

The Effects of Ageism and HIV-Related Stigma on Older Adults' Social Networks

by

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B.A. (University of Victoria) 2019

An essay submitted in partial fulfillment
of the requirements of the

HONOURS PROGRAM

in the Department of Anthropology
University of Victoria

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Abstract

HIV/AIDS has been the subject of culturally produced stigma since its emergence in the 1980s when a positive diagnosis meant certain death. HIV was transformed to a chronic condition with the introduction of antiretroviral therapies in 1996, yet the experiences of people living with HIV are still fraught with stigma and discrimination. Aging is also a stigmatized process in North America where a high value is placed on youthfulness. Through thematic analysis of individual illness narratives, this paper addresses how the intersection of age-related stigma and HIV-related stigma may exacerbate the social isolation already experienced by many older adults. As an example of how stigma can be unintentionally culturally produced, this research takes a critical anthropological view of the “successful aging” paradigm. The narrow normative framework for aging well does not allow for variations of success and can further isolate marginalized individuals. The discussion of themes that emerge from older adults’ illness narratives can help show how biomedicine must go beyond treatments of the physical body and address the social aspects of wellness. Sharing the stories of older adults living with HIV can help increase public understanding and empathy of the illness, reduce stigma, and humanize the individual experiences of HIV.

Keywords

HIV, AIDS, older adults, aging, stigma, ageism, social isolation, social networks, successful aging, thematic analysis

Acknowledgements

I would like to extend my sincerest gratitude to my mentor Dr. Eric Roth for his encouragement, support, and kindness; to the Honours Advisor Dr. Daromir Rudnycky for his mentorship; to my colleagues in Anthropology 499: Honours Seminar for their engagement and encouragement; to the University of Victoria for this opportunity and for honouring me with the Jamie Cassels Undergraduate Research Award and the John Locke Malkin Renewable Scholarship; and to my friends and family for their unconditional love, support, and belief in my abilities.

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Introduction

The HIV/AIDS epidemic is of interest to anthropology because it is biological in origins and manifestations, but it is also culturally constructed, embodied, and interpreted. Anthropological research on the pandemic often focuses on global disparities like “poverty, gender inequalities, political instability, famine, and food insecurity” (Sangaramoorthy, 2013), which cause an unequal distribution of HIV in sub-Saharan Africa. The cultural construction of HIV as a highly stigmatized infectious disease began in the 1980s when it was still a “death sentence” (Harris, Emler, Parker, & Furlotte, 2018, p. 80). Despite the introduction of antiretroviral therapies in 1996, which transformed HIV to a chronic condition, the experiences of people living with HIV (PLWH) in North America are also fraught with inequality and discrimination. The anthropology of aging critically examines the stigma associated with failing to “age successfully” according to cultural ideals which ignore the realities of aging like the “loss of social personhood” and “invariable bodily or cognitive impairments” (Lamb, 2014, p. 42). This essay attempts to address the question: does the intersection of age-related stigma and HIV-related stigma exacerbate the social isolation already experienced by many older adults? I argue, based on a survey of anthropological and HIV/AIDS-related literature, aging is often a marginalizing experience and when combined with another stigmatized condition such as HIV, the individual may be more susceptible to a breakdown of social networks. This breakdown can result in less social support and feelings of disconnection, isolation, and depression.

Objectives

In this essay, I have related my argument to existing work; used existing anthropological methods and concepts; and interpreted the results of my analysis both critically and in relation to other research in anthropology and HIV/AIDS research. First, I support my argument by situating

it within anthropology and I describe its relationship to the work of the other medical anthropologists whose scholarship guided the main points, e.g. Kleinman, Farmer, Manderson, and Lamb. To illustrate how my argument was constructed, I have provided a brief description of my thematic analysis and examples of the themes, subthemes, and quotes.

In the methods section, I explain how my essay draws on biological and cultural anthropology. Medical anthropology is biocultural because all experiences of illness and wellness are culturally embodied and treated. Following this, I introduce the importance of illness narratives which provide an essential emic perspective in critical medical anthropology to help humanize biomedical care. I then provide a description of my data collection process and types of sources used. Then thematic analysis is fully explained with examples and an explanation of the process of developing a concise framework. I touch on the results and introduce possible interpretations for each main theme to support the argument following in the discussion.

In the discussion section, I elaborate my main argument and relate my finding to key concepts, such as stigma, social isolation, social identity, and resilience. I critically analyze the successful aging paradigm as a means of examining the roots of social isolation as a product of normative cultural values. I discuss the limitations of this research including the subjective nature of interpretation.

I conclude my essay by briefly re-describing my findings and stating the possible implications of sharing illness narratives of older adults living with HIV. Finally, I have made suggestions for future research, especially in the area of online social support to mitigate the negative effects of social isolation.

Related scholarship

My argument builds upon the work of Farmer and Kleinman (1989) which “emphasizes the social and cultural dimensions of AIDS” and “the fact that stigma and cultural values can greatly increase the human suffering from the disease” (Farmer & Kleinman, 1989, p. 351). Analysis of illness narratives is important for understanding the human and cultural components of the disease process because “all illnesses are metaphors. They absorb and radiate the personalities and social conditions of those who experience symptoms and treatment” (Farmer & Kleinman, 1989, p. 352). The illness narratives of PLWH are “texts of suffering that we can scan for evidence of how cultures and communities and individuals elaborate the unique textures of personal experience out of the impersonal cellular invasion of viral RNA” (Farmer & Kleinman, 1989, p. 353). Farmer and Kleinman also argue illness narratives can draw attention to issues within HIV/AIDS beyond prevention and treatment of biomedical aspects that may otherwise be overlooked (Farmer & Kleinman, 1989).

My argument also builds on the work of Manderson & Smith-Morris (2010) who challenge previous medical anthropological work that narrowly defined chronic illness through a “conventional biomedical paradigm of temporality (long term versus short term) and linearity” (Manderson & Smith-Morris, 2010, p. 3). This conceptual framework will also be linked to the work of Brown & Barrett (2010) who argue that the traditional “sick role” must be adapted for chronic illness in which being ill becomes part of the individual’s social identity construction process (Brown & Barrett, 2010). Manderson & Smith-Morris state that previous definitions of chronic illness “inaccurately captures the lived experience of illness over time and in different settings, while minimizing the social and cultural contexts and globalizing forces that pattern health and well being” (Manderson & Smith-Morris, 2010, p. 3). They also argue analysis of the

lived experiences of the chronically ill allow us “to question public health discourse and health outcomes” (Manderson & Smith-Morris, 2010, p. 3).

