you think of is 'Can I see myself telling this person?' It kind of jades everything. It makes you look at that person differently right from the get-go. Where normally, 'Sure, I'll go out with this guy', whatever. And now, if I can't see myself sitting down and having a conversation with this person, I'm passing. (Deborah, 52-year-old White female, Vermont)

This fear about the consequences of disclosure was particularly evident among gay men, who described challenges to meeting partners. Gay participants knew few, if any, gay people in their communities and there were no gay bars or LGBT community organisations nearby. Coupled with many participants' reluctance to identify as gay or disclose their sexual orientation, it was difficult to find sexual or romantic partners.

Brian: You know I just I'm sort of accepting the fact that I will be single ... I'm not ok with that. It's sort of sad, you know. It would be nice to have support system with a partner.

I: Sure and so why do you think that you will be single forever?

Brian: I'm not in any type of a gay scene here. I don't meet people that are, you know, gay. (Brian, 60-year-old White and Native American gay male, Wisconsin)

Not only were there few, if any, LGBT-friendly establishments in their communities, participants also faced challenges finding potential partners online. As older adults, many were less familiar with using the internet for dating or social purposes than their younger counterparts. For a few participants more comfortable with technology, online dating sites were a way to make social connections in a space that did not exist in their towns. Yet, this mode of finding partners had its own challenges.

Well, what issue has come up for a couple of years now in terms of my sexual needs ... it's hard. It's hard up here because there's less people. And nobody, very few people want to be with [someone with] HIV and I'm pretty much a stickler on letting people know. And you go through the personals, you look at the personal ads on Craigslist and it's 'disease and drug free'. You know, sexually. It's very stigmatising in terms of people wanting to distinguish themselves. To not have to deal with that whole issue, that really is a big sort of cause for concern for me. It plays some anxiety. (George, 62-year-old White gay male, Vermont)

While the desire for drug-free and HIV-negative partners in online personal advertisements may not seem harmful, colloquialisms such as 'clean' and 'disease and drug free' used to describe potential partners are rooted in HIV stigma and imply individuals living with HIV are 'dirty' or 'diseased'. Thus, to find meaningful relationships and feel less lonely, participants had to contend with HIV stigma from potential sexual partners, ultimately contributing to anxiety, shame and further isolation.

'The D-word': the weight of silence, shame and regret regarding mental health

To complicate experiences of HIV stigma and homonegativity, several participants also described previous or current episodes of depression, anxiety and suicidal ideation. Participants' experiences of depression were intertwined with stigma, isolation and lack of social support, all of which were intensified within the rural context. For example, when asked about whether any home or environmental factors affected activities of daily living, one participant described how north-eastern winters contributed to his depression.

Here, we're talking about 20 below [20°F below zero] and very dark. I've had full-blown depression for several years and I'm very reluctant to spending five months in the dark with the cold temperatures that I can't go outside and stay outside very long. So, that's the only concern that I have with the location that I live. (Raymond, 51-year-old White gay male, Vermont)

Depression was common among participants. Sixteen participants (55%) reported a depression diagnosis or discussed depressive symptoms (extreme sadness, loss of interest in activities, apathy, social isolation), yet only nine individuals reported current treatment. A few individuals experienced depression and obtained treatment for it immediately following their HIV diagnosis, but reported no longer needing treatment. For several participants, the weight of depression on top of a burdensome HIV diagnosis contributed to a resistance to mental health care and made their experiences difficult to even speak about.

- I: Are there any other medical conditions you have?
 Luke: No, not that I can think of. HIV is enough for me.
 I: Heart disease, depression, memory problems, nothing like that?
 Luke: No. Well, I do. The D-word you just used. I don't say it out loud. I run across that quite a bit. I just don't, it's just something, one of those things I just shove inside.
 I: Ok. Have you ever received treatment or talked to anyone about that?
 Luke: No, not really. I guess I'm afraid that I might have to do more counseling or something. I don't know. I just, I guess I have so much on my plate now that I don't want to worry about it, you know? ... I did talk to my doctor one time about depression and he wanted to put me on all kinds of pills and stuff. I was like, 'Nah. I have enough pills.'
 (Luke, 58-year-old Native American heterosexual male, Wisconsin)

The stigma surrounding depression was so pronounced for Luke that he had difficulty even saying the word 'depression' during his interview. He had struggled with depression since his HIV diagnosis in 2005, but the thought of adding an additional medication to an already complicated medication regimen was overwhelming. Furthermore, the diagnosis of depression added an additional layer of stigma many found difficult to contend with. Counselling, a common component of depression treatment, requires individuals to discuss personal, often uncomfortable, experiences and feelings, which can be difficult for those already contending with social and emotional challenges associated with living with HIV, including fears of involuntary disclosure.