To support my argument that stigma is culturally produced, and in turn negatively affects the social support networks of older adults, I drew on the work of anthropologist Sarah Lamb. Lamb’s critical anthropological research on the successful aging paradigm demonstrates how this normative framework fails to represent the diverse possibilities of success in aging (Lamb, 2014). This critical discourse provided examples to compare and contrast the effects of culturally-produced stigma on the social networks of older adults living with HIV for whom the successful aging paradigm is unattainable. Lamb explores how others critique “the prevailing successful aging model for insufficiently incorporating attention to and acceptance of the human realities of mortality and decline” (Lamb, 2014, p. 41). This emphasizes the importance of illness narratives for listening to the stories of older adults living with HIV who are succeeding in their own ways, often in the face of adversity, hardship, and trauma.

Brief explanation of thematic analysis

To help answer the research question, I conducted a thematic analysis of illness narratives of older adults living with HIV to see if recurring themes like social discrimination, or feelings of rejection and fear, point to a greater sense of social isolation. Examination of the lived experiences of older HIV+ adults in Canada and the US through the interpretive approach, including illness narratives, can provide insight into the cultural aspects of chronic illness ignored by the biomedical perspective (Kleinman, 1988). Listening to and sharing illness narratives is an important component of understanding chronic illness without which “we may understand nothing at all” (Farmer & Kleinman, 1989, p. 359). Through illness narratives, anthropologists have described “the cultural context and social constructions of meaning, and of the significance of individual

experience of disease in terms of identity and interpersonal encounters” (Manderson & Smith-Morris, 2010, p. 11-12). My analysis borrows an adapted intersectional approach, which “considers that the different forms of discrimination should not be understood in terms of their cumulative dimension but rather in their articulation” or their intersection (Wallach & Brotman, 2013, p. 1236). This intersectional approach helps show how layers of discrimination exacerbate marginalization of stigmatized groups of people.

Thematic analysis is used to survey and synthesize large quantities of textual data such as illness narratives. I followed a straightforward process of analysis. While I reviewed the literature, I tracked the themes, subthemes, and representational quotes in a spreadsheet according to an established thematic framework for later interpretation. For example, Theme: Social Discrimination; Subtheme: Fear of contagion; Representative quote: "I met one guy's parents about 6 months ago and his dad wouldn't shake my hand," stated by Wayne (Emlet, 2006, p. 6). To show not all illness narratives were of negative experiences, my final category discussed optimism, resilience, and strategies of self-preservation. For example, Theme: Living with AIDS; Subtheme: Resilience; Representative quote: "Be considerate, love your neighbour, love yourself, trust your gut instincts, and enjoy life. You never know when it's going to end. Don't do everything in one day ... do part of it today and the rest tomorrow," – stated by Daisy (Furlotte & Schwartz, 2017, p. 134).

Methods

Biocultural medical anthropology

My research used both biological and cultural anthropological methods and concepts for a biocultural medical anthropological perspective. This allowed me to interpret both qualitative and quantitative data drawn from illness narratives for comparison and summarization (Guest,

MacQueen, & Namey, 2012). The quality of life of older HIV+ adults is affected by culturally produced “health-related social stigmatization” (Singer & Baer, 2012, p. 94), which affects both biological and cultural aspects of their illness experiences. The work of medical anthropology can help examine the phenomenological experiences of chronic illness and the process of aging which is often treated with the stigma of disease. My research topic addresses this unique intersection of stigma felt by older adults living with HIV, which is both biological and cultural in origins. “Medical anthropologists argue that illness narratives are not merely accounts of symptoms but a mechanism through which people become aware of and make sense out of their experiences” (Kaplan-Myrth, 2007, p. 1268).

Biological anthropology, which often focuses on the routes of transmission of HIV and risk behaviors, is interested in the entire disease process of the human body and its environment (Brown & Barrett, 2010). Biological infection of the human body can shape physical and mental health, as well as the social role of the individual. The state of illness also dictates who the person does or does not interact with, e.g., more doctors’ visits compared to fewer social interactions with friends. Biological effects to the body, depending on their severity, extend past needing attention strictly from the afflicted. Older adults living with HIV may have their biological processes surveyed and monitored by several different individuals depending on the stage of the infection, comorbid conditions, and age of the individual. The experiences of living with a condition like HIV/AIDS is affected by biological symptoms and changes to the body but also includes changes to social identity, social isolation, and a break down of social networks, due to stigma (Emlet, 2006). These experiences are also shared by people as they age, making older HIV positive adults even more vulnerable to the negative effects. The role of the chronically ill, like all social roles, is embodied and acted out in culturally prescribed ways with expectations on the individual and those around

them to act in certain patterns of behavior (Brown & Barrett, 2010, p. 149). Medical anthropology is a truly integrated biocultural approach because it accounts for both biological and cultural influences on the human body, health, and illness.

Interpreting illness narratives

The lived experiences expressed in illness narratives reveal people's thoughts and feelings regarding their embodiment of illness and interactions with others. Narratives demonstrate how older adults living with HIV adapt to having chronic illness contribute to the construction of their social reality (Brown & Barrett, 2010). "The events and circumstances in the lives of persons with chronic illness are part of a personal narrative that places the illness experience in the context of the life story" (Kleinman in Bloom, 2001, p. 39). My main goal was to understand people's lived experiences of HIV, stigma, and social isolation through their own words, i.e., illness narratives. "Medical anthropologists argue that illness narratives are not merely accounts of symptoms but a mechanism through which people become aware of and make sense out of their experiences" (Kaplan-Myrth, 2007, p. 1268). Complex lived experiences become something interpreted and are "given structure and meaning" (Kaplan-Myrth, 2007, p. 1268). These narratives are different than the reports of illness provided to biomedical professionals; they are not simply an anamnesis, which is a patient's medical history. When relaying the narrative, the individual is no longer merely a patient, but a human explaining and making sense of their experiences. When people explain their illness experience, which is a self-referential process, they "include not only actions and feelings but also reflections about those actions and feelings" (Bruner, 1986, p. 5). "The difficulty with experience, however, is that we can only experience our own life, what is received by our own consciousness. We can never know completely another's experiences, even though we have

many clues and make inferences all the time” (Bruner, 1986, p. 5). This is why rigor in interpretation is crucial to reduce bias and represent others’ words as accurately as possible.

Data collection

To answer my research questions, I collected data through a literature review. The type of literature review I conducted, also called a research synthesis (Cooper, & Hedges, 1994), focused “on empirical studies and seek to summarize past research by drawing overall conclusions from many separate investigations that address related or identical hypotheses” (Cooper, 1998, p. 3). My literature review is of scholarly sources which contain illness narratives of older adults living with HIV. Medical anthropology can help humanize the biomedical experience by sharing individual illness narratives of underrepresented or marginalized individuals to express their lived experiences in their own words (Singer & Baer, 2012). I had three main criteria when searching for articles. First, I specifically focused on articles of people living with HIV (PLWH) over the age of 50 years old. When the CDC initially began collecting demographic information as part of the HIV/AIDS surveillance in 1982, older adults were classified as 50 years of age and older, so I have used this historical criterion to define older adults in this paper (Poindexter & Emlet, 2006). This age classification has been maintained in part because of the premature aging process that accompanies HIV (Furlotte, Schwartz, Koornstra, & Naster, 2012). Second, the narratives had to be relevant to the concept of the intersection of age-related stigma (ageism) and HIV-related stigma. These narratives also needed to describe how this intersection of stigma related to older adults’ social networks. Third, I compared older HIV+ adults illness narratives from Canada and the US only. After reviewing several articles, I found three articles that met all the three criteria from which to draw my themes, subthemes, and representative quotes (Emlet, 2006; Furlotte & Schwartz, 2017; Wallach & Brotman, 2013).