I'm a 30-year survivor of HIV. So at the time my doctor was already saying, 'Look, you have a problem, you have a depression problem and I can see that you have a problem' and I was in denial. I'm not going to accept having the effects of a chronic disease. You know, I'd rather have to deal with HIV, I'm not going to deal with HIV and depression. So this remains untreated and uncared for and it's in a very, very bad state ... I have learned how to deal, and I guess if you want to know something else you should ask me your other questions. I don't want to go on about this. (Raymond, 51-year-old White gay male, Vermont)

Raymond's reluctance to discuss his depression and mental health treatment during the interview was evident throughout his narrative and common among this sample. As older adults living with HIV, some participants had lived with the knowledge of their infection long enough to have experienced and internalised widely varying ideas about their potential lifespan. The average length of time participants had been living with HIV was nearly 22 years, and many had friends or partners die from HIV-related complications and perceived their own lifespans to be relatively short. Changes over time in treatment options and what living with HIV means for one's future took an emotional and mental toll on participants, not the least of which was reckoning with past decisions:

When I found out that I had HIV, there were no medicines or anything like that. Pretty much I got a six-month sentence to live and they said basically, get your

affairs in order and so that experience became the catalyst to turn things off in my life, shut things down ... What pisses me off is there were certain roads I could have gone down, way back then. So I guess part of having HIV for me is that resentment, you know? I couldn't pursue a lot of things in my life that I wanted to fulfil because I just assumed I was going to be dead ... I try not to be so depressed. I'm really depressed. I mean, the pressure is right there. I really have to work at not feeding into the poor me stuff. (John, 62-year-old White heterosexual male, Vermont)

Unlike Raymond, John was open to mental health treatment but identified too many barriers to access it. He went on to say:

One of the other things on my wish list was if they had a mental health provider that did home visits. They showed up and you know, they had a cup of tea and you felt better afterwards. That type of person would be good. (John, 62-year-old White heterosexual male, Vermont)

In addition to advances in HIV treatment over time that affected the lives and mental health of participants, social progress concerning the rights of gay people were important to participants' experiences of stigma and depression. One participant's loss of his partner to suicide two years prior to the interview provided a devastating example of the effects of intersectional stigma:

He committed suicide. You know, I haven't told anybody that. I just kind of buried the evidence instead of turning it into more of that whole stigma, you know. I know what was going on with him. He had been abused by his father and literally he just felt like we had no future because we couldn't get married; it was before Wisconsin's law passed. (Bill, 58-year-old White gay male, Wisconsin)

Although the consequences of difficult-to-access mental health care and uncoordinated services were rarely this severe among participants, Bill's experience with his partner highlights the need for integrated mental health and HIV care. In addition to access, affordability was also a large concern, as many participants could not afford the co-pays (the amount a patient pays for receiving a health service, the rest of which is covered by insurance) and deductibles (the amount a patient must pay before their health insurance benefits begin to cover costs of care) associated with seeing a specialist or taking another medication. Bill described myriad challenges his partner confronted in his attempts to assemble and access the comprehensive mental health services he needed:

He had a lot of mental health problems and he was involved with various doctors and psychiatrists and it just seemed as though all the services, they weren't streamlined. There were holes in it. Multiple layers upon multiple people giving advice and prescribing things. Lack of consistency in them. The medical case management was just horrible. (Bill, 58-year-old White gay male, Wisconsin)

When they were willing and able to access mental health care, participants' adherence to treatment was hindered by a lack of mental health services in rural communities and inconvenience and expense associated with seeking care in other areas. Participants on Medicare or Medicaid noted restrictions in providers they could see and long wait times to establish care. While these issues are by no means exclusive to the experiences of older adults living with HIV, their impact is particularly important to people like our study participants who already experienced shame, self-silencing and feeling overwhelmed with respect to even acknowledging depression, much less getting treatment for it.

Discussion

This study is among the first to examine how intersectional stigma affects rural-dwelling older adults living with HIV. HIV stigma, ageism and, for some, homonegativity, intersected in ways that contributed to isolation and poor mental wellbeing. Furthermore, the cultural norms and expectations of rural communities made harnessing social support and accessing needed mental health treatment difficult and contributed to internalised stigma, anxiety and social isolation.

In line with previous research, our participants described a high degree of HIV stigma in rural communities (Hubach *et al.*, 2015), and their narratives highlighted the toll that multiple, intersecting stigmas had on their health and wellbeing. For example, given its epidemiological and social history, HIV was often seen as synonymous with homosexuality, such that even straight men had to vie with homonegativity if their HIV status was disclosed. Gay men discussed challenges associated with being openly gay in small communities and the potential political and social consequences of disclosing their sexual orientation, much less their HIV status. In response, individuals socially isolated themselves and were cautious about what personal information to share and with whom. This also made establishing sexual or romantic relationships difficult, a challenge associated with ageing and HIV. Recent research has highlighted how ageism and HIV stigma can have negative repercussions on the lives of older persons living with HIV (Wallach and Brotman, 2018), and our research extends this work to demonstrate the additional impact of homonegativity faced by many older adults living with HIV and the challenges of contending with such stigmas in rural communities.