Literature reviewed

To collect evidence for this argument, I searched for journal articles and books, either primary or secondary sources, available through the University of Victoria's library website or Google Scholar. The journal articles I reviewed focused on: 1)- anthropological methods and theories; 2)- aging and gerontology; or 3)- HIV/AIDS research. The anthropological journals *Annals of Anthropological Practice* and *Annual Review of Anthropology* provided insight into practical applications of anthropological knowledge. I selected *Medical Anthropology Quarterly* because it is an international journal that analyzes issues of health and diseases from a medical anthropological perspective. Research is published with a goal of theory development and debate within medical anthropology and links it to other disciplines including anthropology in general and public health. This journal examines experiences of illness and health as well as globalizing forces such as political or economic influences that affect health (Medical Anthropology Quarterly, 2019). I selected *Canadian Journal on Aging*, *The Gerontologist*, and *Ageing and Society* to look at gerontological issues related to HIV from a cross disciplinary perspective. The latter provided an article by Wallach & Brotman (2013) with qualitative interviews, illness narratives, and thematic analysis of the experiences of adults over 50 years of age living with HIV in Quebec. I also used other journals as reference for methods, theory, and analytical approaches, e.g., Aronson (1995) and Belotto (2018) in *The Qualitative Report*.

A key source in developing my analytical framework is *Applied Thematic Analysis* by Guest, MacQueen, & Namey, (2012). This book provided a systematic framework for thematic analysis based on the researchers' years of experience. Guest et al., (2012), offered rigorous guidelines for thorough qualitative analysis of textual data, ideal for my purpose of deriving themes from illness narratives to address issues of social isolation among older adults living with HIV

(Guest et al., 2012). For example, the authors' description of developing a thematic code as a process of thematic identification allowed me to recognize unique themes and combine similar themes (Guest et al, 2012). People do not often speak in terms of themes but the words they use to describe their experiences and feelings can be easily analyzed through thematic coding, reduction, and categorization. This book helped me develop a plan to analyze a large amount of data from multiple sources.

For an anthropological perspective on chronic illness, *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness* by Manderson & Smith-Morris (2010) offers new perspectives on the topic and critiques past medical anthropological work. This book works to change the ideas of illness and disease as episodic. It challenges this by showing many experiences of illness are not acute, but chronic, e.g., older adults living with HIV. I also relate this to a medical anthropology textbook *Understanding and Applying Medical Anthropology* which also critically evaluates the additional complications of long-term chronic illness that does not fit our cultural normative views of the "sick role" in North America (Brown & Barrett, 2010). Manderson & Smith-Morris (2010) also explore how global forces, biopolitics, and structural inequalities shape our experiences of illness and the perception of those that are chronic ill (Manderson & Smith-Morris, 2010).

Additionally, I drew from a few different works by one of the most influential scholars in medical anthropology, Arthur Kleinman, including *The Illness Narratives: Suffering, Healing, and the Human Condition* (1988); *Writing at the Margin: Discourse Between Anthropology and Medicine* (1995); and his chapter with Paul Farmer in *Understanding and Applying Medical Anthropology* (Brown & Barrett, Eds., 2010). During the literature review, I tracked themes, subthemes, and representative quotes in an excel spreadsheet for later analysis, see figures 1 & 2.

Thematic analysis

The data in my spreadsheet was processed with applied thematic analysis which is a “type of inductive analysis of qualitative data” (Guest et al., 2012). This analytical approach is similar to grounded theory in that it seeks to identify emerging patterns through a comparative process. “Thematic analyses move beyond counting explicit words or phrases and focus on identifying and describing both implicit and explicit ideas within the data, that is themes” (Guest et al., 2012). I defined a theme as a unit of meaning with a unifying and recurring idea (Guest et al., 2012). Themes were identified in the literature and coded with a descriptive word or words identifying that theme, e.g., employment discrimination. People may not speak directly of HIV-related stigma in the workplace, but they may make statements of being dismissed from their job because employers were afraid of becoming infected. Each theme has a clear definition, e.g. “rejection” is defined as feeling dismissed, spurned, or rebuffed by another person or group of people, see figures 1 and 2; see Appendix A.

Thematic analysis is one of the most common ways to analyze large quantities of textual data (Aguinaldo, 2012). My analysis followed a simple step-by-step plan adapted from two sources Aguinaldo, 2012 and Guest et al., 2012: 1) I identified the themes; 2) I collected the data from the relevant literature; 3) I stored data within the spreadsheet according to my thematic framework; 4) I reduced redundancy; and 5) I interpreted all results with explanations and concepts taken from my literature review (Aguinaldo, 2012; Guest et al., 2012). In step five, I rely on several key works for interpretation, e.g., the works of Kleinman (1988); Farmer & Kleinman, (1989); Manderson & Smith-Morris (2010); Lamb (2014); and Brown & Barrett (2010).

Theme	Subtheme	Stigma: Age or HIV?	Representative Quote
social discrimination	stereotyping	Age	"In some cases I believe older people are held to a different standard that, well, for crying out loud, you should have known better "
social discrimination	stereotyping	Age	"Doctors would not even have looked at you as being likely to have HIV even if they saw the same symptoms." (Talking about no one thinks older people have sex.)
social discrimination	stereotyping	Age	"there's a lot of people that go—'you're awfully old to have this disease.'"

Figure 1: An example of how themes, subthemes, and representational quotes were tracked.

Theme	Subtheme	Stigma: Age or HIV?	Representative Quote
social discrimination	rejection	Age	"Yeah, ageism, it's a far mightier sword than HIV." (Talking about the gay community.)
social discrimination	fear of contagion	HIV	"I met one guy's parents about 6 months ago and his dad wouldn't shake my hand."
family relationships	non-disclosure	HIV	"I just keep thinking I'm going to outlive them. I can't see a good reason to tell them." (Referring to her elderly parents with whom she lives)
living with AIDS	non-disclosure	HIV	"I would rather get run over by a truck than die of AIDS. That's what I'm hoping for. I'm hoping that nobody else finds out about the AIDS."
living with AIDS	resilience	N/A	"I'm living with AIDS. I'm living with AIDS, I'm not dying with it."

Figure 2: Another example of how themes, subthemes, and representational quotes were tracked.

Development of the framework

My data was drawn from other researchers transcribed interviews, from which I looked for “patterns of experiences” that “can come from direct quotes or paraphrasing common ideas” (Aronson, 1995). Before my analysis process began, I developed a framework for themes I knew already existed within the data, although I knew other themes or subthemes may emerge during the process. As I indexed data into my spreadsheet according to the existing framework, I reviewed, sorted, and synthesized themes as needed for clarity, logic, and consistency. Some

existing themes that were similar enough in meaning became one theme. For example, the subtheme of protective silence (Emler, 2006), was merged with non-disclosure because the sentiment, explanation, and definition were the same. I also made the main themes broad, e.g., social discrimination or family relationships, because the subthemes more specifically narrowed in on the feeling originating in that individual's statement.

Interrater reliability

I adapted the idea of "interrater reliability" (Belotto, 2018, p. 2625), to assess the confidence of my analysis by reaching out to a peer for review and feedback on the validity of my initial themes and definitions (Belotto, 2018). My peer, who wished to remain anonymous, was a fellow student in anthropology at the University of Victoria who was familiar with medical anthropology and illness narratives. The idea of interrater reliability to review the credibility of my analysis was supported by many of the sources I consulted. "To be accepted as trustworthy, qualitative researchers must demonstrate that data analysis has been conducted in a precise, consistent, and exhaustive manner through recording, systematizing, and disclosing the methods of analysis" (Nowell, Norris, White, & Moules, 2017, p. 1). I provided my peer the list of thematic definitions, see Appendix A, and a copy of my spreadsheet with themes, subthemes, and representational quotes, see figures 1 & 2 for examples. Their feedback suggested no inconsistencies between my definitions or classification and the meaning implied in the quote of the participant as related to the theme and subtheme. I did make one alteration to my themes after our discussions. I originally had a theme titled "breakdown of social networks" but realized this was implicit in many of the subthemes and quotes of participants. For example, the following quote seemed to a better fit in the Theme: Living with HIV/AIDS, Subtheme: Isolation: "My friends are

. . . my friends, it's very limited because the last one died three years ago and I never re established a circle of friends around me," stated by male, 50 (Wallach & Brotman, 2013).

Results

During my literature review, themes were identified in the literature and coded with a descriptive word or words identifying that theme. I developed five main themes: 1)- Social Discrimination; 2)- Institutional Discrimination; 3)- Employment Discrimination; 4)- Family Relationships; and 5)- Living with HIV/AIDS. I developed six subthemes that could be applied to any of the main themes, although not all representational quotes required subthemes because some were directly related to the definition of the theme, e.g., see the first example of Employment Discrimination in table 1. My six subthemes were: 1)-Rejection; 2)- Fear of Contagion; 3)- Stereotyping; 4)- Non-disclosure; 5)- Isolation; and 6)- Resilience. I have provided an example of each theme and subtheme, see table 1. For more information see Appendix A: Definitions.

Theme	Subtheme	Representative Quote	Source
Social Discrimination	Rejection	"It'd gotten around the church that I'm HIV positive. I find myself sitting and eating a piece of cake and drinking punch on one whole aisle of chairs by myself, no one sitting next to me, no one wanting to talk to me."	Paul in Emlet, 2006, p. 785. Discussing rejection from his religious community.
Institutional Discrimination	Rejection	"The staff, when they found out I had HIV they really stayed away from me. They didn't pay me any attention as they did the other seniors that were there. This stuff is everlasting, you're treated differently you know. You feel like you're outcast."	Taleef in Emlet, 2006, p. 785. Discussing rejection from caregivers as the only person living with HIV in a senior community.
Employment Discrimination		"I don't know how they do it, the companies. Even if they do	Female, 53, in Wallach &

		say that it's confidential, I noticed that all those who have insurance, when the time comes to be hired definitively: 'Ah! All of a sudden, they have a lack of work', and then they replace you with someone else."	Brotman, 2013, p. 1229.
Family Relationships	Fear of Contagion	"Because she is afraid of getting AIDS."	Male in Wallach & Brotman, 2013, p. 1227. Participant explaining why his aunt won't kiss him.
Living with HIV/AIDS		"My life is a pie, and HIV is only one piece of the pie ... the first 3 years that I was HIV [positive] it was the pie, and for some people it's still the pie. It's just one part. There are so many things to life, more than HIV."	Violet in Furlotte & Schwartz, 2017, p. 134.
Institutional Discrimination	Stereotyping	"Doctors would not even have looked at you as being likely to have HIV even if they saw the same symptoms."	Christa in Emlet, 2006, p. 786. Discussing how ageism affects medical care and how no one, including doctors, think older people have sex.
Family Relationships	Non-disclosure	"I was afraid of being rejected, that he too would reject me."	Female, 63, in Wallach & Brotman, 2013, p. 1225. Participant discussing why she was hesitant to tell her son her HIV status.
Social Discrimination/Family Relationships	Isolation	"I don't have anybody to share with. It's lonely sometimes; it really is."	Juanita in Emlet, 2006, p. 786.
Living with HIV/AIDS	Resilience	"To me, you never stop learning, you never stop redeveloping yourself. I call it tweaking and in the last 6	Jimmy in Furlotte & Schwartz, 2017, p. 134.

		months, I have been re-tweaking my life. I re-evaluate myself a lot of times, I say ‘Ok, what’s bugging me, who’s a pain in the ass in my life?’... I don’t put up with shit anymore.”	
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Table 1: Example of each theme and subtheme with a representational quote

Interpretation of themes

One challenge in interpreting themes is that most are interconnected in some way because they all relate back to stigma, HIV, and age. For example, Living with HIV/AIDS was the theme in which I indexed experiences of resilience, optimism, survival mechanisms, and day-today life. This theme, however, in a literal sense would apply to anyone living with HIV. I struggled with the meaning of other possible names for this theme, such as Coping with HIV/AIDS, but it did not express the same type of positivity or acceptance of their situation that suited the quotes. In the end, I took inspiration for the name of the theme from a quote by Paul, “‘I’m living with AIDS. I’m living with AIDS, I’m not dying with it” (Emlet, 2006, p. 78). Employment discrimination and institutional discrimination are forms of social discrimination, but I thought they required their own theme as a means of identifying the structural forces which create distinct forms of discrimination and challenges for older adults living with HIV.

Interpretations of all themes were centred around the concept of stigma. I defined HIV-related stigma as discrimination, bias, and negative attitudes, including intolerance, hatred, and fear, directed at people living with HIV. This stigma can become internalized or anticipated which exacerbates the negative consequences. Age-related stigma or ageism refers to discrimination, bias, and negative attitudes directed at people based on their age. The conceptual framework of intersectionality demonstrates how both types of stigma, HIV- and age- related, exacerbate the

negative outcomes of each other, above and beyond either alone (Wallach & Brotman, 2013). This concept helps explain how layers of stigma and discrimination interact with each other to create deeper marginalization and disempowerment (López & Gadsden, 2016). Many participants identified feeling stigma due to their HIV status or age, or both. They identified very specific sources, experiences, and outcomes. All themes had contributing factors and possible implications for overall health. For example, the loss of employment may result in the inability to purchase food, which decreases medication adherence because some HIV medications need to be taken with food, and this could cause severe health consequences (Kalichman, 2015). This intersection of stigma exacerbates the discrimination, social isolation, and other negatively associated health consequences felt by older HIV+ adults.