Intersectional stigma directly affected the social and mental wellbeing of participants. For example, HIV stigma made it difficult to establish romantic or sexual relationships, which was especially evident among gay men, many of whom also had to contend with homonegativity. This is important, as previous research has demonstrated that being in a relationship can improve the quality of life among older persons with HIV (Catalan *et al.*, 2017) and successful ageing with HIV often includes deliberately creating social networks that promote resilience and positivity (Emlet, 2017). Yet, for many in this study, their rural environment and social isolation was such that they had few options for social support, much less romantic or sexual relationships. Rural environments in which individuals perceive homonegativity and HIV stigma and are geographically estranged from other gay men or venues that serve gay men exacerbated social isolation and loneliness for study participants. Loneliness is common among older, rural-dwelling adults, and is associated with physical and mental health impairments (De Koning

et al., 2017), making those living with HIV and contending with depression or anxiety particularly vulnerable to loneliness.

Previous research indicates older adults with HIV report fewer depressive symptoms than their younger counterparts (Crystal *et al.*, 2003; Mavandadi *et al.*, 2009), although depressive symptoms were common among this sample. This difference may be rooted in the fact that prior studies of ageing and HIV have overwhelmingly used urban samples. HIV patients in rural communities are particularly vulnerable to depression and, as explained above, the rural context may limit social support and, subsequently, enhance depressive symptoms (Sheth *et al.*, 2009). Loneliness and HIV stigma, two factors prevalent among this sample, have demonstrated a strong relationship with depressive symptoms among older HIV-positive adults (Groves *et al.*, 2010). Additional research on resilience is needed to identify opportunities to build social support and enhance resilience attributes such as self-acceptance, community engagement and spirituality (Emlet, 2017) among older adults living with HIV to help facilitate this needed support and reduce the effects of stigma (Chronister *et al.*, 2013).

One of the most prominent manifestations of stigma among this sample was secrecy and the selective HIV serostatus disclosure and efforts to control the spread of gossip. Selective disclosure of HIV status among older persons may be rooted in concerns about other adults', particularly older adults', misperceptions and limited knowledge of HIV (Rosenfeld *et al.*, 2016), and concerns about stigmatisation and discrimination. Thus, even those participants who had a support system were often reluctant to disclose their status if they anticipated such disclosure would result in further stigma. Non-disclosure of HIV status is a commonly used stigma management technique (Rosenfeld *et al.*, 2016; Emlet, 2017), yet this can subsequently contribute to limited social support (Smith *et al.*, 2008). In attempts to guard against inadvertent disclosure and the consequences associated with others knowing their HIV status, participants in this study socially isolated themselves and often internalised stigma, further increasing shame and isolation. Despite documented benefits to HIV serostatus disclosure (McFadden *et al.*, 2014), expecting stigmatised individuals to disclose their status to garner social support and reduce stigma is problematic. This approach puts the responsibility to reduce stigma on the stigmatised individual, necessitates disclosure of personal information and puts individuals at risk for further stigmatisation.

Given the increase in HIV prevalence in rural areas (Centers for Disease Control and Prevention, 2015) and an ageing cohort of persons living with HIV (Centers for Disease Control and Prevention, 2013), there is an increasing need for tailored interventions along the HIV care continuum for older adults living with HIV. Although efforts have been made to identify effective stigma-reduction interventions (Stangl *et al.*, 2013; Hughto *et al.*, 2015; Loutfy *et al.*, 2015), little research has specifically examined opportunities to reduce intersectional stigma among older adults living with HIV. The current study confirms that older adults living with HIV have multiple stigmatised identities that affect social and mental health outcomes. Application and implementation of interventions designed for younger persons living with HIV or older adults in urban areas may be inappropriate and ineffective given the changes associated with geographic and social isolation, and intersectional stigma faced by rural-dwelling older adults. HIV prevention

and treatment interventions must be multifaceted, designed and tested with older adults within rural contexts, and include interventions at the community, interpersonal and intrapersonal levels. Furthermore, interventions must take into account intersecting experiences of HIV stigma and ageism, and limited access to services in resource-constrained settings.

Despite the importance of our findings, this study is not without limitations. Although the states included in this study were intended to reflect geographical diversity, other rural areas across the USA may face unique challenges not captured here. Participants were recruited through partnerships with ASOs and, as such, all were currently engaged in HIV care, and many had a case manager, which biased the sample. As described earlier, there are myriad health consequences associated with HIV stigma. Given that all participants in this study were in care, the social and mental health effects of stigma reported here are likely even more evident among an out-of-care population. Six of the 29 participants (21%) in this study were women. Although this reflects the demographics of the HIV epidemic in the USA (Centers for Disease Control and Prevention, 2018), additional research with larger samples of women may be warranted. Finally, only approximately 40 per cent of our sample had been living in a rural community their entire life. The culture, norms and experiences of individuals who were raised or spent a significant amount of time in urban cities likely differ from those who have only resided in rural communities. Our data did not allow for analysis to uncover these differences, but this may be an important factor to consider in future research.

This research adds to a growing body of literature on the effects of stigma among persons living with HIV. This study is among the first to examine the intersections of HIV stigma, age and rural environments, and highlights the unique needs of this growing population. Additional research is needed to develop intervention tools specific to older adults living with HIV in order to address the health and social consequences of stigma.

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