Social discrimination

Based on my thematic analysis of illness narratives, I argue that the intersection of HIV-related stigma and age-related stigma exacerbates the social isolation experienced by many adults as they age. The largest theme developed in response to this stigma was social discrimination. I think the following quote perfectly exemplifies the rejection that results from stigma and produces social isolation for older adults living with HIV. "It'd gotten around the church that I'm HIV positive. I find myself sitting and eating a piece of cake and drinking punch on one whole aisle of chairs by myself, no one sitting next to me, no one wanting to talk to me," stated by Paul (Emlet, 2006, p. 785).

Institutional discrimination

My analysis helped identify possible sources of felt and anticipated stigma which negatively affect older adults' social networks. Anticipated stigma may be the result of past

experiences of discrimination or traumatic events which leaves the individual believing the experience will occur again in the future (Furlotte & Schwartz, 2017). Anticipated stigma can lessen health seeking behaviours in institutional settings like hospitals (Furlotte & Schwartz, 2017). Discerning the sources of stigma and narrowing in on the people that perpetuate these discriminatory attitudes, for example, doctors or nurses, can improve healthcare and the quality of life for older adults living with HIV. Institutional stigma and discrimination are particularly problematic for older adults in assisted living facilities who may possess little agency or freedom of choice depending on their physical or mental health.

Employment discrimination

Based on the articles I reviewed almost all older adults identified feeling stigma or discrimination related to their age or HIV status. Often these experiences were easily identified as one or the other; however, individuals did also identify areas where they overlapped, especially employment. Age was the largest concern when it came to discrimination in the workplace or trying to find a job. When HIV is added to the equation, finding work seems near impossible. This woman's hyperbolic statement captures the despair of trying to find work as an HIV-positive woman over the age of 50. "Imagine a 50-year-old woman, and older, who is not on disability, who has HIV, and she has to return to the workforce! She might as well hang herself! She will not find a job!" stated by female, 63 (Wallach & Brotman, 2013, p. 1229). Her statement demonstrates how multiple layers of stigma work to disempower and discredit people.

Family relationships

The sources I analyzed had many stories of rejection by family. Older adults may intentionally isolate themselves from family to avoid stigmatizing experiences or rejection. Family

relationships offered the most complex mixture of feelings. Family seemed to provide the most rejection or the most support. Some individuals, especially those had been HIV positive since the first decade of the pandemic, talked about feeling like they had created “family” with others going through the same thing. Unfortunately, many other older adults spoke about the rejection from their families and feeling abandoned without regard for their welfare. "That’s my fear, I told it to my daughters, one of them must at least call me more often, because I said: ‘I don’t want to die and then be in my apartment for one week because one of you hasn’t called to inquire about me.’ You know, to die alone. Listen, I’m getting older and it could happen at any time," stated by female, 53, (Wallach & Brotman, 2013, p. 1226).

Living with HIV/AIDS

The final theme of Living with HIV/AIDS was filled with strategies of survival, optimism, and the concept of resilience. Survival strategies are methods of self-preservation like non-disclosure of HIV status. Resilience could be seen in the optimistic outlooks several people had on life. “As long as I have a good, full social life and good friends, life is good,” stated by Mary (Emlet, 2006, p. 788). Resilience in the face of adversity provides strength to continue facing challenges associated with aging with HIV.

Discussion

Main argument

I argue that ageism and HIV-related stigma do contribute to greater social isolation felt by many older adults as they age. This results in a loss of support and feelings of connectedness to others (Furlotte & Schwartz, 2017). Stigma affects nearly every facet of an individual’s life. Stigma causes isolation, but also increases risk of physical and mental health issues, like

depression (Groves, Golub, Parsons, Brennan, & Karpiak, 2010). HIV/AIDS can take over their social identity and result in a “loss of social personhood” (Lamb, 2014, p. 42). The experiences of older adults living with HIV are far from the normative views of “aging gracefully” found in popular discourse. Sharing illness narratives can help combat these narrow views of aging by showing there are other ways of aging successfully. This emphasizes the need for a new approach to treating chronic illness that considers individual experiences not just the biomedical aspects of disease.

Stigma

Stigmatization of chronically ill individuals is not a new phenomenon. The etymology of the word stigma is from Greek and means “a distinguishing mark burned or cut into the flesh, as of a slave or criminal” (McKechnie, 1983). *Webster’s New Universal Unabridged Dictionary* goes on to define it as “something that detracts from the character or reputation of a person, group, etc.; mark of disgrace or reproach” or “a mark, sign, etc., indicating that something is not considered normal or standard” (McKechnie, 1983). Stigma has changed from a literal mark to a culturally based discrimination or fear of the person’s condition. “Stigma has come to refer more to the disgrace than to the actual body mark” and “metaphors of distress and other human problems that were once bodily have become mental” (Kleinman, 1988, p. 159). People living with stigmatized health conditions like HIV/AIDS must often deal with social reactions to their condition, e.g., they are “shunned, derided, disconfirmed, and degraded by those around him” (Kleinman, 1988, p. 160). Older adults living with HIV may come to expect negative reactions and learn to internalize their anticipated stigma as “a deep sense of shame and spoiled identity” which in turn shapes their behaviour and “negative self-perception” (Kleinman, 1988, p. 160). This external process of shame in turn influences an individual’s identity construction. “Chronic diseases create uncertainties

about progression, causes, and effects, and have many different implications for the sufferer. This includes a moral component, the stigma and contagion associated with the identification as a sufferer of a chronic illness, especially AIDS” (Manderson & Smith-Morris, 2010, p. 176).

The stigma of having a chronic illness is reinforced in part by our cultural fear of death. Acquiring HIV/AIDS before the introduction of HAART marked someone for death. People may avoid others who remind them of their own mortality, this can include any older adult, but can be especially true of an individual living with HIV. PLWH who lived through the era of HIV/AIDS as a death sentence often speak of sadness and confusion of their survival. Timothy, a 52-year-old man in Ontario, discusses unexpectedly surviving his diagnosis in the 1980s and outliving friends and his partner, “I was preparing to die and it didn’t happen, so it came out as a loss. I was having a reactive depression, I believe, because of preparing to go to this place and then it never happened” (Furlotte & Schwartz, 2017, p. 130). People may feel an additional layer of social isolation because of the friends they lost to the disease and something akin to survivors’ guilt. Older adults living with HIV need to be actively engaged in a process with researchers to develop strategies to reconcile the historical context of HIV/AIDS laden with death and mortality to the idea of successfully aging with HIV today.

Social isolation

Social discrimination can be felt, embodied, and responded to in many ways, but social isolation may be the most devastating. Social isolation is a result of the rejection, fear of contagion, and discrimination resulting from cultural stigma and prejudice against HIV and aging. Social isolation places older adults living with HIV at risk for a multitude of other conditions (Groves et al., 2010). Older adults are already prone to social isolation so when combined with HIV the associated mental health concerns, like depression, are even more of a concern (Groves et al., 2010). The

relationship between HIV and depression has been shown to have many possible factors, but two are key to this discussion: stigma and social isolation (Groves et al., 2010). This relationship may be worse in “older adults as they face physical and mental challenges inherent to the aging processes (Groves et al., 2010, p. 630). This is cause for concern because depression can worsen the health outcomes of HIV by increasing viral load and mortality (Groves et al., 2010). HIV-related stigma among older adults, however, can be mitigated with social supports which protect against associated mental health issues, like depression (Emlet et al., 2013).

Isolation can lead to a numerous other physical- and mental health-related concerns. “Isolation and lack of connectedness to others have been recognized as predictors of morbidity and mortality” (Rowe & Kahn, 1997, p. 437), from at least the time Durkheim began publishing his work on suicide in 1897 (Pickering & Walford, 2002). In *Suicide*, Durkheim addresses many of the challenges that he described as relating to “‘problems of modern life’ (excessive individualism, isolation)” (Pickering & Walford, 2002, p. 7). These challenges are still valid concerns today and faced by older adults living with HIV. Recognizing isolation as a main social determinant in the contributing factors of suicidality is important to keep in mind when we read the illness narratives of older adults living with HIV. “My brothers found out and they was [sic] just like distanced from me for awhile...I’d say for about three years,” stated by Cricket (Emlet, 2006, p. 785). This is not to say that all older adults living with HIV who feel socially isolated are depressed or that those that who are depressed are suicidal, it merely stresses the point many components of stigma can have adverse effects on health. The individualistic norm of maintaining independence, which is encouraged in North America, implies non-dependence, and is socially isolating in itself. To be dependent on someone for care, even emotional support, is not the normative ideal.

Social identity

Anthropological scholarship about identity examines how the concept “is not naturally ‘given’, but it is culturally defined and constituted, for human beings live in cultural settings” (Golubovic, 2011, p. 25). The construction of social identity is dependent on how an individual is situated within that society. It also depends on the cultural expectations and responsibilities of the individual. The sick role is one of many social roles that reflects “patterns of behavior that are expected by people filling particular positions in a social system” (Brown & Barrett, 2010, p. 149). The appropriate performance of each individual role is ingrained culturally from a very young age. Our roles are performed in relation and reaction to others’ roles because we all share the same guiding cultural rules (Brown & Barrett, 2010). “Social behavior in illness is by definition an interaction with others: to forget the others leaves us blind to influences that may have shaped and motivated much of what someone did when he was ill” (Lewis, 1981, p. 160). These social roles help construct our social reality and our social identities.

The sick role has benefits like extra care from others as well as less expectations to work or attend to school. The sick role also has responsibilities which are directed at getting better again, such as seeking biomedical attention (Brown & Barrett, 2010). It is easier for an individual with an acute illness to follow the sick role script because they eventually do get better. The sick role for a chronically ill individual is more complex because the conventional script does not come to fruition, i.e., the older adult living with HIV will never be cured and may eventually die of HIV/AIDS-related opportunistic infections. The sick role for these individuals turns from a temporary suspension of “normal” life into a reconfiguration of their social identity. “Personal identity is entwined with bodily function, and the literature on chronic illness and chronicity draws attention to the disruptions that occur as poor health punctures social capacity and sense of self”

(Manderson & Smith-Morris, 2010, p. 107). The chronicity of HIV shapes older adults' realities through the biological process, but also through prolonged cultural prejudice against the common modes of transmission, e.g. sexual contact and injection drug use. "Chronic illnesses become part of people's core social identities. The illness experience is a continuing one, to which and individual must adjust. These adjustments can be difficult, especially because of sociocultural expectations about being 'normal'" (Brown & Barrett, 2010, p. 333).

Once the sick role fades, there can be a loss of personhood, and possible reconstruction of social identity as people begin to disclose their HIV status. The subtheme "Non-disclosure" related to how older adults living with HIV must go through a process of deciding who to share their status with. Disclosing, or not disclosing, HIV status is a personal decision which is part of the process of social identity construction. Part of this decision process is related to anticipated stigma and the discrimination they know or perceive may be the result of disclosure. "I think there are people—in the church group of friends—who would cut both me and my wife off," stated by Eric (Emlet, 2006, p. 787).

An older adult living with HIV may only disclose their status to certain groups of people so that they can feel "normal" with other people in their lives. Although it can allow people to have a social identity beyond HIV it can result in feelings of multiple selves. "People have many social identities. As the holder of any *one*, they are encircled by their relationships with other people who have an interest in that aspect of their behavioral potential" (Twaddle, 1981, p. 117). The other people within each social network hold expectations and influence the individual's behavior based on the role they are filling. Older adults living with HIV who navigate multiple social identities "need to take in account the energies and resources needed for other social identities, including similar bargaining with other people with interests in those identities" (Twaddle, 1981, p. 117).

The realities of advanced aging often leave PLWH with little agency in the end to navigate multiple social identities because the severity of the final stages of AIDS necessitates care from other people.

Successful aging

Anthropological studies in older adult communities, such as assisted living facilities, “have shown how the lives of the elderly are shaped by their interactions with the medical system. In addition, the elderly often live in circumstances of age segregation, separated from their families, almost as if old age itself was a stigmatized condition” (Brown & Barrett, 2010, p. 333). My argument goes beyond “almost” and asserts that aging is highly stigmatized in North America which favours permanent youthfulness. To provide an example of how stigma against aging with HIV can be culturally produced and maintained, even though it may be unintentional, I borrowed from anthropologist Sarah Lamb’s critical evaluation of the successful aging framework. Successful aging is often defined as staying productive, healthy, and independent, but socially active, as we age (Lamb, 2014). Ideally, we should stay a younger version of ourselves without really aging at all. The term successful aging originated with Robert Havighurst in 1961, but the seminal work by Rowe & Kahn in 1987 further popularized discourse on the conceptual framework (Lamb, 2014; Rowe & Kahn, 1997). Rowe & Kahn proposed a distinction between two types of older adults that were not suffering from disease, “usual (nonpathologic but high risk) and successful (low risk and high function)” (Rowe, & Kahn, 1997). In 1997, Rowe & Kahn proposed an updated conceptual framework with three main criteria for successful aging: 1)- absence of disease; 2)- “high cognitive and physical functional capacity”; and 3)- “active engagement with life” (Rowe, & Kahn, 1997), see figure 3. Absence of disease also includes absence of risk of disease, e.g., being low risk for diabetes, etc. Functional capacity includes

potential and actual capacity for activity. The third criterion is most concerned with personal relationships and being productive in the sense of creating social value, e.g., work or volunteering. “In addition to the necessity for older adults to do something, it is essential for them to choose what they do wisely, on the basis of long-term health-related outcomes, to ensure maximum quality of life as they age” (Manderson & Smith-Morris, 2010, p. 241). The combination, continuation, and maintenance of these three factors together is the epitome of the successful aging paradigm. This framework has been adapted and expanded on in various forms, but these three original criteria tend to persist across disciplines.

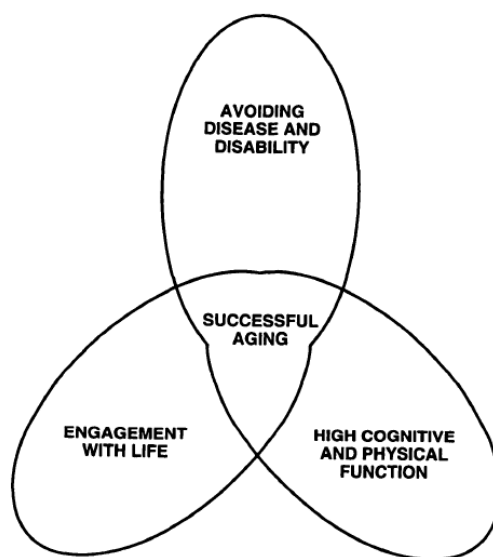


Figure 3: Successful aging model (Rowe & Kahn, 1997).

Instead of being representative and inclusive of all aging individuals in North American culture, this paradigm tends to promote a very specific cultural and biopolitical model for aging with a reality that may never exist for some people (Lamb, 2014). It is a narrow normative view of success that creates stigma for people who are chronically ill, like older adults living with HIV, who are in a sense failing. A main criticism of this conceptual framework is “its failure to consider

the role(s) of personal meaning, trauma, suffering, and membership to marginalized communities in the aging process” (Harris et al., 2018, p. 80). If this discourse of successful aging is meant to inspire others to age well, how can it be applied to people that do not have any chance of filling the three criteria? The biopolitical undertones of this discourse state that we should stay non-dependent on others, i.e., the state, and not use up resources that would benefit others as we age. To use up resources and assert any type of dependence is to be a burden on society (Lamb, 2014). This view suggests caring for people that need help is above and beyond what should be expected of the healthy, younger members of society, who are likewise encouraged to be independent individuals. Value needs to be placed on the health benefits of caring for people because if people receive the proper social support their overall health improves (Groves et al., 2010).

The notion of care possessing value has developed in anthropology over the last decade or so, which has dedicated work to the concept of care that turned away from “discussions of suffering to consideration of the social relations that sustain life in both mundane and dire moments” (Buch, 2015, p. 279). The anthropology of care takes multiple approaches, but each is “concerned in part with different aspects of the ways that care is involved with the social constitution of personhood” (Buch, 2015, p. 279). Particular attention is paid to the idea of caring for people as they age. People who age with a chronic illness, e.g., HIV, require a particular type of care but also possess a distinctive social personhood which should be appreciated as its own type of success. Even discussions that recognize differences in the aging process, however, come back to quantifying care as a resource, implying competition and cost in caring for others. “Anthropologies of care in later life will be strengthened by integrative theoretical approaches to care that attend to its multiple qualities as a form of moral, intersubjective practice and a circulating and potentially scarce social resource” (Buch, 2015, p. 279).

One criticism of the successful aging paradigm is its roots in biomedicine which is often perceived as being culture free. Biomedicine is a cultural practice. If it were not, we would not refer to other medical and healing systems as traditional or ethnomedicine. Discussions in biomedicine about aging often relate to a cost benefit analysis of an individual's life against resources available in the medical system. In the province of B.C., all HIV treatment is free to anyone that needs it, but this is not true anywhere else in Canada or the US. This highlights the issues in North American culture which places emphasis on individuality and independence. Individual responsibility in the illness experience becomes implicit in successfully navigating medical services and insurance plans (Lamb, 2014). This idea of personal responsibility and burdensome costs of medical care add to the discrimination felt by PLWH in the workplace. The stigma of HIV when combined with high medication costs, over \$1,000 a month, may present insurmountable odds for older adults living with HIV in finding or keeping a job. They are not living up to the successful aging paradigm and additionally they are failing in their role as a good employee that does not drain their employer's medical insurance. Indeed, biomedicine is a profit-making industry which creates these structural inequalities for PLWH (Singer & Baer, 1995).

The popular discourse on successful aging is based on common sayings, such as "growing old gracefully" or "growing old with someone special." This implies everyone has an equal chance of maintaining their younger social personhood or finding a romantic partner for life. Based on the work of Mauss, "personhood here refers to people's (human or nonhuman) membership, roles, or status in society that are conferred in and through social relations" (Buch, 2015, p. 281). How do we then confer personhood to older adults living with HIV in a way that does not have their entire social identity become about living with HIV? Not everyone is able to obtain normative goals of success, nor does everyone want to. The idea of staying single and not marrying is hard

for many people to comprehend. This is ironic because it is in direct contradiction to the idea of absolute independence throughout the life course. “Concerns about personhood are continuously and socially negotiated, especially at the beginnings and ends of life, when questions about who, how, and when someone is recognized as included in human communities come to the fore” (Buch, 2015, p. 281). If the ambiguous time period of the “end of life” is fraught with challenges of negotiating social personhood and navigating social networks for an average older adult, then the challenges for an older adult with HIV must be doubly so. Attaining permanent personhood is implied in the successful aging paradigm despite the reality that advanced aging is often accompanied with a “loss of social personhood” (Lamb, 2014, p. 42) and reduction of personal agency.

Resilience

The concept of resilience has been used in a number of ways; I borrowed my definition from the work of anthropologist Roberto Barrios, which is “positive adaptation in the face of adversity” (Barrios, 2016, p. 28). Resilience later in life, and among the chronically ill, is being explored more in depth recently, partly in response to criticisms of the successful aging paradigm (Furlotte & Schwartz, 2017). Resilience as an older adult living with HIV can occur as a reaction to constant exposure to adversity during the life course, e.g., being HIV+ and a member of a marginalized group, which prompts the development of resilience to these stressors (Harris et al., 2018). Resilience may be “typical for some older adults living with HIV” (Furlotte & Schwartz, 2017, p. 126). Despite the stigma that may be experienced by HIV+ older adults many are optimistic and not concerned with the discriminatory attitudes of others. “They don’t like it, that’s their problem, not mine,” stated by Terry when discussing others' reactions to his HIV status (Emlet, 2006, p. 788).

While stigma, discrimination, and socially isolating experiences were common for many older adults living with HIV, they often expressed satisfaction with the friends or family they did have remaining. "It will be ten years in August that I am here, we get along very well. I cook and she cleans. We have a lot of fun together", female, 63 (Wallach & Brotman, 2013, p. 1226). This highlights the importance of quality over quantity when discussing social support.

Limitations

One limitation in interpreting illness narratives is the subjective nature of interpretation, "we have to be cognizant, as we promote narrative medicine, of the politics of storytelling. How those life stories are told, by whom, and the form that those stories take are fundamentally grounded in politics, history, and culture" (Kaplan-Myrth, 2007, p. 1268). Medical anthropology must be critical, cautious, and self-reflexive because "narrative is always political," and "because people choose which narratives to tell." (Becker 1997 in Kaplan-Myrth, 2007, p. 1268). Dilemma of voice arises when presenting what participants say in the interview process. Qualitative research often assumes that what people say is a "more or less, accurate representation of the voices and life experiences of participants" (Aguinaldo, 2012, p. 767). Participants, however, may make statements in contradiction to the narrative previously stated (Aguinaldo, 2012).

Another limitation of my research was that I did not conduct the interviews myself. I do not have a complete set of questions for each interview nor do I have a transcribed copy of the interviews. I do not know what the researchers left out in reporting the narratives and thematic analysis. The quotes represented in the articles may represent reactions to specific questions that out of context imply a different meaning to the reader. For example, one article I initially reviewed had interviews and quotes with older adults living HIV, but the participants were all gay or bisexual black men so the answers to the questions were layered with additional concerns of racism and

homophobia (Haile, Padilla, & Parker, 2011). This is related to another limitation of my research in that I did not collect data related to other types of stigma. I did this because the stigma and discrimination faced by sexual minorities, especially men who have sex with men (MSM), in relation to HIV-related stigma is an enormous topic which deserves its own essay. I wanted to focus on the age category, so I did not explore any other social categories that face regular discrimination, including gender, race, or religion, and particularly sexual identity, which has long been tied to the conversation on HIV/AIDS. To justify the little attention I paid to how the illness has historically caused enormous stigma to the gay community, I argue that to delve too deep into that conversation would take away from my concerns on age-related stigma. There are other social categories, such as being African American or in the prison system in the US today, which are also related to stigma, social inequality, and higher rates of HIV than other groups in the population (CDC, 2019).

Conclusion

The intersection of ageism and HIV-related stigma negatively impact the already tenuous social networks of older adults. My analysis shows that HIV status and ageism are related to job insecurity, social exclusion, less care in institutional settings, and can place a strain on family relationships. Discrimination goes beyond one specific act; it becomes a daily part of the social reality of older adults living with HIV. These effects are far-reaching and impact mental health and quality of life. “Living with HIV has been connected to a variety of social, emotional, and physical challenges” which “may be exacerbated among older adults as they confront the process of aging” (Groves et al., 2010, p. 634).

The implications of these findings emphasize the necessity for healthcare that extends past treating a biological illness with medication and addresses the social aspects of wellness. Holistic

interventions in biomedicine, which address the whole person, e.g., physically, psychologically, and socially, can be made possible through the unique approaches adopted in anthropology. Ethnographic interviews provide valuable insight into the lives of the chronically ill to help increase public understanding or empathy of the illness, reduce stigma, and humanize the individual experiences of living with HIV. Focus needs to be placed on social wellness, which could be defined as a mix of the value provided in caring for someone from the caregivers' perspective, but also on the positive health benefits associated with social interaction. Emotional, psychological, and spiritual support could vastly improve the lives of older HIV+ adults. Quality of life is more than physical health.

Future research

Online social networks present valuable spaces for PLWH to connect with other people like themselves and create a sense of belonging to a community. Most of the research in this area focuses on younger adults and more work should be conducted on older adult involvement or access. I think access to social support online when someone is not well enough to leave home may help alleviate depression relating to social isolation and chronic illness.

One reason the successful aging paradigm fails to be a constructive, inspirational model is that North Americans value individual personhood but also blame the individual when they fail to achieve unattainable ideals (Lamb, 2014). This creates stigma against those who do not or can not fit the normative construction of success, like older adults living with HIV. I think the conceptual framework of successful aging could be improved by including notions of success as defined by older adults living with HIV. Aging successfully with HIV can be achieved by reduction of stigma and normalizing discussions of variations and diversity of health and abilities as we age.

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Appendix A: Definition of key concepts including themes and subthemes

Age-related stigma: (ageism) refers to discrimination, bias, and negative attitudes directed at people based on their age.

Employment discrimination: unjust or bias treatment of people in the workplace or when looking for a job.

Family relationships: the relationships with people the participant identifies as family. Can be blood, adopted, through marriage, or fictive kin.

Fear of contagion: “The irrational fear of contracting HIV from the participant” (Emlet, 2006, p. 786).

HIV-related stigma: discrimination, bias, and negative attitudes, including intolerance, hatred, and fear, directed at people living with HIV. This stigma can become internalized furthering the negative consequences. It can also become anticipated stigma which leads to avoidance behaviors.

Institutional discrimination: unjust or bias treatment of people in institutional settings, e.g., hospitals, prisons, and assisted living facilities.

Intersectionality: this conceptual framework of intersectionality demonstrates how both types of stigma, HIV- and age- related, exacerbate the negative outcomes of each other, above and beyond either alone (Wallach & Brotman, 2013). This concept helps explain how layers of stigma and discrimination interact with each other to create deeper marginalization and disempowerment (López & Gadsden, 2016).

Living with HIV/AIDS: this theme was filled with strategies of survival, optimism, and the concept of resilience. Survival strategies are methods of self-preservation like non-disclosure. Resilience could be seen in the optimistic outlooks several people had on life

Non-disclosure: the decision to not reveal one's HIV status to other, often seen as protective silence or a form of self-preservation, and a chance at feeling "normal."

Rejection: is feeling dismissed, spurned, or rebuffed by another person or group of people.

Resilience: adapted from its origins in anthropological scholarship on disaster as "the qualities and capacities that enable a community to recovery from a catastrophic event" (Barrios, 2016) to define it as the capacity of individuals to cope and remain positive in the face of adverse conditions. In the end I defined it as "positive adaptation in the face of adversity" (Barrios, 2016, p. 28).

Social discrimination: unjust or bias treatment of older adults living with HIV due stigma and based on their age or HIV status.

Social isolation: "a variety of experiences that set the respondents apart from society and caused them to feel alone, isolated, or separate" (Emlet, 2006, p. 786).

Social networks: refers to the people an individual interacts with socially. An individual's social network could be comprised of different groups of people, like informal support, e.g., family, or formal support, e.g. HIV support groups (Nobre, Kylma, & Pereira, 2016).

Stereotyping: negative attitudes, characteristics, or traits attributed to a person or group of people.